

Cystic Fibrosis Trust

Season 2, episode 2: CF and the menopause

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 two, season two of CForYourself. To Mark Menopause Awareness Month, today I'm going to be catching up with 59 year old Jane to talk about her experiences of going through the menopause, her top tips and the need for more awareness and information about CF and menopause.

We also discuss the need for geriatric and menopause specialists within CF teams, with people with the condition living longer than ever.

"As more health problems inevitably arise, it's very easy for non-CF specialist healthcare professionals to blame everything on CF regardless of the problem... *with an aging CF population, I'd like to see geriatricians (Medical experts dealing with growing older/aging) involved in CF teams, getting them to learn from us older patients and more importantly from the CF doctors, nurses and physiotherapists that look after us,*" Jane said in a blog for us last year.

I'm really excited to be chatting to Jane on the podcast today and to hear more about her life with CF and the changes she is calling for in care for those with CF going through the menopause.

We'll also be hearing from Holly Ellard, Information Officer at the Trust, who will share some of the latest information and top tips for those with CF going through the menopause.

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.

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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.

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

Hey Jane. Welcome to CForYourself. How are you today?

Jane B: I'm good, thank you. Approaching my 60th birthday rapid rate in knots. But other than that, yes, I'm absolutely fine. Thank you.

Lucy: That's exciting.

So tell me a little bit more about about yourself and what you do. You just mentioned that you're nearly 60, which is exciting.

Jane B: Seriously exciting. If you want me to talk about my childhood, I was diagnosed when I was three weeks old. Evidently, they did two or three sweat tests at first and they proved negative. But as I found out in my thirties, I'd had a sister born with CF in the 1950s, but unfortunately she passed away at 18 months.

So they were sort of looking for it. But obviously, my parents were hoping for the best in that I wouldn't have it, but along I came out was described as a car with an. A car engine without oil. I remember hearing a doctor, but I'm very pleased to say that I've proved the doctor completely wrong as I'm still here alive and kicking.

Lucy: I mean, like you said, that's incredible to be 60. And I guess the growing up with CF and 50, 60 years ago compared to now will have a lot and you'll have seen a rapid a rapid increase in in medication and treatments. Tell me a little bit about what it was like when you were younger, what treatment was available then?

Jane B: Well, it. The main thing that I can remember is there was no such thing as Creon. It was this Pancrex V 40 Powder because obviously I can remember having it very young and it was this disgusting paste that had to be mixed up that you had to have either before you ate or sprinkled all over your food, whichever way you had it, it was absolutely foul.

And so in those days, it was a case of very low fat, very high protein. So my breakfast would always be shredded wheat, steak and potatoes or fish and potatoes, because it was all about getting the protein in and the tablets just couldn't deal with fat. So that meant a childhood of no ice-cream, no chips, no crisps, no Indian takeaways or fish and chips, absolutely no fat.

I could occasionally have a treat of a bag of cheese and onion crisps on a Friday night so that if when I had the bad stomach it would be over the weekend and not interrupt school. So that was one of the huge things that I absolutely hated and evidently all my cousins were blackmailed never to ask for ice cream or chocolate in front of me.

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So they were always thrilled when I arrived because they too would be on sorbet and fruit pastels and jelly babies because they weren't allowed to have it if I couldn't, which was very nice of them. I think pretty much they all complied.

The other part of CF that to me was the absolute worst thing was having black teeth, because at that time there wasn't the range of antibiotics and knowledge that there is now.

Unfortunately, the antibiotic I had discolored my teeth badly. If every I had a tooth that was slightly loose, I'd pull it out because I'd been told that when my second lot of teeth came through, they'd be pearly white. Except they weren't exactly, they were exactly the same damn color and which oh, it's just horrible. With the name calling and all of the rest of it.

It really was awful, even to the extent that one day I think I must have said at school I wasn't feeling very well. And the teacher said to me, Well, I'm not surprised with the color of your teeth. Which was the final humiliation that even the teacher was joining in with it. I don't think she did the following day, after my mum had run up to the school to have words with her. So that was the most miserable part of CF. I was very lucky. I didn't have to have IV's until I was 15. As I saw I was just very lucky. My mom and my dad were absolutely and totally devoted to me and my life and my wellbeing.

I used to loathe the time that my dad would say, right, let's get dressed, we're going out for a walk. And I absolutely hate it, but I can absolutely see now why he did do it and was so keen on it. Unfortunately, he passed away when I was 14, so it's my mum and I. I had no other siblings and as I say, I didn't find out I had a sister until I was in my thirties.

Main reason being that my parents thought that if I knew I'd had a sister who hadn't survived, then I might not fight in the same way. So yeah, I happened to find out by chance when I was in my thirties. So that was sort of pretty much how it was. I mean schools and things. It was always so difficult. I always feel like because I'm not still the same because I'm nearly 60, I've always felt like I'm the older one.

Pressing doors, pushing at things to make people change their opinions. For instance, I can remember infant school, I wasn't allowed to stay for school dinners because I had to take tablets I could. I was quite capable, even at five, to take my own tablets. But the schools just wouldn't have me. So it's a case that my mum would always have to come fetch me and then go back to school because that was the only way of me getting my lunchtime food in, it was just really, really difficult. There was just absolutely no desire on the school's part until I became a teenager. We moved to a different area of the school, learning how they could support or what they could do to assist it. If you know, just nothing. They'd never get away with it these days. So you were always made to feel that different person that nobody wants to be different. Everybody wants to be the same. So yes, that was how childhood was. Not my best time.

I couldn't wait to leave school to be perfectly honest.

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

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Lucy: And then kind of what happened when you left school and what later happened in your life?

Jane: School when I was 16, as I say, I'd had enough of it. I couldn't stand it. And so at that time there was huge unemployment. But we're talking about the eighties, huge, huge unemployment.

And my mum was very sensible and she sort of said to me, if you're, you know, you can either carry on at school, go to college or get a job, but you're not sitting in the back garden on the sun lounger all summer. Which I was, that was my plan. I was quite happy with that one. So I realized that I needed to do something to get some work experience to, if you like, prove my worth.

So I took myself to the careers office and managed to get myself a six months training scheme at the Tax office as it was. And it was it was purely a training scheme. It was £5 a week more than benefit. Which didn't take into account your lunches or your travel expenses or where this sort of work wardrobe came for. But I did, and it was the best thing I could have ever done because people weren't interested in my health in that way.

And I was just a normal person at work. At the end of the six months that was when it finished and that was that. So that it was a case of signing on and applying for jobs. And I went through a few interviews and got offered a couple of things. But then I was offered a job with the Department for Work and Pensions, or as it was then the Unemployment Benefit Office, and that was where I started work and absolutely loved it.

I worked with some amazing people who was so supportive. It was untrue and that was where I stayed till 2015 when I had to medically retire. But I didn't medically retire because of CF, I had to retire because of the neurological problem, I'd got bored of all things CF and CF diabetes, and I decided to move on to something new and had a neuro problem, which was a nightmare.

Lucy: Was CF as well-known back then. I mean your touching on.

Jane: No.

Lucy: Yeah

Jane: No absolutely no. If you ever if people would say to you, as I often do, I that's a terrible cough you've got. Oh, dear you should see the doctor about that and say, well actually it's not contagious, don't worry about it. This is what it's called, you know, trying to give the the briefest of descriptions and people just glaze over.

They haven't got a clue. Or I'd go along sometimes with my mum doing house to house collections for CF and she'd say to me, don't tell them you've got CF because one you shouldn't, you know, they wouldn't think you'd be able to be up and walking about and two they won't know what it is and most them think it's...what was it she used to say fibro-cytus or something like that.

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She said so just smile. And if they think they're giving money for that instead we've given them the leaflet, we've done what we need to do, let them donate. And that was what it was. And you would get quite a few people...Oh yes, I get that fibro-cytus in my muscles its very painful, so no clue. And if you did ever hear of anything to do with CF, you know, if it was on the that used to be a Sunday night appeal for a charity when it was that charity's week and at the end of the CF one it would always show some of the day and then having their physio in the old percussion method, which I have to say, I still do do that because I am a dinosaur.

Lucy: I do that as well.

Jane: It's the only thing I really, really effective and quick, and gets to it. They would always say at the end of the promo, we're very sorry to tell you that such and such a person has now passed away, which I can understand. Yeah.

So every time we ever heard or saw about CF it would always be followed by this sentence. We're sorry to tell you. I didn't know many people with CF when I was growing up because I had the sister who passed away, she passed away a hospital, a local hospital that dealt with people with CF - babies, children.

So they didn't want me to go there. They didn't feel it was a good idea. So I went to a separate hospital in another part of the city and saw a pediatrician who was excellent, very nice lady. Very stern, very stern. You wouldn't dare disobey her. So there was only one other person, I'd see from time to time who had CF.

And that was about it, other than what I would glean from the news or the news or magazines.

Lucy: And of course, cross-infection wasn't a thing at the start, you would all mix

Jane: Well, we we would have done had I have been with other people with CF. I had this isolated childhood from CF.

Lucy: Which probably in the long run helped you out.

Jane: I know, well what that I always thought they were ahead of their time with their knowledge. But when I was 20 and had to be hospitalized at my current hospital, I still wasn't under a CF team, and I was in an infectious diseases part, so I was already in my own room. That was nothing new to me.

But a physio came along who normally treated CF people and had never heard about me obviously, and had never treated me before. And she suggested it might be an idea for me to meet the CF team, one for the social side of it, because as you rightly say, cross-infection wasn't an issue. And two, as I would get older and develop other problems, I would need the multi-disciplinary approach to medications, whatever.

And so that was what happened. And I then swapped over and the for sort two years I had the most wonderful time meeting other people with CF which I thought was fantastic and we would regularly meet for badminton, which means that most of the night we would stand talking across the net to each other rather than actually whacking a shuttlecock.

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And then we'd all go out for an Indian meal and it would be fantastic because quite mainly it was young, it was men, younger men and a few ladies, but we would be the normal ones because the Creon pots and things would be flying up and down the table because the males of the species had never remembered to bring their tablets with them because our non CF partners would be there as well.

So but we outnumbered and so for once we were the normals and they weren't. It was a wonderful time. And then of course cross-infection came and it was just the worst thing ever. We'd even had holidays together, weekends away. We'd had an amazing time. But if anybody says, is it worth not doing the cross infection? When the cepacia things came to tone, I lost a lot of friends in a very short amount of time.

It is awful.

Lucy: Yeah, in a way, with cross-infection, you're kind of shielded from that aspect. I guess if someone having the condition and getting really close, etc., etc. and how, how does CF impact your day to day life now, Jane?

Jane: You're never going to forget it, are you? But in terms of how are my lungs? They are they are a lot better, you know, an awful lot better, I can't believe it because I'm lucky enough to be on Kaftrio. It's just incredible. But as brilliant as Kaftrio is, it doesn't take away, in my experience, the stomach side of it, the diabetes side of it, and then going onwards to develop other older problems. It's that but you know if it wasn't for Kaftrio, we wouldn't have the opportunity to discuss those older age problems because we wouldn't probably be here.

So it's a wonderful drug.

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

Lucy: I do think that's really interesting and kind of what not necessarily problems, but just life milestones and things that maybe people with CF didn't experience before they are now experiencing. And if we touch on the menopause just because that's kind of it's Menopause Awareness Month, what would you say it's been like for you?

Jane: Well, it was a sheer joy. I'm hoping I'm over the worst of it now. When I first started having hot flushes, I was mainly having them and had sweats, I was mainly having them in the night. So and that was pre-libre. So first of all, I was waking up and thinking, okay, am I having a hypo. Am I just hot or is it just a hot flush that I can ignore?

But because there is always it could be a hypo a bit to get up and check, check my blood. It was a real pain, you know, extra fingerprints and all of that. And I could go out with friends and I just sort of completely drench my clothes with these hot flushes, etc.. So I made an appointment to go and see the GP and to talk about it with them.

And fortunately, one of the times I had a vascuport in my arm for the IV's. I knew from the second it went in there was something not right about it, it just wasn't comfortable and within about five, six weeks it turned into a thrombosis because it wasn't set. In my opinion, it wasn't done properly.

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It was just one of those flukes. But of course it was a thrombosis. So then it was about being on Wolfrin and blood thinners for nearly 12 months until they were quite convinced that everything was fine. So because I'd had a thrombosis, even though it wasn't in my mind, a normal thrombosis, the GP's wouldn't consider a HRT for me.

So they gave me some hormone cream which helped a bit. It didn't help hugely. And I do think because I tried talking to one of the CF consultants about who's very good and very knowledgeable, but she was very much, well, it's not a CF thing, it's a GP thing and the GP really needs to be sorting it. So I said, well could you send them a letter, say that it wasn't a normal thrombosis and you think probably HRT would be okay.

But of course then that puts the ownership back on the CF consultant and CF team. So they weren't keen to do that, which I can understand, but you're sort of left piggy in the middle and I do think as we get older we, I, we need to have somebody like I've said this before to the CF Trust on other Skypes.

We need to have a menopause nurse, bit like we have a specialist diabetic nurse. We need a specialist menopause nurse who can research what would be the best treatment for us, whether that's then just liaising with the GP and getting the GP to prescribe based on their knowledge, etc., etc. But I don't think we can just ignore it.

We do need to have a plan. If like a treatment plan when necessary because we have enough to deal with without the complexities of menopause problems that could have been made a little bit easier if we were able to have treatments like HRT that might help. It seems wrong that we have to sort of almost suffer for it.

Lucy: Compared to kind of symptoms of friends of yours of a similar age who don't have CF. Would you say CF impacted your menopause in other symptoms in any way?

Jane: Well, as I say you you've got the complexities of is it is it just a hot flush or is it something I need to do something about? Am I starting a fever is at the start of an infection. So you have sort of, if you like, little worries, but because CF's such a multi organ delight and can affect you in so many wonderful ways that you've never thought of or heard about, anything extra is another burden.

And I'm talking as somebody with it. You know, who's been lucky enough to have Kaftrio and has responded very well to it. When you're not well, the last thing you need is something else to bring you down as well. It's hard enough sometimes to stay positive and ride that wave, and sometimes it can be the straw that breaks the camel's back, for folk. And it shouldn't be.

Lucy: I always say it's kind of the, in in quotation marks, normal people problems that that tip tip me over the edge when I if I have to have a long line and antibiotic IVs for two weeks it's fine, the minute I get a cold or or some some problem that that another person in the office could have I feel like it's the end of the world. That's that that's the thing.

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Jane: And you don't want to react because you think, well normal, people can just deal with this, get on what's wrong with me? But of course, normal people haven't got the body makeup that we have.

Lucy: Yeah, definitely. And I guess in general since Kaftrio, but also advancements in treatment before that like pulmozyme, Dnase, is there is no no one path anymore.

CF isn't so black and white. It's not so much, your grow aspergillus, we'll do this or pseudomonas is in your lungs let's do that, it is very much different now. And it feels like and I know my consultant said they almost ripping up the old CF book and learning with us which is a bit scary but equally is exciting.

Jane: Absolutely. And that's fine as far as CF goes, but when you and I'm happy to be a guinea pig, I'm happy to be used, to find out if this path works better or that path works better. But we need to be now adding in to the teams geriatrician type doctors who have the experience of knowledge of older people and older people's problems so that they can learn about CF because older people's issues are bound to affect us more and we need them to get the knowledge of CF and the interest of CF

And the CF team to start learning about how best to approach things with us.

Lucy: Yeah, and of course it's not just, it's not just necessarily how CF impacts the menopause or impacts us as we get older it's, it's these again in quotations, normal problems or normal things that we just need someone who understands CF to understand both to put the two together.

Jane: Exactly. And you know thank God for Kaftrio and similar drugs. This is this aging and CF is going to, thank goodness, become more of an issue. Therefore, if we can start persuading people, we need other teams input now, hopefully it'll be here then as we do to get older.

Lucy: I always think when I when I was younger and a teenager and you know, you always kind of look up the life expectancy and.

Jane: Oh yes, what a dream.

Lucy: Exactly. And it's it's just, you know, kind of there isn't really one out there anymore. But I always think it's really for people like I'm 25, for people my age, and people kind of younger, to hear someone like yourself who and I'm not calling you old by any stretch, but I'm you see what I mean? It's really inspiring to kind of chat and let hear your how CF has sort of advanced in your life because just purely because there's you know, it's just really great to hear.

How would you say the CF Trust has changed or has that always been around when you've had CF?

Jane: Yeah, yeah. I mean CF I mean, the CF Trust was formed in 1964, so a few months after I'd been born, there was some something not that long before that, erm I can't remember the details, but it was about another couple of parents who lived in Kent and go together and chatted. Because I can remember my mum saying the pediatrician had given mum their details

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to get in touch with, so she sort of had a little bit of support and, you know, it was good for them to have other people to offload to. So obviously in my first half of my life I would say to me the CF Trust was mainly about raising money for research, which I still think is absolutely needed because we desperately need some new antibiotics that can attack the bugs quicker.

And I could sort of not to give this quite so many pleasant side effects, that would definitely be a bonus. But now I think a lot of it is about looking at the actual person with CF and it's the person with CF rather than CF people, which I think is quite different. And so I think it's really important that the burden of treatment is looked at.

You know, it isn't that the CF Trust would now say research any price drugs at any prize. It's about how does that drug impact upon that person and the fact that we are invited to give our comments on the trial accelerator platform, I think that's really valuable and quite different to many other charities that I sort of read about, looked at.

I feel that the CF Trust very much wants to hear from the CF population and tries to act as much as it can, taking our wishes and thoughts into consideration.

Lucy: And it's personalized medication to each of us now rather than I like what you said it's not just CF people it's a more complex condition now, I think.

Jane: Well, I think as we live longer, more issues come to the surface that need treatment. Whereas I can remember when I was first told I'd got CF diabetes or I might have this when I was 17, and then they sort of went away from it for many years. And then I think when I got to about 37, my blood glucose levels, you know, were high and it was decided, yes, I was diabetic, but I can remember them saying to me, but it doesn't matter what you eat, CF diabetes is completely different to normal diabetes and if you still want to eat your bags of jelly babies, which I'm addicted to, by the way, that's fine, you can do that. You know, which is completely, completely wrong and obviously isn't the advice that's given these days. But you know, you always go to that one step going forward with illness I think sometimes.

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

Lucy: Going back to the menopause, if there's anyone with CF kind of listening to this, going through it or kind of thinks their just about to go through it, what kind of tips would you give them?

Jane: Try and encourage them to find a sympathetic GP who would be prepared to liaise with the CF team, which is easier said and done to get the GP appointment to start with. But I think as at the moment it's, it seems to me to be GP led rather than CF team led, it's about trying to find that a good GP who will listen to you and try and help and intervene, but consult with the CF team to make sure that they're thinking along the same path. I was talking to, she was telling me about her menopause problems which had been horrendous and it was only that she found a very sympathetic GP who prescribed HRT and she said it's made the world a difference and she's followed that GP from practice to practice, purely because they have been so good at helping her through the menopause and prescribing her the HRT.

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Lucy: So after you had the blood thinners and morpherin were you able to then have HRT or what what's been your management of the menopause?

Jane: The only management I've had has been the hormone cream. That's it. Because they just wouldn't prescribe HRT. And fortunately I think I'm through. I don't have the flushes now and I think that's the other difficulty with CF because CF and our medications can cause so many side effects, it's difficult to know sometimes whether actually it is the menopause or it's a side effect of another treatment that you're having for CF.

And that's part of the problem. Hence why if we were to have menopause CF nurses that was their specialism, I really think that would be helpful. I think it would be helpful for the GP as well as it would be for us so much.

Lucy: But also like the menopause is only, I'd say in the last two, three, four years being spoken about publicly anyway, not just in CF. There's so much more now because it was something

Jane: You just had to get up and get on with

Lucy: Yeah, it was something you just had to get on with. And it was like you were all, it was all just HRT or whatever. And then it was like, well, there's actually holistic ways. There's different things. It's different things. And it's not like you said, just the hot flushes, it's everything else.

And it's kind of like I think the general population are only, in the NHS or GP's are only grasping how to do it for them. So then to do it for us, it's they're a bit freaked out by what they should, that we should be in line with the general public on menopause it is, it's a huge part of like a woman's life like at that point.

But then the years after it's it could be like a third of their life or more, you know.

Jane: Oh yes. Because it's nurse I was talking to who I respect very much, her knowledge and her common sense. She said, I still think you'd benefit from it now. You know, I think it would make a big difference to you. Well you think, do I feel up to another battle with with the doctor, with the GP who's telling me, no, I don't need it and yes, I can just get on with it when I think I've passed the flushes stage. So you know, that part is divine.

Lucy: Definitely a tricky one. I mean I think, you know, not all GP's are the same, obviously it is, it depends.

Jane: But then you put COVID into the mix and the lack of availability of appointments you tend to think. And I think most people with CF will say, will think, well, I won't go and bother the GP with, so I'll put up with it for a bit longer and see how I go, because in our minds that's something normal people have and if they deal with it, we should be able to deal with it even better.

Lucy: What, obviously you'll soon be 60. What kind of what are you going to do for that? What what plans have you got for the future?

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Jane: Well, we're going to Mauritius for holiday. When my husband was 60, two years ago, we had a massive party band. Everything else, which is all fab. But it was very tiring, very tiring. So I really didn't want that.

And if we do something, we like to do it really, really well, so hence we went for the holiday option instead. My choice. But now I'm sort of thinking, oh, well, when people keep saying to me, you've got to do something, you've got to do something. I had a party when I was 50, which was lovely, but I don't want to do the same thing again.

So I don't know. I think I might have some mini parties of like 12 people at a time or something like that. And I've got a lot of family who live in Liverpool, so I'll go up there for something. And I quite fancy, a couple of champagne, afternoon teas, that sort of thing, quite sedate for a 60 year old.

Lucy: No, it all sounds absolutely amazing and yeah, happy birthday when that comes. I just want to say thank you so much for coming on the podcast today chatting all about that. And, and it's so interesting, again, just listening to, I can't imagine never having Creon. You know, I can't imagine not being able to open my fridge and just say, Oh, I'll have some bacon. Like that in itself is a whole topic of.

Jane: How my mom dealt with I have no idea because there was no microwave either. If she cooked a casserole she'd have to do it the day before so she could take the fat off it on the day we were due to eat it.

Lucy: Yeah. I mean, it's such that that blows my mind. And then you've got kind of like the physio and everything's not changed much other than the devices people can use. And obviously antibiotics and IVs haven't changed much. But the real, the personalized medication and the Creon seem to be the and Dnase seem to be the things that really like pushed it on and the cross-infection actually. But yeah, it's, it's just been a really great episode. So thank you so much for coming on.

Jane: Oh, you're welcome. You're welcome. Yes when I was 50, I had the party and my husband designed some artwork for me called 50 years. So if you Google on the CF Trust when they had their 50th anniversary, you'll see the artwork on there. And it what it was was 50 years spelt out and then each letter or number was covered in my medication packets, capsules depicting what I'd had for one month spelt out.

Lucy: So have a look at it because it's, it's really quite amazing and it would be interesting if you did it now, the changes in the medication.

Lucy: Yeah, I'll definitely look at that. Thank you.

It was so lovely having to catch up with Jane there. Thank you so much for joining us on the podcast and speaking so openly about your experience with the menopause growing older and your CF journey and it's just incredible to see how much CF care and treatment has changed since Jane was younger.

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Izzie (content lead): A big thank you to Lucy, and to Jane for sharing her experiences and stories. Now we're going to be finding out a little bit more about managing CF and menopause. My name's Izzie and I'm content lead at the Trust. And I'm now joined by Holly Ellard, information officer at The Trust.

Holly, please, could you tell us a little bit about the menopause?

Holly: The menopause is when your periods stop and by definition, you reach menopause when you've not had a period for 12 months. So this usually happens due to hormone levels getting lower with age and usually occurs in the general public sometime around 45 to 55 years, although it can happen earlier due to surgery that removed ovaries, uterus or certain cancer treatments or for reasons that are just unknown.

And menopause can cause symptoms such as anxiety, mood swings, brain fog, hot flushes, vaginal dryness, irregular periods and reduced sex drive. These symptoms can start before your period stop, which is called the perimenopause and carry on afterwards, which is called the post menopause. And the symptoms of menopause may have reduced or stopped in post menopause, but for some people the symptoms can continue for longer.

Izzie: And, you know, how does menopause differ for people with cystic fibrosis?

Holly: So it's been reported that people with cystic fibrosis develop perimenopause and menopause symptoms 2 to 3 years earlier than people in the general population. So in one report, it was stated that people with started menopause at age 46 years, ranging from 39 to 52 years compared to people in the general population, who started menopause at age 49 years, ranging from 45 to 52 years.

And people with CF experiencing menopause or perimenopause have reported symptoms such early awakening, night sweats, stiffness or soreness in joints, neck or shoulder, hot flushes, vaginal dryness, sleep onset insomnia, frequent mood changes and feeling tense or nervous. And it's sleep disturbance and symptoms of depression, which have been reported as the most severe perimenopause perimenopausal symptoms by people with CF.

But the impact of menopause on other aspects of CF is not well known, from research in the general population we know that menopause can impact aspects of health. health, that are already important factors in CF care. For example, bone density is lost rapidly in the first few years after the menopause, and research has found that menopause is linked to a decline in lung function. However, these impacts have not yet been investigated in people with CF.

Izzie: And with all these side effects and, you know, linking to people with CF and having to manage their conditions, what treatment options are available for menopause and people with cystic fibrosis as well?

Holly: So the main treatment for menopause for symptoms of menopause is hormone replacement therapy, which is commonly shortened to HRT. And HRT restores the drop in hormone levels to relieve most menopausal symptoms. And taking HRT can also reduce the risk

Cystic Fibrosis Trust

of osteoporosis, which is a risk for those with CF. There are benefits and risks for anyone taking HRT, which can depend on the type of HRT and how long it's taken for.

And HRT is not safe for everyone, which will depend on things like your family's medical history. And there are different types of HRT. And anyone who's considering HRT should talk to their GP team and CF team to find the best and safe options for them.

Izzie: And for people listening that might be going through menopause or about to go through or even just interested, are there any tips and advice that we could give them either as someone with CF who is currently experiencing the menopause or might be soon?

Holly: So besides HRT, there are other things that can try and help manage and reduce the symptoms of menopause. And these include things like getting plenty of rest and trying to keep a regular sleep routine, eating a healthy diet and talking to a person in the CF team about dietary supplements such as vitamin D for bone health. Exercising regularly, and trying relaxing activities like meditation and mindfulness to help with mood changes associated with menopause. Trying to get sunlight on your skin as this can trigger the production of vitamin D and or contribute to healthy bones.

Keeping your bedroom cool at night. Sort of things like trying a lighter duvet or a cooling pillowcase can help with hot flushes and night sweats. Trying vaginal lubrications to help with dryness, trying to reduce stress levels as much as possible, cutting down on alcohol and caffeine and stopping smoking are all things that can help.

And lastly talking to friends, families and colleagues going through the same thing. The Cystic Fibrosis Trust Forum might be a great place to reach out to other people with CF who are experiencing the same thing.

Izzie: Thank you so much, Holly, and thank you for joining us on the podcast today.

Lucy: Thanks so much, Holly and to Jane 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.

But, that's all from me on this episode. I'll join you soon for the next episode of CForYourself.

Bye for now.