

# Episode 7 – Chronic Pain

## NOTES

### WHO'S HERE?

This episode features regular hosts Paula Leask (CHSS Community Coordinator) and guest host Jay Wilkinson (CHSS Health Information Officer).

This week's guest is Marina from Glasgow who contracted COVID-19 at the start of the pandemic in March 2020 and has continued to deal with chronic pain and fatigue amongst other symptoms. Marina is a member of CHSS' Long Covid support group.

### WHAT ARE WE TALKING ABOUT?

This episode deals with chronic pain, a common and often debilitating symptom of Long Covid. Key points include:

- Chronic pain is often very severe, and may not respond to painkillers or other common pain treatments.
- Pain is difficult to describe, and it is important for health professionals to remember this when dealing with people who have chronic pain.
- Distraction is valuable. Listen to music and the radio, colour in, etc.
- Try to do stretches and keep moving if you can. Yoga is very helpful if you are able to do it.
- Breathing exercises can help to manage your pain and anxiety.
- Look for “joy moments” – small victories, small wins, and the beautiful things in life.
- It is normal to need to try many different treatments and management techniques, and some will work and some will not. This can be depressing, but it is a normal part of the process and doesn't mean it's hopeless.
- People who have been dealing with Long Covid may still be dealing with anxiety and fear of going outside, may even feel that they are still “stuck” in the height of the pandemic. It is important for people around them to be empathetic and understanding of this.
- Put your own oxygen mask on before helping others. Self-care is the key.

### FIND OUT MORE

- You can find support through the CHSS Advice Line: 0808 801 0899
- CHSS has a booklet on [Chronic Pain](#), which you can download online or order in print through our website.
- The [Pain Toolkit](#) is a resource available online or through your GP. It includes a written guide, as well as online workshops available through the website.

- Marina mentions a few self-care resources in this episode, including [Pause](#) by Kim Davis, and the online shop [Take Good Care](#).
- There are several charities specialising in chronic pain which may be able to support you with managing and understanding your pain. For example: the [British Pain Society](#), [Pain UK](#), or [Pain Concern](#).
- NHS Inform, the NHS' information hub, has an overview of [chronic pain](#).

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## **EPISODE TRANSCRIPT**

**PAULA:** Hello and welcome to Chest Heart and Stroke Scotland's Long Covid podcast, Long Covid & Me.

### **[INTRO MUSIC]**

**PAULA:** Hi, I'm Paula. I'm joined by Jay, and with us today is our guest, Marina. Hi, Marina. Thank you so much for joining us. Please tell us a wee bit about yourself.

**MARINA:** Well, I live in Glasgow, and I've had Long Covid since the very start of the pandemic, in March 2020. And I have been housebound all this time, which has been really frustrating and isolating for me - but onwards and upwards, I'm keeping positive!

**PAULA:** I love that. This episode will be discussing Long Covid and chronic pain. So, Marina, what does chronic pain look like for you?

**MARINA:** Chronic pain is absolute torture. Agony. Especially Long Covid pain. It's just never-ending, every single day. That's the thing with Long Covid in general, it's just very unpredictable and you don't know how your body's going to be from one minute to the next. You don't know what day you're going to have.

And your brain is trying to figure out what to do to deal with it, what coping mechanisms, because painkillers, all the general things that we use to help pain, just doesn't seem to work. So, it is just trying to manage it and cope with it on a day-to-day basis, to have a fulfilling life living with Long Covid

**PAULA:** I'm guessing from what you're saying there is: you take every day as it comes. When you wake up, you really don't know what kind of day it's going to be for you, and then you just manage your day throughout that. So I can imagine that can be quite challenging, especially if you're wanting to live life like you're saying - you want to make plans and do things with your day, but I guess it's hour by hour as well.

**MARINA:** Yes, definitely.

It's really listening to your body and my body will tell me, you know, like my torso inside will start sort of shutting down. It'll feel like a car putting on brakes. And that's letting me know that, you know, I can't do anything. I can't do simple tasks, small tasks. I'm also dealing with the post-viral fatigue, which is horrendous as well, on top of the pain.

But again, it is just listening to your body and trying to work out a way of dealing with things, and trying to prioritize your tasks as well. Doing like... if you've got phone calls to do for the days, you may have three phone calls to do, so it's just remembering, okay, even though you feel looking after the first phone call, you have to just take a break, take a rest, because your body's still healing, your body's still recovering from having Long Covid.

**JAY:** And I think that that's something that... People who've been listening to the rest of this podcast might recognize me as someone who, while I don't have Long Covid, I've experienced quite a lot of the same symptoms through ME/CFS. And one of my experiences has been that fatigue causes chronic pain and chronic pain causes fatigue, because it's really easy to underestimate how tiring it is to be in pain, but then the fatigue itself can cause pain. So, it's quite hard to unpick those two from each other. Have you found that as well?

**MARINA:** Yeah. They both seem similar. Pain and fatigue, they're both very, very hard to deal with.

The fatigue is like nothing I've ever experienced before. It's just lying down and when my eyes close, it's like going down a rabbit hole. It's all darkness. It's not like: "oh, I'm going for a nice nap and I'm having nice dreams." It's just like you conk out, and you've just no idea when you're going to wake up.

It's very, very frustrating. It's very debilitating. It's not a tiredness thing, it's like your body is shutting down. Your body cannot cope with simple things. It's a lot more than just, "oh, I'm feeling a little bit tired." You cannot cope. You cannot deal with things. And, yeah, it is very difficult to deal with chronic pain on top of the fatigue as well.

**JAY:** And I think that there's something around chronic pain. which is that, in my experience, when people hear chronic pain, they assume it means like, "Oh, I'm a little bit sore."

I recently broke my arm, and honestly felt really validated to realize that breaking my arm hurt less than the day-to-day pain I get when my chronic pain is particularly bad. Because I've been sitting here for 10 years going, "I'm probably making a fuss."

But it's to understand that: when people talk about chronic pain, yes, sometimes it's "Oh, I've got a headache", or "Oh, I'm a bit stiff and achy." A lot of the time, it's a comparable

level of pain to broken bones. It's not mild pain. I think people quite often underestimate how severe chronic pain is because you start to hide it.

But that's been my experience.

**MARINA:** Yes, definitely people don't realize the level of your pain and they don't understand how severe it is. Yes, it's absolute agony - and it's not something that goes away. And then the level of the pain changes.

And again, when people ask you, can you describe it? And I remember going to the pain clinic in the hospital, and they had the questionnaire with all the different words, like *stabbing* and... and I just thought, none of these words describe it because some days I wake up and I think, oh my goodness. It's like behind my ribs... It's like an actual Olympic boxing team with their fists and they're boxing away. Like, I can't explain how painful it is and how severe it is, and it just lingers and lingers.. And some days you think, *please go away. Please go away.* And then the next day you think, *oh, this can't get any worse.*

And it does. It does get worse.

And yeah, people do underestimate how painful it actually is. Yeah. It is important for people to get the message across, to try and understand.

And also, having Long Covid, people say, "Oh, it's a new thing. It's a new thing. We don't know." And again, that's really, really annoying for me, for people to say, "Oh, it's new. It's new. We don't know. We can't understand what your pain's like because this is all a new virus, a new thing."

**JAY:** One of the things that I know from an academic perspective - so I work in health information, so I tend to take more of the scientific end of things - one of the things that comes up a lot is that difficulty describing it, because we have no way of telling if my pain is like your pain.

When I say that a pain is "stabbing", does that mean anything like when you say that a pain is "stabbing"? When I say that my pain is at a six, on a scale of one to 10 - my six is probably higher than some people's nine. So, it's a recognized thing in medical science and particularly in experimental science, that pain is almost impossible to measure.

But also, people seem to not remember that that's a problem. People have a tendency to still, when you go to the doctor, they're just like, can you give me a number out of 10? Like, I mean, I can, but it won't tell you anything.

**MARINA:** Yeah, I just don't like that number scale thing, because why do they want know these things? Why did ask you these things? It's not of any use or any help whatsoever. The same as the describing words.

Again, you want answers: why are you getting this pain? When's it going to go away? There's these things you want to ask - and what things can you do to get rid of it? What can you do to help? These are the things I'm more interested in.

**PAULA:** It's been so interesting, listening to you both. What will be great for our listeners is you're validating a lot of what people are thinking and feeling. And for someone like myself, who's not living with chronic pain, I'm really listening intently because I'm learning from you what will be helpful to say to someone and what wouldn't be helpful.

And I think as well from listening, you must just be living in some sort of limbo. You want to be able to try and focus and distract yourself, but it's incredibly difficult because that pain is there. You want to rest and recover and heal. But then when you're resting, all you've got to do is think about the pain. So it must be really hard trying to just navigate a day with the overwhelming fatigue and the chronic pain.

**JAY:** And again, I think this is something where, Marina, I know you mentioned, there's all this talk about Long Covid as new. I'm coming, again, not from a position of Long Covid, but from a position of 12 years, 13 years of ME - it starts to be something you don't notice.

And that can also be kind of dangerous. Like, as I said, when I've broken my arm, I've hardly taken any painkillers for it, and it's not because I'm being tough, it's... they don't work for my chronic pain, so I'm so out of the habit of doing anything about it when I'm in pain. I just suck it up and get on with my life, and that's not actually healthy. I mean, I'm not sure it's healthy for the chronic pain, but it's certainly not healthy for...!

**MARINA:** Yeah, I think a lot of people agree with that. They've had enough of taking painkillers, and again, you don't know the side effects that they could be either. And then it's not good to get addicted to them, and it is good to try different things to try and help you.

The pain clinic said the TENS machine, and I tried all the different dials for that, but it just wasn't for me, that TENS machine. In fact, I think it made my pain worse!

And they gave me chilli powder cream, but I took an allergic reaction to that. I couldn't breathe.

It was really frustrating when it's just like we can't help. You know, and you're just like, where'd you go from here? The doctor's just like, "Oh, well just keep taking painkillers, take painkillers, take painkillers." That's their answer for everything, you know?

But in all fairness, they don't know what else to suggest, because it all is a new thing as well. Yes. I think that's how I've just had to find my own way of dealing with it, because you can only take so much, where you're like, I'm not getting any help anywhere from hospital, from doctors, from anyone.

So I've got five different things that I do to try and help alleviate the pain and to try and live a joyful life dealing with Long Covid. So, I would like to share them.

I just want to say like three things that I do use. Before I go into my top five things that I do. I use the ibuprofen gel. I use that on my ribs, and I also use it for the hip pain. The hip pain, it's all down like the outer side of my left thigh. It's just absolute agony constantly. So, I can't sit for long. I can't stand for long. Sometimes it's just like a padlock. My legs lock together. Yeah, sometimes just putting a bit of ibuprofen gel on that takes the swelling down a bit.

Also, hot water bottles, there're like a godsend. They're like, great, because I've got one that you put around your neck, because I get a lot of swelling, get a lot of pain around my neck. I've got the really long one, which I've got at the moment just on my leg, and then I've got like a normal one.

Also in the really bad days, I use the lidocaine patches. The medicated patches. Again, they only last like for the 12 hours, so you have to take them off after the 12 hour periods, but they kind of get me through a wee bit.

But I also feel, dealing with chronic pain, it's important to remember that we all have inner strength and determination within us to cope with the pain. So just always try and keep that at the front of your mind, you know, especially when you're having a bad day.

So, top five things I like to do just to distract myself. Again, each day's different. So, depending whether I wake up and I think, oh, this is going to be a day in bed, or it is going to be a day on the couch. So again, it's listening to your body, taking it hour by hour, seeing how you're feeling.

My number one thing is radio. I just absolutely love radio.

**JAY:** Or you could listen to a podcast... like this one! *[Laughs]*

**MARINA:** Yeah. Podcasts are inspiring, and they're educating, and they spark off ideas as well in your imagination. So yes, they are very interesting and informative.

**JAY:** Sorry, I couldn't resist.

**MARINA:** Yeah, yeah. And it's good to listen to all different stations the same as podcasts. It's good to listen to different topics as well.

My second tip is moving, stretching, yoga. So, moving: again, I'm aware that I've been bedridden, I remember having to get a D-dimer blood test just to check in case I had a blood clot. So, I'm sort of very aware of that now, and just to like brighten myself up, you know, I call it the joy jubbies.

So that is: if I'm in bed, a day in bed, I think: okay, make sure I move my fingers, my hands, and I move my feet just for circulation, my toes. So, I just do that, and I give myself a laugh and I call it the HAF dance. It's hands and feet dance, you know? So I just make sure I'm doing that.

I remember when the physio - I've had a few different physios, like for pulmonary rehab - and they said to me, the best thing you can try and do is just try and move anything in bed, just like moving your head. Sometimes with the pain, your whole body aches. So it's just trying to remember: move some part of your body.

Again, stretching. Again, when the pulmonary rehab physio came to see me, I'd lost all the muscles in my arms and my legs, so it was just all skin, flapping. So, she said, "Well, we'll just need to start from the very beginning", it was just basic stretches. So sometimes trying to just get out of bed, and I'll say to myself, okay, just a gentle lean, just in the outer side of my body with my arm, just up and down on each side. And sometimes it just perks your mood up a wee bit as well.

And yoga, again, that sort of helps my hip pain to try and do tree pose. Before I took Long Covid, I was really fit and active. I loved yoga, I loved Pilates. Tree pose was my favourite for balance. And it was one of the poses where I thought, "Oh, I can do this! I can do this, I can balance in one leg!" Because I remember: all the classes I've been in, people are like falling over, and I was so chuffed that I could do this.

I'm still trying to get my strength back. I still can't reach my arms straight up right above my head, but I still do the tree pose and I put my hands in like prayer position. I love that.

Corpse pose, as well, with yoga - again, that helps me. My ribs are so sore and my hips, sometimes each rib feels like it's bleeding. It's just agony, and I still can't bend. I still can't stretch. So, lying down on a yoga mat in corpse pose. I'm not very good with the whole meditation, switching off, doing nothing, because my brain is always running away. So, when I'm lying in corpse pose, I try and think, "Okay, please get some healing into my body."

Recently I've been thinking, oh, there's these Wombles inside, because I love the Wombles. Those Wombles inside, and they're sort of repairing every nook and cranny, and they're sprinkling their magic dust. So I just visualize that, and they're just helping to take the pain away.

My third thing is self-care. And I think this is really important for people with Long Covid, and there is some simple things that everyone can do.

The first thing is the high five breath. I really like this. Just putting out like your left hand. And then just tracing the outside of it. Starting with your thumb, you're just tracing up the way, breathing in, and then just slowly breathing out and tracing back down. So, you do that with each finger. I really like that one, that really calms you down.

**JAY:** So that's quite like the box breathing that, I think, Frances mentioned on another episode, where you do a similar thing of breathing in on one side of the box and then

breathing out along the other. It sounds like it's the same kind of thing, but with a slightly different shape.

**MARINA:** Yeah, I do find that helps. Like even for hospital appointments, I'm sitting in the wheelchair and I'm thinking, oh my goodness, my hip's so sore and I'm trying to move, and then I'm quite anxious as well, and I just do the high five breath and I think, oh, that just calms me a bit.

Another simple thing I do quite a lot is with a hot drink. Everyone loves a hot drink, but just a mindful thing to just hold your mug. I like to put my two hands around that mug and just feel the heat sensation in every single finger. You know, just sit for a few minutes, and think, "oh, this is really soothing. This... the heat's just reaching every part of my body." Yeah, I like to do that.

**JAY:** At Chest Heart and Stroke Scotland, we've got this strapline of "don't underestimate the power of a cup of tea." And I think that's mostly meant to be about the social side of things. But it's so true. Having a hot cup of tea... because it's like a hot water bottle, but also a hot water bottle for your soul.

**MARINA:** Yeah. But it is like, especially when you're ill, it is: Oh, a hot cup of tea is just *great*, and sometimes you really, really look forward to it, you know?

But, yeah, after I've warmed my hands up, I like to just rub them together, and then just put the palms of them on my eyes, just press them on my eyes, and then, "aaaah..." That just feels like relief, because sometimes your eyes are hot and burning with tiredness. And I feel it gives your face, as well, when you put your hands on your face it just gives your face a little, like, massage.

And again, staying with hands, I like to apply hand cream as well. Another mindfulness thing. I read it in a mindfulness book, and it said, you know, just take one minute, get hand cream if you don't have hand cream, even hand wash, and just slowly spread it onto your hands, in each finger. And just enjoy the sensation of it.

Again, we're still sticking with hands: clapping hands. I just think clapping your hands is a great way to just cheer yourself up. You know, I'm doing so well, dealing with this. You know, I mean, this is coming up for the third year Long Covid, and I just think, come on, give yourself a clap.

It's the same as giving myself a hug. Which I do, again, you can tell I've been on my own for all this time, you know! But yeah, with my two arms, it's just nice to give yourself a hug with your two arms and then just swap your arms over and give yourself a wee hug. I think that's a good thing to do.

And again, I like to make shapes with my fingers. Make love heart shapes. Triangles. I do the hand shadow animals. So...

**JAY:** And I do agree as well because, I mean, my experience and the experience of a lot of people I know with chronic pain is that the hands are one of the most common places, I think because they're very sensitive and you move them a lot, they're often where the pain sits.

**MARINA:** Yes.

**PAULA:** And it's where healing can come from as well.

**MARINA:** Yes. And the next thing is music. I just think music's got the power just to perk you up.

My favourite ones are... Lighthouse Family, *Lifted*. The other one is called *A Wink and a Smile*, it's by Harry Connick Jr. And that's just fun when I listen to it and I just try and, okay, let's just try and wink and smile at the same time. And you know, it's quite hard. It just makes you laugh.

The other song I like is by the Psychedelic Furs, and it's called *Pretty in Pink*. Don't knock the title. It's a really, really good song. It can just get all your anger and frustration out, and it does make you want to wiggle and dance.

I think it's good to just mix things up a bit and think, oh, let's just listen to something that I've not heard before. Or sometimes something which you don't think will help you, actually does help you. I don't know if you find that, Jay?

**JAY:** Absolutely. Honestly, in some ways, trying to distract myself has got me into an awful lot of the music that I'm into. And I think a lot of people, when they think about listening to music for pain or as a distraction, they're thinking of, you know, floaty, meditative, folky kind of stuff. And I do listen to some of that, but I mostly listen to protest songs and heavy metal. Yeah, and those work too. It's not about what the music is. It's about can you engage with it, can you enjoy it, and does it pump you up? Because I think there's quite a lot of music out there that, listening to it makes you feel good. And again, it's not always the happy, cheerful stuff, sometimes it's Linkin Park.

**MARINA:** Yeah, it's something that you feel a connection to.

Number five on my list is: joy moments. Just getting engrossed in what I call a mini achievement. So, it's not like a task on your to-do list, like: "oh, I have to make that phone call. I have to deal with that piece of mail." It's: "Okay. This is a rubbish day today. I just want to achieve something."

Sometimes for me it's like five, ten minutes, and the rest of the day is rubbish, you know? But that just sticks in my head like, oh, I did actually manage to achieve something.

So things that I love... I just love doing jigsaws, and I've done this one yesterday. It's 24-piece jigsaws. I've got a couple of these and there's only 24 pieces, so it doesn't take you long, but once you do it, you just think, "oh great, you know, I've done a jigsaw." So, it just like... excites me to know that I've done something.

The other thing I enjoy is playing Smelly Cat. The song Phoebe sang in *Friends*? Yeah. A lot of people say I look like Phoebe. But yeah, it is good to sing the words. The chords are really easy for it. It's a really short song. It's a really good laugh.

The next thing, colouring in. I love colouring in, and I think colouring in... that's one of the things that's really, really helped me through Long Covid. You don't have to colour in. You can do like stars, shapes. I like the colour-by-numbers as well. I've been doing the adult colouring books and the children's ones. It's like the jigsaw thing, but it's using both sides of your brain. It's very therapeutic, colouring in, because your mind just wonders and it's great, just concentrating on what you're doing. I mean even people who are not into art, not into colouring in, they definitely should give it a try because I do find it really helpful.

I also like to jot down tiny moments of joy. You'll probably think I'm absolutely loopy here, but, yeah, silly things like the shape of wonky veg, counting bubbles coming out of like a washing up liquid bottle when you squeeze... You can really tell I've been stuck at home all this time! *[Laughs]* Like, all these wee little details that you notice, but you have to have something to keep you going, you know? And it's also good to sort of learn something new. You know, that does help with the brain fog as well, every day trying to do new things.

So, I've also got top five tips to try and help people.

So: number one is, keep holding your sense of humour, because that really helps with bad days.

I don't know about other people, but I just, I do not like the two words Long and Covid because again, COVID just reminds me the nightmare of having the virus. I mean, I was in bed a good year, just still with the virus, still dealing with everything all hissing inside me. So: I wake up in the morning and I think of two different words starting with L and starting with C. So things like Liquorice Collector, today I'm a Lollipop Comedian, or I'm Lumpy Custard. You know? Just anything that's not Long Covid. Because you've got to keep explaining to people, I've got Long Covid, I've got Long Covid, and sometimes I just think: "oh, I just want to be myself. I don't want to be this big label on me that says Long Covid, you know?"

But I do think, dealing with chronic pain, you do need to keep hold of that sense of humour. Onwards and ever upwards.

Which leads me on to the second point, is just turning up the volume on your inner voice. So it's not waking up in the morning thinking: "oh my goodness, I'm so sore. I'm in so much pain." It's saying to yourself, "I am optimistic. I bounce back quickly. I will get better. Better days are coming my way." So I just think like that.

**JAY:** My stupid little self-affirmation is: "I'm so powerful that God had to put a damper on it."

**MARINA:** Oh, well done. It does give you that wee bit of power, doesn't it? It gives you that wee bit of push.

Just as a pandemic was starting, I find myself getting quite anxious. Before I took ill with Covid, just, you know, hearing all the deaths on the news, I decided to make myself a yellow post-it, and I still stick by that.

*I will relax, I will eat well, and I will have fun.*

And I think those three are really important to just keep at the forefront of your head.

The next thing, number three, is being open to trying new things to help with the pain. So, recently I've been trying crystals, trying to lie on my yoga mat and align the chakras to put all the crystals. I did do it the other day, after a lot of different attempts, the crystals all falling off me and trying to remember which part of my body... I'm lying with my eyes shut, thinking: which part goes where? It's not like you've got someone to put the crystals on top of you.

But I must say, they did say if you put clear quartz on the area where you're having pain, I have tried this twice. You were to lie still for 30 minutes with the crystals on each chakra and where I had the pain. So I put it in the area of my hip. And I must say, after that, I got off the mat and I thought, "Oh, okay. I do actually feel a bit better!" So, it is worth just trying it, keeping an open mind, you know, sticking with it.

Also, I don't know if you've heard of, like, the whole tapping method. I have been trying like the whole butterfly tapping. So, the butterfly thing's real easy to do. So, it's just putting like your right hand on your chest, and then your left hand on top of it, linking your thumbs together, and then just gently tapping on your chest. So that's to calm, like, anxiety, and I do think that is quite helpful as well to do that.

Number four is rescuing a bad day. I always try and find a joyful thing to do. So, whether I wake up at two o'clock in the morning or seven o'clock at night, I just think, okay, I'll do a bit of colouring in, or I'll maybe do a tree pose or tracing a labyrinth. So again, that's one of the things that's really helped calm me down. It's from a mindfulness pause book by Kim Davis, the labyrinth. So yeah, that is a really good thing.

Number five, the last tip, is to eat plenty of protein to build up muscle. Again, I was aware of all my muscle wastage, but I have read recently that lots of Long Covid people have found that this has helped their recovery, to take the protein powder. I've been taking the rice protein powder. There's no additives or anything added in it, just like a pure rice protein.

Lying in your bed for long periods of time, it does lead to all the muscle wastage, so, especially with the fatigue and everything, sometimes I'm not able to exercise or do much. I'm still actually learning to walk. I've got a walker and everything, so... It is just trying to make sure you're eating plenty of protein to build yourself back up.

**JAY:** There's another food that I would suggest, which the dieticians might get on me a little bit about, but: chocolate is actually really helpful.

**MARINA:** Is there dark chocolate or milk chocolate?

**JAY:** I mean, I prefer dark chocolate, so I can't really speak to milk chocolate. Dark chocolate's probably better because there is like a scientific basis for it, which is that dark chocolate - well, chocolate in general - contains a lot of serotonin precursors, so if you're having trouble with neurological issues, sometimes it can be genuinely, like, chemically helpful to eat... not *too* too much chocolate because as I said in the fatigue episode, aside from anything else, if you eat too much sugar, you will probably crash. But...

**MARINA:** I must admit, I do love the dark chocolate and I do try and take like one square of it every couple of days. I do like dark chocolate, and I'll sometimes take a handful of nuts as well, like almonds. I have heard a lot of the benefits with dark chocolate. So, yeah.

**JAY:** Also, it's nice and to be honest, you should give yourself nice things. Treat yourself.

**MARINA:** Yeah, definitely. Nurture yourself. Nurture your body. Do what feels right for you.

**PAULA:** Definitely. A bit of joy there in chocolate. It's fantastic. A little bit of happy.

**MARINA:** I've just remembered one other thing as well. Peppermint oil. Sniffing peppermint oil. Because some days, I can be quite lethargic with the fatigue all the time, and just sniffing that, it just keeps you more alert and perks you up a bit. And again, that helps with hospital

visits just to take your mind off anxiety. The roller ball, aromatherapy things are good as well. I like them too.

**PAULA:** Yeah, I really like those as well, but I always think everyone is connected to a different scent that'll help them. Mine is definitely lavender...

**MARINA:** I grow lavender in the garden and I make little sachets with it, and I'll put smiley face stickers on them and palm trees, and yeah.

**PAULA:** You can do so much with a scent, I think, as well. You know, you can pop it into your bath, you can put it under your pillow to help you sleep at night, you can take it on the go with you for moments that you feel anxious. Or, like what you're saying, if you're waiting on a hospital appointment, a doctor's appointment. Just having something to focus on. It's a distraction as well.

I also like fidget toys. Really helpful. You know, if you got something just to kind of... that bit of distraction for your busy mind that's thinking everything.

**MARINA:** Yeah. I've got my fidget toy here. Yeah, the stress ball is good as well. I like the stress ball. Yeah. Good to have something to hold onto.

**PAULA:** Yeah, just something to help you in those moments. But I think the most important thing is sharing what helps you, because then someone will think, oh, I never thought about that, and they try it and it's helpful for them. So, anything that can take your mind away from something to distract you or something that distracts from pain.

**MARINA:** All these distractions are so much better than painkillers, I've got to say.

**PAULA:** Absolutely. And do you find that you're taking what you need to take to keep well, but actually you're looking at different things outside and all around you that can help you spark joy, and help your body, your mental health and wellbeing and...?

**MARINA:** Yeah.

**PAULA:** It seems like you're finding lots of good resources as well.

**JAY:** And I think I will say as well, the same thing that I said about fatigue. All of us who've had chronic pain, we try lots of things, and some of them work and some of them don't work, and some of them, you come in and everybody's been telling you that it'll work and then it doesn't. For me, that was cannabis. I'm not sure if I should say that, but... did not work for me, but it does a lot for other people.

It's so individual. The things that will work for the people around you may not work for you. You have to be aware from the start that that's part of the process and part of the healing. Trying things and finding what works also means finding what doesn't.

**MARINA:** Yeah. So again, the mindfulness thing, it is just helping with the fatigue as well. So it is just like calming your body down and relaxing and it's helping with anxiety.

There's definitely a lot of anxiety comes with it, Long Covid, you know. For me it's just not knowing when it's going to go altogether. You know, when you're getting out of that tunnel and you're going to be fully well again. That's still quite a lot of anxiety for myself.

It is just really having to live with each day as it comes and just trying not to get too negative on yourself.

I think being housebound as well, it's so difficult. I'm just not seeing people. It's like you're in this wee goldfish bowl. It's like I'm still in lockdown. Everyone else has sort of moved on, and I'm just visualizing like... oh my goodness, like, I can't remember, what does a clothes shop look like? What does a till look like?

I just, I think the first time that I do go into a shop, that I'm going to be in tears. I'm going to be very emotional - and I'm still wearing my mask. I'm still masking all the time, obviously going to the hospital, getting in ambulance, people coming to the door, I've still got my mask on. And I do feel we need to have a place, even if it's like one shop, where Long Covid people can go and just feel safe, and not be stared at by other people and just still wear their mask and feel comfortable.

Because, yeah, I've still not made out into like the big world, you know, like everyone else. And it's still quite a scary thought. But, yeah, hopefully it'll happen soon. Hopefully.

**PAULA:** I think as well, actually, mindset changed completely. At one point, everyone was wearing masks and then you look changed, not wearing a mask, and then the minute you take your mask off, and people are wearing masks, we just automatically look to people wearing masks.

So, I think it's about making people be comfortable and safe in their own space. If someone's wearing a mask, just accept it. Don't question it. Just: it is what it is. If someone isn't, that's their choice as well. It's just about being respectful to other people and their

decisions, because I think respect for what other people are saying and their feelings is paramount actually.

We can't see how someone feels. We can share experiences to help people along the way, but actually saying to someone: "I don't understand what it feels like for you, share that with me and I will listen and I will do my best to support you." And I think that's something that I've also taken away from this.

And I actually heard from a colleague, which has been so helpful, that she said to me, put your own oxygen mask on first. And I was like, wow. It was that real profound moment because I always go to wanting to help support other people, and that gives me energy as well for life. I want to make a difference. I want people to be happy and enjoy the life that they have, you know?

But then also, for me to be able to do that... Self-care is not selfish. Put my oxygen mask on first, and then I can be the best person I could be for myself and for others. I think it's getting into that mindset. You automatically think, should I be doing this? Is it selfish? So you get lost in that mindset, but actually putting your oxygen mask on first is one of the best things that you can do.

That was just a real light bulb moment for me, I think.

**MARINA:** Yeah, that's interesting.

**PAULA:** And I always say when I meet people: don't think, oh, I'm lucky. It could have been worse. It is what it is. But what you can do, you could actually take it back and flip it and say, well, gratitude for yourself and the things around you. Don't focus on someone else. It's actually for yourself.

Something that I have is a wellness box. And if you just have it in one space so you can access it when you're not feeling good, when you're fatigued in chronic pain, you don't want to have to look all over the house or really try and think: what's going to help me today? It's just all contained in one box - and I'm definitely going to be putting some of your helpful hints and tips in there as reminders for myself.

**MARINA:** Oh, you should look up the website. It's called Take Good Care. So it's a lady set up a business in lockdown. Got some really nice things, some really nice stuff there.

But it is all about self-care though, isn't it? With chronic pain, you are the person that has to look after yourself. You know, no one else is going to do it for you. You have to just look out for number one.

**JAY:** And I think that that's maybe the takeaway for a lot of the symptoms that we've discussed. At the end of the day, if you can't take a pill and make them go away, the best way you can manage them is by being in the best place that you can be. Finding that time to be happy.

**PAULA:** Taking a moment for yourself - and when you were saying, Marina, about the hot drink: as a mum, a hot coffee or hot tea is so hard to come by. I'll go and make it and I'll be sitting there and I'm like, I'll just let it cool for a minute. I'll go and do the washing. I'll go and sort of the kids... I'll come back and it's cold and I'm like, I really am not enjoying this. I made it for myself, but it's now cold, it doesn't taste so great any more, because I've not taken that moment for myself. Like you're saying, I should really just be sitting down, holding it in the hands when it's warm and be like, "The washing can wait."

**MARINA:** It's about that bit of me time. I'm just saying, I'm going to take my time actually holding this mug and just appreciating.

**JAY:** And I think that those sorts of things, people view them as sort of an extra, and I know I instinctively view being happy as almost as an addition to being well. We're brought up in this society to view like medicine as something that comes in a pill and the chemicals and the science - but you cannot cope with the sort of chronic symptoms that Long Covid gets unless you take care of yourself and you take care of your own happiness.

Remind yourself why it's worth coping with.

**PAULA:** Yeah, and then sharing a lived experience will be incredibly helpful to others.

And I think at some point, I mean, our doctors and nurses and all our other specialists are incredible. They do an amazing job. But I think sometimes you just need someone to validate how you're feeling.

For example, when I had my stroke, I was in the hospital and doctors - I kept on saying, "Am I going to walk again?" And they kept saying, "We don't know. We don't know." And for me, I was like: "Argh, why can you not tell me? You're a doctor!"

But I would've done anything to have a stroke survivor and be like, "How do I get through this? How can I feel better? How can I get better?"

But the doctors, they all played a part. Everyone plays a part in everyone's recovery, and there's a place for everybody. And there's a time that things will be helpful, from what you're sharing, Marina, with us today, and Jay as well. So many people are going to be, like, breathing a little bit better - almost being like, "huh, okay, I hear what you're saying", or "Oh, I've not tried that. That might be something."

**MARINA:** I hope it does. I hope people do listen and I hope they do take something from it. I hope they get their pen and paper out and they write down my tips. Act on my tips.

**PAULA:** You've been amazing, honestly.

**MARINA:** Oh, thank you! I'm feeling quite exhausted now. All this excitement.

**PAULA:** After today, you need to hug yourself, you need to clap for yourself...

I think those little things are going to be huge things in someone's everyday. Just being able to navigate and get up and celebrate the small wins, because actually the small wins are the biggest achievements.

**MARINA:** Joy moments!

**PAULA:** Big hugs! Love it.

## **[OUTRO MUSIC]**

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