

# Cystic Fibrosis Trust

## Season 2, episode 1: Living with an invisible condition

**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 also have cystic fibrosis. I'm one of over 10,800 people in the UK living with the condition.

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 catching lots of infections to struggling to put on weight. I was diagnosed with CF at two years old, but CF is part of my life, not my whole life, and it certainly doesn't define who I am.

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

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

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

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

You can call them on 0300 373 1000 or email [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk).

Welcome to the first episode of season two of CForYourself. We're back and I can't wait to share this season's episodes with you. Today I'm going to catch up with 26-year-old Kieron Smith, the face of our latest #CFTruths Awareness campaign, 'You don't see CF', that launched across the UK in April this year.

As part of this Kieron's face appeared on billboards and adverts to raise awareness of the realities of cystic fibrosis and life with an invisible condition. As the campaign highlights, you might not be able to see CF or what it does to the body, but it's not invisible to the 10,800 people in the UK whose lives are affected by it every single day.

The challenge of living with CF is invisible, except for the ones who live with it and their close friends and family.

I'm really excited to be chatting to Kieran today to hear more about his involvement in the campaign, his life with care and the importance of raising awareness. We'll also be hearing from

# Cystic Fibrosis Trust

Sean Chapman, Head of Marketing at The Trust, to give us the lowdown on the campaign and the response from the CF community.

Now, without further ado, let's welcome Kieron to the podcast.

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

**Kieron:** Yeah, I'm doing really well, thank you. How you doing?

**Lucy:** Yeah, I'm good. So for people who don't know your story and kind of who you are, why don't you just tell us a little bit about yourself?

**Kieron:** I was recently involved in the 'You don't see CF' campaign, so I've been on billboards across the country, in the UK and there's a video and sort of campaign all over the CF Trust website.

So that's been great to get involved. I'm 26 years old, obviously got cystic fibrosis myself and I'm a qualified nutritionist, so I work doing, so I work for a start company at the moment helping develop a weight management device. And I also coach people to help them build muscle, loose body fat, stay healthy. So yeah, that's a little bit about me at the moment.

**Lucy:** What would you say kind of like growing up with CF? We're very similar age, so guessing our experiences of when we started things and things that came along and stuff were quite similar. But what was your childhood kind of growing up with cystic fibrosis like?

**Kieron:** There's I suppose, there's been a few different key moments in my life that have changed how CF like impacts me and how it dealt with that and I'd say growing up, for the first six years of my life, I was always very ill, so all my memories of that are me coughing, and me being bloated. My parents always worried and everything on that front. And that was because for the first six years of my life I hadn't been diagnosed, with CF. So I was living with it without any medication, basically because it was completely missed off the test somehow.

But yeah, when I turned about six years old, my nan was doing lots of research because I was really ill and she was concerned and doctor Google, sort of found out that my symptoms were really similar to what someone with CF would expect to experience.

**Lucy:** And what were those symptoms? Because obviously, like, you know, you can Google anything and think that you're about to die. So like, for people who like maybe are listening to this and don't have CF, or just listen to the podcast, wanted to know more about CF, kind of what were those symptoms that you had pre-diagnosis that kind of led you to that journey?

**Kieron:** Yes, so the big one was endless coughing, so always coughing, lots of mucus, breathing quite heavily.

I was always on the toilet, so I'd be going to toilet like five or six times a day, but then quite constipated, so nothing was passing. So those are two massive symptoms. And then one, I think one that really symbolizes CF is that obviously your skin taste salty. And I don't know how

# Cystic Fibrosis Trust

it came about that my skin got tasted, but I think obviously being young and whatever happens, my mum realized that my skin did taste a bit salty and I think that was the main one, which then was like, okay, that's a little bit different to asthma or any other sort of condition that they were sort of hypothesizing that I might have had.

**Lucy:** So obviously you had the first six years of your life not having to do physio, not taking tablets. So I was diagnosed at two years old, so even though for those first two years I didn't do anything like treatment wise because we didn't know I had CF, I can't remember a time where I wasn't taking tablets and I wasn't, you know, to having physio.

So you remember that before you were six?

**Kieron:** Yeah, I do, yeah. Obviously not massive memories because it was, I was very young and I was very ill so memories are quite faded. But I do remember. Yeah. Not not having to do those things but it was all overshadowed by just being ill to be honest and being not very healthy.

But, but yeah. Yeah. Basically once I started taking tablets and got that diagnosis, I then had to start taking these tablets in school in front of people. I would get lots of questions like, Oh, why is he suddenly taking the tablets? Why does he have to eat more food? And I struggled with that quite a lot because obviously I wasn't used to taking the tablets, I wasn't used to having this condition that I didn't really know anything about. Ended up getting a lot of questions at a very young age about why am I different, why do I have to do that? Yeah, and I struggled a bit sort of answering those questions.

**Lucy:** How did you kind of deal with that then? Because I agree, like especially in primary school, as much as that, the teachers are amazing, but they're not the most subtle like I had to have, I had a finger of fudge for my afternoon snack once. And I remember distinctively like the teacher, she put kind of like marks, like come back to me when you get that much, come back for a tablet, come back, you know, and there were a lot of people around. I mean, I didn't mind it. I think I was oblivious when I was in reception.

But but yeah, like as you get older, it's kind of summat you do more discreetly. Not in a in a good way. You just kind of get on with it. But I guess from you going to school one day to the next and then having all these tablets, how did you kind of cope with that? Like you said.

**Kieron:** I think because I was so young, like I was like six, seven years old. I did struggle with that quite a bit. And like you said, the teachers aren't very subtle sometimes. Obviously, they're trying their best and not trying to make you feel seem different, but potentially they don't think about it in the context that we are, we're thinking about it. So for me, it's it was similar to you, other teachers because they found out I had to eat more.

So at like a break time, they'd be like, Oh, Kieran, you need to come to the main hall and eat your extra meal now and then all my friends would be going out and playing on the like playing

# Cystic Fibrosis Trust

football and stuff, and then I'd be out, I'd have to stay in for an extra 10 minutes and eat my meal.

**Lucy:** Yeah, that's so relatable in in break times I used to have to have two glasses of full fat milk, but like it was it makes me feel nauseous thinking about it because it had the cream on top and it was just really horrible and I didn't want to drink it. So I didn't. And then I missed my break time and everyone was running around and it kind of was like I felt like I was forced to sit down eat my toast with butter, drink my milk, and it was like everyone was trying to help, but it kind of gave you this kind of, ooh, like, I don't I'm not hungry. Why do I need to eat that now, kind of thing.

**Kieron:** Yeah, yeah. It's not very nice, is it? It's interesting that you've had that experience as well because I haven't spoken to anyone else who experienced that in school.

**Lucy:** How did you kind of then grow up in terms of erm food wise, kind of, did you enjoy eating all this food or did you kind of feel like it was a lot of pressure so then you, you know, when when children are told you have to do it naturally, they don't want to do that, so what, what was that like growing up trying to eat the amount of calories we had to eat?

**Kieron:** I'm trying to think now. I remember because I was brought up vegetarian, like my family were vegetarian, and then suddenly when I got diagnosed with CF, the doctors were like, you need to eat meat because you need to put on weight so then my my parents were trying to experiment like give me meat. And I remember that being an experience I didn't enjoy because obviously I didn't like meat and hadn't been eating it for the first seven years of my life.

In terms of the food, I played football and exercise a lot, so I always had quite a decent appetite, but I was always quite skinny, so I obviously wasn't eating the amount that I probably should have been eating to be at a healthy weight.

But I've always had a quite a good relationship with food, despite yeah, those those experiences.

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

**Lucy:** Without introducing the treatment you would have improved and I guess been able to kind of carry on with life. What would you say kind of compared to when you were a child to now like how your CF is?

**Kieron:** Well I think after that experience of sort of getting diagnosed and having to take tablets at a young age. When I was like eight or nine years old, my mum and dad split and I actually moved school, so I went somewhere else.

And at that point I sort of had my tablets and my lunch and no one saw me take them. So and I become it was like no one knew I had cystic fibrosis. So yeah, it sort of led me into sort of hiding my CF and hiding my tablets and from that moment on onwards, I never really shared that I was taking, taking Creon or any of my medication with my friend's growing up.

# Cystic Fibrosis Trust

It went from being like very visible, everyone thought I was different to suddenly I can hide all this. No one needs to know that I've got CF, I'll just deal with that at home. And then like with my friends in the public, I'll just be like, okay, I'm just a normal person. I'll keep up with everyone and I'll just hide everything I'm doing.

So that was like my whole secondary school life.

**Lucy:** So contrast that to being on billboards for this campaign and like your face is like associated with this campaign that the Trust did. It was all about how you don't see CF and how it's an invisible kind of disability in inverted commas, and how you look the same regardless on the outside. What was that like for you?

**Kieron:** Yeah, it's been amazing getting involved in this because obviously the big way CF started affecting me, then growing up, going through secondary school and then in my early twenties was that it was very hidden and I had created it created a new problem for myself by hiding it. And obviously over the last like 3 to 5 years, I've tried to be more open and try to talk to all my friends and like make people aware of CF.

And and what I've been living with this whole time. Because I've been hiding it so long its quite difficult to actually open up those conversations. A lot of people are quite shocked like how he how have you hidden this for like the last five years I've known you even 7 years.

And I think this opportunity to be involved in this campaign came at a really like a great time.

Like as soon as I got contacted to get involved in this, it really excited me because it just really resonates with exactly how CF affects me, that it is invisible and I would love it to be there, to be more awareness about it and more conversations around it. And if I told someone I got CF, I'd love it if they already knew what CF was without having to think about where to even start when you're explaining it, because there's so much. It's such a complex condition, there's so much involved with CF that it can be quite a difficult conversation if you're not used to speaking to people about it.

**Lucy:** I think in the public there's a lot of kind of outdated views on CF and kind of like, Oh, do you have to have I get a lot of do you have to have that chest massage? And I'm like, do you mean, physio? Or do you do you have to do that, that thing? And it's like they've got, they've got visions of always being in almost like a, a vacuum.

I think that's quite, not a fault on their behalf, but obviously like. Even though it's the most common rare disease, it's not, it's not well known in terms of compared to other things. And then obviously you do it in your GCSE biology to look at genetics and allials and things, but then that's it really, unless you know someone and I, I get quite a lot of shouldn't you be in a wheelchair with that. And they get confused with that cerebral palsy and muscular dystrophy and like because the words are kind of similar but they're not. So it's like what you said when you tell people. It's well, you don't look like you do and it's like what kind of a like a a sentence is that to tell me?

# Cystic Fibrosis Trust

**Kieron:** Exactly. Yeah.

I think as soon as you tell someone you've got CF it's like, oh, I thought you'd look iller than that. I thought you'd be like, I can't believe you got CF. And then but yeah, if it was, I would love it to be more well known, like what it actually is similar to something like diabetes where if you mention you got diabetes to someone today, I think most people would be like, oh yeah, I know what that is. You've got to take insulin. Your blood sugar is a little bit out of place sometimes.

**Lucy:** Yeah. And that's what obviously the CF Trusts were doing with this campaign to try and get it out there. And all the campaigns they do to, to, to showcase that. So from your point of view, what did you actually have to do for the campaign? What was it like? With like those photos you had taken. Talk me through the kind of the process behind the scenes of the campaign.

**Kieron:** Yeah, it was really great to get involved in it. So it was, basically we did a full day of shooting, so video photography at my home in Chester, and then we went to my gym as well, where I did like jujitsu and kickboxing, and then we went over to a local park as well and just explored some of the town in Chester.

And we just got lots different footage of a day in my life, basically. So its quite raw footage of what it's like to live with CF, and it's what I really liked about it is all the behind the scenes. So it's me doing my medication, like the inhaled antibiotics, saline, things like that. The things that for me, like none, none of my friends see that, that sort of thing. Or even a lot, some of them don't even know that's like part of CF.

**Lucy:** Yeah. And also it's like before work or before, before I go to work, I've had to do like whole regime and you know it's kind of like people don't understand that aspect in terms of if you're a couple minutes late or if you're tired or you know, you've got to get up and do all that and your body's just kind of has to do all that just to try and be a bit more normal.

Like, other people who to just to just get on with with it and maybe just go have breakfast in the morning and that's it, you know, like it's it's that aspect that people don't understand the behind the scenes, which I think is really important, like you said.

And it was also like the CF Truths and I think like the Trust got lots of different people to sort of say their CF Truth. Erm what would you say yours is then like the key thing that you'd want people to know about CF if they didn't.

**Kieron:** Yeah. The key thing I would want people to know is, is that although lots of people with CF have this sort of healthy front where they look completely healthy and that there's nothing going on it is the, the tablets that you take like before your meals, it's the medication that you have, like you said when before you go to work and that allows a lot of people with CF to then be healthy.

# Cystic Fibrosis Trust

But it takes a lot of effort. You got to do it every single day. If you miss your medication one day, for example, like for me, like it can make me feel a bit more groggy, might cough a little bit more, obviously like having Kaftrio now it's helped a lot but yeah, it's that relentless sort of keeping up with its main it's almost like maintenance.

It's like every morning you got to make sure your bodies working, you've got to do all the things you can do to make sure it is working properly and it's that side of thing. Things. Really. Yeah.

**Lucy:** And so when the campaign was kind of was put out to the public and like these pictures of you were like on these billboards, where did you go or where did you see it?

And I guess where I was the biggest place that one of the billboards was.

**Kieron:** I'm actually a bit gutted because I haven't seen one in person yet. I don't know if they're still out at the moment or not. But yeah, I live in Chester and there's no billboards here, unfortunately. But I've I've been to London, and I've been to like Southampton and Manchester, but I didn't manage to see any.

But I've been sent loads and loads of photos from friends and just people that know me like. Sort of being like, I just spotted you in London Tube Station or in Euston Station. I've just spotted you in Southampton and just spotted you in Bristol. So it's been really cool to see that. And some of them are like absolutely massive in London.

So it's crazy to see see your face like blown up that big, like doing a campaign that you really believe in and you really like it means so much to me to see that and yeah to be involved in that is crazy.

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

**Lucy:** If we touch a little bit on like your career and like the nutritionists side, why did you decide to go down that pathway?

**Kieron:** Well, I suppose growing up, I always I was always active because because of my CF probably I always wanted to stay healthy and active and it was always promoted by like my CF team. And then when I got to sixth form, I didn't really know what I wanted to do with my life and where I wanted to go. So I ended up doing a degree in history.

And when I did that, I did an internship with the Civil Service and I quite quickly realized like I didn't want to do a job like that. Sort of like an office job where I couldn't be active as well or I wasn't impacting people's lives in the way that I knew. I knew from my own experience that exercise and nutrition can have such a big impact on your health and your wellbeing and the way you feel.

And so I realized I wanted to give that feeling to other people, like I wanted to help other people feel like that. So after doing my history degree, I was like looking at anything I could do to get into nutrition. I'd already been doing lots of research myself. But erm I just wanted to

# Cystic Fibrosis Trust

like the formal qualification. So I did an intensive access course at the University of Worcester, and then after that I managed to get onto a master's degree in nutritional therapy, and I did that for two years.

And then following that, I got into nutrition coaching, did my personal training course and yeah, then I could help coach people in nutrition and training. And it sort of it just aligns with my values and my values of staying fit and healthy is going to be like the best thing you can do for your health. Like it's the one thing that you have control of like CF might throw random things that you that you can't control, but you do have control of how, like obviously if you're healthy. If you're not healthy you don't have as much control. But if you're healthy, you can eat well, you can move your body. And so yeah, it just resonated massively with me and I wanted to make a career out of that

**Lucy:** And also kind of as much as Kaftrio and these drugs coming through and amazing it's it's almost kind of not solely reliant on them. It's kind of doing your own holistic stuff like exercise and eating well on the side to kind of make you the best you can be. And so what I'm interested in, is obviously when we were younger, like it was just get the get the calories in, doesn't matter how how just get the calories.

And if that's McDonald's, if that's KFC, just get them in. You need to have this amount. You just need to do. But the weight on. Whereas now I think it's changed to like don't just have fast food and, you know, like eat well, eat like fatty oils and, you know, like fish. Would you say that's kind of the shift that's happened since we were little children?

**Kieron:** Yeah, definitely. I remember, like you said, the advice when you're younger is just eat as much as you can. Have five bags of crisps a day, eat loads of chocolate and I think that's definitely changed, especially with Kaftrio, because I suppose our bodies have erm they're more in line with how other people's bodies are now, so we're now. Well, a lot people with CF potentially don't actually need all these extra calories anymore.

And so the nutritional guidance I'd say is almost gone full circle where we're probably going back to what a standard person sort of needs to eat.

**Lucy:** So what's your favorite meal then?

**Kieron:** I'm vegan, so I eat a lot of tofu. I love tofu because it's really good protein source, but I usually try and stick to like quick meals, so things like stir fries with noodles and loads of veggies.

I love lasagna. That's probably my favorite meal, but that's more like a treat meal on a weekend. And then yeah, things like bolognaise, curries, just nice quick things that you can throw together. You can always get a bit of protein in there and then get lots of carbs in as well.

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



# Cystic Fibrosis Trust

**Lucy:** And so I guess kind of looking back where you are now to where you were kind of when you were younger, if you had like one piece of advice for a young person with CF today, what would it be?

I mean, you might not do you kind of regret hiding it so much when you were a child or like young person, kind of what what would your advice be?

**Kieron:** I do, like if I was looking at myself as a kid now and I could tell myself to do something different, it would be to just embrace it like, own that you've got CF. Don't try and hide it and never let it hold you back from anything. It's definitely nothing to be ashamed of. You don't need to try and hide to fit in because like we're all unique. People are a lot more way more understanding than I ever gave them credit for. So I in my head, people would think I'm different and sort of I'd be seen as the outcast for having CF. But that's just not how. It's not how people are in general. People aren't going to respond like that to you. So yeah, for a young person like how I was, who struggles to open up about their CF it's, I think it would be taking it in more stages.

Talking to a few of your closest friends, just making them aware of like this is this is what I've got. This way I'm living with. I just wanted to tell you because you're one of my best friends, so it's good that you more about me, and I think it just allows you to then be comfortable and open up about it.

**Lucy:** So for, for a child or say if they like moving, you know, they've got a lot of erm year six going into year seven, etc., etc.. like I can, I did struggle with this in year seven, like I how I how do I tell people, how do I tell my friends? And I had no idea how to start that conversation. And I think I did it in a really weird and unconventional way, which was we were all we had to do, like PowerPoints and in year seven to raise money for a charity.

So I did CF and I like told my story, just to my like form. And then we won that PowerPoint competition, which I didn't realize we then had to tell the year and then we won the year and then had to do a whole school assembly. And I was kind of like a celebrity. I was able to go to the front of the queue at lunch and stuff, but like that was such a weird way to do it.

How would you advise people? I mean, any age really, if you're starting a new job and telling people and stuff like that, how would you advise or how would you start that conversation?

**Kieron:** I think it's different in different situations. I'm still like I still feel that awkward if I have to tell someone who I've never met before, even now. And I'm like, I'm 26 years old, but what I try to do, if it's if I'm one on one, sometimes I might just bring it up if we're eating food, like I probably get my tablet out and I know they're probably going to ask questions. I'm just like, oh, these are just because I've got CF, so I don't I don't produce the enzymes that digest my food.

And then that sort of opens up the question straight away, the conversation. In terms of work like with the start-up company I'm working with now, works obviously really understanding so the easiest way I found to open up a bit about it is whenever I've got a hospital appointment I'll

# Cystic Fibrosis Trust

just be like, I've got a hospital appointment because I've got cystic fibrosis and that's sort of how I drop it in with employers, because then if they want to ask more questions, they can. If not, they're aware that I've got it.

And I think if I was going back to school and trying to tell people about it now, one thing I know like a lot of people do is just just take your medication in front of people and then if someone says something, just have an answer sort of pre-scripted, ready to go. So you never feel awkward if someone asks you, asks you about it. I think that's what I would do if I went about school now, because it's, you don't really have to say anything. You just doing what you do. Yeah, it might feel a bit awkward first time you get them out, but then you know you've got an answer ready to go.

And then once that first question's happened, it's all the awkwardness is gone then and you can sort of relax that that's out in the open. You don't have anything to be anxious about, be nervous about because I'm sure the response you get is going to be a lot more positive than your head's probably telling you it's going to be.

**Lucy:** For sure. Well, I mean, all that advice is just so helpful and kind of I can see why you were erm the face of the campaign, there's no better person.

Looking to the future. What what are your hopes for the CF community?

**Kieron:** I still feel like people don't understand CF fully, and if people want to know more, they sort of just Google it.

And if you like, I think, I haven't looked at, the Wikipedia page for a while. But I think it's probably still quite outdated. I remember looking at a few years ago.

Erm so I'd love for CF to be much better understood. Like of course people aren't going to have an in-depth knowledge of what CF is, but if people understood that people with CF can look healthy and sort of go about life normally, but then understand that they've got all this other stuff that goes on behind the scenes. I think it just makes it easier for everyone to talk about it and for younger people growing up to be open about their CF.

And so yeah, I'd love that. I'd love for CF to be as widely understood as something like diabetes, like I said. And then I think there's so much exciting stuff going on in the CF community at the moment with obviously Kaftrio in the last couple of years, that's been an absolute game changer in terms of those of us who are lucky enough to have it. It's like it's changed my life in a really positive way.

And I think, yeah, the more awareness we can, the more awareness campaigns that CF Trust does and the more people understand CF it's only going to benefit the CF community because we're going to potentially get more investment. There's going to be more research on new medications, new therapies. And then it's going to become more of a condition that potentially governments are going to be more interested in and more policy, things like that.

# Cystic Fibrosis Trust

So yeah, I hope all those things are to come in the CF community and ultimately all of that leads to people with CF living happier, healthier and longer lives, which is what we want, isn't it?

**Lucy:** Yeah, for sure, definitely. Well, I mean, thank you so much for coming on today, chatting about that and kind of just being so open about your story and all aspects, I feel like we've covered such a range of topics and like the main one, just being like there just needs to be more awareness. And that is exactly what the CF Trust is doing through their CF Week but throughout the whole year with all the campaigns and things they do. So thanks for chatting to me today.

**Kieron:** No, thanks for having me on Lucy it's been really nice to talk to you.

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

**Izzie (Content lead):** A big thank you to Lucy and Kieron for sharing their expertise and stories. Now we're going to be finding out a little bit more about the impact our latest CF Truths awareness campaign had. My name is Izzie and I'm content lead at the Trust. And now I'm joined by Sean Chapman, who is our Head of Marketing.

Hey, Sean, please, could you tell us a little bit about the latest awareness campaign?

**Sean:** Yes, we recently launched our awareness campaign in April, which ran for almost two months. And it's really important for the Trust to both raise awareness of cystic fibrosis, but also raise awareness of the Cystic Fibrosis Trust and the work that we do. So for us, it's really important because we know from our insights that people with CF find it really valuable the more that people know about CF.

So for us, we as an organization, we also want to engage a wider UK public as wide as we can go. Even though cystic fibrosis is a rare condition, it's really valuable, the more people that know about it, particularly people who can influence and help us drive change. So for us, our latest awareness campaign is very much about demonstrating those everyday struggles that people with CF experience. We very much built on our previous awareness campaign last year, which drew the parallels between COVID-19 and CF, and that was developed and driven by someone with CF.

So we really wanted to learn from that and build on that and, you know, really be authentic in that storytelling and making sure that the stories we're telling well curated and developed by people who were affected by CF and we are telling those stories. In addition, as mentioned, we have a lot of insights to reflect that people with CF would like more people generally to know more about CF.

So as part of the campaign, we developed and provided some additional tools for people affected by CF to help talk about the condition, particularly on the back of this campaign, where there would generally be some more awareness. And then connected to this, we just wanted to

# Cystic Fibrosis Trust

make sure people were aware of the Cystic Fibrosis Trust and what we do and that we are you know the UK wide charity for cystic fibrosis.

So as mentioned, the campaign very much built on the framework of CF Truths. Very much telling real life stories, real life experiences of people with CF and what it's like to have CF and that CF is more than just a condition that impacts the lungs, which we really wanted to get across. So the campaign ultimately was something that was developed with the CF community. And what we came out with was a campaign that was very much about cystic fibrosis as an invisible condition. It's something that you can all see and, you know, sometimes that can lead to discrimination or in some cases that can lead to people perhaps hiding, or not revealing their CF because they find that more helpful. But perhaps in some instances, as with Kieron's story, actually, it can also be unhelpful and we wanted the campaign to really shine a light on the fact that it can be an invisible condition.

And there's a lot of work that goes on in the backgrounds for people with cystic fibrosis to stay well, people are very much unaware of that. So it's really to shine a light on the fact of the invisible nature of CF and the burden of treatment and care that goes into sort of staying well.

**Izzie:** Amazing. And you have touched on a little bit about how you decided on what messaging you wanted. But why did you feel like this campaign in particular was so important?

**Sean:** I suppose we know that cystic fibrosis is a rare condition and we also know that awareness amongst the wider public is still relatively low. And whilst most of our focus, I suppose is on engaging and supporting people who are impacted by CF so people with CF and their families. That's actually we need we need a moment and a point in time really where we put some focus on that wider UK public and other influential people who can help support change, positive change for people affected by CF.

So we know, for instance, from our insights and from some of the development of the work we do at the Trust, such as our new employment program, Work Forwards that it can be unhelpful for people with CF when it comes to things like education and or employment that sometimes is unhelpful barriers or challenges around living with CF in terms of taking time out, hospital appointments or other factors, or just that recruitment process and disclosing that you have CF. And if there's literally no awareness at CF, perhaps appropriate things are not put in place in the work place in order to make that easier and more supportive for people with CF.

So we felt we really needed a role really, to make sure that people are aware of those challenges and that pressure and responsibility isn't necessary just for people with CF if we can have a role to support that.

And as mentioned, we know people impacted by CF really want us to raise awareness of CF and through the Trust and the platforms that we have, we can really facilitate those real life experiences those real life stories to really demonstrate to a wider public what it really is like to have CF. So, you know, if people are coming into contact or working with people with CF or policymakers or people in government are aware of certain issues that are impacting CF, if they

# Cystic Fibrosis Trust

know more about CF in the first instance sense it can help really in terms of those decisions that are made.

So we really wanted to engage new influencers but also new donors. You know, we still need to fund new research, we still need to advocate for change. So it was really important that we reached out really to widen that awareness in the new landscape we are in. And I think with this campaign, as mentioned, the messaging was very much co-created with the CF community.

We did a lot of work internally and externally and a lot of focus groups really to really get the messaging and the proposition right in terms of CF as an invisible condition. And we ended up with that through a series of different issues that we looked to tackle, and that resonated really well with both our connected community in terms of people who were impacted by CF, but also the cold audience who we tested this with.

So it was a real sweet spot in terms of a message that resonated and surprised a cold new audience to to grab their attention and want to find out more and also genuinely reflecting the real life experiences of people with CF and a story through our testing that people impacted by, CF, felt comfortable with us telling.

**Izzie:** And what has the response been like from the CF community?

**Sean:** Well I must admit it's been a massive relief. The response has been very positive. I think the co-creation and audience insights and testing really helped with the cross-section of the CF community. So that co-creation piece I think really helped. Some of the feedback we received was that it really resonated with some people found it quite clever, some people find it really true to their experience, some people kind of quite humorous with it I suppose, in terms of, you know, that, you know, they could double the amount of treatments that Kieron took, for instance.

So but I think I think the point was they really reflected on the burden treatment and their day to day experience really of feeling like an invisible condition and that day to day experience of interacting with the wider public, who would not necessarily know that you are feeling, particularly unwell as it's not necessarily always visible or the amount of work that needs to be done in order to stay well.

So I think it also was really good because it also enabled a cross-section of the CF community to share their story and to use our platforms to share their experience of what it meant for them in terms of CF as an invisible condition. It wasn't just Kieron's story. It also enabled other stories to be shared. And I thought we saw some good engagement in terms of people sharing the stories.

And I think Kieron's video in particular was very popular in telling his story. So we're always really grateful when people are so open in order to share their story with the wider public.

**Izzie:** Yeah, it's been amazing to see. And erm what impact has this campaign had?

# Cystic Fibrosis Trust

**Sean:** In terms of impact. I think the sort of different sort of different areas that we looked at.

I mean, I think ultimately the biggest impact we really want it to have is to help make lives easier for people impacted by CF. So I would hope it's helped to facilitate more conversations. And in some way. However small help break down some of those barriers or perceived barriers. In, in any of the sort of disclosure of CF and having those supportive conversations.

I think, what as mentioned, we saw lots of new user generated content from the community in terms of the stories that they were sharing and the sharing of the existing sort of content that you know that Kieron helped us develop. So I thought, you know, we saw a lot of good engagement from that perspective. But in terms of other impact, we also saw some really strong reach in terms of awareness.

So we had some fantastic partnerships with with our out of home partners. And also we we had some strong sort of digital advertising as well. So collectively they had a reach of over 30 million. So in order to get CF as a condition in front of people, you know, we saw that significant reach. So we really wanted something that was going to be eye catching.

And then working with our comms team, we saw some quite strong media coverage as well with Kieron story. So we had some good national and regional media coverage which, you know, out of reach of over 11 million. And then we saw some really strong engagement on our sort of website and social media content and something we sort of measure year on year as well.

So we saw that people were spending longer on the content. So yeah, I think hopefully what it should allow is, you know, it's it's something that's always going to be ongoing, but there is a general more awareness of CF is still a challenge and it is more than just the lungs.

**Izzie:** Yeah, definitely. But it's great to see the steps that we've taken so far and thank you so much for joining us on the podcast today.

**Sean:** Thank you very much. Happy to share.

**Lucy:** Thanks so much Sean, and to Kieron for sharing his experiences and to you for listening. For more information on what we've talked about in this episode or to donate and help make sure everybody with CF can live without limits. Please see [cysticfibrosis.org.uk/podcast](https://cysticfibrosis.org.uk/podcast).

And if you've enjoyed listening to CForYourself, don't forget to subscribe, rate and review.

Thank you so much and until next time, have a good one and I'll see you soon. Bye bye.