

Season 2, episode 8: Behind the scenes at Cystic Fibrosis Trust

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.

Welcome to this special CF week edition of CForYourself. Today I'm excited to be going behind the scenes at the Trust to mark the charity's 60th anniversary. I'll be chatting to some of the team to hear about their role, the changes they've seen in their time at the trust, and how they work with the CF community to create real change.

We're lucky to have four members of staff joining us today. We've got Belinda, who works in the research team. Sangeeta, who is the welfare and rights advisor, community fundraising manager. Jess, who also has a daughter with CF. And Eilidh, who is a social media officer and who also has CF.

So a big thank you for joining us today. Welcome to CForYourself. Can you maybe start by introducing yourself a little bit?

Eilidh, we'll start with you.

Eilidh: So I'm Eilidh. I'm from Edinburgh and I'm the social media officer at CF Trust. My job consists of basically working with every single team in the Trust and translating their work for social and kind of making it into digestible content that we can use for the community, which I absolutely love.

Because, you know, one morning I might be working with Belinda and the research team on creating a piece for Research Wednesday. In the afternoon, I'll be making a video for policy, about how to contact your local representative and then later on be working with Jess in fundraising on a skipping video. So it's really, really fun and varied.

And then occasionally we'll see how we can make light-hearted content and do something fun because, you know, we all need a laugh, especially in this year.

Lucy: And I think that's testament to what you do with all these Wear Yellow Day reels that are coming out at the moment, which are great. So I think what you do is really, really important.

And I guess having CF yourself and working at the Trust, talk to me a little bit about what that's like, and does it ever feel like it's like too much CF for you in like a day?

Eilidh: Yeah, I definitely can see how it could be that. And I think it's a really healthy thing to kind of balance yourself and kind of put your own self, your own CF aside and kind of

look at what you do as a Trust, as a separate entity sometimes so that you can kind of balance everything you're doing.

But I definitely really enjoy working for the Trust and having CF. I think one of the biggest things for me is that I get to see a much more varied view of what CF is like, because when you have CF, you're kind of stuck in your own personal perspective and you're used to the things you do, and then you talk to someone else and it's a completely different experience.

So that for me is really important, really special. And, you know, as well as having CF and knowing so many people who sadly aren't here, I do feel like a lot of what I do, I think about them every day as a way to kind of honour them and carry their spirit forward.

Lucy: There's lots of people at the Trust who have had CF, but you are obviously not all working in the building at the same time. You work from home, and everything is kind of really strictly monitored. So I think that's also a great, great thing that the Trust do that you know, you're able to work together even though it's remote.

Eilidh: Definitely. Yeah. So there are two people in my team at the moment, so Emma Lake and myself who are in the communications team. And yeah, it's sad that you don't get to meet other. But honestly, I don't feel like we're missing out because we talk to each other so much online. And again, it's bringing that varied perspective and we can do really cool things together. And previously I was working with someone else, Nicole, in social media. And that was really fun because we can make videos about cross infection and what it was like to work with someone with CF and never meet them, which is bizarre but super relatable as well.

Lucy: You know, with the stuff you're putting out on socials, would you say it's predominantly aimed at people with CF and kind of informing them on what's happening in particular, you know, the, the Creon situation and things with drug developments as well. Or is it more for for getting the attention of people who maybe don't know about the Trust and don't know about CF to educate them?

Eilidh: Definitely a bit of both. I think we want to make sure that the community are informed that, you know, we really focus and lift up their voices of what they're thinking and feeling. And as you said, with the Creon situation, making sure they're not missing out on important information. But then, you know, part of the challenge with social media in general is finding ways where you can reach out to a wider audience because, you know, that goes into Jess's role in fundraising and letting people know that, you know, CF is still like a really serious chronic illness, and you know, we need people to support this cause, especially as more people with CF grow older. We're facing more and more long term illnesses and everything. It's not a healed illness. So that's that a challenge of working in social media is, you know, how do we reach out to people who don't know what it's about? But yeah, definitely a huge part of our job is to make sure we kind of bring together community, because that's one thing that people with CF miss out in kind of, you know, real in-person life.

Lucy: Yeah, there's definitely either two perceptions that I find with CF, the first one being, 'Oh, you've got that drug. That's great. So are you cured?' And then the other one being like when people don't know much about it and they go, 'Oh, do you have to have that kind of massage thing on your chest?' People either know the physio or with the medication. You're kind of a relatively young age like me in the sense that we've not

maybe seen the Trust change as much as other people with CF who are a lot older than us.

And then obviously things that you put on social media can link and raise questions with people. You know, people can ring the Helpline where they get really great advice and really good tips, and then a lot of people could be then signposted to you, Sangeeta, in terms of welfare rights and things like that. Talk to me a little bit about who comes to you and kind of what you offer.

Sangeeta: Mainly people who need help and advice on their benefits. So welfare rights is primarily about benefits, advice and interpreting social security rules and helping people are all different stages along that process. So it could be anybody who's in receipt of benefits or someone who thinks that they may qualify and they want to know what their rights and entitlements are.

So it's a really, really broad spectrum of people, parents of children who are asking about disability living allowance. There's obviously lots of people who are claiming PIP, which is Personal Independence Payment for over 16 or adult disability payment if you're in Scotland. That's what makes up the majority of my enquiries. But I can be helping anybody from a claim stage or pre claim, if they're not sure that they're entitled right through to challenging a decision and asking for a revision, or letting the DWP know of a change of circumstances, or taking it through to appeal and representing them at a hearing or even beyond that.

So it's a very, very broad spectrum of types of enquiries and different stages that people can be at, including sort of changes of circumstances in their health, you know, and some people giving up work or starting work or changing jobs or changing hours. So variations in their life that happen, invariably people want to know what that means for their household income and whether they're entitled to any support with that.

Lucy: If it's not affecting them right now, they won't know you exist in a way, because they've not kind of needed your services. Like you know there is the social media team, you know, kind of the fundraisers, you know, the people in research like Belinda, what you don't know is there is someone specifically doing your job. If you're not needing that, I guess, would that be a fair thing to say, that maybe a lot of the CF community aren't fully aware that your job exists?

Sangeeta: I feel like after eight years of, you know, sort of 370 odd enquiries a year, I feel like I should know every single person in the whole country. But obviously I clearly don't. But obviously the Trust do a really good job of publicizing my services. But I think the main way that most people get to find out about me through is through their CF teams because a lot of CF centers do have social workers, not all of them. You know, there are some CF teams, big CF teams that don't have social workers, but even those CF teams have specialist CF nurses or physios or dietitians that do know that I can help with benefits.

So I guess the key is that I make sure that the professionals that work in the multidisciplinary teams know to signpost their patients to me, if there's an issue with benefits or even a possible social issue or even an issue with somebody who's just struggling with income, you know, and struggling to manage and struggling with finances. They might not even know that there's benefits, you know, that they could get.

Lucy: Because and I go back to kind of this time last year when I had moved out and was living on my own with my husband for the first time in our house, and, and you don't know half the stuff you need to do to manage your bills and things like that.

You're not taught it at school or you're not interested at school. So kind of to have that signpost and then have those questions be able to be answered by yourself. And that help is extremely useful. Eilidh, you could pick up on this as well as someone with CF. If you've got worries and questions about things that Sangeeta can help with, it's part of that whole team when you go to clinic to have someone like that. It's not just kind of the physical aspect that needs looking after, you know. The worries that Sangeeta can help with, they can sometimes affect your physical health just as much as your mental health.

Eilidh: Yeah, definitely they can. And I'm in the very privileged position of having had Sangeeta's help, and that makes a really huge impact on my life. She helped me through adult disability in Scotland and that I think previously before, you know, I think there were a lot of things stressing me out. And as a person with CF myself, you can think everything's related to your CF, if that makes sense. So you don't really compartmentalize why something's happening in your body or your mind. And talking to Sangeeta was so helpful for me to, I think, feel validated in my issues and be able to separate them and communicate them. So yeah, I'm extremely grateful as a person with CF. And I, I didn't know about Sangeeta beforehand, except for I think a previous person in social media had done a profile with her on our social media, but it was emailing her personally and then having a lovely chat with her that really made me kind of see what the Trust and Sangeeta can offer.

Lucy: And Sangeeta, obviously you've been at the trust for eight years, like you mentioned. Do you feel like a lot has changed in in CF in that time? I'm going to kind of chat with Belinda a little bit about research next. But you know, in terms of the problems people are facing I guess socially with CF, have you noticed changes as well?

Sangeeta: Yeah, I mean in many ways some things are still the same and they're still hard, you know. So for example Personal Independence Payment, it's always been hard. And my job was actually created to deal with the move from Disability Living Allowance to PIP. So still makes up the majority of my claims. And it's still really hard and if anything probably harder because I'm doing a lot more appeals.

So PIP has always been a challenge. But looking back, I think the first change that came in the last eight years was the pandemic. And obviously, you know, not to harp on too much about that, but it was a really big thing for the Cystic Fibrosis Trust because of shielding, because of, you know, people asking what furlough is and all this new language, you know, rights at work.

And so welfare rights was really important. And the benefits system, even, you know, certain rule changes and law changes just happened overnight. So that was a real challenge that, you know, I don't think anyone could have anticipated how we kind of even navigated that landscape. But obviously we did go through it. So that was a challenge for everyone at the Trust and every single person living through it, obviously.

But then there've been some really positive things, changes in modulators. And, you know, the more we listened to people with CF, the more we know how to respond to them. So I've seen lots and lots of changes in the ways that we now work at the CF Trust. We always were really good at working virtually, but then the world is now adapted a little

bit now because of the pandemic. So that's been really positive. And I can now do appeal hearings virtually. And I wasn't able to do them before because you have to attend in person. And now we can do telephone video hearings and PIPassessments are now done by video. So it's almost like the world was made to make reasonable adjustments because they hadn't had to really think about them before the pandemic.

So certain things are really positive. But then, of course, following coming out of the pandemic, we went straight into a huge cost of living crisis. And, you know, not to be too depressing, but, you know, fuel prices were a huge issue for lots of people in our community. Having to choose between heating and eating is not something that anyone with cystic fibrosis should have to face.

So our support service was totally inundated and we had to respond by creating different types of grants, you know, so that we could help people to manage those very, very basic things. So yes, a huge amount of change, some positive, some negative. But on the other hand, you know, even with modulators and obviously not everybody can have those. There are challenges around mental health and challenges around body image and more people coming to us with issues around neurodiversity. So it's an ever changing landscape and you know which we are absolutely ready and able to respond to as long as we communicate well with the people who were affected.

Lucy: I guess if I'm reflecting on the biggest changes I've seen with the Trust, the first one, which was a physical one, was a back in 2012, 2011, which was when the logo changed and the colours changed from the red, white and blue kind of see off CF, it changed to yellow, which I like because I love yellow.

And then obviously kind of more recently, kind of the three goals that have been set and the new Work Forwards that's really helpful for. So it's moving forward. And as we're like so kind of growing older and I and I guess the hardest thing I've seen from, from my perspective would be kind of navigating the whole modulator thing being amazing for, for most people, but then still remembering the 10% and working just as hard for them as everyone else.

So I think like the changes have been great, the I've seen, but the situations around people with CF has made it harder as well.

Lucy: I mean, Belinda, what a time to be alive in research. I know that the European Conference is happening soon.

Belinda: Yes. So I'm in Glasgow, just arrived and the European CF Conference is taking place. It starts tomorrow evening. And actually on my way from the main train station to Glasgow, I actually walked past the entrance and it's already all branded up and it looks exciting. And a few people at, you know, on the train and I just walked to the hotel with one of our colleagues. So yeah, it's a really exciting event to attend. It's going to be over 2,000 researchers and healthcare professionals and clinicians. And that's a that's a huge number. And it's exciting because they are going to be talking about research from probably 8am in the morning until 10pm at night.

They don't stop, you know, once the lectures stop, they will be going down the pub, the restaurants, and they will still be talking about, you know, what they've heard and what they thought of it and what they're doing next. And yeah, it's really exciting.

Lucy: What have you seen Belinda? Then you know what's happening at the moment in research. What's exciting that we can look forward to?

Belinda: So last week we announced over 2 million pounds of research, new research grants, some of which will be starting in the autumn. And I guess, to me, the most exciting thing about that research is that a couple of years ago, we did a project where we looked at what the priorities were for people living with CFS. In terms of research, what research they wanted to see happen in CF, then after that, after those priorities were identified, we put out a research funding call.

Research funding calls take a long time to actually, you know, from start and all of the very rigorous review of the funding applications. But those grants that we announced last week are the first set of grants that are actually addressing the refreshed priorities. And this is something that started in 2017. So in 2017, a group of researchers in University of Nottingham and the CF community and representatives in the community did a big project. And they wanted to say, okay, so, you know, what are the things that researchers should be looking at that matter to you? And they identified a list of 10 things. And the top thing was about treatment burden. And then as you've just been talking about, a lot has changed over the last five years since the pandemic happened, the modulators have been become available for most people with CF in the UK. And so we just wanted to go back and say, okay, so what's changed? You know, are they still your priorities? Do you have different priorities now? And what the results were, which we published at the end of 2022, were actually that some priorities are still the same, but actually there's some new priorities in there as well. That was a really good opportunity just to test the waters and to see what everybody was feeling, where everybody was at with everything.

And so this is a really exciting time that we're addressing some of those research priorities and in this new lot of funding. So it ranges from treatments, or laboratory research that might be able to benefit people who aren't able to access modulators, right through to investigating reproductive health in women and girls.

So there's lots of things to think about. You know, we know from the UK CF registry report in the last couple of years that lots more women are starting to have a family with CF now, which is absolutely amazing and fantastic. But actually being pregnant takes a big toll on anybody's body. And having CF as well, that could have additional complications. We need to really understand that. And obviously when they did the testing for Kaftrio to see if it was safe and effective, they didn't test it on pregnant women, they didn't test it in women who were breastfeeding children with CF and all sorts of things like that. And we don't know the answers.

And of course, later on down the line, you know, as people with CF are getting older than they're experiencing the symptoms of menopause. And so we really want to understand everything that's going on in women's health from, from beginning to end. And so that's a really exciting project.

Lucy: And so, you know yourself, how long have you been at the Trust and how did you get into research? Because you can tell you've got like a real passion for it. How did you get into that?

Belinda: So I've been at Trust for seven years. I was previously working at another research charity and very similar role, explaining the research that we fund to those who are living with the condition. I wanted to learn about some new science, and I can

remember very clearly my boss at the time telling me, 'oh, well, you'll get to learn a lot about the lungs.'

And I just thought, now, looking back on that comment, I just think, oh my goodness, there's so much to do to like raise awareness of just how many different types of symptoms that people have. And I've absolutely loved learning a lot about, you know, everything there is to learn about CF and about why infections are such a big problem for people living with CF and just the CF community is really fantastic and they're always so willing to help to explain things.

And really, you know, if you think I'm sounding passionate about research, then I can guarantee that all of the researchers that you talk to are equally as passionate and committed to actually making life better for people living with CF. And Eilidh has met one of them. She went up to Newcastle, or down to Newcastle for Eilidh, to meet one of the CF researchers last summer.

Lucy: Yeah, we've had a few on the podcast and I just find it fascinating how so much research is going into it as a condition. Some small research that has such big effects. And then you've obviously got the likes of Vertex and all the others doing bigger, bigger stuff.

And I remember when Pulmozyme came out and how different that was. And there's people who are older with CF I've spoken to who remember when Creon came out. So obviously they're key drugs. But all the research in terms of it's not just drugs and things like that, is it? I guess that your research looks into.

Belinda: No, absolutely. I mean, there's a whole range of different things. I mean, we're funding a research study in Nottingham looking at the GI effects of CF. They are doing things I say is simple, but and maybe it sounds really obvious, but they're actually, you know, asking people to track what symptoms they have because, you know, you could get anything from, you know, blockages in your intestines through to bloating and nausea. And I think the tendency has been that all of those symptoms are caused by the same things happening inside your body, but we don't actually know that. It's led by a professor in Nottingham, he is called Alan Smyth. And so what he's doing is he's looking at all the symptoms that people with CF experience and then also doing scans, magnetic resonance imaging scans, MRI scans, on people's tummies and intestines and actually comparing the two.

It's a very multidisciplinary group. So you've got, you know, Alan who is a CF paediatrician, but you've got researchers based up in Newcastle who are looking at the bacteria that are growing in your intestines and things and looking at how that changes in CF and, you know, whether those changes that they're seeing could be linked to their symptoms. And if they can really understand all these different subtypes of symptoms, then we can tailor treatments to the particular symptoms that people have, rather than having this one size fits all treatment. That might work for some people and doesn't work for others.

Lucy: I guess, Belinda, you know, we've had 60 years of the Trust. Where do you see research in 60 years time?

Belinda: So I'd really like to think that we have a treatment for everybody. So a treatment for everybody, no matter what mutation they have, that everybody has an effective treatment that is as good, if not better than the modulators are today. That we have a really good understanding of the risks that people may have for diseases of older age,

which, things like coming down the track, everybody has risks of heart disease and Alzheimer's and cancer and things like that, no matter who they are in the population. But I think it's really important that we understand more about how those risks affect people with CF.

And I also hope that there will be really good antimicrobials, really good treatments for infections with less side effects. I think all of CF medicine should be tailored to the individual with CF, and I think that is really possible because I think there's a lot of genetic technology that will help us be able to do that.

Lucy: Well, it's very exciting and I think optimistic, you know, for people with CF and parents and families of those with CF listening to this.

Lucy: Jess without your team, a lot of these other teams wouldn't have the funds or, you know, financial support to do this. So being the community fundraising manager, there is a lot of money that's raised for the trust. And people do such fun things, like people are skipping at the moment, and I'm seeing people more and more tired and exhausted from doing that each day. But what, you know, for you, that must be quite a big responsibility, knowing that there's other things under you that are kind of funded by what we are all able to fundraise.

Jess: Yeah. I mean, obviously we'd like to take credit in the community team for raising that money, but it certainly is the CF community that are out there every single day doing amazing things to raise that money.

I mean, part of my role is obviously we look to facilitate the opportunities to do that. As you've mentioned, skipping challenge is happening with gusto at the moment. Lots of people have sore knees but pushing through! That was a grassroots thing that come out of other mothers and fathers who got together and decided to create a community.

And obviously the big one we've got coming up is Wear Yellow Day, where see so many people doing amazing things that just garner together on the 21st of June, from bake sales to balls. And yeah, we couldn't do the work we do without those people doing the fundraising.

Lucy: Like Sangeeta said, the pandemic was a tough time, especially for the charities in the sector raising money. Would you say that you've seen an improvement since the pandemic in terms of kind of fundraising events that have been able to take place? Because obviously we had FeBrewary, which had to be on Zoom. I remember doing that on Zoom because of Covid.

Jess: Like Sangeeta said, it's like the world has kind of accommodated the nuances of CF, where we've always had to do more remote events to make sure that we can include everyone who has CF for cross infection reasons. You know, we have moved a bit towards that. However, I think charity wide across the whole sector, obviously Covid had a huge impact on the ability to fundraise. People still gave donations if they humanly could to make sure that obviously their needs were still met with a cost of living crisis. But, you know, we are starting to see that activity creep back.

You know, it's to be seen across the charity sector whether we make it back to where we was pre-COVID. People may not have as much money to give if they're having to pay high amounts for their energy bills, but we are starting to see that coming back, which is really great to see

Lucy: In your time at the trust. What's been the quirkiest fundraising activity someone's done?

Jess: Well, I'd like to say I think the skipping challenge sounded quite sensible and normal when someone come up with it, but actually, yeah, it's turned out to be a much bigger task for everyone to take part in doing 11 minutes of skipping every day.

So I think, you know, it never ceases to amaze me the weird and wacky things people do, you know, going the length and breadth of the UK walking, jumping out of planes, semi clad! People have done it all to raise money, which, you know, we absolutely salute them and support them every step of the way.

Lucy: Talk to me about your team and the fundraising team in general. If someone's listening to this going, oh, I actually have got an idea that I could do something. How do they get in touch with you and who is the well, the community team?

Jess: There's 11 of us. And, you know, obviously we want to make sure we cover the length and breadth of the UK because you know that's who we fundraise for. So we are a team that's across the country remotely. So if someone contacts in Nottingham, we'd put them in touch with their local community fundraiser, which would be Rebecca in that instance.

So I'd always say to people in the first instance where you can contact us in omnichannel ways, we're available on social media, we're available on email. If you want to email us at events@cysticfibrosis.org.uk. Or you can call us or you can WhatsApp us as well. We have a facility of that through the website. So there's many ways of contacting us, but we want to make sure obviously we're having that that 1 to 1 communication with you to make sure that all your fundraising needs are met.

Lucy: There are, like you said, so many things that people can do. And even a child taking cakes into school and raising 20 pounds, that is no less of an achievement than a ball that raises 50 or 60 grand, is it? In terms of the passion behind it?

Jess: Absolutely not. And I think this time of year is a real reflection of that as well. When we have so many schools involved in Wear Yellow Day, it feels like such a simple thing going to school, selling cakes or doing a dress down day. But no matter what amount of money is raised, it not only raises fundraising income for the CF Trust to be able to make the change to people in the community. It's the awareness it causes as well.

So small children going to school, talking to their peers, talking to their teachers, that's then more knowledge about CF that's passed on and in turn raises more money.

Lucy: And how long has the CF Trust had this day? So in terms of kind of obviously Wear Yellow Day fits with the yellow of the of the brand. But you know there's not always been this day. It's a great day for awareness like you said.

Jess: Well I think historically we've always had CF Week. We've always had that sort of one week where we were dedicated to raising awareness about CF as a condition. But, I think historically we started with the advent of social media, it was the Yelfie. We wanted people to wear yellow, do a text to donate, you know, get celebrities involved, anyone who wanted to share. And that was a call to action for the community. But it's just naturally grown where people feel actually, that's a great day to do some fundraising. So off the back of that it was born. So it just gets stronger every year the campaign runs.

Lucy: We definitely get more celebrities and people with CF doing it and high profile people. You get a lot of dogs and cats, you know, with the t-shirts on and things like that. It's always nice to see social media flooded with yellow. Even if they don't donate even the awareness of all of that, I think it brings people back to the Trust's website and all the resources and things that you do.

And I guess a question for you all would be, I mean, we kind of touched on it a little bit with Sangeeta, but, you know, the biggest challenge facing the CF community, maybe not facing the trust but the community. What would you say, Sangeeta? And also, can you tell me how people can get in touch with you? Because if they don't want to go through the helpline or they don't want to ask their CF team, how can they get in touch with you?

Sangeeta: They do need to get through to me through the Helpline. So I don't know if you have that number handy, but you can email them on the helpline@cysticfibrosis.org.uk and they are available on WhatsApp and I pick up emails from that.

But also my colleagues will have a look at the enquiries first and then make referrals to me. So it is through the Helpline that I'm contacted, otherwise I would be too flooded to be able to be effective at what I do.

Lucy: I've got the number here, so it's oh 0300 373 1000.

Sangeeta: That's it. And it's 10 to 4 Monday to Friday that they answer the phones and then available on email as well on WhatsApp.

So that's how they get hold of me. But did you want me to say about challenges?

Lucy: Yeah. What you think maybe is the biggest challenge.

Sangeeta: Yeah I mean I've spoken a lot about challenges, but I suppose I want to say that the benefit system is so complicated. You know, it seems to me that sometimes it's dealing with your benefits entitlement can make you more unwell in terms of stress, you know, and people are scared. You know, people are scared of having, really important, you know, sort of safety net of income taken away from them because so many people use their disability living allowance, their personal independent payment and the adult disability payment to actually, you know, live rather than for extra exciting things.

So of course those benefits are to encourage independence, but people are using them just to, just to sort of afford basics these days. So I think the biggest challenge facing people in cystic fibrosis is just the navigating of the system really, because it is complex and it can be frightening. And I think, you know, that's what I'm there to do to sort of, you know, be in the middle and guide them through that and to make it less scary and to give them power really. Power and knowledge to navigate that system, you know, without being too frightened.

Lucy: I mean, it's a shame that we're having to cram all of your work into the one podcast, because I could have episode after episode with each of you. What Jess would you say is maybe one of the challenges that we're currently facing?

Jess: I think what's previously mentioned, people living longer, obviously comes with anxiety in itself that, you know, co-morbidities. What's the future look like? I don't have a retirement plan. These are all new things that maybe the CF community hadn't thought

about before and now having to take on board. So I think that's a big one, specially within my family. We've started to think longitudinally about which probably we historically never would of. And I just think obviously, as Sangeeta has mentioned, the challenges around the benefits system at the moment, there's a lot of uncertainty with general elections looming.

Sangeeta has been a great help to me in the last few weeks having to revisit the horrible world of DLA. So, you know, we don't know what the future holds with new governments and things like that. So I think that would be the biggest concern for the future.

Lucy: So Jess with your daughter who's got CF, you know, as a CF parent, kind of what, you know, if you were to sum up the Trust for what it means for the parents with CF, how would you do that?

Jess: I think is probably one of the reasons I come to work for Cystic Fibrosis Trust. Like many people, I'd not heard about CF until we had, you know, the day that someone gave us a diagnosis and the support we got from the Cystic Fibrosis Trust, with the diagnosis packs, help with the DLA forms back then, grants, information for when they went to school. I don't think we would have got through those things without the support of the Cystic Fibrosis Trust.

And I know a big area of concentration is neurodiversity at the moment, which my daughter also has. So it's really, really positive to see, you know, us branching out into that area and looking at those issues that might have a further impact on the health of people with CF.

So yeah, the work the Trust does is really important to me as a CF parent.

Lucy: Eilidh, what about yourself and how you feel the Trust has helped people with CF? But also the biggest challenge that you think we currently face?

Eilidh: I think you know what I really appreciate what the Trust is doing especially in trying to look at making sure they are supporting people from all the like, devolved nations. Looking at what we can do in Scotland and also Northern Ireland, Wales as well as England. To make sure that, you know, everybody with CF can be supported by the Trust.

In terms of what I think our biggest challenge is, I do think it is kind of looking at, you know, disparity in treatments and making sure that people with CF aren't just kind of seen as cured and not in needing support, especially from those in power who have the ability to make sure that we can access funding, and access new medications.

So I think that's something we really need to make sure that we're focusing on as time goes on and advocating for people with CF. I think there's a lot of things, you know, that given finances, I don't think we're too far away. By too far away, you know, that could be 10 years or 20 years from solving. One of the biggest things for me that I'd like to see solved, besides having a cure, is being able to meet with people with CF.

And I almost want, you know, CF to become almost undetectable in our bodies so that we're not at risk of passing infections on. So it's not even something that, you know, we have to consider. And I'd love, you know, a kid to be born, you know, in 10 years time that they're not even having to think or realize about all the issues we're struggling with. It's just as nonsensical to them. But yeah, I definitely think it's part of, you know, we have to keep our feet to the pedal, keep on pushing, keep on pushing for fundraising, keep on

advocating and keep on, you know, expressing how important it is to support people with CF. And I think we can see some really incredible things coming soon.

Lucy: For me, the biggest challenge with cross infection in terms of how lonely it can be, but also how many people don't realize. You know, I had a situation with work where they didn't know it. They didn't know to what extent that it was a problem. And so education with people I think it's hard. And how people don't understand how it is, you know, they think it's like Five Feet Apart. Well, no, it's not like the American film or it's like it was in Covid. Yeah, but there is not an end, you know, like it's quite difficult.

Lastly, Belinda, what would you say is kind of maybe the biggest challenge that you see in the CF community?

Belinda: I think all of the above. I mean, it's been really humbling listening and I don't have the opportunity to spend so much time with people with CF, perhaps less so than anybody else on the call.

I guess from a research point of view and a treatment point of view. I would guess that one of the challenges is and continues to be the treatment burden. I mean, I remember so clearly talking to someone with CF and asking him to do some filming for us just about his day to day life. And I remember sitting at his kitchen table and he just got this, and I'm sure this so familiar to you all, pile of pills and just having to take them one after another, just keep going, keep going.

I know that people with CF have to take so many medicines and how much time that takes. And you know, I think that is something that we've really got to do something about.

There is study going on at the moment which is looking at how people are just all constantly adding to their treatment and schedule, you know, and actually it's time to start taking things away. If you're healthy and you know Kaftrio it's working for you, then maybe we can start simplifying your treatment burden.

And I guess the other challenge, which is very much research specific, is, you know, there is research going on but it takes a huge amount of time. And, you know, I think particularly for people who don't have access to Kaftrio you know, they can sometimes feel that there isn't anything happening to them, that there isn't work underway to try and get an effective treatment for them.

But actually, there is lab work going on every day of the week, and I mean that over the weekends, too. And I'm really optimistic that we will get, you know, effective treatments. But I think it must be really frustrating to have to wait to find out what those are going to be,

Lucy: On behalf of people with CF and from my own experience, a huge thank you for all your different teams and people who work at the Trust. And the voice you are, the united voice for us, when we're not even able to be together.

So yeah, really great. And I guess here's to the next 60 years and what will happen at the Trust. So a huge thank you for joining me today.

Thank you so much to Sangeeta, Jess, Eilidh and Belinda for joining me today. It was so great catching up with them and hearing more about their work. Some more information

on what we've talked about in this episode, or to donate to help make sure that everybody with CF can live without limits, please see www.cysticfibrosis.org.uk/podcast.

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