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Hi. I'm Heather. I'm part of the movement for health team. Today we're in Edinburgh speaking to Chi about their meaningful movement. Of chronic fatigue and chronic pain. Today we'll be discussing how the movement has evolved from the past to the present and their hopes for their future movement. We'll also be speaking to Kai about how their relationships and social network support them to move.

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Hi. So thank you both for joining me today on our Movement and Conversations podcast. So, Corey and Kai, I'm really glad to be speaking to you today.

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So the podcast episode is just going to be speaking about your movement, and how your long term health conditions have

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impacted that movement and how that's changed throughout your life. And we'll just speak a little bit about your life experience and things like that.

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Yeah. So I think the best place to start is just introducing yourself a little bit.

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Well, yeah. So I'm Kai,

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I am currently unemployed because of my disabilities and struggles and stuff like that. And, yeah, I live with a few people. One of them is Corey.

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We've known each other for about, I think eight years now.

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I have a degree, in neuroscience currently not applying it unfortunately,

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the way that started for me was like, I got diagnosed with ADHD and then I started kind of like working on then kind of discovering that

stuff. And then by figuring out ADHD, I figured out, you know, disabilities and how stuff works.

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And then after graduating university, I kind of started experiencing more severe like symptoms, which I thought, you know, was just like ADHD, burnout and stuff like that. And then eventually, you know, through the past couple years, we've kind of, me and my doctor have, like, discovered that I most likely struggle with, I mean, like, chronic fatigue, and yet chronic pain.

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I, I also just, like, socially, you know, kind of, deal with autism and, Yeah, hypermobility. So there's, like, I would put it this way, there's like a lot of emotional stuff. There's a lot of physical stuff. I don't have labels for all of it. Really? Yeah.

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following on from that, movement, how has that looked like throughout your life?

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So I've never been, the most active person, but I would say like it was for a lot of my life, it was just kind of standard. So, like, back in high school, like, I would have my daily walk to school back from school.

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So that kept me fit, obviously. Like, I could easily participate in P.E..

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I also really love volleyball. So like at various points in my life before, I was also able to like, participate in that.

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basically I think maybe when I was like around 15, I started noticing that, like, you know, coming back from school, I'm like really exhausted. And then I had a couple of illnesses which might have been like triggers first off.

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yeah, I think like after uni specifically like the burnout really kicked in.

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There's like some trauma, and obviously like those can be triggers for chronic fatigue syndrome, chronic pain and things like that. And it just

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over time has significantly worsened, which meant that movement wise, I could start doing less and less and less over time, just, you know, kind of scary if you think about it, to be like 24 and like being homebound most of the time.

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you obviously recognising that and seeing that within yourself, thinking, oh gosh, a few years ago I could do this and now let's change. So definitely recognising that within yourself is, I can imagine, quite a scary thing to go through. And so like that kind of leads me on to the next question of what is your current movement?

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How do you manage your movement day to day really?

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Most of the time I'm homebound, so I spend most of my time here,

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Yeah, majority of the time, like, basic daily tasks are like a struggle because, you know, I experience a lot of, like,

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pain in my muscles or even, like, just not even pain, but, like, just discomfort as well.

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Which I don't think people will talk about, you know,

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and so very little movement like I have used, walking aid in the past, in the past couple of months because it has gotten to the point where I can't do normal, like, you know, average daily activities, like, you know, non-disabled people can,

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you're saying that you spend most of your time at home at the moment, and obviously you live with people like Corey. So how having that social network, how does that help you day to day. How does

that does that support you.

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I'm really lucky to have my support network at home with me.

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living with people who are like, understanding, and are aware of my situation is really helpful because they can do what I found most helpful is they can do tasks for me so that I can,

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gather up energy for bigger things.

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So, for example, like most of the time Corey or Cassie or someone else will make me tea, right? And for a lot of people, that doesn't seem like, a huge task. But like, for me, it's like getting out of bed, walking to the kettle, standing by the kettle, waiting for it to boil. You know, doing all that

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when you have to do those small movements, couple times a day, it adds up and I end up being very exhausted with basic tasks, having people who can do that for me or like, you know, even cook, like standing my, the, the hob also can be quite exhausting.

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Also can put me into pain. So having them do those tasks for me means that I can save up energy for something that I'd like to do that's, you know, more positive for my mental health or something like that.

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So, Corrie, you we've spoken a little bit about you supporting Kai throughout this conversation, and, we've spoken about how you will do task for the purpose for them.

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Is that one of the main ways that you find yourself supporting Kai? And how do you are you quite aware of that, or does I have to remind you sometimes and things of that, or you because you guys are really close or is that just a natural?

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Yeah, I think I, I like a lot of the way that we kind of, I would

say that we see it as a flat as I feel like it's kind of like a collective, like team project to make sure that you're okay, like, including from you, like, you're kind of like the project manager, you know, like, what your,

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ability is, but there's a lot of

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stuff, like where everyone I even like or like or flat has different strengths and, like how we can support Kai. So there's a lot of different things that, like, everyone tries to like, remind, like remind you of because sometimes, like, so sometimes we do do things like, like there's a lot of, like doing a task, instead for you, but often, like, it's also just being encouraging when you are feeling up to doing something.

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And, yeah. And then also there's a lot of like, I think we. Yeah. Like, flatmates doing like, the smaller tasks so you can do the big task you want to do, like if you are like, like it's one of the things that's really difficult for you is cooking because of all of the movement required for that.

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But if you want to do a cooking thing, then you can kind of like delegate, okay, can you do this small bit so I can do that, like actual cooking or like even if you're just moving from one activity to the other activity like, often and like, like one of us will, like, help you, set up for that activity and, like, get you, like, tea or hot water, stuff or, like, just move stuff around you so that you can do the, like, I guess, like the main point.

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Yeah. It's one of the things, but also. Yeah, like, just try to be, you are usually it's actually much better, I think, than you think you are. You are aware of like, when a movement is going to be too much and everyone. But then everyone's also like, checking in, like, are you okay or what's not okay?

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But I think there's also an element of like sometimes forgetting that. Yeah. Or like, I think I have a good level of maybe understanding of, of when things are too much. But there's sometimes that element of like me forgetting that like, oh no, chi chi won't be up for this, or also not being sure because it is very different.

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Like it depends on the day completely, of course. So I think, yeah, it's like a team effort of like I think each other I would feel I don't. Yeah, yeah,

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Is there any movement that you quite miss you want to partake in again? But, for external reasons, maybe not just your own long term health conditions, is there any, would you say, barriers to accessing that movement?

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volleyball is a big one that I miss, that I would like to take part in, but I can't. And I guess another one is like swimming as well, but there's also like issues around it that like, people don't even think about because it doesn't influence them. Like for me, love swimming, love swimming pools.

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It's so cold around swimming pools. And that wouldn't be an issue if it wasn't the fact that, cold temperatures so much worse like, makes me so much worse. Like, it creates so much more unnecessary pain that I just gotta avoid it, you know? Yeah,

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what goes through your mind when you're thinking, oh, I'm going out with Kai? Are you thinking about the specific support or are you just.

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So it's stuff like, like a few times that we've gone, we've gone out. It's kind of like, what is the noise? What is the ability to sit down? What is the ability to leave the big one?

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Like, like, you know, what are the what are the people like? Like, and stuff like that. And then, and then like all of, all of that, goes into it, but yeah, then there's a lot of other things, like the smaller things to think about if it's like, yeah, just going out with like what? Like how much are you going to be able to rest?

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What do we need to bring for you to rest? How much pain? How much how quickly is the pain gonna build up? Like we even like but like, that's the thing. It's like we're all kind of like, it's. It's still in a way, newer to you. So we're all kind of figuring out stuff together, like you're talking about when you would go with the

picnic blanket, out to the harbour.

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But I think there was a first time we went. You didn't realise that, like, oh, I could just bring my hot water bottles and I'm would make it so much easier.

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I don't have a consistent movement for me. I just try and remember, like, whatever feels good on the day. I'm going to do, because, like, yeah, as I said, like, ADHD makes it really difficult to stay consistent. So I could set out to do stretches and I could say to my flatmates, okay, remind me every day to do those stretches, but I'm going to get really bored of them.

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I, I'm going to overdo it because I'm bored. And or I'm going to like, forget about them. They're going to forget about them. And I want to stay consistent. Like, I think one of the things that I found really important while having other people is just communicating and being like, hey, I want to do this thing, but, also maybe try and not, like, push me too hard.

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And they've been really cool about it. So it sounds like they do have that ear and almost about when to push you and to support you and to.

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I think it's quite a hard like it's a balance that oh that's, that's like developed over time. And on like when like it's definitely like was not an easy thing to tell about.

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Like when like a big thing, a big struggle for you is going into the shower, for like, like 20 reasons, right? But one of them being you have to stand for a big period of time, and figuring out when should we push Kylie to shower and when can I actually not shower, like as an example of, like, I still don't know if I'm, I just I know because sometimes I like the guy.

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I'm like, I mean, do you want me to bully you today to shower or do you want me like, do you want me to stop that? Because, like, it's like it's really hard for you to figure out, like, how much is even in something that you could push yourself into and how much can you just not do it.

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So this is like, I think, a constant thing we're figuring out. So like we figured it out better, but I don't think like it's still there's a lot of things that were like work in progress. And yeah,

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I guess having that relationship and obviously you guys have been friends for years. So like having that built relationship up, I think you're able to communicate quite well.

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So being able to know each other, I think allows that understanding as well to come into that as well.

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looking forward into the future, what would your aspirations be for your movement?

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currently, I'm proud of the fact that a lot of the days I'm able to get out of bed and come into the living room, just sit and that's my movement for the day. But I yeah, I'm just really hoping that, like, slowly, I can build it up slowly, I can sit upright more,

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I'm just kind of hoping to, like, stay proud of the movements that I managed to do

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find more safe ways of, you know, kind of going outside or, even doing like stretches at all the, the one, you know, messed up my back or something, you know, that sort of thing.

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So I hope I'll me and Corey actually planned to go swimming at some point together and we are definitely going to have like a conversation about what it's going to mean and blah, blah, blah. But, yeah, that's kind of what I'm hoping to do.

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I mean, you have this just with you in general, but also with your movement.

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You have a big problem. Interesting the way that you perceive how much you move because I'm like, I, you actually move a lot more than you're saying you do. But like, you, like, I feel like you have a big problem of overestimating your goal and then underestimating how much you do, like, over. It's like

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putting this far away goal that you should do, and then underestimating how much you actually do because you're like, oh, you get out of bed and you sit in the living room.

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But like I've said, I've noticed you. I think you're doing better lately. And I'm actually like, am I doing better? As like, I noticed how much you move in between, really. Like, you aren't just sitting in the living room like you move in between rooms in the day. You're able to do different activities in different rooms. You're like, I feel like you have more of an ability to leave the house more days.

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And, and I think that, like, I it would be like I think even I guess externally, I would be really happy if you are able to be content

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if I went to the gym, that would be the only thing I went for that did for the day.

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And I would much rather save that energy and actually go see my niece and nephew and play with them a little bit, you know?

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I'd much rather use my energy for that. Know again, it's that party of movement.

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Like I might get some social benefit and, mental benefit from the gym, but you're also going to get that mental and social and physical benefit from seeing family members and things that or going out with your flatmates and things of that. So it's about that balance and picking and choosing and seeing again. I think that's really good that you're recognising and having a conversation with yourself.

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What is your current movement and what is the direction that you want your movement to take? Really? I think that's really good to be able to sit down and speak to yourself and recognise what you actually want and where your movement lies at the moment and things like that.

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we've been asking everyone on the podcast series so far, what their meaningful movement is.

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And, that can be whatever you see it to be in the past or the present. So, yeah. What is your meaningful movement?

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So I've actually been trying to do my best to have like all of my basic movement being meaningful because, you know, I used to I never realised how.

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You know, I would put it like, well, I had it when I, when I didn't have high support needs

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because it was just so easy to walk from place to place. And I didn't even think about it, you know. So now, one of the things that I've been trying to do, like in therapy and stuff like that, is being proud genuinely and taking meaning from like basic things.

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So even just sitting up and doing a little doodle or, you know, even sitting up and playing a game that's, you know, some form of movement I've set up. Right.

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you can get excitement from just other people around you and that kind of can motivate you as well.

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Definitely.

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being, you know, disabled. It can be quite, I can find myself sometimes jealous of the fact that they can do certain things that I can't, or they're meeting up with people that can do certain things

that I can't like, I don't know, going on a hike.

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And so we've thought about it and we try to figure out, like, how can I feel better? Because obviously, like, I can't control, you know, what they're doing. Like, it's unfair, you know, but they want to be kind to me. They want to make sure that I feel okay. And so we've developed this idea of like them bringing me a little thing from outside, to so that I can get excited about something while I'm not feeling great.

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having that social element to your meaningful movement is just fantastic to hear about. And thank you for sharing.

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That's been really fantastic to hear.