

## Ableism, Cystic Fibrosis with Izzie Jani-Friend

### Speaker 1:

Welcome to the Sunflower Conversations, where we explore the hidden disability sunflower and its role in supporting people with hidden disabilities.

### Chantal Boyle:

Welcome to the Sunflower Conversations with Chantal. Joining me today is Izzie. Izzie is a journalist and has a passion for changing the image of disability by using her own lived experience. Today, in our conversation, we're going to be talking about ableism. Welcome, Izzie. How are you doing?

### Izzie Jani-Friend:

Hi. Yeah, I'm so good. Thank you for having me. How are you?

### Chantal Boyle:

I'm good. Very much looking forward to our conversation today. So you have cystic fibrosis, which I believe is a disorder that causes severe damage to the lungs, digestive system and organs in the body. Is that correct?

### Izzie Jani-Friend:

Yeah. So basically, it causes the passageways in my lungs and digestive system to become blocked with thick, sticky mucus, and that will eventually lead to fatal lung damage. And then I also suffer from chronic pancreatitis and osteoporosis.

### Chantal Boyle:

Are those three conditions linked or you were just very unlucky that you've got the three or how has that happened?

### Izzie Jani-Friend:

Yeah, they're linked. Yeah. It's quite common for people with cystic fibrosis to have a number of problems, not just with their lungs. And so yeah, pancreatitis is something that people with cystic fibrosis either are born without a working pancreas, or if they do work, they tend to have problems with them. And yeah, problems with joints and bones is also quite common with people with CF.

### Chantal Boyle:

So that sounds very painful. So your pancreas, what does your pancreas do for your body?

### Izzie Jani-Friend:

It produces enzymes to basically help you digest food. And so if you don't have a working pancreas, then you'll have diabetes. And with cystic fibrosis, it's called cystic fibrosis related diabetes. And it's basically a combination of type one and type two.

But it's managed with insulin. And on the whole, people with CF can manage quite well with

that version of diabetes. And because I have chronic pancreatitis, I'm essentially waiting for my pancreas to stop working and then I will have CF related diabetes. But at the moment, my pancreas is causing me a lot of pain. It's severe pain that flares quite regularly for me.

And it means I can't eat properly. And it kind of affects my mobility as well, because the pain is so bad. And it's kind of difficult because with cystic fibrosis, you're meant to have a high calorie, high fat diet. And because of my pancreatitis, I'm being warned to kind of be low fat, low calorie, which is really hard to balance because they're both really affecting me. And so yeah, that is quite a challenge.

**Chantal Boyle:**

That does sound very challenging because what you put into your body is your fuel, isn't it?

**Izzie Jani-Friend:**

Yeah.

**Chantal Boyle:**

That's what motors your engine and your body's fighting against itself in a sense, it sounds that way.

**Izzie Jani-Friend:**

Yeah, definitely. It's difficult because if I get a lung infection, I need the strength to be able to deal with that and help my body kind of fight that. But then if I'm not eating and not getting that energy, then I'm putting a strain on my lungs too. So it's sort of like this negative cycle that is really hard to kind of get out of.

**Chantal Boyle:**

So on a day to day, what is life like for you? How often do you have your flareups? Do you have any energy if you're not able to eat the right foods that your body needs?

**Izzie Jani-Friend:**

Yeah. On a day to day, especially since October, I've been having a pretty consistent flare up. Usually, they would last a couple days a week, but then I'd have a few days where it was better. Whereas, now it's pretty constant. So it has been very difficult.

And I have felt things like with my lungs getting more difficult just because getting movement and doing physio and things like that to help get the mucus out of my lungs is so important. But when I can't move because of the pain, that's hard too, but I mean, so it is difficult my day to day.

I'm kind of used to it now, because it's been since October. So I'm kind of into my rhythm of dealing with the pain and my lungs and things and how they've been recently. But I guess, day to day I have a four hour medicine routine. So it involves tablets, inhaled antibiotics, Mucolytics, inhalers, tablets, physio, things like that. And about 30 tablets a day as well, so.

**Chantal Boyle:**

Wow. That's a lot. This must interrupt with your everything, your work, your social life.

Izzie Jani-Friend:

Yeah. I mean, it is hard to fit in having to do two hours in the morning and then two hours later in the day. I think trying to find that balance of, I want to live my life and do things, but then I need these medicines to do that. So finding that balance is quite difficult, I think.

I definitely struggled more when I was younger because I felt like, oh, I was missing out on a lot. I think now I find it a bit easier maybe to manage, but it is still difficult. I'm still tired. It is hard doing a full day of work and then having to do that and then do stuff that I enjoy.

But I guess, it's just trying to find the balance, trying to fit in, doing my medicine while I'm watching tele or something. So then after that I can spend time with people and trying to, I don't know, make it a bit more manageable, I guess.

Chantal Boyle:

In a sense this is your normal, isn't it?

Izzie Jani-Friend:

Yeah.

Chantal Boyle:

And you decide that you want to have a life as well. So therefore you are merging the things that you have to do to keep yourself here on this planet and moving with the things that you enjoy. Do you mind if I ask how old you are?

Izzie Jani-Friend:

I'm 23.

Chantal Boyle:

23. So you're very young and cystic fibrosis is diagnosed at birth, is it not or as a young child?

Izzie Jani-Friend:

Typically, yeah. I was diagnosed at six. I don't know quite what happened, but I think I was very poorly for the first six years of my life, but they just couldn't...

They didn't maybe do the test. I don't actually know. But when I was six I was diagnosed. So yeah, I kind of, it is all I've known. And so I guess, if I was to be diagnosed right now and have all that change, I think it would be harder to cope with, whereas I've known it from basically the start, so.

Chantal Boyle:

Yeah. So with all your lived experience, brings us onto the article, which you wrote recently. Can you tell us a little bit about the article and what prompted you to write it?

Izzie Jani-Friend:

Yeah. So I mean, cystic fibrosis is on the whole, an invisible illness and there are a lot of invisible illnesses and there's a lot of stigma around it and a lot of ableism directed towards people who don't look disabled, which I don't know really what that means, but there is a lot of stigma and discrimination.

I've noticed that those kind of negative mindsets have got worse since the pandemic. And I've written about discrimination faced by invisibly disabled people before. But I wanted to write about it again because I don't think many people might realize that it's got worse.

Because I think at the very start of the pandemic, things seemed like they were going to be better because there was more awareness, more kindness, more sort of community to help people who were vulnerable and needed extra help. And then I think the narrative sort of shifted and it became quite difficult. I mean, I'm clinically extremely vulnerable.

**Chantal Boyle:**

Yes.

**Izzie Jani-Friend:**

So basically, I had to shield. And I noticed that as time went on, people were saying, "Why can't the vulnerable stay inside and everyone else live their life?" And there was a lot of anger and negativity directed towards people like me.

And then it started to kind of trickle out into the services that disabled people use and whether that's using disabled toilets or disabled seating and people kind of policing those spaces and looking at somebody and deciding based on their outward appearance, whether they're disabled or not and directing their opinions to that.

And it's quite scary, especially when you're not feeling very well or you're feeling vulnerable, then having somebody kind of question you and make you feel that you shouldn't be using those services. You can feel kind of intimidated. And maybe in that moment, aren't able to kind of stand up for yourself.

And so it was an opportunity for me to kind of raise awareness about that through the article. And yeah, they're just a lot of these kind of negative ideas, whether it's people kind of telling me I'm too young to be disabled when I mention it or whether it's people telling me with regards to COVID, that I'll die soon anyway so I may as well stay at home.

**Chantal Boyle:**

Oh my God. That is absolutely disgusting.

**Izzie Jani-Friend:**

Yeah. I mean, it's difficult to hear that. I mean, I guess, being a writer, I'm kind of used to getting nasty comments. But I think the thing that worried me most about that is that anybody can become disabled at any point.

**Chantal Boyle:**

Yeah.

Izzie Jani-Friend:

And so people making those comments, their families or their loved ones could become disabled and then they have that mindset, which is I just hope that they don't treat the people in their actual life like that, but.

Chantal Boyle:

Well, it makes you wonder doesn't it? I think as in a statistic is only 17% of disabled people are born with a disability. The rest are acquired as we live our lives. You just don't know what's around the corner, do you?

Through environment, social interaction, whatever they might be, that one in five people have a disability. So the people sending in those nasty comments should really think again.

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The comment about we need to get back, everyone needs to get back and that the vulnerable, people who are vulnerable stay inside and continue to protect yourself. In essence, do you agree with that or was it just the vitriol that was coming towards you or do you not agree with that sentiment either?

Izzie Jani-Friend:

No, I don't agree with that sentiment at all, really. The kind of suggestion that to say, well, people, elderly people are vulnerable should stay inside while everyone else lives their lives as if our lives aren't-. I'm really sorry.

Chantal Boyle:

Don't worry. It is fine. Just go on mute and just take as much time as you want. Just don't rush yourself. It's fine.

Izzie Jani-Friend:

But yeah, I think that the idea that vulnerable people or elderly people, whatever, should stay inside while everyone else kind of gets back to the normality is really dangerous. I think that it suggests that our lives aren't valuable or worth anything.

And people like me when we was talking about the COVID restrictions easing, we were never asking for there to be a permanent lockdown, which is what was suggested quite often.

If we were suggesting that, then we could just lock ourselves down forever and not say anything, because that's the same. I could just stay at home while everyone else lives their life. I think we wanted just basic measures that made society safer for us.

It's the same as just in general day to day life having services that accommodate disabled people, whether there's a pandemic or not, whether it's accessible seating or services that can be used by everybody, it's kind of the same thing, making society safe for everybody.

And it's not really a surprise that it didn't happen like that and that there aren't really any protections in place for vulnerable people because there's a lot that could change in society. There's a lot that needs to change and is needed to change before COVID even came about, and so.

**Chantal Boyle:**

I can picture the scenario as well because all hospitality environments, retail environments, social environments, they've removed all the seating, didn't they? And for somebody who's got a health condition, being able to sit down when you're out is incredibly important.

It's a decision between going out or not going out, if you can't find somewhere to just rest for the time that you need to. And then I guess, not being in a wheelchair or having a really obvious external sign that you have a disability, the commentary towards people with non-visible disabilities has been really, really bad.

I know that we work with the RNIB and people are getting verbally abused for not social distancing in the queues and things like that when they can't see. So how would they know what two meters is? It was a very traumatic time. So your article is about ableism. Can we discuss ableism? What's is ableism?

**Izzie Jani-Friend:**

So ableism is discrimination and social prejudice against disabled people. And it kind of covers a lot. Yes, it can be really small, subtle things or it can be a lot bigger. So I mean, I've been told not to use disabled services because I don't look disabled, because I don't deserve them.

That's kind of bigger, I guess. They're speaking to me directly. And I guess, more subtle could be when people look me up and down when I tell them that I'm disabled or they shake their heads or they kind of just give that impression.

And I think it's often very hard to prove that you've experienced ableism because it might not be that obvious to other people. And there's not much you can do about it apart from kind of hoping that society will learn about things. But even for example, in a workplace, I've been ghosted many times as soon as I mention that I have cystic fibrosis.

I don't hear back. Even though, before they might have said I was a really strong candidate. And so I know that that's because of my CF, but I can't prove it because they've not directly said, "We're going to ghost you because of your CF." So there's not much I can do.

And it becomes quite difficult because then you start questioning, "Is it me? Am I not good enough?" But you have to remember, it is because of your disability because that's, they've made that quite clear. They only ghosted once I've said I have CF.

So clearly that is the reason. But it does feel sometimes very overwhelming and it can, for me, it makes me quite angry sometimes just because they've just decided that to know. They didn't want to even try and see how they could accommodate for me, even though

they, before that saw my CV, my job application and thought I was good.

They've now decided that all of that doesn't matter. Rather than kind of seeing, "Oh, she's done all this and she has CF. So clearly she's been able to do that." But they don't see that. They kind of completely just ignore it and focus in on disability, which is just really difficult.

And yeah, something I can't prove. If it was more direct in a workplace, you could probably take them to court or something, discrimination. But it's not so easy when it's subtle like that. And you kind of just have to accept it and.

**Chantal Boyle:**

We need to be working towards the social model whereby it's not accepted and everything gets levelled up so that society makes adjustments to not accommodate, but so that to normalize disability so that everyone has a level playing field. And it's like racism, isn't it?

I'm not going to give, this candidate's got all of the right skills, great portfolio or what have you. But then they see the colour of the person's skin or they make an assumption because of the person's heritage that they're not going to fit in to their role within their business.

I know that there's an issue around when people apply for jobs if they've got foreign names, which are difficult to pronounce, their CVs will not be looked at first because somebody's made an assumption about that person because of their name, it's not English, it doesn't roll off the tongue, whatever.

And again, it's making a judgment on something that really should never ever be considered your disability, your race, where you come from. And so by writing your articles, hopefully it is definitely going to be making some inroad to changing perceptions among employers and employees and in society and in communities.

So you've spoken about in the workplace where you've experienced that or trying to get a job. Have you got any other experiences, so socially or that you've observed from things that you read in the media or that you watch?

**Izzie Jani-Friend:**

Yeah. I mean, speaking socially, I mean, I'm lucky in that the people in my own life are not ableist towards me. I mean, they wouldn't be my life if they were to be honest. But I've never kind of had that with friends or family, just been very understanding and accommodating.

I think socially though when I've been using disabled services, like priority seating on a train, I have been asked to move, even though there are other people that maybe weren't in priority seating, but they could have moved for this person. And because I look, I don't know what in their mind, but I look fine.

**Chantal Boyle:**

Healthy.

Izzie Jani-Friend:

In their head, that then they think that it's okay to sort of shame me and call me out and make me move. And when I'm using the priority seating, because I am wary about using it, even though I shouldn't be, I should just be fine, but I just do get scared for that confrontation.

But when it is at the point that I'm using it, it's because I'm in a lot of pain and I need to use it, obviously. And I'm in such a vulnerable place at that time that I can't stand up for myself in the way I would like to.

I am a lot more outspoken about disability than I was before I started writing about it. But I still, when I'm not feeling very well, the last thing I want to do is kind of have a conversation with somebody. I just want to focus on, I don't know, just getting home so that I'm not, you know?

Chantal Boyle:

Yeah. Because you are in a vulnerable position, aren't you? You're on your own, you've got people making assumptions and judgements about you who don't know you, you don't feel well, you've got a chronic health condition.

You need to get home, you need to get to your bed, you need to get to medical support, whatever that might be and then trying to, or having to express and explain yourself to a stranger. I mean, it's just not on.

Izzie Jani-Friend:

Yeah. Yeah. And I mean, I haven't been on public transport since the pandemic because... Well, really public transport isn't the best for my health. I'm usually always ill when I go on it. So I try to avoid if I can. But when I can't, in those situations that have happened to me a number of times, I tend to just move, which I know is wrong and I shouldn't do, but I just want to be left alone.

And so I'd rather sit, try and find somewhere to sit on the floor or whatever, just so that I can just be on my own and not have people kind of talking to me that I don't know. And trying to give me that input and their opinion on my life.

Chantal Boyle:

Yeah.

Izzie Jani-Friend:

When they don't know anything. And I mean, if I was in that situation now I hope I would kind of say something, but again, when I'm in agony my mind isn't in the right place to even think coherently. So I don't know if.

Chantal Boyle:

Yeah.

Izzie Jani-Friend:



If I would, and there's no shame in not doing it. It's not on me. In a way, it's on them to kind of be a bit more open minded and understanding that a lot of people that are disabled are invisibly disabled and often being told, like I said, that I'm too young to be disabled, which is just kind of a ridiculous thing to say.

Because I don't know how we've got to that idea that to be disabled means you're old. I don't know where that came from. And then you asked about the media. And I think in the media, there is a lot that needs to change. I mean, firstly, we hardly see disabled people in the media, even if that's on TV, film, in just general people that are presenting the news or things like that.

There are disabled people of course, but there's not enough. There's not enough representation and there's not enough positive representation. Usually, when there's a story about disability, it's because it's about how tragic it is or how awful it is or how inspiring somebody is. You never just see a disabled person existing. There's got to be some story that is attached there.

And I think a lot of the tabloid news have kind of demonized disabled people, calling us benefits scroungers, or saying that we abuse the systems or that... These narratives have really harmed the way that disabled people are seen. And although maybe it doesn't happen as often now, but it was in the past, especially when I was growing up, I did see that kind of mindset a lot.

And it made me feel really nervous about speaking out because I was thinking that people would call me a liar and say I don't deserve the help I get or that I'm abusing systems and taking advantage of the NHS and things, which is ridiculous. Because if I didn't have that help, I would die. I think yeah, those mindsets are very dangerous.

#### Chantal Boyle:

You're totally right though, with what the media have done in that respect, benefits scroungers. You'd be nervous to tell anybody you're on benefits, wouldn't you? Just because of the ideology that they have presented and brainwashed everyone with that if you're on benefits, you're either lazy, you're scrounging, you are taking advantage of the system.

And I think actually it's something that came out of the pandemic when people maybe who worked even in those media outlets were getting made redundant, people who had a career for however many years, because of the financial implications of the pandemic were made redundant. And homelessness shot right up. And I'm hoping that people's perception of being on benefits has changed because the judgment is just, it's very cruel and damaging and hurtful and painful.

#### Izzie Jani-Friend:

Yeah, definitely. I think that also, because I work in an industry that does kind of perpetuate those ideas, it is difficult. And journalists don't always have the best kind of reputation. And I think that the reason I wanted to go into this line of work is because I wanted to be able to sort of change as much as I can.

I mean, there's only so much one person can do. And I mean, there's loads of people doing it, it's not... And I wasn't the first to do it and I won't be the last. There are lots of disabled people out there who are trying, in the media who are trying to make a difference and raise awareness.

But I think that even if it's a few people that read something I write and decide that they're going to be a bit more open minded and treat disabled people in their life or that they come across better, then that's really important and kind of worth it.

Because the more we talk about it and hopefully there are other disabled people that are seeing how the media, some outlets write about disability and seeing it in a more positive way, that we're raising awareness about it.

But we're not writing it as if it's tragic or if it's inspirational, just writing it as fact. And talking about the problems as well, that hopefully, it's slowly changing the kind of negative impression that the tabloids have given to us.

**Chantal Boyle:**

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Ableism, is that quite a new term because it's an umbrella word, isn't it? For racism, homophobia, sexism, apartheid. I've got a few, I've got a little list here, reverse discrimination. So it's a collective word.

**Izzie Jani-Friend:**

So I think that ableism is probably relatively new in a mainstream conversation. I think that it did emerge the US in the eighties alongside the disability rights movement. But it has been used a lot more recently in the media because it just specifies the disabled experience rather than just discrimination.

And kind of ableism shows it's directed towards those who aren't abled bodied, whatever. I don't know. I don't really like that phrase, but I guess, it's towards people, disabled people who are seen less than able bodied people or non-disabled people. And so, yeah. But I mean, the term has been around for a long time. But I mean, it's just getting more and more used because it does describe the experience, I think.

**Chantal Boyle:**

What do you think society needs to do to eradicate ableism? How can we do this?

**Izzie Jani-Friend:**

I mean, I think with all these issues, it kind of starts at the very beginning and having better education. But I think it's showing disabled bodies, disabled people through education, whether that's in sex education, seeing disabled people in that, having disabled people in that discussion, in those lessons having learning about the range of disabilities.

I think that, like we said, a lot, most people become disabled later in their life. They're not

born with being disabled. So learning about that is important because every time we go out the house, we probably come across, we obviously come across disabled people. And having that better understanding just makes for kinder people and makes society more accommodating for people.

I think that greater awareness, representation in whether that's in children's TV having disabled characters. It doesn't have to be about them being disabled, but just having them there to show that it's fine and people like that exist, there's a lot of people like that. And.

**Chantal Boyle:**

Representation.

**Izzie Jani-Friend:**

They don't need to be treated as other. They don't need to be othered or kind of seen as people that maybe need saving or whatever. Just seeing them as normal people like everybody else, I think that's super important. Because it just makes kids more open-minded and I think that it helps going forward.

But I think also just having disabled people in the workplace. There's a lot of companies where people at the top aren't very open about disabilities. And many of them might be disabled. Many of them might have mental illness, physical illness that they're not being open about.

And if they start talking about their experiences, it will affect the rest of the company, because other people will feel safe to speak about theirs. And it will create a better culture.

Or whether it's listening to disabled people and asking them what needs to change and then implementing it rather than holding an event about disability and then never changing anything in the company because you think that the event is enough.

That happens a lot. There's so much that needs to be done to eradicate ableism. But I think seeing the changes as beneficial to everybody. If there are changes that are made, for example, more ramps or wheelchair access or BSL interpreters or braille or things like that, there's so many different adjustments that could be made.

They benefit everybody. For example, a lift or an escalator. If you're just feeling tired one day, carrying a heavy box or something like that, you can just use that.

You don't have to be disabled. And I think that that can be applied to most adjustments, that it will actually help everybody. And I think seeing those as helpful to everybody will really help people kind of change that mindset and that will make society better for everyone. But I think education is obviously the main thing that is going to change it.

**Chantal Boyle:**

There are some excellent suggestions. And I think you're right. When businesses have disability awareness days, that's one element of doing it, but it needs to go down into the culture and part of their diversity and inclusion agenda. Make it part of the DNA and how

businesses operate as you said, and not just an extra add on for it to be genuine. So what are your thoughts about the Sunflower?

**Izzie Jani-Friend:**

So when I was first writing about the discrimination I'd faced and when I was using these services, I didn't actually know about it. And I haven't really been in a situation to use it since the pandemic just because I have been needing to be careful still.

But I think it's a really great initiative to kind of give people the power to kind of say, to show that they're disabled, but they don't have to kind of say anymore than that.

I think that with everything, it's good if people don't exploit it. However, I think that more often than not, people don't exploit these things and it's just one or a few people and it kind of makes things difficult for everybody.

But I do think on the whole, most everyone is using it genuinely. And I think that sometimes it can be, and I guess, this is the same with being invisibly disabled or not is that if you're invisibly disabled, you kind of have a bit more control over whether people know about whether you're disabled.

And so if you don't want people to know, you don't have to tell them. But I think that using the lanyard, it gives you that decision of, if you do want people to know, then that's how you can let them know. I think that it could really help stop invasive questions.

I think that if more people kind of knew about it, knew what the scheme is. So then they know that if they see somebody, they don't need to say, "Why are you using this seat?" Or "Why, you don't deserve these toilets?" Whatever it is, they have that kind of understanding that, "Oh, okay. They need to use it and I don't need to ask why."

**Chantal Boyle:**

I think... Yeah, I think that I do a lot of these podcasts and chat to people and parents, young children and a lot of them have said that they wish that when their child was young and experiencing might be a meltdown, for example, if they were autistic or whatever it might be, that having their lanyard would've been such a great help to them for the reasons that you've just said, that people are not going to judge and you don't have to explain.

And the feedback that you are going to get from strangers is very different, "Okay. There's something happening here. We'll either offer a hand or we'll just step back and let them deal with it, or we'll offer them a quiet space to go to." And that's the essence of it really. And it is very much about the individual chooses when, where and why they want to use it.

So I'm pleased that you also recognize the value in it. Thank you very much, Izzie, for giving us your time today to share your lived experience, your professional knowledge as well within journalism and the observations that you have made.

And we hope that your journey along with what we are also trying to achieve at Hidden Disability Sunflower, to raise awareness of non-visible disabilities and stop ableism is a

successful one. And we wish you all the best with your pancreatitis as well. And I hope that you are able to emerge from your flare up at some point and not be in so much chronic pain.

**Izzie Jani-Friend:**

Thank you. And thank you so much for having me. It's been a really great conversation.

**Speaker 1:**

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