Episode 8 – Best and Worst Advice

NOTES

WHO'S HERE?

This episode features regular hosts Paula Leask (CHSS Community Coordinator) and Dr Amy Small (GP and Long Covid advocate), along with a range of guests from throughout the series:

Jay Wilkinson, who guested on the Fatigue episode, is CHSS Health Information Officer and has been living with ME/CFS since 2010.

Frances Tait, who guested on the Breathlessness episode, is the CHSS Physical Activity Coordinator and has years of experience helping people with long-term health conditions.

David Martyn, who guested on the Employment episode, is an employment lawyer with Thompson's Solicitors and has been working closely with Long Covid patients to support them in workplace disputes.

Marina, who guested on the Chronic Pain episode, is a member of CHSS' Long Covid support group and has been living with the condition since early 2020.

WHAT ARE WE TALKING ABOUT?

Over the course of recording the series, we asked our guests to tell us the best and worst pieces of advice they had come across for people living with Long Covid. Their answers, ranging from personal memories to more general thoughts, are collected in this episode.

FIND OUT MORE

- You can find support through the CHSS Advice Line: 0808 801 0899
- CHSS also offers booklets on Long Covid, Long Covid Fatigue, Long Covid Breathlessness, Life with Long Covid, and Exercising Safely with Long Covid.
- There are many worksheets and tools available to help with pacing, including the CHSS worksheets for Energy Mapping and Battery Tracking.
- In this episode, Amy mentioned the book "Classic Pacing for a Better Life with M.E." by Ingebjørg Dahl. You can find this on Amazon here, and it is also available for the Kindle.
- If you have questions or topics which you would like to hear us discuss on the final episode this season, please email us at **podcast@chss.org.uk**

EPISODE TRANSCRIPT

VOICEOVER: Hello and welcome to this special episode of “Long Covid and Me” from Chest Heart and Stroke Scotland.

There's a lot of advice out there for people with Long Covid. Some of it is good, some… eh, not so much. Over the course of this series, we asked our guests to share the worst advice that they've ever been given about Long Covid, and these were their answers:

AMY: The worst piece of advice I've been given is actually a really difficult one, and I think I find it particularly difficult because it was from friends who were meaning well, but actually, it ended up backfiring just in terms of my relationship with them.

I had chronic fever with my Long Covid that went on for well over six months on a daily basis. And I remember telling my friends about it - medical friends - who said, “Oh, well, does your thermometer work? Have you tried… Is it one that goes in your ears? Is it a reputable brand? Have you tried a different one?” And I remember listening to them and thinking: gosh, maybe I'm wrong. Maybe this is all in my head.

And I think just their doubt in that, and me listening to their doubt in that was actually really damaging, not just in my own illness and, and me almost gaslighting myself, but also then it made me realize how others might not understand what I was going through, perhaps didn't believe me…

And particularly challenging as they were medical, and therefore part of me felt that they should know better, and they should be more empathetic. And in all of that, I've realized that really you've got to be so careful who you speak to about these things, because not everyone does always believe you. And that's what's particularly challenging with an illness that's so invisible.

And it also made me really realise how people living with chronic conditions like Chronic Fatigue Syndrome and M.E. had been belittled and misunderstood and gaslit for years. It was a really sad but really eye-opening moment for me, and it just made me realize that, you know, I know me best and I know what was going on with my body best, and I really shouldn't listen to anyone else and have them tell me otherwise.

JAY: Over 13 years, I've been given a lot of terrible advice [laughs] and I think anyone who's lived with really any illness for a long time will understand when I say that if someone tells me to try yoga or kale, I'm going to scream at them. But the worst piece of advice I ever got wasn't to me, and it was before I was diagnosed.

So when I was, I think I will have been 17, I'd been living with fatigue and living with these mysterious health problems for around a year. Took a while for my mum to figure out something was up with me and to drag me to the doctor.

And at this point, I'd been missing school a lot. I'd gone from being at the top of my classes to being… I mean, I ultimately had to retake a year. I was sick all the time because my immune system was suppressed. I felt like crap. I was in pain…

And we went to the doctor and we told the doctor all of this, and my mum's sat next to me. I'm still very much insisting that there's nothing wrong with me, because I didn't want to be ill.

And the doctor turned from me to my mum and she said, "Sometimes teenagers are like this. Have you tried waking her up in the morning?"

And I swear to God, my mum is like the chillest person that I know, and I have never seen murder in her eyes the way that I saw it that moment. So, I would have to say that that is the worst advice I have ever heard was, "have you tried getting her up in the morning?"

PAULA: That sounds like terrible advice, and go your mum for standing your corner!

FRANCES: Maybe perhaps not quite Long Covid related, but possibly the worst piece of advice I have heard is that someone was told that once they started their medication, that they will be on that for life.

I found that quite difficult to understand, because most of these things are a medicinal intervention which is needed at a certain time. Many people will perhaps be on medication for the rest of their lives, but for someone to say they've been *told* that they will be on that for the rest of their life is a little bit soul-destroying, when everything can start from you as an individual, what can you change?

And, of course, we need medical intervention, that's an absolute must, but can we do something on our own, as well as?

PAULA: Thank you for that. I think that what that says is actually, you know, living with hope. You know, if we have hope, we can move forward - and you shouldn't just stop it right there. We should all be hopeful to be able to move forward in our lives, to live our best life.

MARINA: The worst bit of advice. I wouldn't say it was advice really, but I did get referred to a clinic, and I think I obviously got the lady a bad day there, because she phoned me and she was shouting and bawling, and she was supposed to help me with fatigue and she ended up saying, "Oh, you'll never work again. I wouldn't advise you to go to any job. I'm telling you right now, you'll never work again."

And that was pretty upsetting to hear.

JAY: That's awful.

PAULA: Yeah, and I had heard that other Long Covid people had said that, you know, was really good, really helpful… but I've obviously just had the wrong person.

PAULA: And I think the advice we can get from, actually, you sharing that: don't just go for the first person and think it's not worked out for me, I'm not gonna go back again. Go to the next person, because we all vibe with different people, we all get different things. That's probably put you off and you're like, oh, I'm not really sure if I want to try that again.

That shouldn't have been your experience of that. That's the person, their reaction towards it and actually what’s there is a lovely therapy that you deserve to enjoy.

VOICEOVER: Of course, it's not all bad. We also asked our guests to tell us their best piece of advice for people dealing with Long Covid, and here's what they told us:

AMY: The best bit of advice I think I was given was probably on Twitter by a person living with M.E., who told me to go away and learn about pacing. They told me about a book called Classic Pacing for a Better Life with ME, which… was a really difficult book to read, but actually a really, really helpful one, and it really drilled down to the basics of pacing, from someone who largely couldn't do anything to someone who's a lot more active.

It encouraged me to keep a symptom and activity diary, and really helped me to understand where I'd been going wrong in the months preceding getting this advice. So that's my advice to you guys, is go out and learn how to pace in whatever way that you find helpful.

But I can highly recommend that book as a really good source of advice, no matter what the chronic condition it is that you are suffering from. The advice is pretty generic and can be really helpful.

JAY: Actually, the best advice I was ever given was to count how many hours I spent doing high-energy activity. I no longer do that, but it made such a difference having a number that I could put on how much I'd done in the day, and over the course of a few months, that I could start to see that it was getting easier and easier to make that more consistent and to not be constantly in this boom and bust cycle, where I was doing everything for a few days and then crashing out and useless for a month.

So, yeah, I would say that was my best advice, was: count it. It feels really counterintuitive to start with, but sitting down and putting a number to how many hours you've spent doing high energy things, how many hours you've spent doing low energy things, how long you've been asleep… World of difference.

MARINA: Yeah, best piece of advice was: take short breaks throughout the day, even if you don't think you need to. Just stop and do nothing. Calm your mind. Try breathing or guided relaxation techniques.

I think a lot of people don't understand the word “rest”. I think it means different things for different people. Rest and recovering with Long Covid, some people are like, oh, they're putting the TV on, they're on their phones. But that's using your brain all the time.

So, the Royal College of Occupational Therapists, they're saying rest just means completely rest. Like, do nothing, like, give your mind and body a break.

I think if you're an active person, it is hard to just switch off and do nothing. Cause I've tried to do things, you know, sit in the garden, just listen to the birds, and I think to myself, okay, I'll try this for one minute, and it can be like 10 seconds and I'm like, right, what will I do now?

I think that is quite helpful, the whole pacing thing because again, people think, oh yeah, I'm doing okay and I'll just keep going. But it is important just to stop.

PAULA: It's about listening to your body, but also: don't let it get to the point where it's so overwhelmingly feeling extreme. It's actually preventative things as well that you can do. So it's not getting to the point where you're like, “oh my gosh”, but actually as well: “Well I'm going to need to stop this. If I go on any longer, I will be feeling this feeling, so I'm going to stop now.”

So it's about not letting the batteries completely run out, but when they're nearly running out, you need to recharge them.

DAVID: I think probably the best piece of advice is: Make sure that you do not suffer in silence, and that you contact your relevant medical practitioner as often as possible, and that you are satisfied that they have clearly understood the nature of your conditions and that that is properly recorded.

That's not exactly a punchy piece of advice, but it‘s really important when it comes to the sort of work that we do, that we have a clearly set out record of what the best medical view is of this person's medical condition.

Because where there is vagueness, it's very easy for employers to kind of sneak through that gap and say, “Well, it wasn't quite clear from that report.” And then subsequently somebody says, “Well, maybe the doctor didn't pick me up in terms of what I said. And I did tell her that, but she didn't record it in the notes of her conversation or in any report.”

So, I think that's probably it. Don't just sit back and let a single report - be very, very clear with your doctor that you've explained all the conditions and what the impacts are on you, because it makes it a lot easier later on in proceedings.

Doctor's views are given extreme importance later on in the process - perhaps too much. Perhaps less so when we get to court - and I don't know, Amy, if you may or may not have ever appeared in court in terms of giving expert evidence? - but once you get to court, then doctor's evidence tends to be questioned, and you can get different experts giving different opinions.

But most cases don't go to court. Most of the time, whatever a doctor says informs the outcome of the case.

And that's why it's important. If you've not told your doctor everything, they're not going to give an accurate report of your condition. So, be as upfront and open with your doctor as you can, and make sure the report properly reflects what you've said to them.

AMY: That's made me massively reflect on my own practice now, so… [laughs] I shall make sure that mine and my colleagues' documentation is robust.

FRANCES: The best piece of advice I would say is: Try not to feel alone in that journey. There is support out there, there are support networks.

Physical activity is really important, but as is connecting with people, you know, peer groups that understand what you're going through, just so you don't feel quite so alone.

The help is there. Please take it. Make it your own, so that you can do, you know, whatever you can do to meet your life, the best quality of life you can have whilst living with Long Covid.

And don't be afraid to talk to people about it, or to ask people "how is it for you?" And it will be different for others.

But yeah, the best advice is just don't go through this on your own. There is help there, there is support there, and let's find the best support for you so that you can live the best life you can.

PAULA: I don't know if you could say it's advice, more just very powerful words that made a huge impact on me.

I'm sharing this advice, not from someone with Long Covid, but from someone supporting people with Long Covid.

What I am, is a stroke survivor. And I remember being in the hospital after my stroke, it was like the rug had been taken from under my feet. And I remember asking all these different doctors, I just kept saying, “Am I gonna walk again? Am I gonna walk again?” And they kept saying, “We don't know.” And I just couldn't cope with the words: “We don't know.”

And my husband, William, said, “Paula, stop asking the same question, because you're getting the same response and you're just getting yourself upset.” And I remember saying, “William, I need someone to give me something. Like, I need something here.”

And one day, this doctor, I asked him the same question. “Am I gonna walk again?”

And he said: “You have a chance.”

And it felt like an anchor. That moment of “You have a chance” was my anchor to move forward. I'm going to reach for that! And it just put me in a different mindset, and my husband said something just changed in me that day.

It just goes to show, though, how powerful words can be. They can build a person up, or they can tear a person down.

At six months, I went to visit my GP. I was a bit concerned about my hand. I'm saying a bit, I was terrified. I could only lift my right arm up just ever so slightly. Nothing else was working from the, say, the elbow down. And I remember saying to the doctor: “Is my hand going to work again?”

And he said: “This might be as good as it gets.”

And those words crushed me, because I wasn't ready to stop rehab. I wasn't ready to give up. I wasn't ready to settle. I remember going home and just crying, just sobbing, and you know, the next kinda few weeks after that were quite hard, and then I just thought back to those words: “You have a chance.”

And that was enough for me to get that fire in my belly again. Accepting I'm gonna have my off days, where I might not feel so good. Obviously I was in the flow of all the emotions at that time. Some days I was happy and fighting and some days I was just low, thinking I just can't cope with this. But with the support of everyone around me, I just kept moving forward. I had that hope to move forward.

Being supported with that, you know… We can't change things that's happened. We certainly can't, you know, turn back time. But what we can do is hold out our hand and say, “I'll help you through this. You're not on your own.”

And that's so important, and that's what we want to do as an organization at Chest Heart and Stroke Scotland.

We want to tell people: you're not alone. Your life is not condition-led. Your life should be led by you, and it's really important that your life is not half lived. And that's what we want to do. We want to give you the best possible support - and hear from you as well. What's working for you? What's not?

What's most important is: what matters to you, matters to us.

Thank you very much for listening.

[MUSIC]

VOICEOVER: Thanks so much for listening and for coming on this journey with us. We hope you found the series interesting, and remember: you don't ever have to do this alone.

We're here to answer your questions two weeks from now. If there's something that you would like to hear Amy and Paula discuss, or something that you think our listeners should know, you can still email your questions and comments to us at mailto:podcast@chss.org.uk- and we'll see you in two weeks!

ADDITIONAL CREDITS

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

- Jay Wilkinson (Primary editor and voiceover)
- Serena Battistoni (Transcription and online support)
- The CHSS Graphics and Communications team (Artwork, advertising, and circulation)
- Robyn Donoghue (Communications lead)
- CHSS Long Covid Support Group (Consultants)

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