

Cystic Fibrosis Trust

Season 2, episode 3: CF and dating with Lyndall Grace

Lucy (host): Hello and welcome to season two of CForYourself, a podcast brought to you by UK charity Cystic Fibrosis Trust. I'm your host, Lucy Baxter, and I myself have cystic fibrosis. I'm one of over 10,900 people in the UK living with the cystic fibrosis.

Now, CF is a genetic disease that causes a build-up of sticky mucus in the lungs. So that means I can experience a range of different symptoms, like struggling to put on weight, feeling breathless and being tired. I was diagnosed with CF at two years old, but CF is part of my life, not my whole life. And it definitely doesn't define who I am.

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

Welcome to episode three, season two of CForYourself. Today I'm going to be catching up with Lyndall Grace, star of season ten of Married at First Sight Australia to chat about growing up with cystic fibrosis, opening up about CF and relationships, finding love and her future plans, plus so much more.

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

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

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

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

You can call them on 0300 373 1000 or email helpline@cysticfibrosis.org.uk.

So, without further ado, let's welcome Lyndall to the podcast.

How are you today Lyndall?

Lyndall Grace: I'm pretty good.

Lucy: For people who don't know you, you're not in England, not from England. Why don't you come in a little bit about yourself and kind of where you are in the world.

Lyndall: Well, right, I'm Lyndall, I'm 28 and I live in Perth in Australia. I have grown up in Australia but moved around a little bit. I have cystic fibrosis. I'm an accountant by trade and I

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guess like the reason anyone knows my name at all is that I did Married at First Sight Australia this year. So.

Lucy: There'll be so many questions that people listening to this podcast will have about kind of growing up with cystic fibrosis in a different country, obviously the podcast here is mainly listened to by people in the UK, so it'll be really interesting to hear just a little bit about growing up in Australia in maybe like a hotter country as well, if that's that's better for your lungs and kind of, I don't know if by the sea or anything kind of what was it like growing up with CF in Australia?

Lyndall: From what I gather, I think Australia is a couple of years behind the UK in terms of treatments and research and awareness I think as well. In terms of like clinic appointments, I don't really I don't know how your system works, but we just go every three months, six months, once a year, depending on where we live. When I lived in a regional area, we used to have to travel all the way to a capital city to go to clinic.

And yeah, in terms of like climate, I honestly wouldn't know what those what the studies or the research says about how the climate impacts the severity of your CF. I know that when I've lived in humid places, I'm more likely to get infections. So even just like holidaying in places like Thailand and Fiji and things like the humidity is just insane.

So when I lived in Queensland, that was probably when I was my worst. But now I'm in Perth and it's a really it's like hot, but it's a dry heat, so there's just not as much condensation in the air or something. But yeah, I don't know.

Lucy: It's interesting as well because when I was originally diagnosed with CF and living in the northwest of England, it's a very damp, very wet area and my parents had the conversation to move to Canada because it was drier and it was kind of better in terms of kind of advancements in treatment.

Maybe not as much now, but we didn't move and we're still in the the damp northwest, but what was kind of your journey with CF then? Talk to me a little bit about when you were diagnosed and kind of what growing up with CF was like for you.

Lyndall: So I diagnosed a few weeks after I was born. I was the first of my parents children and nobody else in the family CF, so that was a bit of a shock to everybody. Growing up when I was a kid, I was really quite well and then went to hospital twice when I was in primary school. I never really struggled too much. Once we got on top of that and then it wasn't until the end of high school that I started getting really unwell and that's, I don't know.

You hear all these different things. I went to so many different clinics all over the country when I was moving around through school, and you know every doctors got a different way of explaining it to you and a different kind of outlook on what your options are. I think. Yeah, think the high school was really awful because it was it was grade eleven, and you're kind of preparing for your last year and getting everything prepared and you're going through all these changes and being a moody teenager and I had always been quite well. And so when I got

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unwell it's a bit of a shock. I ended up finding. So I've never had *pseudomonas*, which I don't know for you, but certainly in Australia it's most common infection, and I've never had it.

Still to this day, have never had it and I couldn't understand why. But when I was in grade 11 they found *Burkholderia Cepacia*, which is quite a rare, complex infection, and I didn't really know what that meant. It had been so long since I'd been in hospital. I hadn't been in hospital since 2001, so it was almost ten years, and yet it was like in and out of hospital just slamming me with antibiotics, like all the time.

I'd never missed so much school. I was falling behind in everything. Then because I was on all these antibiotics, I end up getting another infection, *ABPA*, which is *Aspergillus*, but I'm allergic to it. So it made my lungs really inflamed. And so then I had to go on steroids to try and like keep the inflammation down. And then because I was on steroids and IV's all the time, I ended up getting C diff.

Oh god I've forgotten how to pronounce the word. But anyway, I had C diff and that ended up meaning that I lost so much weight and I was sick for like only a few weeks but had to go to hospital again. And about a month after that, all my hair fell out because my body was just it couldn't keep going.

Like it couldn't keep doing what it was doing. And it had just shut down all the unnecessary functions of the body. So all my hair falls out. I'm at the end of grade 11. I'm doing my exams in hospital. I'm not doing very well. My lung functions all over the place and I basically just told them enough's enough, like my hairs fallen out now.

Every time they tried to fix something, it just got worse. And then they would try to fix that and it would get worse again. And so I had a pretty poor relationship with CF and clinic for a while after that. I basically because I was like 16, 17 at the time, as soon as I transferred over to the adults hospital, which I don't know if that's how you guys work, but when when you turn 18, you transition to adults.

And as soon as I did that, as soon as it was my responsibility, I was like, Well, I'm not going anymore. And I always like blamed the clinic and the doctors and things for what I went through. And so I didn't go back for like two years. And I was lucky that my lung function actually stabilized once I got off all of the meds that I was on.

So the *Cepacia* didn't really it didn't affect me then and I was good again for another five years or so. And then it was that all right, you starting to decline and we don't know why. There's no new infection. There's nothing really changing in your life that would mean that. But yeah, it was. It was what you always get told.

What I was always told is that eventually your lung function will just start to slowly dip down. And that's what started happening. And then I guess, you know, like that was hard because no one could tell me why. And nothing I was doing was helping, even though I was doing everything right at that age, was doing all my physio, and taking all my tablets and inhalers and doing sport and all that kind of stuff and just nothing helped.

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And they just kept saying like, hold out, there's this new drug coming. And that's what I did. And starting on Kaftrio, it's been just an absolute dream. I never thought in my lifetime I'd feel like this again.

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

Lucy: So like you said at the start, earlier this year, you were on season ten of Married at First Sight Australia. Tell us a little bit about how this came about and just more about it because it's really interesting.

Lyndall: So for me, not everybody applies but I did apply. I basically you know it was the start of the year and I was like, all right, I'm going to set all these goals, which was just to challenge myself a bit more and kind of take big leaps into new things to, I guess like, I guess I'd like gotten to a point where I was really comfortable in my life and it wasn't really in a good way. It was like, you know, I'm just cruising through it all and I'm not very good at sitting still. Anyway, I honestly was just I was working from home one afternoon and I thought, Oh, yeah, that's the thing, and Trikafta's just been approved.

And I swear to God, the first thing I said when I hear because I had a reporter called me, obviously because they knew it was going to be approved. And so they were writing up a piece for the next day and they call me and they tell me the day before it gets approved, so nobody else knows it's happening and they just told me and the first thing out of my mouth was, Oh my God, I can get married.

Oh my God, I'm going to have kids like which, you know, it still might not even happen for me, but it was one of those things that, like, I just I'd never even let myself think about it for so long.

And I wasn't even on Kaftrio yet. Like, I hadn't even started it when I applied I was just like, Yeah, this is going to happen and it's going to be amazing, I hope. I think. And yeah I just sat at home, I was working from home. I didn't have much to do that day and I just sat there and I filled out this massive application.

It was like it was a little bit therapeutic and actually, because it asks you all these things about your life and your relationships and I guess like your perspective and all these kinds of things. And anyway, I never expected anybody to actually read the damn thing. You think of how many thousands of people apply to do something like that every year?

I just I wasn't expecting to hear back for months you know and I don't I don't really watch it, I watch like I always watch the weddings at the start and then I don't really watch the middle bit because it's a bit much. But yeah, I had a call the next morning asking if I wanted to jump on a Zoom and I was like, Yeah, okay, of course.

How funny is that? And then I'm calling all my friends like, lol, these people think I'm interesting enough, that's crazy. You like it'll never happen, but I want to like, see the process through and see how it goes. And I guess the more I went down the path of the application, the more I

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explored I guess the doors that were opening for me in terms of the future and the more I attached myself to the idea and the more that I let myself think about it in a really hopeful way.

And yeah, it was wild. And they were just they were just a bunch of Zoom calls with all different people. There was there was one week where we did three interviews with the three experts that we have. You've got to do a psych evaluation. You've got to do like a publicity thing where they're like, Tell me your secrets so that, you know, if they come out while it's airing, we can manage them.

You know, there's all these kinds of things and you've got an STI check and do a medical. But it wasn't until like mid-July last year that I was told I was on and then my wedding was in like three weeks. So it was pretty crazy. Yeah.

Lucy: I could not, I don't think marry at first sight, like just talk me through the whole, the wedding.

But then what happens after? Well, you know, So do you get to pick your dress? Do you get to pick anything about it? And then obviously you're matched to the groom and then you like walking down the aisle and that's the first time you see them. Is that literally That is no word of a lie. That's what happens.

Lyndall: No word of a lie, that's what happens. They come, they come to you and they film your back story, you know, like you do to reveal to your friends. They don't use everything that they found at all. They use such a small percentage of what they actually film.

Lucy: In that did you ever mention about your CF at that point or in the application?

Like what was the point that you expressed that to kind of the team and people?

Lyndall: I told them in my very first application that was a lot of what it was about was like, why are you applying for MAFS? And I was like, Well, because now I can get married, so I might as well not waste my time anymore.

Like I've avoided this for so long with like, I've been so long, like 26 years in my life, I might as well just jump in the deep end. And I think as well, I have this perspective of if I'm going to meet the one, they're going to be the same kind of insane that would be like, Oh yeah, why not like YOLO.

Let's you know grab the bull by the horns and do something crazy and see how it goes. And I talked about it then. And obviously I know that a big part of why I was selected for this show was because I had that that story and I was there to find someone. I wasn't really interested nor prepared for actually being seen and known by people globally.

So I knew I knew that that was a big part of why they chose me. I talked about it from then, and then when they came over to do my back story, we did a big like master. They do, they call it your master interview and you sit down for like hours. And you answer all these questions that they procured for you based on your applications and all the meetings that you've had since and mine was very heavily centered around CF.

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And I think I was very lucky that I have the relationship that I have with my CF now because I could not have done that a year before hand. I could not have done that five years beforehand. I really was not comfortable talking about it at all. And I guess by the time they told me I was going on the show that I was going to be part of the cast, I think I'd really had an honest conversation with myself about what I did want and how I wanted to represent myself and how I wanted to represent CF, because I knew that there was quite a lot of weight and that it was going to be important.

I wanted to represent our community well. I wanted to make sure that if I was going to talk about it, I did it in a way that wasn't just like toxic positivity about the whole thing. Like, I'm so grateful. It's like I am grateful for a lot of things, but it also was really hard and this is what was hard.

But here's this hope, and it's not all hope. Sometimes it's scary and like being able to have like very candid conversations to hopefully maintain that they have a good amount of content and a good variety of content to tell the story well and I was actually so amazed and so happy with how it all came out because I think they did a really good job of striking that balance between.

I have had hard times, this is a really hopeful thing. And I don't know, I think they did a really good job of like rounding out the story. I was pretty pleased.

Lucy: And so how nerve wracking is it like walking down the aisle to a stranger? Like, I got married two months ago and he is not a stranger. So like I and that was nerve wracking. So what was going through your head? And.

Lyndall: I mean, okay, so firstly, just to go back quickly. Yes, you get to pick your dress, you get a budget and you get to pick your dress and your brides people's outfits. And that's about it, really. They ask you what you want at your wedding, but whether you get an actual say on that, I'm not sure.

Lucy: Where your family there and like people there?

Lyndall: Yeah so because because I'm from Perth and we filmed over in Sydney so that's where we lived. But my wedding was in Byron Bay which is beautiful.

It's on the coast and obviously Cam's from Darwin, so we both got ten guests each. I think it's different if you're from the city that they're filming in because obviously they don't have to pay for flights and everything. But yeah, we got ten ten guests each. I had my parents and my sisters and my nanna and then the rest were my closest friends and I think Cam was about the same.

He had his parents, his siblings and a couple of friends as well. So yeah, everyone's there with you, but you're not allowed to see them on the day until you know it's all being filmed and you kind of you rock up. It's, it takes forever. So I was up at 5 a.m. getting my hair and makeup done, which I hated, but the way, I absolutely hated my hair makeup on my wedding day, and the only way that I could get through that was just telling myself that at least that's the first episode, and it'll only get better from there for the viewers.

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But yeah, up at five am, getting my head on, getting everything ready. The my mum came over and we have a little chat and then my friend Kat, my maid of honor, Kat, came over and we had a chat. We get in a limo, we go to the place. There's a lot of waiting. Like you're just kind of sitting there like, right okay.

And they take your phone, so I don't have any photos of me on my wedding day. Like, like they obviously have them the production do, but I don't have any photos with my friends or anything. What little waiting around, but our ceremony, like exchanging the vows was at like quarter past eleven in the morning. So you do that and then you do a little rerun.

Not with that. Not not with all the vows, but you just like walk the scene again so they can make sure we get shot and everything. And I didn't think I would be nervous. But then I'm in the limo and they're driving me to the venue and I'm starting to go like, Oh my God, oh my God, Look, I'm in this dress and I'm doing this thing and I can't believe it.

And what if they're terrible? What if they're great? What if this is the love of my life? And what if it's not? What if I hate them? It's a lot because it kind of hits you, right in the feelings of. God. What have I done?

Lucy: And is it like an a legal wedding? Like what happens if it don't work out like an even divorce? Like, what is the legalities of it all?

Lyndall: Okay, look, I like to think that I'm stupid enough to say yes to something like that, but smart enough not to actually legally get married. So you don't legally get married. There is no legal divorce in any way. You aren't even classed as like a de facto relationship or anything. You just you rock up and you exchange vows.

You don't sign anything, Thank God. Yeah. I mean, I had a really good wedding day and then it just slightly declined as the weeks went on.

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

Lucy: What would you say for dating with CF in general. So obviously this was you in the spotlight, inverted commas, marrying someone. But, obviously beforehand and, and potentially after like. What is dating with CF to you? And I guess kind of I don't know.

Some people don't tell that other half until it's later on. What would your advice be with that as well?

Lyndall: I think I've done it all kinds of different ways in terms of like there have been people that I've dated that I haven't told and there have been people that I've dated that I told before we were even dating.

I think generally at this age now and, you know, looking for a serious partner. One, everyone already knows if they know me at all, it's like, you know, it's on my social media. It's been a long time since I've had to sit someone down and be like, Hey, by the way, this is a thing. Even just exchanging your socials on a dating app, it's like one of the first things they see.

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So it's been a while since I've had to tell anybody. I personally think that it's so much easier to tell someone you've just met than it is to tell someone that you have all of these feelings and care for because on one hand it's about trusting them and waiting until you feel comfortable and safe to share that information with them, especially if it's not as broadcasted as mine is.

But on the other hand as well, I think generally the people that I connect with most in my life, like all of my closest friendships, all of my best relationships, all the people that I, you know, people that are in my circles are people that understand whether it be because they have a relationship to CF or whether they just know about chronic illnesses or disabilities a bit more than your average person. I personally would always say something maybe not in like the early dating stages, but definitely before before you start talking about getting into something serious.

Because if they aren't prepared for that and as well, I think like I always tell someone and then I like try to gauge how they react because I've had people before be like, Oh, that's so fine. I'm going to stick it out with you and it's going to be all great. And it's like, all, well, I'm going to say until I have like until I call you to say, Hey, I have to go in a hospital like, could you bring a bag for me? Or like, would you mind bringing me lunch tomorrow? Because hospital food is crap.

Like, it's a very different thing to see and to witness. So I always try and, like, suss out whether they're like a little bit, like, in denial when you tell them or whether they're not really taking it in. It's hard. And I just think you have to do what feels right for you. If protecting that information for you for a bit longer feels better. Do that. If you if you don't want to muck around in any way, just just tell them straight up. Because if they're not for you, they're not for you, you know?

Lucy: Yeah, exactly. I think with with Phil and I. So I was on television in the UK to like kind of help with the campaign of Kaftrio etc. And that's, that's where Phil saw me on the TV.

So in a way he, he already knew worst case scenario and everything in that respect. But yeah I don't know how I mean I would tell them, but I don't know how I would because I think it's hard. I remember in year seven with friends sitting them down and telling them and and I think it's kind of you, you think that you've got the worst thing with CF and it's it's the strain on the relationship or whatever but actually they might then come back and be like, Oh well I've got this.

So you know, something else that's hidden. And it's like, Well, actually everyone's got their own thing and it's that particular person that you're seeing or, you know, want to go out with, etc., doesn't like that or doesn't doesn't want to go out with you because of that, then they're never the right person and they're actually not a very nice person and reflects more on them than than yourself. But I think is a hard thing to kind of know what to do. So I think your advice is right on doing what's what's best.

We also know that you're into gaming a bit. Tell us a little bit about the games you play and how you got into it? Oh, there we go.

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Lyndall: I'm actually at my gaming desk now. The first game I ever played was Spiro on PlayStation one, and it was because my uncle at the time, who I don't think I've ever seen again since to be honest, gave me his Spiro game because I was just absolutely, you know, bedazzled by the thing.

So that was the first thing I played and then it kind of went from there. And my dad's always got the newest console. So growing up we always had them. I think as a teenager I really stepped back from it because I was like gaming ew nerds, like, you know, for whatever reason. But I was like that with everything when I was a teenager. So you don't want to do anything that's a little bit uncool.

And then when I moved in second year, uni and I really struggled because usually you've got school and you're making friends and you're enjoying sports and like it's all very natural to change schools. But when you're at uni and you're an adult and all those things are a choice. They're not just put out in front of you. For you to go, Oh I'll do that one and not that one.

I really struggled to make friends and I think I had about six months of just sitting in my room and I would get cravings for muesli because every time I sat down to play my PlayStation, that's what I was doing. And then if I ever sat down without the muesli, then my my tummy would be like, What are you doing?

But I remember I sat down and I just played on our old PlayStation. This this game, Assassin's Creed, that like I just never played before because it was, you know, an adult game. So I was like, Oh, I'll play that. And it was one of the best games I've ever played. And that just sent me into a full, deep dive spiral.

I went out and I bought all of the Assassin's Creeds and I went back and I completed all of my Spiro games and was really into the Sims. It definitely helped me get through that time and I still play them now. It's still my favorite game. Buy yeah I'm more into the adventure things you have like the lead and it needs to have a good story and uncovering things.

And it has to have a beautiful map. I'm a big fan of a nice map, so I'm not really into the Fortnite and the COD where you're like shooting things and it's like a five minute, you know, like who can win this one again and again? I think I need a little bit more depth in the story and like, control over who my character is and what decisions we make and all that kind of stuff.

But yeah, I absolutely love it and I never really talked about it until a year or two ago, and I started just posting on my Instagram about it, which was not big at the time. It was like a thousand followers or something. And so many of my friends, especially, especially female friends, are reaching out, being like, omg I game as well.

And I'm like, What? Well, are we all out here like secretly gaming, but we don't want to say anything because it's weird and it's been such a lovely community since because even my guy friends are like, you know, they help me with, you know, I have a PC now and I had beautiful friends help me put it together and choose different pieces for it and choose the one I was going to get and all that kind of stuff. It's actually such a good community and I was already playing PlayStation before I came on the podcast.

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Lucy: So. So what console have you currently got? Is it the PS four or five or?

Lyndall: So, I have a PS four, the dream is, one of the goals of the year, which is a bit embarrassing, but one of my goals of the year is to get a PS five.

But I also have a PC that I love and adore, she's my baby. Apart from one of her hard drives malfunctioning at the moment, but otherwise I love it.

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

Lucy: So just to kind of sum up, if you had one piece of advice for like a younger person with CF today, whether it's kind of, you know, you touched on the dating side, you touched on that kind of fitting in inside and kind of game side. What kind of piece of advice would you give?

Lyndall: A big one for me, and especially especially through my MAFS experience is, all through my MAFS and from getting Kafrio as well, is that you're not a burden. You're allowed to have things and you're allowed to have flaws, and having CF is not a reason why you can't be loved the same way everybody else gets to be loved.

It doesn't it doesn't mean that you should miss out on those things or that you don't deserve them. Another one that I've been thinking about a lot recently, because I've been doing a little bit more work or working towards working with teenagers that have CF is that I found so much guilt around the way that I behaved as a teenager and the relationship I had with CF when I was a teenager.

And I still find it so hard to forgive myself for being insufferable to my mother, who was just trying to help me, you know, to not listening to my doctors when they were just trying to get me to do the right thing for me, for forgiving myself, for not being perfect with my physio, you know, like getting angry at yourself for not having the lung function that you want or for getting sick or, you know, for maybe the way that you acted because you're dealing with this thing that nobody really seems to understand.

That's okay. You didn't know any better. And like, you're allowed to have those days and you don't have to be perfect with everything all the time, like it helps. And just do your best but just do what you can. Just don't be too hard on yourself. That's the thing that I really still struggle with as an adult.

Lucy: That's really good advice. And I think that whole bit about being loved is so true and will help a lot of people. So finally, what are your hopes for the future other than getting a PS5?

Lyndall: I guess, like short term, I think I'm doing a lot of work with the CF community at the moment, but it's definitely connecting to teenagers because that was the worst period of my CF life and it was when I was so disengaged with the whole thing.

And I think it's just like that problem area for all kind of charities trying to get awareness and create that community because teenagers just don't want to participate in it. But if we can help to normalise the feelings and the things that you're going through at that time, I think that will be so helpful in making them have some role models and some structures to be able to like,

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even just read from a distance if they don't really want to participate yet, because I think that's what we would never have really would have helped me.

So that's the kind of work I want to do in a CF space. I'm about to go on a big holiday over East to catch up with all of my friends from the cast. I'm going to go to New Zealand and go skiing for the first time since being on Kafrio, which I'm really excited to see how that feels because the altitude and everything is always so like you never know, its hit and miss with such cold weather.

And then I guess like more long term, I still really do want to find my person and I do really think that having a kid would just be the most incredible experience, like it's so far away from me right now, but it's something that I spent so much of my time just like telling myself off for wanting that.

That like now I don't have all of that guilt associated with it. Like, I just I would just love to do. That's the goal. But if it doesn't happen, than that's also ok because it's not the be all and end all.

Lucy: Hopefully one day it might creep up on you when you least expect it.

Lyndall: Hopefully I'm expecting it a little bit because do not want a surprise pregnancy.

Lucy: Yeah, the baby would not creep up. Maybe the person would creep up.

Oh Lyndall, it's been so lovely to talk to you and I think all your advice and kind of just been so honest about your experiences just really helped so many people. So thank you so much.

Lyndall: Not a problem. Thank you so much for having me. You guys to such an incredible job.

Lucy: It was lovely having a catch up with Lyndall. It was so inspiring and I really, really enjoyed getting to know a bit of the behind the scenes of Married at First Sight Australia. 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 Lyndall for sharing their expertise and stories.

Now we're going to be finding out a little bit more about the Trust's forum and how people with CF can get support and advice from others in the community. My name's Izzie and I'm content lead at The Trust. And now I'm joined by Matthew Delooze, Helpline Manager at the Trust.

Hi, Matthew. Please, can you tell us a little bit about the Trust's forum?

Matthew: Yeah, no problem. So the Cystic Fibrosis Trust Community Forum is a safe space for people who are affected by CF. To ask others in the community questions, share experiences, and ultimately just support one another. Whether that's through sharing information or just offering a listening ear and a supportive word on a difficult day. People on the forum can talk about many different things relating to CF.

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It's very, very varied. The range of topics and discussion points that are posted onto the community forum, some recent examples just to show you the breadth of what people discuss on. There are things like moving abroad and working through that, school worries and employment and lots and lots of other things. The benefit as well of the community forum is there it is anonymous, which means that that helps some people feel more comfortable posting, more comfortable opening and sharing their experiences, knowing that it's not going to be tied to their name and and not going to expose them.

So it gives them a little bit of safety when they're posting as well. And in addition to that as well, we do moderate the forum daily. So to make sure all the posts are in line with our community guidelines so that the community can feel confident that it's a safe space to post and and share what's going on for them.

Izzie: Amazing. And who can actually use the forum?

Matthew: So anybody over the age of 18 who is affected by CF. So you could be a parent of a child with CF, you could be an adult who has CF yourself or indeed you could be somebody who may have lost somebody to CF as well. So as long as you're over the age of 18 and are affected or have been affected by CF, then you can use our community forum.

Izzie: How does forum help people with CF?

Matthew: We make sure that we provide a safe judgment free space. I mentioned earlier we have our community guidelines and that just allows us to make sure that the space remains supportive, empathetic and keeps it a safe space for people with CF to share with each other. They can do a few different things and it can help people in different ways.

So some people use it to ask questions, to find out how other people do things, or how people have grappled with a particular problem that they may have relating to their CF. Some use it simply just to connect with others who have CF. We know that of course, due to cross-infection risk, it makes it really difficult sometimes for people with CF to connect with each other.

So this forum provides a space for that as well. And also sometimes people just may go on, they just to say they've had bit of a tough day. How is everyone doing and just check in with each other and someone may respond with just like a supportive message in a kind word. But ultimately this this service is only possible because the community respond and talk to each other.

It's very, very organic in that way. We as the Trust very much take a back seat. We don't post ourselves, we don't start conversations and things like that. We think it works better that it's it's fully led by the community and it's their space to use as they need to. So we make sure that we moderate posts, but we don't actively post and things like that as well, which really helps the, the organic nature of the forum.

And we know that as well that more and more people are turning away from other online platforms such as social media, for many different reasons. So this provides a safe and moderated alternative for the community to connect with those who are affected by CF.

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Izzie: Where can people with CF go if they'd like to get a bit more support?

Matthew: We have our multi-channel helpline where you can contact one of our helpline team for support.

You can reach us via phone, email via our social media channels via WhatsApp. So there's a few ways that you can get in touch with us. And we're open weekdays 10 till 4 p.m.. So again, if, if you have a specific question, you can contact us and we'll do our best to answer. If you just need someone to talk to and a listening ear that's, that's something we can offer as well.

So it may be that you don't even have a specific question. It may be that you've just had a difficult day and just need to offload and and share that with somebody. And our helpline team can give you a safe judgment, free space to explore how you feel about how somethings gone and and give you a space just to talk it through.

For parents who have children, we see we also have a peer support service CF Connect. And through that service we can put you as a parent of a child with CF in touch with another parent with CF who is one of our trained volunteers, and they can also provide a space for you to talk and connect directly with another parent.

Izzie: Amazing. Thank you so, so much Matthew for joining us on the podcast today.

Lucy: Thanks so much to Lyndall for sharing her experiences and to you all for listening. For more information on what we've talked about in this episode or to donate and help make sure everybody with CF can live without limits, please see cysticfibrosis.org.uk/podcast. And if you've enjoyed listening to CForYourself, don't forget to subscribe, rate and review.

Thank you so much and I'll see you next time.