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We're here today in a breezy and bright East Lothian to talk to reps. Curtis Moss about their experiences with long term health conditions, chronic conditions, autoimmune disease and how that has impacted on their relationship both with being physically active and all forms of movement.

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Rebs., thank you so much for talking to me today and the Movement For Health coalition on our podcast Movement in Conversation.

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We're going to come on to your experience of movement and what you like to do now, what you like to do. When you were younger, and you're kind enough to share some information about your health and how that maybe impacted your relationship with movement. But first, if you could just introduce yourself a little bit about yourself for our listeners, please.

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Sure. So,

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I'm Rebs. I, work as a digital fundraising and communications consultant. And the charity sector. And I've been freelance for nearly two years now.

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Lovely. Thank you. Thank you. And we should say that we've known each other for quite a long time. Yes. Through the sector. My goodness. 50 ago. Right. That crept up on me.

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Okay.

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Could you talk to us a little bit about your health firstly and what long term health conditions that you live with. And then we'll talk about maybe those symptoms and how that impacts on your movement. Sure. So I

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was diagnosed with asthma when I was five.

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I kind of had asthma, obviously, like pretty much my whole life, but it's always been fairly well controlled. I used to have kind of like, I always used to joke that about every two years, I'd be like, due, a chest infection. Yeah. But other than that, it's pretty much. It's very well controlled. And actually doing exercise really helped control it as well.

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But in the last like year, in fact, it was a year to the day yesterday that I got discharged from hospital with my asthma. But I've had really big issues with my asthma. And got whooping cough last year and then got hospitalised with it. Then I got RSV, which is like a respiratory virus infection. I got that in December and then I was hospitalised again with that.

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So it kind of feels like it's really ramped up. And all of a sudden it's like I'm struggling to, like, just control my smile, just with, like, antibiotics and steroids at home and do get sick. So, yeah, that's been kind of a big, a big change. And then three just under three years ago, I got diagnosed with coeliac disease.

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And I wonder if maybe potentially those two things are related , like, I've been diagnosed they're not immune disease. And then suddenly it's like everything's just gone a bit haywire. Plus, I've had, ovarian. I used to have an ovarian cycst, it's now been removed, but have had a, overian cycsts since birth. But I didn't have any real issues with it until.

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Again, a couple of years ago, I started experiencing, like, chronic pain to the point where I was having to be to hospital to have morphine.

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but I got that taken out last year. But I'm still experiencing a lot of pain.

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So I'm now getting further investigations as to like why that's the case. Like, is it a phantom pain? Is it scar tissue? Is there something else going on? So I'm kind of getting other investigations, so. Yeah. Everything seems to have kind of not completely gone downhill, but like, gone downhill a little bit in the last like 18 to 24 months.

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Yeah. It seems like it's culminated. Yeah. And it's like multiple things have all flared up at once. So yeah, that's kind of where, where I'm at with my health right now.

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Can we go back then to five, ten to twenty year old Rebs? Your experiences of the asthma. And you've said there that actually moving and being active really helped.

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Yeah. So what did that look like? What was your preferences? What did you enjoy?

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Well, I first got into swimming when I first kind of started working full time. Really. Basically, I put on quite a lot of weight after I left university. I think just like it happens, a lot of people, I think they'll start a desktop.

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They're suddenly not moving around as much. They're not as active as maybe they were when they were a student. Yeah. I hadn't really ever done any proactive exercise prior to that. So I kind of started swimming. That was kind of what I got into was I started, and I kind of got into it quite, quite heavily, like, I was like sort of maybe three times a week, a mile each time.

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I was going for like a masters class, all that kind of stuff. So I got really into, I was quite a keen swimmer for quite a few, probably about seven or so years. And then I kind of switched, I think I maybe just got a bit bored of it. Yeah. And I kind of switched to the gym.

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And then I started getting more into weights and stuff like that in the gym and then running and cardio and then cycling as well. So it's kind of been a mixture, I guess, of, I mean, really I should do triathlon when you think about it. Well, we try the things, but yeah, I kind of moved from one thing to the other, really.

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And then I do a lot of walking with the dogs as well. Although greyhounds don't famously don't need a huge amount of walking. So it's not like, you know, it's not like I'm walking the dog for like,

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four hours , but, you know, dogs, you know, I've definitely out the dogs every single day.

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On a walk. So. Yeah. Yeah, but that sounds very much you were purposefully active. During that period of time. And then would you share some of your symptoms around your, experiences a few years ago that made you very unwell? Yeah. So. With. Before I got diagnosed with coeliac disease? I had quite a serious head injury off the bike, so I was cycling,

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fell off the bike, got a really bad concussion, developed something called post-concussion syndrome.

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Actually, when it happened, it was it was so bad, I heard this massive clang in my head, and they think that that was actually my brain rattling, like, like thoughts. Yeah. So it was quite a but it was quite a back concussion. Basically I went back to work too soon because I went back to work too soon and I didn't take it that seriously.

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Yeah, it is what it is. But end up being a lot worse than it could have been had I actually rested. Yeah, I'm taking it a bit more seriously. I think you just sort of cycle, you know, you're indestructible and it's fine. It's just a head injury. It's just your brain.

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because that happened. I think that triggered my coeliac disease. Right. Okay. That's what the doctor thinks is what can happen is if you have any sort of traumatic incident happened in your life, emotional or physical trauma, it can spark any form of autoimmune disease, which is absolutely terrifying and not something I knew about.

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But the result of that has been, yeah, I've been diagnosed with coeliac, but that took years. Because I got progressively sicker and sicker. Refused to go to the doctor.

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and it got to the point where I was so unwell that I was sleeping. Probably, I don't know, like 18 hours a day sometimes, like, I was so tired and so exhausted all the time, and I was just so well that eventually my wife made me go. I like she like made the appointment, took me to the doctor.

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We're good at that. Yeah, yeah. You have to do something. Because this isn't normal.

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the blood test came back and, they immediately said, oh, we need to redo the blood.

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So I went back in and I spoke to the same phlebotomist again, and I said, oh, did you lose the last test? And they said, no, we think you have coeliac disease. And that's how I found out. Yeah. Okay. So that was a real shock. And I was just completely in denial.

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And I was like, no, I think they've made a mistake. It will be over. And then I had,

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endoscopic endoscopy. Yes. And then dos copay. And then they confirmed it was they confirmed it was that there and then. So that was kind of that. But I have felt a lot better since.

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Seriously, I've been very, very careful in that respect. And I do feel a lot better. It's just strange that since that's happened, there's been so many other issues with, like, chronic pain, my arse about being a lot worse.

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and what. Just chronic pain. How does that manifest itself.

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Just really horrendous pain. Like across the back. Around the back. Yeah. Just where the SAT was basically but overall basically went into torsion a couple times. So I then had to go into hospital, thought that they weren't very sure if they were going to have to remove the ovary or just the sex. They ended up just taking this aside, but it was a lot bigger when they took it out than they thought.

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Like they thought it was like less than five centimetres. And they said it was the size of a big potato.

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I'm glad I was really glad to get out, but it's just a bit strange that I've still got the flare ups of pain, and they're just not very sure if it's like kidney stone or thinking it might be a kidney stone, or it could be scar tissue

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So in amongst all of that, what was your relationship like with moving? Being physically active. I mean, I don't know, I'm still trying to get to the gym as much as I could.

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For me, going to the gym isn't. So, like, the physical benefits of it are good. But I found, like, the mental health benefits massive, for for keeping active and keeping fit. So I was still trying to go as regularly as I could, but I'd say I definitely went through periods where I fell out of habit of going, yeah.

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And then I just said, I'm going to get back into it. I'm going to get back into, And then the longer I left, the more difficult it was. And the irony is that during Covid, when all the gyms were shot, I was so, so adamant that I wasn't going to fall out of the habit of that, that, you know, I kept up like a boxer weight, so I was doing everything at home.

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I had a whole system set up, and it was only after the bike accident that really, things took such a massive turn for the worse.

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So I went from being able to do cardio and really enjoying it, to not being able to do anything. Yeah.

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Really. And that was really soul destroying in a way. Yeah. Yeah. Well, I just had a big impact. It was really difficult because you go from feeling like you're really you really fit and you're on that and you're in control. You're in control. Yeah. Exactly that. Like, I just felt like I was completely paralysed. I'm a body, but it's just completely.

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I really dramatic, but I felt like my body was failing me.

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am I going to be stuck like this forever? Is this ever going to go away? And I'm basically just going to be able to go to work and pretty much keep working? Yeah, but that's it for the rest of my life. Yeah.

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Luckily it did go away because I start seeing a new physio and that made a massive difference.

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And then things were okay for a while. But then I started getting all the coeliac symptoms, and then I started going, really all thought. So then it was just like it has just sort of been one thing after another. Yeah. Yeah. And even now, like, I'm still trying to get back into my get back into my fitness.

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Unknown
every time I have been in hospital, for example, my asthma, I've tried to get back into the gym as quickly as I can because I think the longer you, the longer you leave it, the worse it sort of becomes.

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I don't know if this is just my way of coping with that, but I find the more tight, the more knocks you have. The more times you get back into, the stronger, like literally the stronger you become and the faster you recover from things as well, physically and mentally.

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Yeah, exactly.

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I'm wondering about so I'm picking up what helps you most is getting back on your horse.

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It's gonna take Greyhound. I don't enjoy that very much. Getting back on your horse as quickly as possible. Yeah, that's something we've been talking to people about that are living with long term conditions. Talk about the importance of pace and rest for them as

well. And is that something that you've had to become more aware of? It's just from what you're saying there.

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I mean,

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definitely, prior to all of this afternoon, it was just a case of going out and doing things I never wanted to do them. And suddenly that's kind of not knowing that it's annoying and it's not really the case any more. I do have to pace myself more, to be honest. It's more things like, like I was on holiday recently, before we went to Japan.

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I was really, really worried I was going to get ill and we wouldn't be able to go because we'd already had to cancel the holiday and rebook it, because I'd had my operation six months prior. And because obviously your immune system's already compromised. Exactly. So it's like the things you have to think about when you're immunocompromised are not things that I'd ever really had to consider before.

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Like, right, we're going on holiday in a month, so I probably shouldn't go to the gym two weeks before in case something up. So you purposely isolated yourself? Yes. I wasn't like, I'm meant to have a neighbour run for dinner. I didn't do that because I was, like, scared that, you know, they might they might have packed something up somewhere and give it to me.

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Like it's just silly things like that. Like I wasn't seeing any friends, like, in person. If I met up with anyone that was outside, it was like being in Covid. Yeah. And then the whole time we were there, it was like face masks everywhere. So yeah, it's like things that you don't, you don't have to thought about previously.

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Unknown
And it's funny because I only really started considering myself probably chronically ill, as little as, like six months ago. Right. Prior to that, I would say I didn't. I just thought I had a couple of blocks, but I've now been in hospital as an inpatient five times in the last 12 months. So like I think that probably does count at this point.

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I was like, yeah, that's how I would probably see it because it has had an impact on my life and that, you know, if I want to do something, I have to kind of prepare for it. And a lot of

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Unknown
planning. Yeah. Logistics. Like not even just backtracks, but like if I want to go on a bike, bike.

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Right. I have to sort of be like, right, okay, well, I'm going to rest the day before or I'm not going to do too much in the days up to that if I'm going to take care of me afterwards. Yeah. Like not always. It's not always like that. Yeah. If I'm going to a flare up, definitely. I have to be more considerate about that.

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I just,

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limit what I'm doing and, you know, consider the whole spin city thing, I guess, like query cycle for they got a finite amount of things that I can do. So which ones, you know, prioritise. Like which ones are the most important, which things I absolutely have to do. Yeah, I have to work today. The doc has to be work today.

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But what things can kind of get but not not get done but get bumped off the last

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So I'm really glad to hear that you are still enjoying your physical activities, though maybe a bit differently now or a bit more sporadically. Yeah. So something that I've asked everyone on this series is what does Meaningful movement look like to you now?

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So what brings you the most joy or what's the most important movement for you at the moment?

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for me, actually, cycling is one thing that definitely brings me a lot of joy.

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I do enjoy running as well, but again, I just don't. I'm not doing

enough. I need to get out and do do a bit more, but I. Yeah. Do you and your wife do any movement? Gavin. Walk dogs together? We did. Used to be one of those nauseating couples that went to the gym together. Oh, nice.

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We're trying to get back into that,

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but she's been in incredible support.

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Absolutely. For all of this. Absolutely. Oh, yeah. 100%. I don't know where I'd be without Lauren, especially with, like, all the coeliac stuff. Like, as soon as I got diagnosed, she was pretty much like, like, we're going to, like, cut gluten from the height. We don't have any gluten in the house. Yeah, have a gluten free kitchen, all that kind of stuff.

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And that didn't come from me. That came from her.

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She probably knew more about it than I did when I first got diagnosed, because she had so much written about it and all the rest of us. So she's been an incredible support. When we went to Japan and she was like, finding all the gluten free places that we could eat,

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she's been a great sport. So get okay reps. Thank you so much for sharing your movement for health with this today.