Season 3, episode 5: 60th anniversary special with Chief Executive David Ramsden

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 fifth episode of CFYourself. This month is Cystic Fibrosis Trust's FeBrewary fundraising campaign, where the CF community is encouraged to come together with friends and family, host a tea party or coffee morning and raise vital funds so the Trust can be there for everyone with CF.

To get in the spirit, today I'll be hosting my own virtual FeBrewary tea party on the podcast. I'm excited to be joined by David Ramsden, chief executive at the Trust

and Trust supporter Paul, who is 71 years old and has CF. As February also marks the end of the Trust's 60th anniversary, we'll be chatting all about the progress we've seen over the past 60 years and what's changed for the community.

We'll also look to the future and the work that needs to be done to ensure everyone with CF can live a life unlimited. So, without further ado, let's welcome to the podcast Paul and David.

Lucy: So I thought I'd ask you very quickly what drink you've brought to our kind of virtual tea party. I'm boring and I'm on water. This is my favourite drink. Paul, are you having tea to drink today?

Paul: I'm 71. It's tea only. All the way.

Lucy: Strong tea?

Paul: Baby tea actually.

Lucy: And David. What is your drink of choice?

David: Like Paul, definitely tea. A tiny bit of milk in it. And I'm very particular about not asking or expecting anyone to make me a cup, because I know exactly how I like it!

Lucy: So, starting with you, Paul, can you introduce yourself a little bit and tell me a little bit about yourself?

Paul: Yeah, I'm Paul Stanley. I've got cystic fibrosis and I'm 71 years of age. I'm from Glasgow, by the way. When we talk about cystic fibrosis. My mother had a child in 1952, and he died in 1952. He was called Val and he was my big brother. But when I came along, what happened then was that my mum knew I had cystic fibrosis because of the nappies. The doctor said I didn't have it, but my mother knew almost straightaway.

Growing up for me was really difficult, simply because we were going along and we were all friends in the cystic fibrosis community, and we all went and mingled with each other. But slowly everybody was passing away. All my friends passed away and left me a wondering what was happening and very vulnerable.

I found it really tough at that stage in my life and the problems I had with cystic fibrosis were different from others. My lungs were in a pretty good condition, but I kept getting blockages in my bowels and that's the main problem I had when I was younger. And in those days what they did was they cut out the infected part of the bowel. So I have several lines on my stomach were parts of the bowel were taken out.

Awareness of cystic fibrosis was very low when I was growing up, so there was nobody to look up to. And when I said to doctors I had cystic fibrosis, they just shook their head and said never heard of it.

So I was going to the Children's Hospital in Glasgow up until I was about 25, sitting in the children's seats, waiting to see some doctor that really didn't have a clue what was happening. So it was really tough and there was no to talk to about it. When I turned 19/20, there was nobody left apart from one girl named Carol who I became friendly with. We used to meet in those early days, because cross infection wasn't even discussed and wasn't realised. And then as cross infection became a thing, I became very isolated because I had nobody to talk to. I found it very tough.

The problem with me being that my bowels were blocking up fairly regularly, and I was having to take lots of medicine to ease the pain, because I'd be lying there for days, absolutely cramped up and really struggling. And so that was my battle in my teens that I was going through.

My mother was an extraordinary woman. Probably opened the first CF charity shop, she opened in '64. There's a photograph of a Scottish celebrity standing at the door and shaking her hand. And my mother ended up being very successful in business. My father died in 1960, so my mum had to take on the business, which was bag shops. Remember when people sold bags in shops! So she became very successful and because of the situation with my dad and brother both being dead, I was really the most spoiled child you would ever meet.

She poured her heart and soul into me and the CF charity. She worked her socks off for me and she was just an incredible women. She wrote letters to try and get help with the fibrosis. And I still have a letter that somebody wrote, a specialist from Harley Street wrote back to her, and I can't read the letter because I'll cry my eyes out. But he says he's sorry that he can't help but he sends his best to my mother, and that was generally the kind of letter you got back.

Lucy: Your story is so different to children nowadays, and you know, you mentioned cross infection. You mentioned all sorts of things. And the fact that doctors didn't know what it was and the fact that there wasn't much out there to treat it. And David, I'll bring you in on this and, and you know, introduce you as well. But just the, the polar opposite end of the scale as to how your life started, Paul, and how a child's life now starts with cystic fibrosis. Just really shows how medication, treatment, research and the fact that Cystic Fibrosis Trust and what they've done in the 60 years.

Lucy: So, David, do you want to introduce yourself as well and explain kind of how long you've been at the Trust?

David: Firstly, hello and thanks for having me on the podcast. And Paul, thanks for sharing your story as well. It is incredible to hear, and as Lucy was saying, the contrast with hopefully most people's experience now and the developments which I'm sure we'll touch on later in this conversation.

But yeah, I'm David Ramsden, I'm chief executive of Cystic Fibrosis Trust, and I've actually been there for about eight years now. I joined right at the end of 2016, and before this role I worked for BBC Children in Need. And actually it was through a project that they funded that I started to learn about CF. I went to Manchester to

visit one of the projects that was funded, which was supporting young people to transition from paediatric to adult care, which I know is a constant and recurring theme in cystic fibrosis.

And in that morning, I learned what I now know is a tiny little bit about cystic fibrosis. But it was some key things like, you know, the repeated hospitalisations, the length of treatment in hospital. But honestly, the thing that I walked away with was what we were just talking about, which is that cross infection and the isolation of the people that I saw in those rooms at that centre.

And so when the role came up in the Trust, I was really interested and genuinely excited because I could see that the Trust was in a position to play a really important part in such a wide variety of areas that that can make a difference. And when I looked at the history and saw the bold numbers of what had happened since the early 60s when the Trust had been created, I was really impressed by what the Trust had already done. And so being part of what was to come next was something that really appealed to me. And then I think what also happened, and we all know this when we've gone into job interviews and those sorts of processes, I just really liked the people I met and was drawn into the organisation through their deep commitment, and I haven't regretted it one day.

Every day comes with challenges, but I'm really proud to be part of the Trust and to see what we have delivered and continue to deliver as we look to the future.

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

Lucy: So, I guess we're still reflecting back on the 60th anniversary of the charity. So I've always been alive when the Trust has been a thing, I've seen it kind of rebrand, redevelop and grow. You know, David, you've kind of steered the ship as chief exec since 2016. A lot has happened in the last five, six, seven, eight years. You know, major changes in medication, major changes in kind of health of people with CF and not just physical health, but, you know, emotional wellbeing and things like that. And you've kind of really been a spokesperson as well, working with Parliament, with NHS England, with NICE, when all these doors were shutting in our faces to do with access to medication.

And I guess a lot of people will know your name and will know that you're the chief executive. But I kind of want to know during that time, maybe what was going through your head and how much, you know, we were all wanting this medication and we'll touch on, you know, the research happening for the 10% who can't take Kaftrio. But did you feel quite a big weight on your shoulders in these negotiations and things?

David: It's a very good question, Lucy. As I said, I joined the Trust right at the end of 2016. I remember practicing, ahead of my interview, how to say this strange word Orkambi because it was a word I hadn't encountered before. And I think even when I went into the interview process and then I was lucky enough to be offered the job, I don't think I fully appreciated at that point just how much access to that

drug and the modulators that were following in the pipeline would dominate the next few years of my work and the Trust's work leading up to that special moment in June 2020, when the provisional deal for Kaftrio was announced.

And I remember saying at one of my earliest CF conferences that the real challenge for, I think all of us in the community, was it was the thing, this thing, the single thing that was the most important, but also arguably the thing that we had less direct control over because it was clear, particularly from the reports of what we'd seen from Ivacaftor, but also the reports of what was coming through on the triple, that these drugs had the opportunity for those who could benefit from them to make, you know, a very profound difference for some. And trying to find the way and the tactics to deploy and the people to work with during what was some really dark and challenging times for the community, was something that was a real challenge to make sure that we all work together.

And there were a number of times when I remember speaking to people right across the community who had different views on the approach we should take, you know, and I said, we've got to be realistic. You know, we all have the same objective, but we will have different tactics and strategies we want to pursue. But what was fantastic was the fact of the way the community came together. And actually, I remember being in Parliament and fortunately, after we achieved some of that success, some parliamentarians telling me that they'd actually never seen such an effective community campaign.

And that's a tribute to everyone right across the CF community. So in terms of what I've seen, that's the biggest change over this period of time. And actually for that then to almost directly overlap with obviously the Covid period of time and again, the way in which the community came together, and I think the Trust responded in a way that we never envisaged we'd have to respond. By providing information and support, almost on an around the clock basis during those initial points of concern and challenge. It was something that I was really proud of the team. But also proud of the whole CF community for coming together.

Lucy: Yeah, because you forget when we had to shield in Covid, that you were all there with the resources and the help, and helping us kind of feel together still.

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

Lucy: Can I pick up on the changes that have happened since your childhood, Paul? So you said that you were in paediatrics till age 25. Just kind of talk to me from then. And I know you're on Kaftrio now. So that kind of moment when you took that and just fill me in on the next part of your story,

Paul: Can I say one thing that's happened over the years is that when new medicines came out, it was always in the newspaper that it was a miracle cure for CF. And in reality what was happening was it was all slow steps until we finally got to Kaftrio I would say. And that's made the huge difference. I was becoming a bit blasé about seeing 'this is a new cure' because over my 60 years I read that in

newspaper headlines a lot, but Kaftrio is really a game changer as far as myself is concerned. I'd like to make that clear because over the years I've read it millions of times, you know, new cure, but it was never that, it was always a small step to where we are now.

Lucy: And when Creon came out that must have been quite a change for you as well?

Paul: Yeah it was. So I was taking all sorts of medication to help my digestion and then in my younger days it wasn't a pain, but by the time my teens came along, the problems really started.

But, as I say, I think if you want me to go on and talk about the changes, there's been more meds and better meds, and more awareness. You know, the more I talk to doctors, the better. Quite funny a story I tell. I used to go to USA for my holidays and one year, my ears get blocked and I had to go and get one of them cleared. And I was in my 50s at this time. And the doctor in America didn't believe that I had cystic fibrosis. He just couldn't believe it. He still charged me $65 to clear up my ears, mind you, but that's the kind of thing that I've had to put up with a lot.

And it's quite difficult sitting where I am now, dealing with old age this is something that I'm finding quite hard mentally to deal with because I'm not supposed to be here. I was told I won't be here, you know? So as I get older and older, mentally, it plays funny games with my mind sometimes because I wasn't prepared for old age because when I was born life expectancy was 5 years old. Every time I've hit one of the marks, I'm thinking there's something not right here, you know. I keep going by the marks, you know. And that does play with your mind all the time, those games. And that's probably the most difficult thing. Sorry I'm rambling all over the shop.

Lucy: No it's so interesting to hear. I'm 26 and listening to someone talk about the introduction of Creon for example. I know in my lifetime when Pulmozyme came out, that was the big thing because it was, you know, like breaking down the mucus. But it's something recently that kind of I know people in the community have been having Creon shortages and there is kind of direct help on the CF Trust Helpline and website for that. But that was a tablet I take for granted, there would have been a Creon pot in the dining room, in the living room, in the kitchen, all on the go. So it was super, super easy. In various handbags that I have just not bothered to swap. But that was something when there was a shortage that I thought, gosh, you know, back in the day, they didn't have these and having to eat simple food, or not fatty food. It's so interesting to hear from you how things have changed.

Paul: I used to take this drink rather than Creon. And I took that every day when I was a child and I couldn't go to school dinners because I had to drink that. So every day I had to rush home to take some of this medicine, get my lunch and back to school.

So I couldn't join in with the others again because of me having to leave the dinner, you know, and go home. So it's all those wee things that add up to, you know, you feeling a bit on the outside. You know, you're not quite the same as everybody else.

When I was four, the local council didn't want me to go to the normal school, and my mum had to fight tooth and nail for me to get to go to a normal primary school. So once again, my mother coming to the rescue and there were hundreds of wee fights along the way just to get where I was.

Lucy: I'll pick up on that, so I think every CF parent does fight for their child. People with CF are born with this resilience and determination that they won't take no for an answer. And then I think that stems from like the parents who are also helping them fight their battles too. Because it is an invisible disability and, like you said, the amount of people that don't know about cross infection. And if I mention CF, people they still say, 'oh, is that the thing where you've got to have the massage on the chest?'

But you were saying about the fights, the little fights, the big fights you had to do. And I guess, David, when the CF Trust came about, you started taking on those fights for us. And I guess also in the period of the Trust and your role now, it's about helping us as much as possible with daily life. It is about securing these, these big milestone drugs, but it's the daily life now that you're also helping with.

David: I think that's absolutely right, Lucy and the most important thing that we do is talk to the community and hear from the community, because I would just pick up on Paul's comment about, you know, how he's experienced aging. We know that many people who've been benefiting from the new drugs have talked about their own reflections on passing milestones or anticipating passing milestones that they didn't otherwise expect, and that can be an unsettling and unnerving position to be in. At the Trust we're very mindful to make sure that we're responding to that by thinking, well, what sort of information, support programmes and guidance are people going to need over the coming years and decades?

It's been great to see us develop things like a programme which is supporting people to get into employment, where perhaps they've had disrupted education or not been able to work in the way that they would have wanted. And, you know, I'm sure you know that our overall vision is a life unlimited for everyone with CF, and actually we spend a lot of time thinking about, well, what does that mean in this evolving CF landscape where people's lives are changing. And at the same time not forgetting that the drugs don't work for everyone and are not a cure for anyone.

So actually, we know that although we can see in the big numbers that people are, you know, thousands of people are living longer and healthier lives. We know we also need to keep focused on a very broad spectrum of lived experience and advocate for people. And I think Creon is a classic example. We wouldn't have imagined a couple of years ago that we would face a Creon crisis. Actually, us getting stuck into that and doing all we can, all that is in our ability and raising the

question with the people who have the power to make a difference has been a really important component. And actually if you look at the history of the last 60 years, you see lots of little interventions, lots of little improvements, which meant that the platform for success when the modulators came along was higher than they otherwise would have been.

Lots of innovation, lots of thoughtful clinicians, you know, people taking forward research and actually at the heart of it, people with CF taking forward their own lives and making sure that they, were driving themselves forward to be in this position.

Lucy: Why do you think the CF as a whole still has some unawareness within the public? And also kind of why do you think there's been so many little battles that we've constantly had to have? I'm sure it's the same with every condition fighting for the, the money pot, you know, that NHS, NICE etc. have. But what do you think the issue has been?

David: We sometimes use the phrase that cystic fibrosis is the commonest rare condition. It sort of falls between two stools because, you know, with a community of 11,000 people, that is a lot of people. But that does mean that it's not in every family. But I have found that, as I'm sure you have found as well, that quite often when you raise it, people will remember something from some point, or somebody at school or work at some point. But on the whole, it's quite a latent level of knowledge rather than right at the forefront of people's lives.

So I think when we are, competing isn't the right word, but when we are competing for attention with, conditions, for example, the cancers or dementia, which will affect many, many families. I think that's why we sometimes have a challenge for, getting our message through. That said, I think things like this podcast, but other forms of media and I think the work the Trust and many people across the community does, it has done a fantastic job of raising that awareness. I really have enjoyed over the last few years the awareness campaigns that we've been running, which have shone a light on things like cross infection and the sheer weight of treatments that people with CF are expected to take.

But I think it will always be, particularly in this world where people are so bombarded by different messages, that we'll have to work hard to tell those stories. And I think particularly as well to tell the changing story of CF, because it's easy when, you know, as Paul was saying, when people hear wonder drugs or think that every drug has been one that will make a profound difference, and we have had a drug that has made a difference to many. But we know there's still so much further to go. So still telling those stories, still making sure that we can command people's attention is always going to be a challenge. And then when it comes to, you know, cold, hard cash, it is making sure that we campaign really hard to protect those hard won gains. The multidisciplinary teams, the investment in research, which has been the bedrock of driving change in CF.

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

Lucy: And David, what would you say it means to you to see people like Paul at 71 years old. You know, who have defied the odds from their age and their life expectancy when they were young, but are also kind of living their best life now.

David: Well, I'd like to thank Paul, actually, because, you know, sharing your story is really important to us, but also to people across the community. You are a real trailblazer. We know and are very hopeful that there will be more and more people in the coming years and decades that will be crossing some of the milestones that you're describing. But that also means that we at the Trust and across the community really try to understand what growing old with CF looks like, because it is different from growing old without CF.

And a lot of research and thought is going into what are the particular types of support people who are living with CF into older age are going to need. What should we be making sure people are getting screened and tested for? What's the nature of the changing support? Have people got adequate financial support at that phase of their lives? Perhaps again, if they've had disrupted working? And I think we can learn so much from you because it allows us to take that lived experience into designing the programmes and the information that we can help to support that wider community going through this transition in the years to come.

Lucy: Paul, you're obviously retired now, but kind of what is your advice for others with CF?

Paul: I find it hard to give advice and to be honest, because my journey has been a very particular one and every one has their own journey.

What I've done, and I can only speak for myself, is I've been very positive about everything. And having a loving family, my wife is sitting behind the camera, nodding approvingly or shaking her head or what have you. But mostly shaking her head, actually. My mother was one incredible woman and she fought tooth and nail for me every day of her life until she passed away at 90. And the day that she passed away, she still called me her golden flower. So these are, the kind of people that surround me and with that positive attitude that, for me, is the way that I got through everything.

For me, it's been the mindset. And I know it's difficult for others and other situations, but the mindset for me has been what has made me be able to get to the age of 71 and be very happy. As I sit here in Tenerife in 72 degrees.

Lucy: Well, I was going to ask if that's some advice. The NHS should prescribe CF holidays to some hotter countries away from the bugs here.

Paul: Yeah, I think that should be the next thing. I think they should fund it because here I am with my shorts on, the sun is blazing outside and it's just one of the things that I do to get away from the British weather because otherwise I'd be sitting in for 2 or 3 months looking out at the rain, and I'm lucky enough to be able to come out here.

David: It might be one of our harder lobbying campaign. So I'll be honest. Let's just set expectations at this stage for everyone, getting a holiday in Tenerife might be quite a hard ask. I'm up for it, but let's just be clear.

Lucy: Everyone who's listening we're joking. We're not all sending emails and letters to David Ramsden for this. It is a joke!

But yeah, I mean, I think going back to Covid times and how, you know, when people were wearing masks and things, I think that's when people without a condition realised that we are more vulnerable. And I think that kind of as a secondary effect helped in a way, you know, I am vulnerable, I'm prone to chest infections or whatever. Please stay away. And I think people respect that, well in my workplace, they do a little bit more. And the kind of common acceptance of wearing a mask, you know, I went to the theatre last night, I wore a mask because I was sitting around a lot of people, and I think things are shifting in in the world as well, which has helped CF slightly, but I still take your point of a holiday, Paul!

I mean, David, we have seen such incredible things and we've been touching on a few of them, in the past six decades. We know CF isn't done. It's not cured. What's coming up in the next 60 years? I mean, hopefully you'll be retired to Tenerife at that point. And there'll be a lot of stuff you can't share because of it being confidential and negotiations and things. But what glimpses of hope are there in the next decade of research? Do you know what I mean? I'm asking a very vague question on purpose.

David: But Lucy it's a very important question as well. I mean, one of the things that has really struck me is I have the opportunity, the good fortune, to go to the major European cystic fibrosis conference every year and the North American one. And it's hard to bring over, particularly the North American one, the scale of effort that is being committed to CF. So you might imagine, if you were outside the CF world, that this news of progress was sort of depressing, the level of research that was taking place in CF, I would say it's exactly the opposite, actually. In that there is such momentum building and built around making a difference for CF, that people are really getting stuck in to push things forward with greater speed.

In fact, the chief executive of the foundation over in the States used a great word in his opening speech, which was urgency. And this is the urgency that is really injected across the whole community in the number of different strands of research. Obviously, we've just seen the approval in the states of the next modulator, and we know that's coming hopefully here in the coming months.

But there's a whole raft of treatments behind that as well, that are going to be looking at the underlying cause. But also the Trust, along with others, is investing a great deal in anti-infectives and other areas, but at the same time keeping focused on the non-medical aspects of a changing life with CF. So what I am really hopeful.

If we look to project forward, I won't project forward as far as 60 years, but I think in the early part of the next 60 years, CF is going to be the condition that increasingly people are living with and not dying from. And I really believe that it won't be very long and I'm not over promising here, but during the next few decades of the life of the Trust, you know, we will genuinely be focused on delivering a life unlimited for almost everybody with CF and ultimately everyone with CF. The disease will have changed that profoundly.

And you know, one of the things that's been really interesting, you know, we were very clear we weren't celebrating 60 years of the Trust. We were marking 60 years the Trust. But that does give an opportunity to look back at what people were saying at different milestones in the life of the Trust and I'm clear that all the people who were there at the beginning would be amazed by how far things had come, but also pushing us further. And that's how I feel. Yes we've done so much as a community and we going to keep running hard.

Lucy: What I live by is kind of like keeping myself as well as I can until there's something else, until there's something else, until there's something else.

Two questions I'll ask you, David, and then I'll kind of wrap up and we'll close. The first question, people will have seen about that American drug that that's out now, but is there going to have to be this negotiation with NICE and NHS about securing this next medication for access for people in this country?

David: We're not anticipating there will be. We're hoping at the moment, from what we know, that over the coming months, and we're expecting actually the process to conclude during this calendar year, it should be relatively straightforward. That always comes with an asterisk. But NICE has now started its element of the process. And obviously it also has to go to the regulator and agreed by each of the NHS's. But because of the existing arrangements in place for the funding of Kaftrio and the other modulator drugs, we're not expecting the placards to have to come out of the cupboard.

I always say, though, that the placards are in the cupboard ready to go, but I'm hopeful, just as we found with the latest NICE process that actually we will be able to build on the understanding between the negotiating parties, but also an understanding of what these drugs do and the impact they have. So I'm really hopeful that that won't be the case.

Lucy: Yeah. And I think it's good to have that transparency. Whilst we've got you on the podcast to ask you that, as it's so kind of relevant in what's happening at the moment. And then I guess my other question is, so when I was diagnosed at two years old, obviously the Trust was at a different point. It was very much likw my parents fundraised a lot for the cure, because it was kind of like we'd need X amount of money to then have gene therapy, etc..

How far would you say along that, that gene therapy, or even a cure, might be in the works? I know you've said it's about living with CF and it not affecting life as much, but, you know, on the kind of gene therapy and cure angle, where are we with research?

David: Well, I think there's been a lot of progress, actually. And if you look at the number of different genetic based therapies that are in development, and actually now some in trial. We perhaps haven't got to that point as quickly as people might have imagined 20 years ago. But we are there now. So when again, the conferences I was referencing earlier, they put the graphics up to show where they are in development.

I think it's also important. And, you know, there's some good resources on our website that explain what a genetic therapy is, that it is not necessarily automatically curative. It actually often is acting a little bit like the modulators or improving treatment because, as I'm sure you will have picked up in the various challenges along the way, it's tough to put stuff into the lungs because the lungs like to get stuff out of the lungs, but it looks like there's again, real momentum building there.

And, you know, alongside the campaign that the foundation has, there is real, tangible progress being made in the building blocks that can lead towards that cure. But again, I'm always wary and final remark Lucy, of course, that's where we want to get to. But also, it's critical that we're supporting people's diverse, lived experience now while keeping our focus on that and also not creating an expectation that this is going to be something that is straightforward and quick, because this is hard science that people are leading on.

Lucy: Yeah, and exactly that. What the Trust does is you're looking to the future, this research going into the future. But physically you're there with us now with the day to day, physically well, mentally well and fulfilling our lives. Right now, as well as looking at the future.

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

Lucy: Paul, I mean, what do you feel like having CF has taught you in your life?

Paul: Just to be resilient, you know, and try and be strong. It's a difficult question to answer but I guess it's also taught me to do what I can and what is possible. You know, people say, don't do this, don't do that. I often try to do those things up to as much as I can.

So, CF has just taught me to manage my life, so to speak, you know, manage my life and expectations. And it's been hard because the expectations haven't always been great you know, and always in the back of your mind, is this going to be your last year, you know? But resilience, positive attitude and having loving people around me has made all the difference to my life. And having that really good team, and the Glasgow CF team are amazing. Really, really good people. Always there.

Lucy: For me, that's the third part of the, well, fourth part of the square, I guess. The family, the person with CF, the Trust and then the teams, the teams that see us day in and day and out.

Okay. Final question for you both. This is something we ask all our guests. It's not meant to be a trick question, but what do you wish more people knew about CF? So I guess David will start with you.

David: I wish people knew that 1 in 25 people in the UK carried a mutation that caused CF, and we have the second largest CF community in the world.

I wish people knew that people with CF are advised not to meet, because I think that's such a particular aspect of, living with CF. And finally, I wish people knew that the CF community is on the move and we've picked up some real momentum and we're not going to stop.

Lucy: Paul, what do you wish that people knew?

Paul: I've got one thing, I want people to know that the future is positive. I'd like everyone to look at CF more positively. The cure is ahead of us! But all the hard work you and David are doing, just makes it more positive every single day. And I'd like to thank you for all the hard work you do from a CF old codger.

Lucy: Well, I was just going to, to echo that, thanking you both. Thank you, Paul, for sharing your story. I mean, that will give so many people hope, if they are feeling you know, down or anything. And David just an opportunity for myself and everyone in the CF community. Thank you to all you do and everyone at the Trust. It's an incredible charity where we're with you forever and not just with you for a specific time and then move on from the charity. We're here for the whole time and, and we just want to, thank you.

David: Well, can I thank you both as well? But also thank the community and the amazing bunch of people I get the chance to work with. I'm really lucky that I've got such a talented, committed team around me. So thank you.

Lucy: It was lovely having a tea and catch up with David and Paul. Thank you so much for joining us on the podcast today and helping us mark FeBrewary and the end of the 60th anniversary year of the Trust. To find out more about how all you listeners can get involved in FeBrewary, or if you'd like to donate the cost of a brew to Cystic Fibrosis Trust, please go to www.cysticfibrosis.org.uk/FeBrewary.

I've been Lucy Baxter and I'll see you next episode. Goodbye.