00:00:03:06 - 00:00:18:10
Speaker 2
When I describe my fall into M.E. as being, like falling through the safety net. And in three days, my whole life changed. And long Covid did that again.

00:00:18:12 - 00:00:25:24
Speaker 2
And I think most of us have lived through something like that, which is shocking. It brings grief.

00:00:25:24 - 00:00:38:04
Speaker 2
But the thing that's beautiful about it is how we have all had to creatively adapt. And that's at the heart of what we're sharing today.

00:00:41:21 - 00:01:06:14
Speaker 1
Movement for Health is delighted to be at Edinburgh's Botanical Gardens today with poet Alec Finlay and members of the Day of Access Community. Most people are sharing their experiences of having long term chronic conditions, including long Covid. And we are so privileged to hear about their meaningful movement today amongst the trees and this beautiful space.

00:01:06:14 - 00:01:17:03
Speaker 1
A lot of people with chronic illness, chronic fatigue, long Covid, M.E. they're in a constant state of

00:01:17:03 - 00:01:30:13
Speaker 1
inner difficulty that they don't feel is understood outside of them. And there’s an enormous relief when you are with a mirror that’s truthful.

00:01:30:13 - 00:01:45:06
Speaker 1
When we're all together in nature there's a kind of comradeship, and the relief is knowing that we’re the same.

00:01:45:08 - 00:01:53:13
Speaker 1
And it's just a kind of basic human starting point for belonging.

00:02:01:07 - 00:02:05:14
Speaker 1
I'm Rory Hamilton, and I'm an artist. Quite a lot of the time.

00:02:05:14 - 00:02:08:21
Speaker 1
I'm also someone who suffers from sarcoidosis.

00:02:08:21 - 00:02:16:11
Speaker 1
And that's an immune disease which affects lots of different parts of the body. But for me it's mostly the lungs

00:02:16:11 - 00:02:20:20
Speaker 1
and my kidneys. And it gives me a lot of fatigue as well.

00:02:20:20 - 00:02:25:09
Speaker 1
And it's something that really I've only been diagnosed for about three years.

00:02:25:09 - 00:02:29:00
Speaker 1
Obviously the symptoms have been around for a lot longer than that.

00:02:29:00 - 00:02:42:13
Speaker 1
I can think back to 20 years ago when I started having a cough or whatever, you know, but I’ve basically got about 50% lung damage at the moment. So it does affect quite a lot of what I can do.

00:02:42:13 - 00:02:56:17
Speaker 2
And we're talking today about people's movements, and what I'm trying to capture is what movement might have looked like maybe before. you were unwell and what movement looks like these days.

00:02:56:20 - 00:02:57:05
Speaker 1
Yeah.

00:02:57:09 - 00:02:59:02
Speaker 2
So what was the before?

00:02:59:02 - 00:03:04:22
Speaker 1
If I go back 20 years and I mean, and you know I'm in my late 50s so I'm older,

00:03:04:22 - 00:03:12:10
Speaker 1
But I still, a lot of my friends just now go hill walking and you know, go away for the weekend and do quite adventurous things.

00:03:12:10 - 00:03:17:16
Speaker 1
And those are the things that I used to do when I was like in my early 40s, I guess.

00:03:17:16 - 00:03:25:18

Speaker 1
Certainly when I lived in London there's lots of really great walks you could do just from, at the end of tube lines, things like that. And we used to do that very often.

00:03:25:18 - 00:03:30:18
Speaker 1
But now I'm really limited in

00:03:30:18 - 00:03:35:12
Speaker 1
any kind of slope, any kind of elevation and I get out of breath really easily.

00:03:35:12 - 00:03:44:02
Speaker 1
I do struggle with that. I just have to really take my time. It takes me twice as long as everyone else and then often I have to stop.

00:03:44:02 - 00:04:00:06
Speaker 1
Even things like going to social events. Wanting to get there without being out of breath when I get there is like, you know, stopping 50 yards before and getting my breath back before I then do the final walk in to say hello to my friends.

00:04:00:06 - 00:04:03:00
Speaker 2
How does it, how does that make you feel?

00:04:03:12 - 00:04:10:11
Speaker 1
It's annoying. But I can, you know, you learn, you just learn what to do. You learn what to do.

00:04:10:11 - 00:04:19:24
Speaker 1
I think one of the things that when I go out with friends, even just walking around the town, is getting people to slow down and keep the same pace as me. And is that what your meaningful movement is these days?

00:04:22:23 - 00:04:24:07
Speaker 1
Yeah, I think so.

00:04:24:07 - 00:04:37:19
Speaker 1
Yeah, that kind of wander with your coffee at either end and a bit of exercise for me. And yeah, I think that that really makes it.

00:04:37:22 - 00:04:45:16
Speaker 2

And do you have any hopes for the future with anything you'd like to still do?

00:04:45:16 - 00:04:58:08
Speaker 1
I've never I've deliberately never had a car when I lived in a city because I didn't really feel like it was worth it. But now I think I'm getting to the point where I probably need it to go anywhere kind of slightly further afield.

00:04:58:08 - 00:05:05:18
Speaker 1
And it's really just for me, it's learning, it’s a kind of learning process. But as you say, like, sharing with people is really is really good.

00:05:05:18 - 00:05:14:07
Speaker 1
And I do go to sarcoidosis patient group as well and kind of talk about all this kind of stuff and quite a lot about fatigue and things like that.

00:05:14:07 - 00:05:16:02
Speaker 2
And does your art help?

00:05:16:02 - 00:05:45:20
Speaker 1
I think that the... It has helped me have a purpose to some of the journeys that I want to take. If I go, if I get here then I can do this drawing then that will be an achievement. I might not I've walked right up this Monroe but I've gone to a certain point and done a drawing which has captured, for me, a kind of movement and something that just kind of show people as well

00:05:45:20 - 00:05:50:01
Speaker 1
and everyone's kind of been really kind of responsive to those drawings, too.

00:05:50:01 - 00:06:02:09
Speaker 1
And I mean, the art for me is just kind of, a very kind of as a calm kind of place where, you know, I'm just I'm doing it for myself. I'm not doing it to make money or get famous or anything. It's like, I'm happy just making it, yeah.

00:06:02:09 - 00:06:02:21
Speaker 1

00:06:02:21 - 00:06:04:13
Speaker 2
So thank you for sharing with us today.

00:06:04:14 - 00:06:07:16
Speaker 1
That's all right. Cheers.

00:06:09:00 - 00:06:12:23
Speaker 1

00:06:12:23 - 00:06:29:01
Speaker 2
Out of the my bedroom window it looks out on the back greens. Very typical Edinburgh back greens, which is, which is lucky in many ways because that's been a large part of my world the last few years.

00:06:29:03 - 00:06:36:06
Speaker 2
It's... it is my window on the world. It's a substitute for all sorts of things, substitute for TV

00:06:40:02 - 00:07:10:21
Speaker 1
These window frames were a little, creative device that Alec and I first started using when we were working together on a collaborative project with people who experienced seasonal affective disorder, “SAD”. Where they are significantly impacted in terms of their mental health and their overall well-being by low levels of light.

00:07:10:21 - 00:07:25:03
Speaker 1
But using these devices as just a means to actually focus on, the hugeness that is the infinite space that is up above our heads.

00:07:25:05 - 00:07:58:16
Speaker 1
You can use it also, of course, as a picturing device on the horizontal to find landscape scenery, but we figured that here actually with a lying back on your back exercise with the dappled light and the kind of variegated view of the sky through the vegetation here, that there might be something quite nice and enjoyable and pleasurable about that exercise of sky framing.

00:07:59:23 - 00:08:33:19
Speaker 1
As a device it creates a connection between the things you see and the things that you're feeling. I know if I reflect just momentarily on the sky frame for me. I got to see so much movement that was happening above my head albeit tiny little movements that perhaps otherwise I might not have seen had the frame not been there.

00:08:33:19 - 00:08:41:01
Speaker 1
I'm really lucky I've got the garden. But, you know, I was usually just looking like this and not looking up.

00:08:41:01 - 00:08:50:13
Speaker 1
The last year I've barely been able to even get out to my back green and recently I started to be able to go out there a few times and there's a garden bench out there, and I've started to lie on the garden bench and it is weird.

00:08:50:14 - 00:09:04:12
Speaker 1
It started off really weird, lying in the back green on like a bench because nobody lies on the bench. Now occasionally I'll get to the park around the corner and I'll lie on a bench. Nobody lies on a bench, but i’ve started to, the more you do it the more normal it feels.

00:09:05:24 - 00:09:16:04
Speaker 1

00:09:16:19 - 00:09:20:22
Speaker 1
Thank you for coming and speaking with me today. Would you just introduce yourself?

00:09:20:22 - 00:09:21:17
Speaker 1
Yes

00:09:21:19 - 00:09:23:02
Speaker 2
I'm Sophie,

00:09:23:02 - 00:09:30:14
Speaker 2
I'm about to turn 40 and I've had long Covid since September 2020. So 35.

00:09:30:14 - 00:09:39:17
Speaker 1
What we're talking to people about today is their experience with their symptoms, their journey with their long covid or other chronic condition

00:09:39:17 - 00:09:46:07
Speaker 1
and their relationship with movement and what movement means to them as an individual.

00:09:46:07 - 00:09:48:24
Speaker 1
Would you mind taking us back to before your diagnosis?

00:09:48:24 - 00:09:53:11

Speaker 2
Well I have a very active background. My family are really active.

00:09:53:11 - 00:10:12:09
Speaker 2
I used to run numerous times a week. Back in London, I'd do various sort of short runs and then long runs at the weekends and often run from one side of London, home from work, to the other side of London.

00:10:12:09 - 00:10:19:09
Speaker 2
I did a lot of yoga, so I sort of found yoga in my early 20s and did yoga every day.

00:10:19:09 - 00:10:30:22
Speaker 2
I worked full time in a quite a physical job in fashion because you're always up and down in the studio and doing fittings and just running around like a mad person and commuting.

00:10:30:22 - 00:10:37:01
Speaker 2
So a very active, busy, busy life before long Covid, before my first Covid infection.

00:10:37:01 - 00:10:41:17
Speaker 2
So I haven't been able to exercise for, yeah, coming up to five years.

00:10:41:17 - 00:10:59:06
Speaker 2
I have tried for the first couple of years, I, you know, I really did try because we didn't really have any kind of advice that told us to stop. So I tried to go back to work. I tried to run. I tried to walk.

00:10:59:08 - 00:11:06:13
Speaker 2
I tried to do yoga and I carried on doing yoga for the first year even though I was in agony.

00:11:06:13 - 00:11:12:19
Speaker 2
And so now I use a wheelchair from most of the movement outside of the house.

00:11:12:19 - 00:11:18:13
Speaker 2
I have, over the past year or so, tried to do a bit more supine exerc... stretching really.

00:11:18:13 - 00:11:19:01

Speaker 2

00:11:19:01 - 00:11:29:15
Speaker 2
But really because I've had issues with my lungs, the tops of my lungs and clots. It's been more breathwork, that's really been my focus.

00:11:29:15 - 00:11:33:07
Speaker 2
And I get a lot of joint pain and muscle pain.

00:11:33:07 - 00:11:37:04
Speaker 2
and tremors for the first few years. I had constant tremors.

00:11:37:04 - 00:11:41:08
Speaker 2
But the joint pain is really prohibitive. I can't, you know, it really

00:11:41:08 - 00:11:48:16
Speaker 2
affects how much I can walk. But I really struggle with the sort of M.E. side of things with the PEM.

00:11:48:16 - 00:12:00:19
Speaker 2
So really, it's just getting by in the house, mostly sort of surviving within the house, and it's just meant that my partner and my parents became my carers.

00:12:00:19 - 00:12:11:08
Speaker 1
You mentioned there about the cost of doing things and something I've been writing down was people were talking at today's meeting was, what is the cost of doing?

00:12:11:08 - 00:12:17:09
Speaker 1
What might tomorrow the week the month look like now, after something like today?

00:12:17:09 - 00:12:33:08
Speaker 2
I think that we're all in quite a similar situation where we've been ill for a long period of time, so things aren't as triggering. And it is, you know, finding the community was a real, was life saving for me.

00:12:33:08 - 00:12:41:16
Speaker 2
To have these safe spaces to talk, but obviously it's exhausting,

and cognitively, I still have a lot of issues.

00:12:41:16 - 00:12:50:18
Speaker 2
I haven't worked for the last two and a half years. I lost the ability to spell and read and all sorts.

00:12:50:18 - 00:13:07:17
Speaker 2
So, yeah, cognitively, it will be it will take some recovery. In terms of prep, my partner willed me to the bus stop for me to get the bus to then be here and I have to decide whether to take a taxi home or the bus.

00:13:07:19 - 00:13:09:22
Speaker 2
So it would be a few days rest.

00:13:09:22 - 00:13:19:14
Speaker 2
Yeah, it's really, you can't imagine the kind of rest you need before you're sick. It's like not talking. It's,

00:13:19:14 - 00:13:33:23
Speaker 2
someone bringing you food, having a bath because your joints and everything hurts. You know, even if you don't do anything that physical, it's it comes out in sort of physical symptoms.

00:13:33:23 - 00:13:35:08
Speaker 2
It's really strange.

00:13:35:08 - 00:13:38:05
Speaker 1
What movement is meaningful to you?

00:13:38:09 - 00:13:45:16
Speaker 2
My meaningful movement would be the supine stretching that I've started to do a little bit more of,

00:13:45:16 - 00:14:03:21
Speaker 2
and then I guess meaningful movement will be sitting up and having dinner with my partner. I'm trying to work my way back to work, so it might be sort of testing myself to see sort of how long I can sit up and do something or read something,

00:14:03:21 - 00:14:17:06
Speaker 2
I have these small times throughout the year where I can, where I see my friends, so, friends that I went to uni with and it can be I usually have about two times in the year that I will have a weekend

with them, and that's massively meaningful.

00:14:17:06 - 00:14:23:04
Speaker 1
Lastly, then, I'm asking you for one what you hope for in the future.

00:14:23:04 - 00:14:29:09
Speaker 2
I would like to work again because I love what I do or did.

00:14:29:09 - 00:14:32:19
Speaker 2
Just having some independence back, I think would be amazing.

00:14:32:19 - 00:14:35:01
Speaker 2
Not having to rely on people so much.

00:14:35:01 - 00:14:41:06
Speaker 2
It’s just not easy for anyone, and there's really not much help out there at all. At all.

00:14:49:17 - 00:15:08:07
Speaker 1
It's kind of a very simple visual poem. So an t-sròin is the snout, the nose. And one of the things, when, you know, Gaelic hill names is you find how many bits of the body there are in the landscape.

00:15:08:07 - 00:15:18:11
Speaker 1
So do it like that. And then bring your elbows out. That's the British Sign Language for a mountain.

00:15:24:16 - 00:15:28:23
Speaker 1

00:15:28:23 - 00:15:33:11
Speaker 2
This is a poster that we made at the end of the last series of events.

00:15:33:11 - 00:15:42:19
Speaker 2
We're trying to create a new idea about what access is rather than the conventions of

00:15:42:19 - 00:15:52:01
Speaker 2
people who are blind, being led on walks through the hills. We're trying to explore something more experiential around limit and vulnerability.

00:15:52:01 - 00:16:05:17
Speaker 2
And some of the people here have some of the deepest wisdom about what I would call creative adaptation. So that's really why you're here as experts.

00:16:08:17 - 00:16:10:21
Speaker 1

00:16:10:21 - 00:16:21:06
Speaker 1
Katie, thank you so much for joining me today. So I'm Amanda Solomon from movement for health. And we have a podcast which is called Movement in Conversation.

00:16:21:06 - 00:16:23:13
Speaker 1
Would you mind just introducing yourself?

00:16:23:13 - 00:16:29:23
Speaker 2
I'm Katie, and I've lived with long Covid now for five and a bit years.

00:16:29:23 - 00:16:32:07
Speaker 2
it's had a big impact on my life.

00:16:32:07 - 00:16:43:04
Speaker 1
So what does long Covid look like for you Katie, if you don’t mind me asking? Sort of, what does it bring with it? Your day to day life,

00:16:43:08 - 00:16:44:17
Speaker 2
what's changed?

00:16:44:17 - 00:17:09:02
Speaker 2
Everything, yeah. It's fluctuated and changed quite a lot over that time as well, so what it brings for me this month is quite different from last month and last year, last week. And as a result of being here today, it’ll impact how, you know, the next few weeks are as well.

00:17:09:02 - 00:17:26:13
Speaker 1
I was wondering what, what the cost is for coming along, being social, being together with others and what is the cost for you after today and when you get home next days, next weeks?

00:17:26:15 - 00:17:27:12
Speaker 1
You can elaborate

00:17:27:12 - 00:17:28:15
Speaker 2
a little bit on that?

00:17:28:15 - 00:17:40:13
Speaker 2
The cost of it is increased symptoms, reduced function, and increased uncertainty as to how long that goes on for.

00:17:40:13 - 00:17:45:09
Speaker 2
I can already feel it kind of starting in the last half hour or so,

00:17:45:09 - 00:17:48:16
Speaker 2
things become harder. And I have to start, making

00:17:48:16 - 00:17:56:04
Speaker 2
specific choices about, the simple daily things that I can or can't do.

00:17:56:06 - 00:18:11:04
Speaker 1
You've had long Covid for around five years, you said. Yeah. Can I ask what you enjoyed doing before long Covid? If that's a happy place to, to go back to, we'd love to hear.

00:18:11:04 - 00:18:14:01
Speaker 2
I was always quite an active person. So,

00:18:14:01 - 00:18:23:02
Speaker 2
one of my favourite things was cycling, but not in a kind of competitive way, in a exploring on my bicycle kind of way.

00:18:23:02 - 00:18:26:03
Speaker 2
Yeah, used to love doing that. I went on holidays, like

00:18:26:05 - 00:18:36:11
Speaker 2
popped my tent on the back, or I'd stop at youth hostels and I’d hop on and off trains and just kind of follow wherever, wherever I fancied on any given day.

00:18:36:11 - 00:18:39:17
Speaker 2
That was how I used to interact with people as well.

00:18:39:17 - 00:18:42:01
Speaker 2
I used to like doing things with people.

00:18:42:01 - 00:18:45:02
Speaker 2
So that was how I used to, yeah

00:18:45:08 - 00:18:53:13
Speaker 1
Part of who you were and who you are, and how you went from day to day socialising, relationships, etc. It's

00:18:53:13 - 00:19:05:09
Speaker 1
a lot of freedom in what you've just said. Something about it feels very free. Yeah. Spontaneous potentially as well. Now, making some assumptions that a lot of that is lost?

00:19:05:09 - 00:19:06:15
Speaker 1
All of it. Yeah.

00:19:06:15 - 00:19:22:15
Speaker 1
I guess what we're trying to do with this work is, is really understand what meaningful movement is for people after a diagnosis, after coming to terms with the changes that diagnosis and symptoms mean.

00:19:22:18 - 00:19:32:00
Speaker 1
So I'm just wondering what meaningful movement means to you now. Rock climbing, gorge walking, all the rest of it looks very different.

00:19:32:00 - 00:19:32:22
Speaker 1
Yeah.

00:19:32:24 - 00:19:40:24
Speaker 2
I mean, that's totally gone. Certainly the last few months really that I could consider something like this

00:19:40:24 - 00:19:43:16
Speaker 2
but as we discussed that even this comes with a cost.

00:19:43:16 - 00:19:53:18
Speaker 2
So I think meaningful movement for me at the moment is hyper local, it's mostly for me at the moment

00:19:53:20 - 00:19:57:13
Speaker 2
within my house being able to move from room to room.

00:19:57:13 - 00:20:01:16
Speaker 2
I'm lucky enough to have a garden, so being able to get out into the garden and

00:20:01:16 - 00:20:08:15
Speaker 2
lying in the grass, or maybe doing a little bit of garden work.

00:20:08:15 - 00:20:17:09
Speaker 1
What about the community, then, around you? Do you have support within the community or friendships within the community?

00:20:17:09 - 00:20:21:07
Speaker 2
Not where I live because it's quite suburban.

00:20:21:07 - 00:20:25:03
Speaker 2
And even I think, socialising is something

00:20:25:03 - 00:20:31:21
Speaker 2
that takes too much, it costs too much. But, so dipping into these little online

00:20:31:21 - 00:20:35:17
Speaker 2
connecting through in some ways other people

00:20:35:17 - 00:20:41:24
Speaker 2
like we've met today, their own little hyper local experiences,

00:20:41:24 - 00:20:44:01
Speaker 2
that's my community these days.

00:20:44:01 - 00:20:50:10
Speaker 1
And there's a sharing in that, as well as the sharing of experience, but a sharing of creativity.

00:20:50:10 - 00:20:51:04
Speaker 1
Yeah. That

00:20:51:04 - 00:20:53:18

Speaker 1
you are finding together. Yeah. Which is

00:20:53:18 - 00:20:56:15
Speaker 1
really special I think as well.

00:20:56:15 - 00:21:01:17
Speaker 1
Can I ask what you hope for in the future.

00:21:01:17 - 00:21:12:03
Speaker 2
Hope is a word that, I've spent a lot of time thinking about because I guess for a long time I hoped to get better, and I hoped for help, and I hoped for,

00:21:12:03 - 00:21:17:20
Speaker 2
drugs, and I hoped for rehabilitation, and I hoped and I hoped and hope was

00:21:17:20 - 00:21:23:09
Speaker 2
pushing me to things that were making me sicker.

00:21:23:11 - 00:21:33:04
Speaker 2
so, in some ways, I say that giving up hope was one of the best things I ever did, because it allowed me to be where I am now.

00:21:33:04 - 00:21:36:13
Speaker 2
in some ways, I'm finding a little bit of hope again.

00:21:36:13 - 00:21:40:20
Speaker 2
And I think meeting Alec was one of those places because he's so full of

00:21:40:20 - 00:21:45:18
Speaker 2
hope in a different flavour to the one that I was looking for before.

00:21:45:18 - 00:21:54:23
Speaker 2
Through the work that I've seen of his, and through these new creative ways of connecting with people. That's that's where my new

00:21:54:23 - 00:22:00:08
Speaker 2
hope lies is, you know, I can see something there that is

00:22:00:08 - 00:22:03:01
Speaker 2
meaningful to me. Yeah.

00:22:03:03 - 00:22:04:20
Speaker 1
Thank you for sharing.

00:22:09:15 - 00:22:25:04
Speaker 1
What was interesting for us all today, is we're so used to resting on our own, and we're so used to then being with other people and trying to mirror them and doing too much and too much might just be hanging out.

00:22:25:04 - 00:22:34:12
Speaker 1
One of the difficult things about any illness that involves chronic fatigue is you do tend to isolate yourself in order to rest.

00:22:34:12 - 00:22:43:13
Speaker 1
And that's a little bit sad because you end up having a lot of time on your own, and you also feel like people don't see that.

00:22:43:13 - 00:23:08:01
Speaker 1
For those of us with M.E. thinking, oh, thank God, long Covid, it’s all going to get sorted now. And we've all seen the incredible ability of a culture to suppress, really quite fascinating but it's so skilled at it. It doesn't matter how many millions of people there are, it can still put a lid on it.

00:23:08:01 - 00:23:10:18
Speaker 2
I wrote a poem this morning.

00:23:10:18 - 00:23:32:24
Speaker 2
It's hard to believe it will end well. It will end well. It's hard to believe it will end well. It will end well. It's hard to believe it will end well. It will end well.

00:24:41:02 - 00:24:47:04
Speaker 1
To actually rest is quite a lovely thing.