Episode 2 – Fatigue

NOTES

WHO'S HERE?

This episode features regular hosts Paula Leask (CHSS Community Coordinator) and Dr. Amy Small (GP and Long Covid advocate).

This week's guest is Jay Wilkinson, Health Information lead for CHSS. Jay is 30 years old, lives on the West Coast, and was diagnosed with ME/CFS in 2010. Despite this, they gained a degree in Biomedical Sciences in 2017. They have spent much of their adult life managing fatigue and acting as an advocate for people with invisible disabilities and chronic illness.

WHAT ARE WE TALKING ABOUT?

This episode deals with fatigue, which is one of the most common symptoms of Long Covid. Key points include:

- The difference between clinical fatigue and normal tiredness is that fatigue is constant and does not go away when you sleep.
- Fatigue can look like tiredness, but can also cause pain, "brain fog", dizziness, emotional numbness, and other symptoms.
- The most important tool for managing fatigue is **pacing**. Managing your activity levels and tracking your daily routine can help.
- Having people around you who understand your fatigue and can support you is vital.

FIND OUT MORE

- CHSS has a booklet on Long Covid Fatigue, which you can download at the link or order in print.
- CHSS also have downloadable worksheets for tracking your energy: the Battery Tracker sheet and the Energy Mapping sheet.
- You can find support through the CHSS Advice Line: 0808 801 0899
- The NHS patient information website, NHS Inform, has a page on Long Covid fatigue which may help you.
- This video on pacing, from the Dialogues with ME/CFS project, includes useful fatigue management information.
- Other charitable organisations which may be able to offer you support include: Covid Aid, Action for M.E., and the WorkWell Foundation.
- Jay makes reference to Spoon Theory in this episode. You can find Christine Miserandino's original 2003 blog post archived here.

EPISODE TRANSCRIPT

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

[**INTRO MUSIC]**

PAULA: My name is Paula Leask and I would like to welcome my lovely co-host, Dr, Amy Small.

AMY: Hi!

PAULA: And with us today we have Jay, thank you very much for joining us today.

JAY: Hi Paula, yeah. Thanks for having me.

PAULA: Today we're discussing fatigue, what that looks like, what that feels like for some people. Jay, tell us a little bit about yourself.

JAY: I'm actually the Health Information lead in Chest Heart & Stroke Scotland, but I've also been living with chronic fatigue syndrome for 13 years now. I'm hoping that I can maybe share some of the things that I've learned over the last 13 years that might be applicable for people with Long Covid.

PAULA: So, what is fatigue? How is it different from tiredness?

JAY: So, the difference between sort of your normal tiredness and clinical fatigue… firstly, clinical fatigue doesn't go away when you sleep. So you can't rest up and have it get better. It will come and go, but it will stick around.

The other thing is that severe fatigue tends to come with a lot of other symptoms. So you might be dizzy, you might have what we call brain fog, which is difficulty thinking straight, difficulty remembering things, sometimes difficulty communicating. Sometimes you'll get aches and pains, sometimes you'll get other various weird sensations.

One of the things that I've experienced a lot, and that most people I know who've had fatigue have experienced a lot, is sometimes you just feel like there's a ten-tonne weight lying on your chest, and it can be physically really difficult to stand up or to sit up or to do anything.

What makes it fatigue, I guess, is that all of that responds to… if you do too much, if you push yourself too hard, then all of your symptoms get worse.

Tiredness is a part of fatigue, but it's only a part of fatigue.

PAULA: You mentioned brain fog. How could someone manage brain fog?

JAY: So, there's a few ways that I've found that are helpful. The first one being just to know that it's something that can happen - making sure that the people around me, and the people that I deal with a lot in my day to day life, that they know that brain fog is a thing that can happen, and not to put too fine a point on it… some days I'm just going to be stupid.

Another thing is to try and write things down. To keep notes. I swear by keeping a solid calendar and a diary because if I didn't do that, there would be days when I just entirely forget what was going on. There still are sometimes, but that's a different issue. [Laughs]

AMY: So, I guess one of the things I've noticed about Long Covid and fatigue - and I guess very similar to your fatigue, I imagine - is that my pre-Covid self would never have forgotten to put eggs in a cake. And my post-Covid self is so incredulous that that could even happen when I am doing something that I used to do all the time.

So basically, and I noticed loads of my friends and peers with Long Covid found that really frustrating. And I think what I find equally difficult is when people say, “Oh, but I've always been like that!” therefore sort of minimizing your experience, which I think can be really frustrating at times, when you hear people say that.

That's something I've noticed, but I've also noticed - and I guess you’ve probably experienced this too, Jay - something I didn't realize before: that cognitive fatigue can cause physical symptoms. And that was a really big surprise for me.

JAY: Oh, absolutely. It was one of the first things when I was diagnosed that my specialist said to me, he gave me this table to fill out, this like… energy tracking document. And the first time I came back to him after that, he was like, “You filled this out completely wrong, because you were at school during these times”.

And I’d sat there and was like, “But I was just sitting down. I wasn't doing exercise. That's not high energy.” And I had to have it explained to me that thinking a lot also wears you out.

AMY: I think that's something I've noticed in terms of how even watching TV or listening to music can make one tired. And I guess that kind of leads me on to: how can we advise people to manage their energy? Because actually, if you classically think, well, if I just sit down, watch something that's investing, but that is then fatiguing… What can we do to manage our energy?

JAY: Yeah. And this is still something I struggle with. When I was first ill, I had a long fight with my doctor about what I was allowed to do that counted as rest, because all the things I brought up as what I did to relax, he was like, "that's not rest, that's actually very high energy."

What I would say is sit down and really think about - during a time when you have enough energy to think! - sit down and think about when you're doing things, and trying to build like 2 or 3 hours a day in where all you're doing is *being*. I know a lot of people find meditation or mindfulness exercises very helpful.

For me, it was listening to music. Because it was something that I could do for a relatively long time without getting incredibly bored.

A lot of the time, it's just going be about finding what works for you. I would love to sit here and say: "Here's my foolproof plan for fixing fatigue!", but if I had one of those, I would be a lot richer. So…

AMY: And do we know why Long Covid causes fatigue?

JAY: That's a really good question.

Honestly, we don't *quite* know. Most severe illnesses will cause fatigue, because your body uses up a lot of energy mounting an immune response. And with something like Covid, that can be really hard to clear out for your system, even if you haven't had severe symptoms. For a while, your body kind of exhausts itself. It's put out so much trying to sort the virus out that it just is knackered.

That accounts for some of it, but particularly with people for whom that lasts for months afterwards or for potentially years afterwards, that's where we start to get into the question of chronic fatigue generally, which has always kind of been a bit of a mystery!

There's some theories that it might be around inflammation, that there's swelling and a sort of continued response to being ill inside your body. And that that's what affects your metabolism and affects how much energy you have. There's some theories that it might be around changes to how you produce energy in your body.

The short answer is that it's still a bit up in the air, but at least some of it is probably just physical exhaustion from working through the virus.

PAULA: I was going to say, Jay, that as someone who had a stroke a few years ago, I've had post stroke fatigue, and it feels different to everybody. And I remember someone saying that fatigue feels like being caught in the rain. And for me that was the moment saying: Yes! That's the way to describe… that's how it feels for me. It's not something that just builds on throughout the day. It's just something that comes upon you and there's just kind of no way of stopping it. It’s almost like a wash, a wave of this extreme feeling, and you just don't know how or where to put your energy or channel your energy. Just almost have to stop.

JAY: Yeah, and then on the other hand, sometimes it can feel more like you're drowning, so you can see that it's coming, but you just can't do anything about it. Like the water's just rising.

And I think that's a really important part, is understanding how often it can feel completely different, not just for different people, but like… at different times.

PAULA: And I've also heard about a spoon theory. It's a really good way to explain fatigue. And you've spoken about that before, Jay, could you just explain to people what that spoon theory means?

JAY: Yes. So, the spoon theory was actually created by a woman with lupus - quite a long time ago now, I think in the early 2000s. She made this blog post, and it kind of took on a life of its own among chronically ill communities. And it's a way of explaining how energy works.

She describes that she was having this conversation at a cafe with a friend. So teaspoons were what were nearest to hand. And if you imagine that at the start of the day, you start out with a certain number of “teaspoons”, and they represent how much energy you have for the day. Anything you through the day will cost a certain number of spoons, and you have to give them away.

Under normal circumstances, if you don't have fatigue, you will start the day with more spoons, but also things will tend to cost fewer spoons.

So… someone without chronic fatigue might find it really strange to imagine that brushing your teeth would cost a spoon, but for someone with Long Covid, for someone with chronic fatigue, someone with lupus, that might cost half the spoons that they have for the day.

So, it's just a way of envisioning it as: when you have chronic fatigue, energy is a finite resource. You get so much of it at the start of the day, and you will spend it on anything that you do.

PAULA: So really the messaging is, protect your spoons. Manage your time well, that's best for you, and look after yourself. That's self-care. Don't give all your spoons away at once, preserve the energy.

JAY: Aye. And that's also about being aware of what costs a lot of spoons and what you can do relatively cheaply. As I was saying around resting: for me, sitting and listening to music or knitting is pretty cheap energy-wise, whereas reading a book or going to work costs quite a lot of spoons, so I can't do it all day.

AMY: Now, I think one of the things I found really helpful was keeping a symptom and activity diary, which I read about in a pacing book for people living with ME. And it kind of made you sit down and write all your symptoms that you had and what you've been up to that day. And it was really helpful, over the space of a week to two weeks, you kind of reflect backwards and see, "Oh gosh, I was exhausted".

But actually, when I look at all the stuff I'd done, but the day before, two days before that, because sometimes it can be quite delayed, can't it? I realised actually doing a meeting and cooking lunch back-to-back without resting, even though I thought having a meeting on Teams wouldn't be that draining, was too much.

And I guess for a lot of us, you know, the majority of people living with long covid that are young, we're not used to having to rest in between doing things. But actually keeping that diary, looking and seeing exactly what I was feeling, or the physical symptoms I had, just like you said, all the stuff that comes with that fatigue, I could then work out actually, by breaking my day up and organising it, mounting my fatigue better that I didn't have so many physical symptoms and I felt better in myself.

JAY: Yeah. And I think one of the things that early on in my experience, I found really helpful was… I mentioned that the doctor who diagnosed me gave me these energy tracking sheets? So, they were just tables with little boxes for every hour of the day. And you coloured them in different colours depending on what sort of activity you were doing. So whether you were doing high-energy activity, low-energy activity, resting or sleeping.

And originally, he gave me those so that he could use them for diagnosis, so that he could look at what my days looked like and go, "wow, you really are sleeping a lot!" But I ended up, I used those religiously for four years because it was so helpful, even without writing down my symptoms, just to be able to look at it and go, "Oh, I did, like… there's a lot of red for high energy on that day. So maybe that's why I had to take it easy for the week after?"

It was also really nice in the long run because it allowed me to sort of realize that I was actually getting better, which is one of the really difficult things with fatigue, because when you're tired, when you're exhausted, it's really hard to get a grip on whether you're more or less exhausted than you were last time you were exhausted. [Laughs] So, it's quite nice to have that like quantifiable proof that over time things can get better.

PAULA: I think one thing, as well: people can see fatigue as, like, a very physical state, but it's actually not just about that, is it? It can have a rippling effect throughout our whole lives. Could you just explain how that may feel for someone?

JAY: I think one of the things that people often don't quite register about fatigue is: a lot of the time it hurts. So that can be a part of it, but also, it's just… it's so wearing. It can really start to get you down. And as Amy was saying, especially if you’re relatively young and you've previously been pretty active, it's depressing.

I feel bad about saying this - like, it's not exactly a cheerful way to put it! - but it is just…mentally, psychologically, it can be really wearing to constantly be aware of all the things that you can't do. And so it can have all of these knock-on effects.

It does have an impact on your social life, if only because a lot of the time people will invite you to things and you will have to say no, and eventually people stop inviting you to things.

And I would say that it's often very important if you want to keep being invited to things, to say that to people, just straight out.

All of that has knock on effects on how you live your life, day to day. Most of it can be managed by having people around you who are understanding about it. Also, frankly, by having people around you who will tell you to stop. I think that’s one of the most important things for me, having somebody who, when I'm trying to do ten things at once, will say “That's probably a really bad idea and you shouldn't do it!”

PAULA: Speaking about other ways to help manage fatigue, are there any other treatments out there to help support someone with fatigue?

JAY: There are quite a lot of things that, anecdotally, individual people have found helpful. There are a limited number of things that have sort of that scientific base. Part of the problem with fatigue is that it's so different from person to person.

Absolutely I would say that pacing is the most important thing, and it's what I would recommend for anyone who's dealing with fatigue.

Some people have found that meditation and mindfulness can help to bring them some energy back. Some people found that oxygen therapy can give them sort of a temporary energy boost.

A lot of people that I know have found that the biggest boost has actually just been finding somebody that they can talk to about it. Because, as Amy said, cognitive stuff, thinking about stuff is also exhausting. And the problem is that, like I mentioned, being fatigued can be very emotionally wearing.

So it is incredible how, if you can find a way to get that off your chest, that immediately gives you some spoons back. Starting therapy was amazing for me, just having somebody who I could speak to and say, “I'm so frustrated being tired all the time!” made a world of difference to how tired I was.

Yeah… I would say there's no pill that you can take that will make fatigue go away. Some people will recommend caffeine. And I just want to say, do not, don't! I've tried it, it will come back to bite you after a couple of hours. The crash is not worth it. [Laughs]

And the same with sugar. It could be really tempting to load up on sugar and then you feel great for like half an hour. And then again, if you're anything like me, can't move for the rest of the day.

So what I would say is look around, ask around if you know anybody else who… particularly, actually, people like me, who've been living with chronic fatigue for a long time, because I know that long covid is still relatively new. And the symptoms of fatigue are sufficiently similar to chronic fatigue syndrome - to what used to be called ME - that a lot of the time, if you come and find us, we've already tried a lot of things, and we may be able to say, “Oh, well, this helped me, this didn't help me…”

Again, I would say, bear in mind, it's very individual. So just because something has helped somebody else or hasn't helped somebody else, doesn't necessarily mean it will have the same effect for you. But yeah, ask around. Try things out.

I think one of the most difficult things, but also one of the most important things, about chronic fatigue and honestly, I guess chronic illness in general, is: you are going to fall back down. There are going to be times where you try something, and it doesn't work, and it feels absolutely rubbish. And I think a huge chunk of dealing with it, is being aware that is not a failure. That’s not that you’ve done it wrong. That's just part of the process. I still try things and they don't work and I feel like crap about it, but I know that that's normal, and that makes a huge difference. It's a lot of trial and error.

PAULA: Lots of good advice there, Jay. It's just about trying something, finding things that are right for you. Some things will work for some people and not for others, but it's about trying to see what works, what's out there and what can work for you.

And just really… managing your own energy, looking after your health and your wellbeing throughout the day, and telling the people around you: This is how I feel. This is what it will look like for me.

And once your friends and family have an awareness of it, then it actually takes off some of the pressure and stress as well, with regards to that. Do you feel that, when people around you know what you're living with and how it can affect you throughout your whole life, then it makes things a little easier?

JAY: Absolutely. And I will say, wee little plug here, Chest, Heart & Stroke Scotland do now have a set of documents. We've got a fact sheet that explains what brain fog is. We've got a fact sheet that explains what PoTS is - that's the dizziness when you stand up. A booklet on Long Covid fatigue. We've got booklets on other Long Covid symptoms. And that can help as well, if you can have something that you can just give to somebody rather than having to come up with an explanation on the spot.

So that's my little plug for Chest, Heart & Stroke Scotland.

PAULA: I've actually looked at them, they're really good, really helpful information on there. So yeah!

JAY: We are also working on doing some worksheets again. Because it helped me so much, I'm working on putting out a template for that energy mapping sheet. So hopefully we will have that online sooner rather than later, and you'll be able to download those and print them out and use them as you see fit.

PAULA: That's excellent. And that peer support element is going to be helpful to so many people out there sitting thinking, how can I move forward from this? It's not about moving forward, it's actually about being in the moment and just do the things that help yourself and people around you that are living with this condition.

JAY: And I would say as well, because I know that it's something that's very scary when you're first dealing with a chronic illness: particularly if it doesn't seem to be getting better, you can be sitting there and going, “Oh God, I'm never going to live a normal life again.”

And I kind of want to use myself as an example that even if it doesn't go away - if that's the case, and it may well not be, many people with long covid do recover - but even if that's the case, because I still very much… I live with chronic fatigue every day. As I say, it's been 13 years at this point. I don't expect it to go anywhere.

But once you get your head around how to manage it, you can still live a full life. You can still work, you can still have hobbies, you can still have a life. I work full time. I have… very nerdy hobbies, but I have hobbies. I have friends. I have built all of that through chronic fatigue. And that's not to say, “Oh, look at me. I've done such an amazing job because I'm brilliant.” It's just to say it's not the end of the world, even if it feels like it sometimes.

PAULA: Thank you. I am going to say you're brilliant and I'm going to say you’re inspirational, and thank you.

AMY: Absolutely.

PAULA: Thank you so much. We really appreciate you being here today and talking with us.

JAY: Thank you! Thank you for having me.

[OUTRO MUSIC]

VOICEOVER: Thank you for listening to Long Covid and Me, a podcast from Chest Heart & Stroke Scotland. If you enjoyed this episode, please like us on your podcast app and consider sharing the podcast with your friends, family, and anyone else who may be interested.

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If you have questions or feedback about the podcast itself, or if you would like to be involved in future Chest Heart and Stroke Scotland podcasts, you can contact the podcast team direct at: **podcast@chss.org.uk.** Please note that we cannot provide individual medical advice through this email.

If you would like to read a transcript of this episode, or if you would like to view links and further information, these can be found in the show notes. Thank you for listening, and we hope to see you again next time.

ADDITIONAL CREDITS

This podcast was made possible by the support and skills of:

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