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**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](mailto: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](mailto:helpline@cysticfibrosis.org.uk).

**Lucy:** Welcome to the first episode of season three of CForYourself. I hope you've had a lovely summer, but it is good to be back.

To mark Organ Donation Week, which takes place from the 23-29 September, I'm going to be having a virtual tea and chat with Zanib Nasim to talk about her experience of having a transplant.

We'll be chatting about adjusting to life post-transplant, Zanib's hopes for the future and what the experience has taught her. Zanib is a member of the Trust's involvement group, so we'll also be hearing about how she uses her voice to influence the work of Cystic Fibrosis Trust.

To give us the lowdown on what it means to be part of the involvement group and how you can get your voice heard, Louise Hodge, who is involvement co-ordinator at the Trust, will also be joining us. Now, without further ado, let's welcome Zanib to the podcast.

Hi, Zainab. Thank you so much for joining me today. How are you doing?

**Zanib:** I'm good. Thank you. Thank you for inviting me today.

**Lucy:** First episode of season three. So yeah, a huge welcome. So in this episode, we're going to talk a little bit about your transplant journey. So do you want to kind of give myself and the listeners a little bit of your journey I guess, and kind of tell us about yourself.

**Zanib:** So obviously I've got cystic fibrosis. Part of CF, unfortunately, is that sometimes that our progressive lung disease causes issues. And then you know, the last resort is a transplant. It was mentioned to me around the age of 27 that I might need one. It just started with a decline in lung function, keep having regular IVs and I was very unwell. They usually bring up the transplant topic when you have a two-year window of when they can like predict that your lung functions can decline quite drastically.

And that was my case. Yeah. I was offered an assessment for transplant, which I was quite reluctant to even think about transplant because it's quite a scary, a very scary idea at the time. Thinking back, it's quite scary thinking about it. And, yeah, I had it. I had a bit of a wait.

Thankfully got my transplant, but it was it was quite a difficult journey for me, personally speaking. I did have a lot of bumps in the road. My health declined quite drastically very quickly. So it is a big change in lifestyle as well.

A general background is I was a normal 25/26-year-old, had gone to uni, had gone to college, studied. I wanted to pursue a career in pharmacy. It was all of those elements of trying to live a normal life as well as deal with the chronic condition as well as deal with transplant. So that's everything in a nutshell.

But yeah, like that is kind of my journey. I did have to wait about two years, two and a half years for my transplant. Being an ethnic minority put me at more of a disadvantage because obviously I've got, you know, with transplants, you have to have a vigorous test. So your blood group, your tissue testing, you have to be like, a perfect match.

Yeah, that was quite difficult for me. And I'm quite petite as well, which just added more to the unpredictability of trying to find me a match.

**Lucy:** I mean that that really resonates with me because I'm 26 now and I can't imagine how difficult that must have been. Like you said, when you just kind of on the brink of starting out in a career and in adult life, I guess. So when you got your transplant, you kind of explained kind of the wait and the difficulty I guess with finding a match. How did it work post-transplant? You know, immediately after.

There's obviously a period of time where your body could reject the lungs as well. So do you want to talk to me a little bit about that, cause that must be quite frightening.

**Zanib:** So before transplant it was mentioned to me that there's always a possibility of rejection. And rejection can happen in the initial stages of transplant, which is basically acute rejection. And that is quite common. You can get chronic rejection, which is basically rejection, but over a longer period of time.

So everybody is different. Everyone's body works differently. Rejection is quite scary. It's quite a scary thing. But it's not as if it will happen instantly. Acute rejection is quite scary because that happens within, you know, when you get your new lungs.

It can happen whenever. Chronic rejection is over a longer period of time, similar to how CF decline happens. It's very similar, but obviously the symptoms are very different because you're swapping one illness which is CF for another.

The symptoms of CF are very different to the symptoms of a transplant patient. I think that's one thing it took a while for me to get my head round, because dealing with CF, we've grown up with CF from a child into adolescent into adulthood.

And then going from being an expert in your condition and the doctors asking you what you need at most occasions and most times. Or you knowing your body very well, to a transplanted body where, you know, your lungs are transplanted. It's all new. That was quite scary because the complications that come with the transplant are very, very different to what the complications we have with CF.

And it's just new. It's just something new. And I think it just takes time for you to learn your body and to know what's normal and what's not normal for you.

Initially, I think I was quite reluctant because I had my transplant just before Covid as well. So I had it in the January of Covid year, and then Covid happened in March when the whole country went into lockdown.

So, you know, that was quite scary because nobody knew about Covid and no one knew what it caused. And being isolated. And I'd got a new lease of life and then everyone, just suddenly, the whole world went into isolation. So it was a bit frustrating. But yeah, that did add to, you know, me trying to learn my body

basically. It's just you learning new skills. It's like a bit like a new job really. When you go into a new job, you have to learn a new skill set, and it's a very similar to that really.

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

**Lucy:** You look really well now. How would you say you're doing now? And I guess a secondary question to that is how is post-transplant CF, in terms of physiotherapy, medication that's taken. How different is it if the long you've got are not CF lungs if that makes sense?

**Zanib:** So everyone is different. Everyone's body is different. And I think the doctors give different advice to different patients. But thankfully like, you know, post-transplant I am a lot better than what I was pre transplant.

So pre transplant I was on regular IVs, I was pretty much very unwell. And you know I, I couldn't do a lot of things for myself. Post-transplant, I'm very much, you know, able to do a lot more for myself.

There are limitations. When I do get unwell, it is slightly different to what it was pre-transplant. The symptoms have been different. You know, in terms of physiotherapy you don't need to do as much. You know I only do chest clearance when I have a chest infection then I'll actively do it.

But on a day-to-day basis I don't need to do it other than just trying to clear my chest, through like exercise, walking, trying to be more active. That is enough for me to keep my chest and my lungs as healthy as possible.

So I think the care pre-transplant and post-transplant, the level of care or the treatments that I needed are very different and that was another thing that I had to learn quite quickly. I found it very, very weird how pre-transplant I had a very strict routine. So I'd wake up in the morning, do my nebs, do my physio, nebs again, then set out my day to work or, you know, whatever I was doing.

However post-transplant that changed quite drastically. So I remember having my transplant and asking the transplant doctor, oh, do I need to do physio every single day like I did before? And they were like, no, you do have to do some level of physio, but not as much as what pre-transplant you had to do. So I found that very, very weird and I found it, it took me a while to get out of the habit of, you know, chest clearance and waking up in the morning and being able to do my nebs and then not needing to do physiotherapy.

**Lucy:** Also, though, even though the lungs don't have CF, so to speak, the pancreas is still affected and you still need Creon. Because obviously CF isn't just a respiratory condition, it's every organ and every cell of the body. So even though like you said it's increased and, you know, lung function and everything, the other parts you'll still have to do, which are maybe less intrusive as like the physiotherapy every day.

**Lucy:** But I think it's interesting and important. And like you said, every transplant case is different as well. What would you say are maybe the biggest misconceptions then around lung transplants and transplants in general? Because it's like you said, not a spoken about topic.

**Zanib:** Well, I think the biggest misconception is that you're cured, which is not the case. So I think when I was going for transplant, and when the question was asked whether I wanted to have transplant or not, like my friends and family, they were supportive. But I think they were very much like, why can't you just say yes? You know, you want to live, you want to live your life.

And I think the very common misconception is people don't really understand how scary it can be as a person on the other end, receiving it. And people just think that it's an instant cure. So you just swap your damaged CF lungs for healthy lungs and jobs a good'un. And unfortunately that isn't the case with transplant.

You know you do have bumps in the road and you can have a you know, you can have complications. Every transplant patient and every CF patient is very, very different. So it's not as if every patient fits into the same box. And so I heard good stories about people having transplants and bad stories about people having transplants.

And when I was undergoing my decision of having a transplant, a lot of people around me, unfortunately, who had transplants, had a lot of complications. That did scare me a little. But I think the support that I got from everybody, like, within my family, within my CF team, it helped me make my decision.

And I think although the two conditions are very different, I don't think I would have changed my decision in any way, I would have done the same thing regardless.

I think the main misconception is basically people think that it's just a cure, when unfortunately it isn't. It does come with the other aspects like, you know, complications and all the problems that come and can cause issues later on because of your transplant.

So, like you said, you know, it's not just your lungs, it's all the organs in your body as well. So every patient is different. Some people with CF have a lot more liver issues. They don't have a lot of lung issues. Some people have digestive issues. It's just very much individualized. And I guess it comes down to genetics because there's so many mutations for CF, every mutation has a different physical characteristic and they show it differently.

I guess it's just every patient is different and everyone would react differently. But for me, I think I think it was just the initial starting point of when the question was raised for transplant. And it was quite scary. But I think after gathering all the

information, talking to different people, I came to more of a better-informed decision.

And I knew, like in terms of like, you can get complications. It's not just an instant cure.

**Lucy:** Like you said, it's great that your consultants were supportive and gave you that information and that you had conversations with a wide range of people to make that informed decision and that it wasn't just thrust upon you. I think that's really important.

In terms of the donor. What is the process and what do you know about the donor? Are you in touch with the donor's family? There's another side of it, isn't it?

**Zanib:** That was quite a big thing, because I think initially when transplant was raised to me, the first thought that came to my mind is like a lung and heart transplant, it has to come from a deceased donor. Whereas a liver transplant possibly, or kidney transplant can come potentially from an alive donor. And I think for myself, I think the instant thing that came to mind when transplant was mentioned to me, it was that someone has to pass away in order to give me a new lease of life. And that was quite sad in a way, and disheartening that someone had to, you know, die, you know, quite frankly.

But I think I'm so blessed that whoever it was, they've given me a second chance. And I've been able to do the things that I am doing today. And it couldn't have been possible without that kind donation and that kind selflessness, really. And even the family. It must have been such a hard decision for them to make for their loved ones to be a donor.

But like whenever I accomplish something or do something, I just think it's through my donor, you know, I'm doing it for them to make them proud. Because at the end of the day, their kind selflessness that has allowed me to be alive today and be able to do the things that I've wanted to do.

I did get in touch with my donor's family, after transplant, and I did get a bit of an emotional letter. It was quite touching and emotional and, you know, I think for myself, I just thought that I wanted to, it gave me more of a motivation to do more, and make the most of the life and the second chance that I have now, because, you know, quite frankly speaking, nobody knows how long they have left in life and no one knows that. And, you know, just making my donor proud and their family proud is just so important to me now.

**Lucy:** Thank you for opening up about that. I know it's an emotional topic and you know, anyone who's a donor family would be so proud to see what you're up to and know that you're doing well, and that their lungs have been able to carry on providing life. So it's really special.

**Lucy:** I kind of want to move away from that now to talk about your work with the involvement group at the trust. Talk to me a little bit about what this is and how it helped shape the work that Cystic Fibrosis Trust does.

**Zanib:** I've just recently joined like an involvement group and we're just trying to hopefully shape the work of the Trust, and like it's just a number of patients who will come together to help.

I think transplant patients are, quite frankly, forgotten about. Pre-transplant is excellent and everyone tries to and go above and beyond whatever they can do for you pre-transplant. But I think post-transplant it's very different. So I think it's a new territory, a new field and it's a growing field.

With like Kaftrio coming out a lot of patients don't really need transplants anymore. A lot of the new modulator drugs have meant that people have moved away from transplant. Which is amazing and it's just so good, but I think unfortunately we as a CF community do sometimes feel like we've been forgotten about post-transplant.

So, it's just trying to help other patients. We just get together, try and brainstorm ideas as to how services can be run more smoothly between different centres and between different teams.

Like between the CF team and the transplant team, because it's quite important as a patient coming from CF to transplant to have that maintenance of care and have that continuity of care, just so that any sort of like complications, further problems are prevented. Preventive medicine is a lot better than treating patients. So it's just trying to get together and see how services can be improved, how we can like standardize services.

Because from what I've come to experience now is across the country a lot of patients do have different care. So some patients would get their care continued from their CF team and transplant team.

However, some patients, their CF team would withdraw their treatment and handover all of that care to the transplant team. And it's not very standardized at times. And I'm beginning to learn that. And we're trying to work our way through how we can try and shape it and how we can change services to benefit people and, you know, help people post-transplant.

Because the whole aim of having a transplant is to live longer and make the most of your transplant. In order to do that, you need to have been given the right level of care.

It's not just a simple lung transplant. I mean, transplant is not simple anyway. But it's not just you're dealing with the transplant, you're dealing with CF and a transplant, which just adds to the complications that come with it. So, ensuring that you have a good team to look after you, both transplant and CF team is so, so important to make sure that you know you're thriving and making the most of

your new lease of life. Because at the end of the day, I think that's what everybody wants to make the most of and to add years to their life.

**Lucy:** Yeah, for sure. What you said there was great. And as well, just encouraging people from all different areas and communities within the CF community to get involved in the involvement group. You know, like you said, post-transplant, pre transplant, those on Kaftrio, not able to take Kaftrio. More common mutations, less common mutations, different cultures. A whole range of people are needed to be able to represent the Trust in a representative way.

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

**Lucy:** The final couple of questions to end the podcast. So what advice would you give your younger self if you were back pre-transplant? And I know you said you wouldn't do anything differently, but what would you say to yourself back then or someone younger who's listening as well who may be in the pre-transplant stage?

**Zanib:** I think for myself I would just say just make the most of what you have and look after yourself, look after your health. Focus on yourself and just be, you know, happy and be happy with what you have. I think that's what I would say to my younger self; not to stress, because I used to be a stresspot. And I think just looking after yourself and looking after your health is so, so, so important. Because if you have your health, you can do anything at the end of the day.

And yeah, I think that's what I'd say to my younger self, just make the most of life and I think even now post-transplant, I'd say the same, just make the most of what you have and that's for everybody. CF, no CF, pre transplant and post-transplant.

**Lucy:** Such a such a good tip for anyone listening as well. And you were talking about kind of the fact that these new lungs have given you like a new lease of life and things you're able to do now, what are your hopes for the future and what are you kind of wanting to do now?

**Zanib:** I think, I think for myself, make the most of the life that I have now. I spend time with my family, my friends, you know. Pre-transplant I made a massive bucket list of all the things that I couldn't do.

**Lucy:** What's on the bucket list?

**Zanib:** There is nothing specific, but it's just go on holidays, do sports, cycling. Just try new hobbies, learn pottery. I really want to hopefully, write my own book. So I think leaving something behind is important to me. And I think that's one thing that I would really love to do in the future.

**Lucy:** Well, I mean, a great point to end on. And thank you so much for coming on the podcast to chat about that. It's been very open and honest, which is great



and to represent the post-transplant community within CF and to acknowledge, you know what, what your journey has been.

**Zanib:** Thank you very much and thank you for the opportunity. And it's been lovely being on here today.

**Lucy:** It was really lovely having a catch up with Zanib. Thank you so much for joining us on the podcast and speaking so openly about your experiences of having a transplant.

**\*\*mini interlude\*\***

**Lydia:** Hi everyone. I'm Lydia and I'm content lead at Cystic Fibrosis Trust. Today I'm joined by Louise Hodge, who is involvement co-ordinator at the Trust. As you might have heard in this chat with Zanib, Zanib is a member of our involvement group, so we thought it would be great to catch up with Louise about what exactly that entails, how other members of the CF community can get involved, and the kind of opportunities that we have coming up.

**Lydia:** Thanks for joining us today, Louise. I've got just a simple question to start with. Can you tell us what exactly is the Cystic Fibrosis Trust involvement group?

**Louise:** Hi Lydia, thanks for inviting me to chat about our community involvement group at the Trust. It currently consists of over 300 members, including adults with CF of all ages, parents, siblings, partners and other family members.

The group share their experiences and knowledge of life with CF to influence the work of the Trust and wider CF research. We send out a monthly involvement opportunities email to our involvement group members, and they choose the activities to take part in, with activities covering a wide range of topics and themes relating to life with CF.

Opportunities take place in the form of focus groups, document reviews, 1 to 1 interviews and various other ways to suit the project or individual. It's all very informal. There's no set time commitment, and you can join as much or as little as you'd like, and you'll be fully supported by our team.

**Lydia:** It sounds brilliant. And why do you think that it's important that the CF community can shape the work of the trust in this way, and really have their voice heard?

**Louise:** So by signing up to the involvement group you can share your insights and make sure that the lived experiences and expertise of people with CF are at the heart of everything we do. This helps to ensure that the priorities of the Trust and the priorities of researchers match and accurately represent the priorities of people living with CF and their families. Sharing lived experience of CF to support the work we do at the Trust, makes sure that the Trust stays relevant to our community. This could be anything from reviewing resources to helping shape

projects around the requirements of the CF community. There are many projects and resources across the Trust, where involvement was really key to ensure that the voice of the community was heard.

**Louise:** Parents from our involvement group have helped shape the new parents, pack and supporting emails, and recently a couple of our involvement group members have reviewed the new Standards of Care document and are helping to shape a summary document for the CF community.

**Lydia:** And am I right in thinking, as well as shaping the work of the Trust, members of the involvement group also have the opportunity to shape CF research in a similar way?

**Louise:** Yes, definitely. The community can also sense check new research, making sure it's relevant. They can shape and design studies to meet the needs of people with CF, making it accessible, inclusive and as straightforward as possible for people with CF who will take part. This makes sure that the practical and logistical considerations of living with CF are factored in.

We've held focus groups for researchers to help shape studies to improve methods for lung MRI, dietary intervention, as well as informing the design for a potential new diagnostic tool to detect pseudomonas.

**Lydia:** And if someone's listening to this and wants to get involved, just like Zanib has done. How can they how can they sign up?

**Louise:** It's really easy. You can email us at [involvement@cysticfibrosis.org.uk](mailto:involvement@cysticfibrosis.org.uk) or head to the CF Trust website community involvement page for more information, where you can sign up to the involvement group by completing a short form. One of the team will get in touch with you for an introductory chat.

**Lydia:** Brilliant. Thank you. And can you tell us about any exciting opportunities that we might have coming up that people could potentially get involved with?

**Louise:** We have a variety of opportunities that cover topics such as nutrition and exercise. Growing older with CF, employment, access to medication, research and clinical trials, including genetic therapies and alternatives to modulators. So lots to get involved with. There's also a range of opportunities, and these depend on the type of project and individual preference for the involvement group members.

So there's different ways to get involved, which include reviewing documents and information resources and giving us feedback, discussions on managing treatments and how to improve medication design and streamline the admin process. Taking part in a focus group and 1 to1 interviews, as well as opportunities to speak at events and also join smaller project groups.

**Lydia:** And finally, why would you encourage people to be part of what sounds like a brilliant group?

**Louise:** You don't need any additional skills or experiences, as members of the CF community are already experts by experience. Whether you have CF yourself or a parent, partner or family member of someone with CF. You're welcome to join our involvement group to use your lived experience to shape the work of the trust and research.

**Lydia:** Thank you Louise. Thanks so much for joining us today. And I should say to our listeners that we'll have all the details of how you can join the community Involvement Group. In the episode notes.

**Lucy:** Thank you so much to Louise and Zanib and thank you 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 [www.cysticfibrosis.org.uk/podcast](http://www.cysticfibrosis.org.uk/podcast). And if you enjoyed listening to see for yourself, don't forget to subscribe, rate and review.

I've been your host, Lucy Baxter. Thank you so much for listening and I'll see you next time.