

Our voices: My Condition &...

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Trigger warning:

The podcast talks about young people's experiences with their mental health, anxiety, low mood and experiences of living with different long term conditions.

Support:

If you need support with feelings of low mood, stress, or anxiety, there are lots of organisations out there that can help. Go to www.hubofhope.co.uk and type in your postcode to find out what is in your local area, or text SHOUT to 85258. If you need urgent help, Young Minds has a list of organisations that you can contact <https://www.youngminds.org.uk/young-person/find-help/i-need-urgent-help/>

Joseph 00:11

Hello and welcome to another episode. My name is Joseph, and today's episode is called My Condition &... We'll be looking at the theme going beyond in the clinical. We've had lots of useful discussions with healthcare professionals and young people. Find out what they think about the topic. We'll also be having some poetry and we hope you enjoy.

Shreya 00:35

Hi, my name is Shreya. The idea for My Condition &... came from Demi and I and stemmed from the experiences that I and others have had with paediatricians who see us as just patients and those who see us as people. In this section, we're going to have a conversation about what My Condition &... means to us. For me My Condition &... is about seeing us as people, rather than just patients with a condition that needs to be solved. Because for many of us, our conditions have the ability to change our day, from excellent to terrible within a space of an hour. I'm now here with my fellow Podcasters, including Demi, and I'd like to give them a chance to say what My Condition &... means to them.

Demi 01:31

So as Shreya said, I'm Demi and we came up with the idea from a previous group session. So we had a topic in epilepsy, where we decided that it's not just about our individual conditions. It's about everything as a whole and that we're individuals that have a lot going on in our lives, apart from our medical and sometimes it's good to like, have conversations on that. So for me it's My Condition &... pets 'cos I love pets. They're just amazing. I have a miniature zoo and it's great!

Joseph 02:21

I'm Joseph and to me My Condition &... means the condition I have and the effect it has on my everyday life. So like the treatment I get at school, the help I get for that.

Demi 02:37

My Condition &... seeing me as a whole person, not oh, "We can't have you do this because you know something might happen" or, you know "We can't do that. We can't even ask you the question because we're too scared to see if it's like something you'd be able to do." cause it's like, the stigma and the "Oo what if?" or, you know?

Aiden 03:00

Disconnected if that makes sense. Like, like doctors are disconnected, and it makes me feel a bit anxious or uncomfortable. Like meeting them, if that makes sense.

But like then there's some, like other doctors that are like, good with it and all that sort of stuff.

Demi 03:20

It's the being seen as less than someone else because you've got more going on. But it doesn't mean that I am not able to do things. I just do it in a different way.

Abbie 03:37

So I'm Abbie. I absolutely love this topic because I feel like it opens you up to so many different areas. And to me, My Condition &... is about how sports and things like that can be so much more than my condition. So sometimes it's just taken for granted. I'm just seen as my condition and it shouldn't be like that.

Shreya 04:03

I personally really related to what Abbie said because as someone with asthma who also plays netball, it can be quite challenging at times, and I'm often seen as less of a netball player as my teammates and I normally get a lot of surprise glances from people in my year when I say I'm on the netball team, because they don't expect someone who has asthma to be able to play netball.

Ali 04:34

Hi I am Ali. Asthma is the most common long-term condition among children and young people, with 1.1 million children currently receiving asthma treatment.

Abbie 04:46

It's estimated 8% of Olympic athletes live with asthma. Did you know Paula Radcliffe, who is a legend of UK Athletics and women's marathon world record holder, managed asthma throughout her career?

Shreya 05:00

I just want to add that question of what sports do you play? Because like, it varies for everyone and obviously your condition impacts that, if you're fine with sharing what your condition is.

Abbie 05:09

I do athletics. So, my events range, but I have quite a rare condition like, whenever I say it like, I'll be at athletics and they'll be like, "Oh what conditions do you have?" And I'll say it and no one will know. So, I have CRPS and I also have scoliosis which is less rare,

but that one's more noticeable like, people can see I have that. But people can't see I have CRPS. So. It always seems to be I'm known as the girl who has that, instead of the girl who does the sport.

Shreya 05:45

I understand what you're saying because for a lot of people, especially if you've had a condition since birth, it can be quite defining and also when you've been recently diagnosed, a lot of people have said to me that they've struggled to like, come to terms with that it's now part of the identity and I don't know if anyone else feels the same way, but it's annoying when people define you by a condition, which is such a minute part of you because you have a life outside of it.

Abbie 06:14

I've actually had people introduce me as "oh this is Abbie, she does this event, this event and oh, by the way, she has titanium rods in her spine!" And it's like, well, is that really like, part of me? Do you need to introduce me as that?! It seems to always come up with the most irrelevant conversations.

Joseph 06:38

So I've got Autism and a lot of time, people don't notice or they won't think about it and then either I, or someone else will bring it up and "oh, do you really? That's unique. That's special. I guess" and then a little bit of mocking comes out of that, sometimes.

Demi 06:56

I feel like it happens a lot and it's not just like students, like teachers do it all the time as well. And they'll say things that are so minute to them. But if you tell them that you don't want certain people knowing, for example, that you don't, you don't see very well, you need bigger fonts or you know you need, like special adaptations, they'll somehow find a way of letting the whole class know, "Oh, you needed that extra bit of help." And now, like everyone knows, and it's kind of like, so disheartening when you're like but I didn't want that, that now makes me feel uncomfortable because you've just told everyone that didn't know anything.

Shreya 07:39

Personally I see what you're saying, like a lot of the times when you have like, a supply teacher and or assistant teacher coming into the classroom. The teacher does introduce you as oh it's this person and they also have this condition, which I understand that they need to know if they're helping around in the classroom. But it's also when they do it in front of all the pupils.

Aiden 07:58

People don't even like conditions real, which is just upsetting because people work so hard and many have spent their entire life trying to educate people. Especially with less known conditions. You try to explain the symptoms and a lot of people tend to be like, "That makes zero sense. How does that even happen?!" So it's trying to get people to understand without sharing details that you feel uncomfortable with, but also not coming across as aggressive.

Demi 08:26

Because as a person, I've been told that when I'm trying to explain stuff I come across as aggressive and I don't mean to. It's just trying to show people what I feel and how I experience it, in a way that they can understand as a person who might not experience it.

Abbie 08:43

It's not just a label, it's not just like a title. Like it's not. We're not just our conditions and people forget that we actually have to live with this. We have to go through the struggles and we have to go through the medication, the dealing with it, the anxiety, the fear that comes with every appointment, I feel like people just kind of forget that and just to kind of take it for granted, just go. "Oh yeah, well, you did that yesterday." Or "You did this today." like, erm as you would say with migraines people can't see it so they just go "oh you are being dramatic" . Like with my pain, oh yes, I was in hospital maybe a week ago. Like, but today I'm doing better than I was then so I'm going to live my life and do what I want to do but people then judge and go but surely you should be recovering and things like that but recovery for us is different to recovery for someone who doesn't deal with this on a daily.

Shreya 09:40

That's the thing with conditions you can't see just because you can't see them it doesn't mean that they don't exist. It's like your condition can manifest in physical ways, whereas sometimes it's the way you act. You have to wear or do certain things that, like, are obvious. But it's also when you it's like something permanent and it's the way when people look at you strangely and you can see, and especially with, like teenagers and children and people who haven't, like, maybe, learnt to not stare is that they do stare. You can tell when they're whispering behind their hands, and you can see the way they point to you and they talk to their friends. And they're like, "Oh do you see what they're wearing?" 'cos to them it's just a piece of mindless gossip. But to us, it's something a lot more than that.

Joseph 10:33

Again it's about that invisible condition. People don't really see it from the start. They then assume it's either not there or it's much, much worse than it really is.

Abbie 10.49

So I personally I was on crutches for like six months but on and off. So, it got to the point where, you know, people are judging, so then there's this fear, stress that comes with using something you need to use. I'd be like, oh, but they'll make a comment or they'll think something or I'll get questioned. And then you force your way through making something worse, just because of the stress that comes with it. I don't think it's always realised the stress that comes with a condition and how much anxiety can be brought on by the lack of understanding and the judgement, I don't know if that made sense, but yeah, I'm not sure if anyone else understands that or gets that?

Demi 11:29

Yeah, I think it is. And it's also like a lot of a lot of like you guys have said that young people and the stigma, but also I find in healthcare appointments. Aagh! It just gets so annoying when, you have to constantly re-explain to different professionals what's going on, because they either haven't read the notes, or they didn't understand what was in the notes, or they just go. "Well I don't, I don't actually wanna focus on anything else but tell me how your life's going" and then you're like. Well actually, this, this and this is going on. They're like. "Well, I don't want to know about that. I just want to know about this section." And you're like, but you're not seeing me properly because the whole, the whole thing is I'm a person, and I have lots of body parts that you're

investigating. So can you just let me rant out for a minute of what's going on and then, help me go through it?

Derick 12:27

Hi, I'm Derick. Up next, an excerpt from a play written by Podcaster Ali, who studied and collated RCPCH research into young people's experiences of healthcare. This performance by Jack and Kweku from the RCPCH Children and Young People's team, took place during the closing plenary session of the 2023 RCPCH Conference in Glasgow.

Kweku 13:00

Hospital consultation. Somewhere close, yet so far away.

A door knocks

Jack 13:08

Come in!

Kweku 13:10

The door opens.

Jack 13:12

Hi, how are you? Please take a seat.

Kweku 13:15

The patient settles down.

Jack 13:21

(Sighs) Oh, I'm so sorry. That was rude of me. I'm fine, thanks. How are you?

Jack 13:28

No worries. I'm fine. Thank you. And Mum?

Kweku 13:30

An inaudible response along the lines of "I'm fine thanks." Is signalled.

Jack 13:37

Great. So I understand today is the, er, the er second time you've seen me or sorry, rather someone from our unit?

Jack 13:45

No, actually, I I I think that's a mistake. This is my first time in this building.

Jack 13:54

Oh, sorry. So you've transferred from another hospital department?

Jack 14:00

No. This is my first appointment with a consultant.

Jack 14:05

So how long have you been waiting for an appointment?

Jack 14:09

I we've been waiting for like 18 months for an appointment.

Kweku 14:15

Simultaneously across the country, there are several other young patients with familiar situations. Patient One

Jack 14:23

Six months

Kweku 14:24

Patient Two

Jack 14:25

Two years

Kweku 14:27

Patient three

Jack 14:29

How long has it been Dad? Four years?

Kweku 14:32

And then we're back to the original conversation.

Jack 14:34

Oh, OK. I'm so sorry to hear about that. So how old are you now and, what school year are you in?

Jack 14:40

Year 11

Kweku 14:42

Then from across the country. Patient one

Jack 14:45

Year nine

Kweku 14:46

Patient Two

Jack 14:47

Year 10

Kweku 14:48

Patient Three

Jack 14:49

Year 12

Jack 14:51

Oh wow! Haha! Quite an important few years ahead of you!

Kweku 14:56

All patients together.

Jack 14:59

(Sigh) Yeah.

Eve 15:07

Hello, this is Eve. The guidance created by the National Institute for Health and Care Excellence states that no one should wait longer than three months between being referred and 1st being seen. But this data shows that the vast majority of people, 84%, which is 133,000 people, have been waiting longer than 13 weeks. An autism diagnosis is vital to getting the right help and support. Without diagnosis, many people struggle at school and develop mental health problems like anxiety and depression. And some cases end up in crisis or even in hospital.

Demi 15:38

My mind's like a prison is constantly engaged with fear, worry, anxiety, rage and dread, always repeatedly swirling around in my head. Mental health. We all talk about it as it doesn't just affect a few. We all have it, whether it's good or bad, it's not something that pops up for a day and then goes away.

Like just being sad, it's another thing to add to the endless list of conditions, medications, appointments and physio regimes it's endless conversations about it's a phase you weren't born to fit in, but to stand out, to be unique and to be brave, to stand tall. It's all in a day. Tomorrow will be better. Take some time for yourself, sit back, chill and unwind.

When I take that moment, I'm stuck inside my mind. Sit, sob and cry. Repeatedly go over my day, plan for tomorrow and what's going to change. Well tomorrow is here. I've got up. I've got ready. The fear is stirring it's real now. I'm ready. To face an appointment. What is it this time? More tests, more meds, more physio, more rest.

Updating and constantly re-explaining because no one likes the bother with the summaries. Too much time taken up. Not enough money. A system under pressure then makes me feel like I don't matter. My age. My postcode. My race and my gender can have a fundamental impact on how quickly I could get better.

Funding is a big topic that's often brought up. Due to my age, you think it's OK, but have you ever thought of my stage regardless of age? To some, I'm another problem to fix. To others I'm just another statistic. I can be seen as a page in a book, as soon as it's turned I'm no longer in sight and this is when I realised I'm already losing this fight. Only to find new monsters in sight invading every effort and thought. Hijacking my feelings and then transition. You say? Hmmm!

Could we leave this conversation for another day? There's already so many things I've heard you say. Sitting there watching and listening. I start to fade away. In appointments. You only see a part of me. A mask I wear when trying to function. You don't get to see me for me, but only one part of me. Riddled with fake smiles, full of worry and anxiety. I'm getting quieter now. I have nothing to say. You'll carry on. And my parents and carers will take it from here.

I'm here, but only just. I'm fading away. I'm shutting down.

Eve 18:06

Young people belittle their own experiences and needs. 23% of young people who had experienced trauma said that they didn't feel that their problems were serious enough to reach out to mental health support.

Joseph 18:19

Young men find it particularly difficult to open up about their mental health. 37% of young women over 16 who've received mental health support, have received this from a friend. However, only 15% of young men over 16 state that they have done the same.

Aiden 18:36

Anxiety is more than it seems. It is a ruthless beast ripping apart your relationships and your happiness. You decide one day that, that was it. You couldn't go through it alone. You'd had enough. You asked for help. Went to counselling. And they tell you to apply yourself. That problem is you, never them.

They treat you like a child, like somebody who can't understand. You'd had enough you thought one day. Maybe it is me that's making me feel so low. You talk to your counsellor again, to be greeted with a smile. It could always be worse. She had said to you, you'd had enough.

Somehow you'd managed to feel even worse than when you'd started. You blamed yourself again and again before trying somebody else. Maybe they'd listen this time, you'd have enough. Maybe medication is the way to go. Those life-saving words, those words you've been begging to hear. Your relationships were saved, your happiness restored. Take that anxiety. You've done enough.

Aiden 19:47

This poem was written about a young person's experience going through our mental health system. Through this piece. They wanted to portray the way in which the system failed them. They told them that their anxiety was their fault, and that their

methods are the only way that anxiety should be thought about. Being autistic, standard methods didn't work for them. And the system wasn't willing to question that. So the message with this is, please don't go blaming the person struggling for their inability to get better. There is often something else underneath. Look for it.

Jack 20:28

Sorry to hear about that. So, how old are you now in and what school year are you in?

Jack 20:34

Year 11.

Kweku 20:35

And from across the country. Patient One

Jack 20:38

Year 9

Kweku 20:39

Patient Two

Jack 20:40

Year 10

Joseph 20:41

Yeah so I've been pinged around between a couple of different hospitals as well. And I remember a couple of different people have gone too, but again, there were some that I trusted more than others, and it's about what they spoke about while trying to analyse my brain and I think the longest I had one for is about three weeks and I remember them best, because they kept trying to, well, take my mind off things while still focusing, I guess. They're asking me questions about what I like, but also while looking over that, then trying to take off my mind with other things about why do you

like it? So there was something about what subjects do you like? Well I like science, maths.

All that they were looking for a topic or a theme that goes between them. And then while they were trying to work that out, they were saying, alright, well, why do you like those quite so much? So, I trusted them slightly more than the others who again, just sort of saw me as a number in the hospitals.

Demi 21:45

It gets to a point sometimes where things just become overwhelming and that's when things aren't only your physical health, but also your psychological health. And people don't always correlate them together because they're like that only affects your legs moving you know, it shouldn't affect anything else! Well actually no, it actually affects all of me.

Joseph 22:06

I think I'm the, flipside of that. My condition sort of... It adapts my brain and it makes me feel better about things that maybe I shouldn't feel quite so good about. But it helps me get over things fast. So while some people are brought down by their condition. Mine helps me get over things easier, which could help improve it, sometimes faster.

Shreya 22:31

Normally when people associate your condition with mental health a lot of people are like, oh, it destroys your mental health so it's good to have, like, a different perspective. And one of the main things that we do, these podcasts, especially this one, is to increase awareness. And it's really important that we do do that. So if you don't mind sharing, I'm not going to put any pressure on you. Would you like to expand?

Joseph 22:56

Yeah. So I've got Autism, and sometimes people will take it as "Oh it's a bad thing." Sometimes will people will just ignore it. Erm but I think what it helps me with is... It helps me not really care what people are thinking about at times, so that might sound not very good. But maybe like while some people are getting dragged down and all...

upset or worried about maybe exams coming up. My brain tells me, nah it's gonna be fine. You'll be alright and it... I don't focus on it. I don't dwell on it quite so much.

Or while some people are still worried or concerned or upset about something I can...Sort of ignore it or get distracted by something else. So it's not always the best thing for the situation, but it is normally quite helpful it helps me, 'cos again, with like the peer pressure that I normally don't care what people are thinking about it. So if someone says oh, it's bad, my brain says, nah it's fine. I don't worry about what people think of me.

Demi 24:02

Can I just cut in and I... I just. I really like what you said because it makes me feel like, you kind of, you have a superpower. You know you don't. You're not stuck in the negative of it. You're actually like, oh, there's benefits to this. I feel like a lot of us are stuck in the negative. And, you know, like at conference. When I spoke, I did... I had this little quote behind me of "Your superpower is to be you, because there's only one you and you're unique." And I just love the way that you just said it, Joseph, because... You've literally just spun it around, and you're, like, well a lot of people will see it as a negative, but I'm going to take it as a positive. And you know what? I feel like I can jump on this train with you and say, with some of my health conditions. Yes, there's there's negatives but also, when you go to amusement parks, you get to stand in like, less of a queue ...You know, you get access passes so... that's a bonus! You know, less queues!

Joseph 25:03

Sometimes I'll try and... not exactly cover it up, but I'll just gloss over it 'cos it's, you know, not important. Again, I don't care what people think. Sometimes I might try and take advantage of it. In some situations, like maybe getting something faster because I don't have the focus, I don't have the attention I have to do this now, otherwise it won't happen. So, but then maybe get help with revising for exams. Like I was not exactly...mm don't know how to word it...I can get help faster when I needed it. Like maybe teachers are more focused on me so I don't need it all the time. I don't abuse it. But it... you know that 25 minutes extra in GCSEs definitely helps bring up my grades!

Joseph 25:55

Thank you for listening to My Condition &... We hope you enjoyed this episode. Stay

tuned to the RCPCH &Us website for news and updates on the next installment. Thank you.

Ethan 26:04

We hope sharing our experiences will go some way towards helping to improve healthcare for children and young people across the UK and beyond. Until next time. Stay blessed.

Support:

If you need support with feelings of low mood, stress, or anxiety, there are lots of organisations out there that can help. Go to www.hubofhope.co.uk and type in your postcode to find out what is in your local area, or text SHOUT to 85258. If you need urgent help, Young Minds has a list of organisations that you can contact <https://www.youngminds.org.uk/young-person/find-help/i-need-urgent-help/>