Season 2, episode 7: Youth Advisory Group takeover

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.

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

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

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

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

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

Welcome to episode seven season two of CForYourself. Today I'm catching up with Tilly, Rosie and Tehya from the Trust's Youth Advisory Group, which is also known as YAG. We're going to be talking about all sorts of things such as growing up with CF, managing friendships, transitioning from paediatric to adult care, and navigating high school with CF and much, much more.

So without further ado, let's welcome Tilly, Rosie and Tehya to the podcast. For people who are joining this podcast episode, it's going to be a really exciting one. Talking to three girls with CF who are on the Youth Advisory Group, YAG. So we'll talk a little bit about what that is in a minute. But first of all, maybe if we start with you, Tilly, why don't you just tell me a little bit about yourself and kind of growing up with CF.

Tilly: I'm Tilly, I'm 16, and I was diagnosed with CF from birth. I really love acting, so I think being active in, like, drama is really important for me to stay healthy with CF. But actually I want to become a doctor. So that's also what CF has kind of been a big part of my life because I think if I didn't have it, I might not want to do medicine. So I'm very proud to have CF.

Lucy: Yeah, I mean, I don't think at 16 I knew what I wanted to do like that. So that's amazing. And to have like a hobby where you can, you know, where you can kind of let loose, is really good for like mental health as well. So that's really cool. Tehya what about yourself?

Tehya: I'm 15. I absolutely love dance. I've got such a passion for dance and that's really helped with CF, like always getting in the exercise, everything like that. I do dance like every day of the week, so it's my life. And when I'm not, I'm going more towards like my singing and my acting when I've got my break from dance, like on my break days.

I just don't stop. If I'm not dancing, I'm singing. And that's kind of where I want to go. But I don't know what I want to be going more towards dance or musical theatre. I will definitely want to like make sure that no matter what happens, I'm always talking about CF and getting CF out there.

So even like when I'm not in work, when I kind of do like a part time thing, like making sure that I've always put CF out there and that more people know about it.

Lucy: Yeah you could take over from my job doing this. Rosie, what about yourself?

Rosie: I'm Rosie. I'm 15 and I love playing music. I play piano, guitar, and I've been doing that for about ten years, so a long time. And I really want to go into work with animals and like wildlife conservation. I have been very set on that since I was about, I don't even know how long, but basically as long as I can remember I wanted to do animal-based work. So I was quite determined to do that, even with like medical risk that can come with being near damp hay. I'm researching ways to fight for it because it's definitely what I want to do.

Lucy: And I think that's such an important part of growing up with CF as you develop what you want to do in a career, but also kind of living day to day as a child, knowing the risks and how to mitigate them, but also looking at how you can still live a normal or as normal life as possible and just making a few adjustments to achieve that. So that's really good that you are still all kind of going for your dreams.

What was life like at primary school and secondary school? Did you tell people at high school you had CF? How kind of open have you been with it and what was the transition like from primary school through to high school? Maybe if we start with you Rosie.

Rosie: So in primary school I was quite open with it. If someone goes, why are you taking a tablet, I'd say 'oh, it's a medical thing'. But I never really specified. I didn't really expect people in my school would understand it because we learnt about similar stuff and they never really understood it.

So I just said, 'Oh, it's a medical thing'. And then when I moved to secondary school, I think from year 7 to 9, I was really quiet about it because people were like very judgy when I had to like get my phone out, check my levels, leave class to go to the office to do my insulin or stuff like that.

And then it got to year 10 and I'm just like, 'Yeah, I don't care what you say anymore, I'm going to tell everyone'. And especially because when my school did lessons on it, it wasn't very accurate information. So I was going out of my way to make sure people knew that what the school told them wasn't correct

Lucy: And that's all people really know if they don't know someone with CF, what they're taught in biology class about the genes and the alleles and all that and that's it.

And then I remember when that happened in my school, then everyone looked like, what this is you? Yeah, but it's more than just there's alleles.

Tehya, what was kind of your mindset into kind of sharing your CF with people?

Tehya: I mean, in primary school I didn't really talk much about having CF because I didn't know how to explain it myself, let alone to other people my age and I mean speaking to teachers and stuff my mum did it for me so I didn't really have to talk about myself at all.

Getting into secondary school when I started properly talking about it, like I would only speak to my really close friends because I only trusted them and I didn't really want everyone knowing because I didn't want to open myself up to anything that, you know, people could say behind my back or to my face. I didn't want anything like that. I just wanted to kind of keep it to myself and my friends.

Until around about year nine, when I just thought, you know what, I don't care. Like in one of my lessons, there was something about CF and they were saying how life expectancy is a lot shorter than mine and everyone straight away thought that was Teyha. And I was like, 'No, it's not' And then I started to tell everyone how it wasn't accurate and all of that. And then everyone was like, 'Oh you do have CF'. And I would like own it like a t-shirt. Everybody I'd met I'd be like, 'I've got CF', to the point where that was all I'd talk about. I was so happy I could finally say it so calm and everyone was like, 'Oh yeah, Teyha's got that' and it was like a genuine thing that people knew.

Speaking to teachers was so much easier knowing that I could do it myself. I knew exactly how to explain it. I knew what I was doing, and it was just so much easier in secondary school.

Lucy: Yeah, and it comes with age kind of understanding more how it works rather than it being just a lung condition, you kind of get to know the terms and kind of how it affects you more specifically day to day.

And I guess the textbooks are all so out of date. In terms of like every subject really, you know. They might be printed in 2010 or 2015 or whatever. So it's not going to have the newest life expectancy in, or the newest amount of people with CF and the newest medications and things. So it is like they are kind of teaching decade old kind of statistics sometimes.

You were nodding and smiling Tilly when Tehya was saying about she'd wear it with pride like a t-shirt. Is that something that you've been like with it, you know, going through high school and kind of telling people?

Tilly: Yeah, definitely. Especially because like through primary school, I didn't really even fully understand CF because I would say it's really difficult to ever, you know, speak to someone with CF. So I didn't ever really fully understand what it was and how other people live with it. But then when I joined YAG, and I got to hear everyone and I've got a lot more comfortable asking questions about my condition, like I do that a lot.

I thought that it allowed me to actually understand more about my own body and that made me lot more confident to talk to everyone at school about it. I look forward to like writing speeches on it and like making presentations and to share it with everyone. So I'm very similar to Tehya in that I wear it like a t-shirt. Yeah, I thought that was a good way of putting it.

Lucy: Yeah for sure. Like back when I was at school, which is over ten years ago. In high school we had this public speaking competition where each form had to do a PowerPoint about a charity and you had to do it in front of everyone. So I did the CF Trust and then did my story and told everyone and then our form won. So then we had to do it in front of the whole year. And I was like, 'Oh gosh, I didn't expect this!' I then had to tell everyone in the whole year and then we had to do it in front of the whole high school. So I was like on stage at the whole school assembly saying about having CF and that was like gutsy. But then I got to skip the queue for the lunch that day. So I felt like it was justified!

But it sounds like you've all been quite open about it, which is great. But have you got any tips for people who might be listening, who might be in year seven? Or parents of children who are at high school who just don't want to tell anyone, or kind of who are just in that phase where they are worried what people think, or they're ashamed of what people might think. What tips might you give people?

Rosie: If you want to tell people, like you don't have to worry about like telling everybody all at once, like the whole year. I started with a small group of friends and then I worked from there. And then if anyone said to me like, 'Oh, why are you taking tablets?' My friends would kind of like be there to say maybe don't ask and that's not really your business.

And then it was from that point if anyone asked me, I would feel more confident and I could say 'I have CF so if you want to know more about it, you can look it up.'

Lucy: Yeah, that's good advice. And I guess it's kind of the stage in which not just health, but with appearances and things that people are bothered what they look like and stuff.

So Tilly, have you got any advice or tips as well?

Tilly: Oh, I was going to say, especially for parents, from like the transition from primary school to secondary school, to speak to like the school nurse or like receptionists or whoever you have at school that will kind of look after your health.

Because especially if you're going to be like the only person in school with CF because of cross infection. The school nurse can be a really great source of kind of comfort or like any questions you have about how you're going to live the next few years of your life at school with CF.

And that's what I did. And eventually I got to the point where I didn't really need to go and see her all the time. And that's definitely a way for you to like see your confidence with your condition grow.

Lucy: That's really good advice and Tehya anything to add to that?

Tehya: Yeah I think you don't need to rush telling anyone. Because it's an invisible disease like no one's going to think anything. You just look like everybody else. It's not like anyone's going to say, 'Oh has she got CF' and you have to feel like you have to tell everyone. Like no one's going to know if you don't say anything.

And also to the parents, if there's like a head of year or a head of house, if they let them know that you've got CF before and the possibilities that might happen. Like you have to leave class quite a bit to keep filling up your water bottle. It just stops you having to tell teachers and then potentially somebody hearing if you don't want everyone to know it. Teachers can you know, say it in the staffroom or in a meeting. Just like to let your teachers know you've got CF and then you don't have to say anything.

Lucy: I definitely think before starting high school that a meeting should be had with a teacher or a head of year, or someone at the school should know so then they're able to kind of keep an eye on you with everything. Like if you're late for school, you don't need a detention for that if you've been ill or if you've had to do IVs. Or, you know, something's happened in the morning. And that carries on through work and through life as you get older.

That's not just a school thing. Like people need to be adaptable to the fact that not every day is the same and you can feel different depending on how you wake up, etc.

You were mentioning cross infection, Tilly. So obviously we're all on Zoom. Separate little boxes on Zoom chatting. But it can be really hard and lonely, don't you think, living with a condition where you can't meet? And I guess my question is when did you realise that you couldn't meet? And as you've got older, and we'll talk about YAG in a minute and how that's helped, but did you feel kind of that you were the only person that had CF and what was it like for you?

If we start with Tilly.

Tilly: In my primary school, I don't think I actually properly knew not to like meet anyone with it. I think I just thought I was the only one in my primary school with CF and I thought that was just a coincidence. Personally, I don't think about it. It's not like the most terrifying thing of having CF. It's definitely more kind of something you get used to. Just like taking your Creon. Obviously like Tehya said it's invisible, so you don't ever really need to worry about it because you could sit next to someone on the bus who has CF and you'll never know.

Personally, I don't think it's too much of a worry, unless you know for sure that someone has it. And it's only happened to me once before, so it's not too bad.

Lucy: Yeah, I think it's definitely an unknown risk. Nevertheless, still a risk. And I think like you said, you could be in the cinema, and you could meet someone. Like I was volunteering somewhere over Christmas and was scanning people's tickets as they came into the cathedral to look at an exhibition. There was a little girl chatting to me right next to me. And she stops and she goes, 'I've got cystic fibrosis'. And I looked and I was like, 'Okay, on you go'. I didn't want to worry her or her family that I had it because I just felt like that wasn't a worry that they needed to have when they have this six year old who's got the condition. But I was really terrified because that's never happened.

Like at my school there was nobody with CF, at my work is nobody with CF. I've only ever been the only person in any school or situation like that. So to have her right in my face was quite scary. But then it makes you feel like you can't really communicate in person. There's no kind of social gatherings or meetings where you can, like explain what it's like to someone who has it, it’s all online. What about yourself Rosie? You were kind of nodding along to that?

Rosie: I've grown up in schools where there is no one in any of my school who has had it. And I've always had a basic understanding of I can’t be near anyone with CF and the moment that really hit me is when I was walking through the corridor from the hospital to get from my consulting room to go get an x-ray on my chest. I was walking down and I saw one of my doctors with another kid and they looked at me and were like, ‘Oh no!’. And both of us got shoved into opposite ends of the wall and we had to shuffle along with our backs to each other because apparently that kid had an infection that I could not get. And that really hit me that I'm never going to be able to be near anyone.

I've been accepted to a college and they told me at the interview that they’ve had somebody else accepted with CF who's going to be in the same year as me. And they said, like, you've got to give us a list of things like how we cannot be close and stuff so they can sort it out. There's like going to be somebody in my school but I cannot communicate with this person whatsoever.

Lucy: It'll be good advice to kind of maybe get a picture of what they look like and have their number so you can kind of work out your timetables and where you walk, etc.

But yeah I think the thought of having to be quickly put into another room and things like that, people don't really understand as much, do they? And like you said, it's invisible, so it can be quite scary, I guess, like if that was to happen. What about yourself Tehya?

Tehya: When I was really, really young, I knew that I was the only person in primary school who had CF and that it was fine, because for me, when I was younger, it wasn't bad. All I had to do was my Acapella treatmemt one day and that was it.

I just thought, you know, it's just a coincidence I’m the only person with CF. I've never met anyone with CF but I'm only six. I probably will at some point. And then when I started to go look around secondary schools my mum would speak to teachers and ask have you got anyone with CF? And I would think, 'Why do you need to know that?' And then it would hit me that I can't meet anyone with CF.

And I guess it's the same as Rosie. It really did hit me when I was in hospital and along the hall there was somebody else with CF and the receptionist stopped me from going into my room because he was too close to my room. I had to wait for him to go down for like a minute and then I could go in. It was like, I really can't meet anyone. No matter how much I want to. I really just can't do it. People started asking me 'Is it five feet apart?' And I was like, 'It actually is!' But they don't know how stressful it is. Even when I'm on the bus or something, I think I could be sat next to someone with CF and I really wouldn't know.

I went to a Pink concert. I was looking around and there was so many people and I thought any one of these people could have CF and I really don't know who it would be. Like if any of them do, if most of them do, I don't actually know any of it. It was like going over my head the whole time. That's why going into big crowds I get really anxious, I'm like, 'Who has it? Does anybody have it?' It's so stressful on me. But as time went on, I realised I don't need to stress about it because they probably don't, but you just never know. So it was always in the back of my mind.

Lucy: Yeah, it's an unknown and I think that film Five Feet Apart that came out or it was like six feet and then they fell in love and made it five feet or whatever. But that made the conversation more out there and then obviously COVID hit and you need to stay six feet apart from people to not get it. That made people kind of understand respiratory conditions and the importance of space. But we've been social distancing even prior to that, with all the people with CF.

Like when you were talking Rosie about the other person who said they have CF. It's definitely always good to write it down, you know. Like if there's a form or anything to write down that you have it and so then it can be flagged if someone else has it and everything like that. I think that's like a great tip. Even if you don't want to tell people publicly, just to write it down just so people know.

So obviously you've kind of talked about not meeting people with CF and what that's like, but you've obviously got this great support group in YAG that brings people digitally together. Young people with CF together online. Does one of you want to talk to me a little bit about what it is and kind of how it's helped you like friends with CF?

Tilly: So YAG is the Youth Advisory Group for the CF Trust. So I mean, the youth is that it's everyone from I think about 13 or 14 to about like 26. So it's all very much people who experience the same things that you are in terms of like school and transitioning up to adult clinic, GCSEs, and then like going into your first job and things like that.

So it's very supportive and like the same people who have just recently experienced like exams and things. For me, I think that's really good because I get to hear about what's happening and everyone's kind of school and work and it's definitely become very relevant to me right now, which I think is really helpful.

The advisory part is that we create projects, surveys and we do kind of workshops and things that help the CF Trust accommodate the youth of the CF community. So it's very, very helpful for the CF Trust. It's quite like a small, close knit group, and even if you're choosing which meetings you go to, if you're quite busy or even if you go to them every month, everyone's very welcoming and everybody always like catches you up on what we're doing and it's all very beneficial work.

Currently we are in the process of making a children's dictionary on all different terms the child might hear in hospital surrounding the condition. So it's very beneficial to the community in general and in raising awareness of CF, which is definitely something that I think everyone wants to do and I love it.

I think it's made me feel so much prouder of my condition and it's opened up some new opportunities where I just feel lucky that I have CF, which I think is very hard to do. But it managed it and I love having CF because it brought me to this little group I love.

Lucy: Oh, that's so nice. And Rosie, I guess for you, has it meant that you're kind of in contact digitally online with more people with CF? And do you think that helps you kind of to know that they are going through the same thing?

Rosie: I really like it. So in 2020, I did a lot of social games nights and stuff, which Ellie and Bahar run. I used to go to them all the time because I loved having people to talk to. And then because I was going to like every one of these social nights, they were like, 'Hey do you want to join YAG?' and I was like, 'Yeah, sure, I'll do it!' And then I joined towards the start of the dictionary project and I love it.

It's great talking to people who have to deal with the same things as you because I'm the only known one in my family to have it. So it was very nice having people who are dealing with the exact same stuff with school. And also on the CF side of it, it's a very useful thing and I really love it.

Lucy: Tehya, what about yourself? Do you find that like having friends with CF now that you have met through YAG has helped you deal with maybe tricky at times? Or kind of just helped, you know, that there's people out there?

Tehya: Yeah, 100%. Just before I started, I started feeling very on my own with CF. My best mate, she was amazing and every single hospital appointment, she would always be asking how it was, how it went. She still does. If I'm being like I don't want to do my treatment, she will make me do it because it is just how much she cares. But I always thought that no matter who I was talking to, they're never going to understand and they don't know how I feel. No matter how good and supportive they are, they're never going to feel like I do. And that's when I started to feel more alone; it feels like I'm never going to meet anyone. It's not going to happen.

So I was speaking to my mum about it and she was like, 'Why don't we find you like a group or something?' And we didn't really know how I was going to do it. And so my mum goes, 'I found you a group and it's called YAG and you're going to go on group calls and just talk about CF and whatever they're doing at that time.'

And I don't think I've ever been happier to hear anything in my life because it feels like there's going to be a group of people who feel the exact same as me and we actually get to talk. But it was just hearing that I could actually speak to people with CF which is amazing.

Lucy: And do you find, though, that it still is important to have friends who don't have CF as well? So you've got kind of the best of both worlds in a way.

Tehya: 100%, yeah. I mean there's so many times where I've like spoken to everyone on YAG. And then I've also spoken to everyone at school and all my friends and my friendship group. And funnily enough, they say the exact same things. Even though my friend group don't have CF, they always put themselves in my shoes and they always say what is best to benefit me. But also when I'm speaking on YAG, I get everyone else's opinions as well on how they've dealt with something. And then I get my friends saying what they would do in my situation. It's so good having friends who don't understand but also do understand!

Lucy: You're all kind of 15 and 16 and now is the time that you'll begin to transition from paediatrics to adult units, and kind of start talking about getting more independent with your treatment and things like that. Maybe if we start with you, Rosie, you're in the middle of transition.

Obviously transition doesn't happen for everyone at the same age. It's kind of more when you're ready, so you have this conversation between like a sort of age bracket. So you're in the middle of it. Talk to me a little bit about how that's going and maybe some worries you had but maybe don't have now, after speaking to people with kids who are going through it?

Rosie: So at first I was quite worried about getting a whole new team because I had the exact same team like my whole life. I've had the exact same set of doctors who have been there as I've grown up. But I have met my adult team now. They came to my hospital because my adult clinic will be in a different hospital because my hospital near my house only does paediatrics. So I need to go like an extra 30 minute drive.

It was very good as they did like a session talking about transition to adults on YAG and that was really useful to me because there's a lot of us who are in that transition stage and it's definitely very useful to talk about, because it's a universal thing. It's one of the things that all of us will deal with and all of us will experience. And I think we've had quite a good support network for everyone here.

Lucy: That's good. It's definitely something I remember when I transitioned. I think I was 16 or 17, and I was quite nervous because you open up to them just about life and how it's going and you have to make new kind of connections with the doctors and team that will take you on, you know, for the rest of your life.

And yeah, it is nerve-wracking. And then the more times you see them and chat to them about what you do and then they remember things and you know, I guess they want to make you as comfortable as possible so you don't feel unsettled. I feel like it took me two or three visits to like get used to them and feel more comfortable.

But my mum would still come with me. Like it's not the case when you go to adults that suddenly your mum or dad or anyone can't come with you, you know, they still very much can. And it's not the case when you go to adults, they expect you to do all your treatment on your own. That is definitely not the case at all.

And there's like some really good people in the adults teams who will help if you want to kind of get more independent with things. They'll help suggest ways to do that. So I think it's definitely not as scary as it's made out. I remember when I was moving to adults, I thought I'd be told off because I wasn't doing everything myself. It was definitely not the case.

Tilly you're also in the process of it. Talk to me a little bit how it's going with you?

Tilly: It's going pretty well. Well, I'm basically the same as Rosie, so I'm almost moving into adults. I've just got a couple of paediatrics appointments left. But I think another really important part about transitioning is when you turn 16, you'll be applying for your personal independence payment instead of your disability living allowance, which you might have had when you're a kid. And I think that it is widely known in the CF community that PIP is very scary, takes a long time and is a bit of a drag.

And me and my mum were kind of trying really hard to fully wrap our heads around it. So what we did is we just we spoke to Ellie, who runs YAG, to ask for any help that she could give us with it. She was able to help us out and direct us where we had to go with the CF Trust.

So that's like another reason why YAG is so important, because without that, I would be spending ages trying to sort it out and then we'd be worrying whether it was like good enough and if I'm even going to be able to get it. So now because of YAG and Ellie we were able to make it the best we can and not be worrying about it.

So that's just like another part of the transition I think, and another part of YAG helping out with that.

Lucy: Yeah and it is sad when you leave your paediatric doctors and everyone because they've looked after you for so long. It's like when you move from primary school and you know it's quite emotional and sad, but you're ready for it if that makes sense. And then suddenly you're the youngest again. And obviously you don't see anyone else because you can't. But it's kind of weird again

To finish with, if you had one piece of advice for all the young people with CF, either the same age as you or just a bit younger than you, what would that piece of advice be?

I guess I'm just thinking for myself. I think it would be to kind of get on with my treatment and then just, you know, go to the park with my friends or go swimming after school with them all. Not to kind of isolate yourself, to just get on with everything that you want to do, and do your treatments to enable you to do that.

That would be my tip. What about you Tehya?

Tehya: It's probably just don't be ashamed of it. That's your life. That's how you going to spend your life. That's how you have spent your life. It's not anything to be ashamed of. That's how you live and that's how other people are living as well. You just don't realise it.

But just because you're not the exact same as your friends. Just because you know they are at the park and you have to come home for the treatment, all of that. It's just you. It's not anything bad; it's nothing to be ashamed about. It's your life and just be proud of it.

Lucy: And they might not be able to skip the queue at Disneyland but you might be able to because of your CF. You might have to go home from the park, but you can skip the queue at Disney. Tilly, what about you? Your tips?

Tilly: I think my top tip would be to do whatever you can to make yourself feel lucky to have CF. Whether that be, you know, taking as many opportunities as you can to make a difference in the community, like through YAG, like through different projects. It doesn't matter if it's through YAG or not. Even if you just make presentations about CF – you don't even need to perform them, just make them. Or writing speeches or getting involved in campaigns. Just anything you do to feel like you were meant to have CF and that would make you happy to have it, because you're part of an amazing community and just anything you do that will make you feel lucky.

Lucy: Yeah, really good tip. And Rosie, finally with you?

Rosie: I'd say don't take on everything all at once. Like it's a big time. You're expected to take charge of treatment and do exams. You're going to a new school. It's a lot to deal with. And moving up to secondary school is a lot to deal with on it's own, let alone with medical stress on to that. So I'd say don't take everything on at once. Don't be scared to ask for help.

If you think I'm having a bit of trouble trying to manage my own treatments on top of trying to now manage school, ask your parents for help with that. You don't need to take on all this responsibility all at one time. You're going to be dealing with a stressful time anyway. It's a lot to deal and you need to make sure that you're taking time for yourself and not piling it on and stressing yourself out.

Lucy: Really good tip. And then I guess my final tip would be to do all your treatments and keep kind of doing all that so that so that you'll be able to be like the doctor, the musician, the actor, dancer, all these things that you guys want to do.

In terms of what you were saying. Rosie, to finish off, though, it is true when things kind of all pile on, it is important to ask for help and support, whether that's through the CF Trust's Helpline, parents, guardians, family, friends, anyone.

An example, obviously like I am 10 years older than you. So last year I got a new job, moved out for the first time and got married all in the space of like six months. So that was a lot to do all that. So it is important to ask for help and for people to still support you.

Well, I want to thank you all for coming on the podcast. I think it's been really inspiring, and I'm going to say that word, to hear all your tips and everything. I mean, you're all 15 and 16 and it sounds like you've been here so much longer with all these wise words of wisdom. Thank you all for coming on. It's been great to chat to you.

It was really, really lovely having to catch up with Tilly Rosie and Tehya and to see them 10 years behind where I am now. It's just amazing to see how positive and inspirational they all are. Thank you so much for joining us on the podcast and for speaking so openly about your lives and CF journeys.

Izzie: A big thank you to Lucy, Tilly, Rosie and Tehya for sharing their expertise and stories. Now we're going to be finding out a little bit more about the YAG programme and how people can get involved. My name's Izzie and I'm content lead at The Trust, and now I'm joined by Ellie Mindel, our lead for children and young people here at the Trust.

Hey Ellie, thanks so much for joining us on the podcast.

Ellie: Thanks for having me.

Izzie: Would you be able to tell us a little bit about the Youth Advisory Group?

Ellie: Yeah, of course. It's a group of young people with CF or with a connection to CF. So we've got someone who's got a brother with CF, and we got a couple of people who have babies with CF, and they're all aged 14 to 25 and they work on projects to help the community and make the world better for young people with CF.

And they also advise on projects at the Trust and make sure that the Trust are listening to young people and make sure that our work is relevant to what young people want and need.

Izzie: Amazing. Sounds like such important work and who can actually get involved?

Ellie: So it's anyone with CF or with a close family connection to CF, who's aged 14 to 25. And we're a very, very welcoming group. We love welcoming new people and you can join whenever you like. And if you're really busy for a certain period, then you know, you can take a break and then come back. We're really, really flexible around you and what you need.

Izzie: And how does the group help young people with CF?

Ellie: It's an opportunity for young people with CF to get together and talk about having CF, share their experiences and really make friends with people who get it. But also share things about them that aren't to do with CF and talk about things that they enjoy and feel passionately about.

And there are lots of really exciting opportunities. So people in YAG have written articles, like obviously been on this podcast, and they lead projects to make the world better for other young people with CF, which is a really exciting thing. And actually one of our members even met the King a couple of years ago!

So there's lots of really exciting opportunities as well as making loads of new friends.

Izzie: Wow, that sounds so exciting. And so where can people go then if they want to get involved?

Ellie: You can find out a bit more about YAG on our website and then really you just need to email the CF youth email address at the Trust. So that's cfyouth@cysticfibrosis.org.uk and then you'll get through to me or my lovely colleague Bahar and we'll give you a little bit more information about it and we'll have a chat with you if you want to on the phone. So you can just ask us any questions and then you can come along to a meeting and see if you fancy it.

Izzie: Amazing. Thank you so much Ellie.

Thank so much to Ellie, Tilly, Rosie and Tehya for sharing their experiences and to you for listening. For more information on what we've talked about in this episode or to donate to help make sure that everybody with CF can live without limits, please see cysticfibrosis.org.uk/podcast.

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