

# Episode 4 – Mental Health

## **NOTES**

### **WHO'S HERE?**

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

The guest is Ada Siu, a trainee health psychologist at Glasgow Caledonian University. Her doctorate research focuses on post-COVID ME/CFS for people living with pre-existing health conditions. During her placement with CHSS last year, she provided support for individuals living with stroke and/or heart conditions using Cognitive Behavioural Therapies and person-centred therapies. She aims to improve the quality of life for people living with health conditions.

### **WHAT ARE WE TALKING ABOUT?**

This episode deals with mental health, which can often be a struggle for people with Long Covid. Key points include:

- Long Covid symptoms can make it difficult to manage mental health, both because of the symptoms themselves, and because of the isolation and loneliness that may come with them.
- Post-traumatic stress is common in people who were hospitalised with COVID, but also in those who were at home throughout.
- Remember: the Long Covid is causing the mental health difficulties, not the other way around!
- Try to avoid reading or watching the news if it is stressing you out, including social media.
- It's important to seek support wherever you can. This might be through the NHS mental health service, through friends and family, or through self-help and self-management tools.
- As a friend or family member of someone with Long Covid, the best thing you can do to help them is to listen and be compassionate. Doing practical tasks and reducing the burden on someone who's struggling can go a long way! However, you also need to look after your own health, as caring for someone ill can be stressful.

### **FIND OUT MORE**

- You can find support through the CHSS Advice Line: 0808 801 0899
- CHSS has a booklet on [Mental Wellbeing](#), which you can download or order in print from our website.

- In this episode, we discuss the Long Covid peer support group which is arranged online by Chest Heart and Stroke Scotland. For more information on how to join this group, you can also call the Advice Line or refer yourself to the Services Team directly through [this link](#).
- For NHS support available in Scotland, you can look at [this NHS Inform page](#). This site also has a range of mental health self-help guides.
- You may be able to access further help, support, and services through mental health charities such as: [SAMH](#), [Penumbra](#), or [Health In Mind](#).
- If you are looking into private counselling, the British Association for Counselling and Psychotherapy (BACP) maintains [a register of accredited counsellors](#), which you can search by specialism and area.
- The NHS also has a project called [Every Mind Matters](#), offering a range of self-help and support tools for your mental health.
- There are a lot of smartphone apps for meditation, calm, and combating anxiety – search in the app store to find them!

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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]**

Hi everyone, and thank you very much for joining us today. I'm Paula Leask, a community support coordinator for Chest Heart & Stroke Scotland. And joining us today I have my co-host, Dr Amy Small.

**AMY:** Good morning. How are you?

**PAULA:** I am fine, thank you. And we have Ada here. Thank you so much for joining us. Thank you for your time.

Now Ada is a trainee health psychologist. And what we're going to be talking about today is long covid and mental health and wellbeing - what that can look like, some coping strategies, techniques, and just how we can offer the best support possible. It's still unfamiliar territory for a lot of people, but there's a huge community out there that really need support, and this is what we want to do, and this what we want to achieve.

Can I just ask you, what's the link between Long Covid and mood? What's out there about it just now?

**ADA:** So that's definitely a lot of different relationships and links between, not only mood, but mental health in general with Long Covid. As you know, Long Covid, that really affect not only our mental, but physical side of things. So, let's say we feel fatigue. Sometimes we feel a bit, like, breathlessness. So, in terms of physical sensation, sometimes we feel dizziness, you know, we have poor concentration, poor memory sometimes...

In terms of mental health, it does contribute sometimes to our anxiety and depression. And because of, let's say, the pain, and let's say the memory loss as well, it does give us some of the panicky feeling sometimes, or maybe feeling a bit anxious, not knowing the uncertainties, not knowing what's going on with our body, really. So it does have an emotional impact on people who have Long Covid.

So I'll give you a few example here. So some of the ongoing symptoms, in terms of the emotional impact, could be: feeling anxious when struggling to catch your breath, when your heart's feeling it's racing, and when sometimes you just feel like "Oh, I can't remember stuff." Feel, like, a bit of brain fog there. You might feel a bit low in mood, poor sleep, and uncertainties as well, wondering if it ever will go away, or how long is it going to last? And a lot of worries - so I guess a lot of people will worry about, okay, when can I actually get back to work, get my life back, and to get rid of all the fatigue, get rid of the tiredness, and more worries about family and friends.

So, let's say when you have Long Covid, you might worry about: "Okay, how about my family and friends? Are they going to suffer for a long time? Am I going to suffer for a long time?"

And sometimes also, if we look at the medical model, in terms of medication - that might not always be helpful in a way, because you're not sure: is there any medication that might help with the emotional and physical impact of Long Covid? And if we look at the other side of things, so let's say if you're staying or treated in the hospital, you might have unwanted or unpleasant images or memories of your stay, having been quite a traumatic experience and offence. And you might have flashback about it, some nightmares, feeling a bit panicky about all the hospital reminders. So, it definitely affects, let's say, your sensory inputs.

So, you have a lot of sensory changes - and social problems as well. You might not be able to go out and socialize as much. And that definitely contributes to your low moods and contributes to your mental health, yeah.

**AMY:** Yeah, I think that's really key what you said that, Ada: that it's the chronic disease that's leading to the mood changes. I think probably some of our listeners will be quite familiar with having gone to see their GP, maybe earlier on in the pandemic or earlier on in this illness, and have been labelled with mental health illnesses - that the mental health was causing their long covid, rather than the long covid causing their mental health.

And I know that a lot of people, a lot of my peers who've had Long Covid, they've been to their GP who said: "Oh, you sound very anxious. If you weren't so anxious, you feel better."

Which is always really unhelpful kind of comments, I think, that people have been facing and found really challenging. And so, whenever I give talks about Long Covid or I talk to my colleagues about it, I'm always saying: "Of course, your life's been turned upside down!"

When I lost my job, my roof was leaking. My husband's salary was being halved because he had Long Covid. I had to find money to send the kids to nursery, because they were tiny and there was no one else to look after them. Of course I was anxious! Of course my mood was low! But it wasn't my mood and anxiety being low that caused me to be ill.

And I think that's just such an important distinction that we've got to make - that, you know, yes, mental health could impact on our physical health, but we have to be really wary when we're speaking to people with long covid that, yes, you're unwell, and that's making you feel sad and low and anxious - for all the reasons you just mentioned, Ada. Of course, if your heart's racing, you're feeling breathless, that's going to make you feel anxious, but it's just so important that we continue to remind healthcare professionals of that distinction.

And, yes, sometimes as a GP, if I have someone with chronic disease who has got low mood as a consequence, I will sometimes talk about - definitely talking therapy and will come on that - but also, there are sometimes medications that can be helpful if the mental health has spiralled out of control and we're not able to get on top of it.

So, I think, yeah, it's a really complex intertwined thing. But I think, you know, you really helpfully described how much it's the illness causing the mood rather than the other way around.

**ADA:** No, I totally agree. I think you also give a really good summary there as well. So sometimes, I guess, it's a lot of self-blaming there sometimes, because we're not sure what is happening, what's going on. Is it because of us? Is because of me? So, I think it's a definitely clear linkage in there.

And also knowing that this chronic illness actually causes the depression triggering all the anxiety, and there may be posttraumatic stress as well. So, it's quite important to notice that.

**AMY:** Yeah. And I think it's also important to highlight that posttraumatic stress isn't just in people who are hospitalised. That's something I often talk about when I'm giving talks about Long Covid: that a lot of people who got sick, particularly at the first wave, during the very beginning of the pandemic... You know, people were told to stay at home to protect the NHS. So a lot of us sat at home with really low oxygen saturations - where nowhere else in history would we have sat at home with oxygen saturations in our 80s, in otherwise fit and healthy people.

You know, I have a colleague who wrote goodbye letters to her children, she wasn't hospitalised. And I think it's really important to remember that PTSD impact that can have happened not just for hospitalised patients.

Scottish government did put out a lot of funding initially – or, not a *lot*, but they put out some funding for mental health support for people who had been hospitalised. But there was no mental health funding for those who hadn't been, although I know that's currently a work in progress.

Ada, what are you aware of - what organizations, or where can people go for support for their mental health?

**ADA:** Yes. So, in terms of support, there's actually quite a lot of support right now.

So let's say for the Chest, Heart & Stroke Scotland, they do have a peer support group right now, to support people who have long covid and just want to really talk about and share their experiences. And I actually went there one time, and I feel like it's a really supportive environment, and people are quite open to talk about their problems and their struggles. And I feel like even just being present there, feels very warm and very welcoming.

So, I feel like that is definitely something quite important: to have a good network, a peer support group.

And in terms of other support, so let's say the NHS, they do provide mental health support. They have psychological therapy support. So, let's say the PTSD theme, they might provide one to one or group sessions. So, for one to one, they might have counselling sessions and some person-centred approach sessions, or maybe some cognitive behavioural therapies as well.

So, for me particularly, I feel like - of course it depends on the symptom, it depends on your life stories - but CBT, or Cognitive Behavioural Therapy, would be really useful for Long Covid patients, because especially sometimes when they have, let's say a negative thoughts or chronic fatigue, and find it really hard to cope with, really hard to go back to their daily activities in their life... CBT focuses on challenging your behaviour and thoughts, basically. So, by challenging your negative thoughts, it affects your emotions and behaviour. So it helps you to sometimes... like, activate your behaviour as well, and to identify, okay, maybe I'm having a really negative core belief or negative thoughts about myself, that's why I'm feeling really, really bad. And then my behaviour would be like: I'm just going to disengage at home. Stay at home all day and not really going out.

So, you know, by identifying all these different aspects, it helps you to know yourself a bit more. And it helps you to go out there and try to reengage, really - to the socializing and to your friends, and really give you some coping strategies as well to cope with depression and anxiety, and the pain as well.

So, there's definitely a lot of different support there.

**AMY:** I think also, in most GP surgeries now in Scotland, there are a lot of them you can access direct mental health OT support within the practice. So you don't even need to make

an appointment with a GP; you can actually directly make an appointment with your local mental health support, to an occupational therapist that's based in the practice. GPs can also refer, as you say, to other therapies. And they can also, in more severe cases, refer to the community mental health teams.

Peer support, as you mentioned, Ada, is absolutely key in terms of, you know, making sure you are not alone in this and knowing what other people have found helpful.

And CBT, yes, can be helpful. I think it can be a bit of a controversial area when it comes to CBT and fatigue. I know that there is lots of different thoughts out there, so it's just to highlight that there are different schools of thought in that. And I think, you know, some will find it really helpful. And I personally had CBT for post-traumatic stress disorder as a consequence of losing my job through Long Covid and I found out that CBT amazing - but also because the therapist herself was phenomenally good and it was very emotionally centred.

But it's just that there is so much stuff out there. But yeah, if you're struggling to know where to look, the Advice Line can help signpost through Chest Heart and Stroke, and your GP and your GP website probably can help signpost, as well, where to go to.

**ADA:** Yes, I totally agree. And I think there's a lot of different platforms there for you to gain the support that you need. And again, I think it goes back to: there's no one specific mental health or psychological therapy that suits everyone. It's more about you and yourself, you know, what way suits you the most? What, what's 's your preference? Like, do you want to be more like directive? Do you want to be more like, maybe more about the empathic understanding. It's more about you, really?

Yes, so, I do agree.

**PAULA:** I'm just going to say there a Chest Heart and Stroke Scotland have a Long Covid peer support group running currently at the moment. It's virtual, and you had met with them. And I'm just wondering, what does that support look like for the group at the moment?

**ADA:** So, I've only went there once, but I do know that it's more about just chatting about, let's say, how Long Covid is and what you're struggling and feel like. Basically, feeling you're included in a society, in a community as well.

And Long Covid is a very, very hard journey. It could be, if you're isolated and alone. And what I like about this long covid group is also some, like, education. So sometimes they invite guests over to talk about things from a different perspective. So, let's say, they invited Amy last time when I was there. She's really amazing. So she talked about how the medical side of things affects Long Covid, and what we can really do more as the community, or what the government can do more as well.

So, I'm hopefully going to be one of the guests later on after New Year's. *[Ed. – This episode was initially recorded a few months ago!]* So I'll talk a bit more about the mental health side of things, and how that impacts Long Covid – and, to be honest, how self-help could help as well. So, what we can do as family or friends, or for ourselves, to cope with the Long Covid symptoms.

**AMY:** Yeah, I mean... the support group, I've been quite a few times. Sometimes just as a person living with Long Covid, just to, you know, share - and listen, of course.

But there also is a Facebook Group that is part of it. So, people who are on Facebook who are in the support group can also share stories in there, or have comments.

But you very helpfully led us on our next question, Ada, about self-management. You know, are there things that we can do when we're living with Long Covid that can help us to self-manage the mental health aspect side of it?

**ADA:** So, there's actually a lot of different self-help resources online. So even for like, let's say CBT that I mentioned before: they have a lot of self-help materials, just basically online materials for you to download it and look at, to really read through.

And even sometimes, even at home, when you feel like you're comfortable and maybe experiencing like chronic pain, fatigue, you don't really want to go out and meet people... just at home, using your laptop, you get access to a lot of different information.

But let's say if we have to talk about more practical stuff right now, one thing I would recommend is: avoid watching too much news on social media that makes you feel really anxious. One thing about Long Covid is, it's ongoing. And for COVID as well, it's not going away yet, you know? So sometimes watching all the news, and to catch up on the social media, may make you feel really stressed and really nervous. So, I would really say that, if you're feeling overwhelmed, maybe avoid watching too much news, and the social media as well.

And the other thing is maybe talking to friends and family about it, be open about it, because they are not you. They don't really know what is actually going on with your body and with your mental health as well. So, be open and speak about it. It's very important just to get the support.

And another thing is - it really depends on your physical ability - but maybe try to do some activities that you find enjoyable and relaxing. Not to push yourself too much, but do something that you feel like: "Okay, I might enjoy doing a walk today. I'm just going to go out for maybe 5 minutes, just to get some fresh air." So that could help, you know, just to have some goals for yourself and try to do it when you can.

And that leads to my next advice. Don't be too hard on yourself, when you feel like you have all these ambitious goals and all that. Tell yourself that it's okay to just relax sometimes,

focus on myself and know that, okay, this is my presence and now. So it's okay to just take things one at a time. And remind yourself that recovery just takes time, and focus on what you can control, instead of focusing on the uncertainties and unknowns.

**AMY:** I think that's so important. That was one of the hardest lessons I had to learn. You know, I was previously a typical – well, I still am! - Type-A personality, you know, used to just doing everything all the time, pushing myself, never stopped, never had a break, two young kids, working as a doctor all the hours... And then to completely flip that on its head, and be ill and not be able to do stuff.

I think particularly, like... because it's a condition where you have relapses: when you have relapses, not being completely catastrophic about it, and going, “Okay... Well, actually, I have felt worse in the past, but I did start to feel a bit better again. And it's okay now to have a day or a few days where I don't feel well, and I do nothing.”

Allowing myself my headspace to kind of come to terms with that was a really, really big journey, but such an important one, in terms of, you know, just knowing how to move forward and not constantly reflecting on the past and catastrophising and worrying about the what-ifs. And just saying, okay, today is a bad day, and that's fine to have a bad day, and it's just going to be a bad day, and tomorrow I will wake up and it'll be a new day.

That was a really difficult - difficult, but good, lesson to learn.

**ADA:** I love how you rephrase it. You know, it's about reflecting. It's about reflecting on our life, really, reflecting on how we approach things.

Because even, let's say, when I had COVID, and then I still feel quite fatigued sometimes. So, you know, when I look back to how I approached things before, I know that: okay, I'm always so ambitious, so fast-paced, and all that. But it's more about reflecting on that and knowing, okay, I'm going have to slow down a bit, focus on what I can do instead of what I can't do, and focusing on here and now, instead of uncertainties, the unknowns, and the daunting bits, you know?

So it's focusing on right now, on what you have. And I love how you rephrased it.

**PAULA:** That's so nicely put from both of you there.

When I meet people as well, I think it's so important that we have goals, ambition, drive, but it's really important to find peace with your here and now. Of course, it's important to move forward, and if we've hope, we move forward in a really beautiful way. However, to be okay with your here and now and do what you're doing, be kinder to yourself and just make peace with that - I think that's a really important place to be because it's a nicer head space than thinking “I'm not there. I'm not there. I'm not there”. And you're still kind of trying to catch up with yourself.



Just take a moment, and live in the here and now, and find things around you that can bring you joy and bring you hope. Yeah, that's been so interesting listening to you both there, just from the different perspectives.

That brings us to the next question that I'd like to ask. So: what can I do to support a relative or a friend who is living with long covid?

**AMY:** I guess maybe that's even easier for me, actually, to answer, having been someone who's lived with it. I think - and is this something that I'm hearing a lot from people in the various forums that I'm in, in the peer support group - I think now, down the line, people who've been living with this for more than two years, of which there are quite a number, some friends and family have fallen away. And that's a sad reality of what people are living with.

People don't understand. Relationships have fallen apart completely. People's spouses have left them because they don't understand. And I always said, like, as much as it was awful that both my husband and I were ill at the same time, I was kind of glad that we were, because we both got it.

So if one of us was having a really bad day, then actually, you could turn around and go: "okay, I know you're not faking it."

Because, ultimately, people don't understand it. They look at you, they see you're doing nothing, they see you're lying in bed, and they don't get it. They don't get why you can't get up. They don't get why you can't go and get dressed, why you can't have a shower, why you can't make the kids tea, why you can't put the kids to bed, why you can't go to work. And I think it's so important for people around us to understand that.

And so: what can you do?

Well, rather than saying "What can I do?", just *do* stuff. You know, bring someone their shopping if you can. Bring a cooked meal that literally just needs to go in the microwave, the oven - nothing that needs to be prepared. Go around to someone's house and say "I'm going to make your coffee, I'm going to tidy up your kitchen, and then I'm going to leave. I don't expect to have a conversation with you or chat to you for hours, because I know that you find that fatiguing." And it's still that checking in with people.

And, you know, I think it's sometimes saying, you know, "How are you?" and expecting them to go "I'm okay" - but you know, *how are you?* How are you coping? Are you sleeping? Are you managing? You know, I think sometimes just digging a little bit deeper - if you're ready to listen to that person. Because I think that's always the hardest thing. Because it's so *boring* being ill all the time, my God!

You know, the number of people that turn around and go, "how are you?" and you go: "Yeah, I'm still really breathless. I'm still really struggling."

But actually, knowing that they want to listen to that, I think is really important, because it's so easy to just go into your world that you then live in and you become so isolated - as you

mentioned, Ada, that isolation is so rampant in chronic disease. And knowing that someone's actually willing to listen to how it's *really* affecting you, how you *really* feel, is absolutely key.

So, I think: just giving people that time and space, but also being aware of their fatigue, and not questioning them. "Can, can I, can I just say for half an hour? Really, can't you... what do you mean, you can't...?" You know. A lot of people do get those kind of questions. So maybe then allowing people to explain why they can't manage longer is also really important.

But yeah, definitely... just stopping in, doing practical stuff. That is just so, so helpful.

And I was amazed when I got sick, the people who I didn't realize were my good friends came out of the woodwork. Like, even a mum from my nursery, who I hardly knew, our kids played together... She came, picked up my children, took them away for the day - the *entire* day - fed them dinner, and brought them back in their pyjamas, so they literally just had to go to bed. And I'd only ever spoken to her for a few minutes at the door. And I never got to return that favour. But wow! That just felt so amazingly helpful. She had three kids of her own and was a single mum, but she absolutely knew, I guess, what it was like to be struggling. And, you know, I would love to some point pay that forward.

**ADA:** Thank you so much for sharing that.

I think words have power, and words can act as a great act of kindness. I really think just saying "Are you really okay?"...

And, you know - as a stroke survivor, not someone living with Long Covid - something I found really unhelpful was people saying to me, "It could have been worse." And I just think that was really unhelpful, because for me that was my absolute worst, you know, my world came crashing down. So for me, in that moment, it was my worst. So I always respect other people's feelings, and when they're saying "I'm not okay", I would never say to someone "It could be worse". Because their feelings are so unique to them, and it's important to respect that as well and be kind.

And: "Are you *really* okay?" Again, that speaks volumes, because I think when you really emphasize "Are you really okay?", someone will then open up and find it's a really safe space to say, "I'm actually not okay. I am not feeling good about this." And that's a moment to have a conversation, which would be so helpful and supportive to someone - like you're saying there Amy, it was that parent from the nursery that made such an impact on you, which is so lovely.

But I just wanted to add that bit there. Thank you.

**AMY:** And I just want to reflect on one more thing, exactly what you just said. It's: when someone says "You look really well!", then follow it up with "and how how do you actually feel?"

Because it is that “you look really well” bit, isn't it? I think with all these invisible illnesses that we all have, that is the tough one. That “Oh, you look really well!” Yeah.

**PAULA:** It's important not to assume everything's on the surface. You know, our feelings run much deeper than that as well. Feelings are there.

**AMY:** Absolutely.

**ADA:** And just one thing to add in: to be sensitive, you know, about situations, about people, and empathetic understanding as well. So, understanding that situation, but also show empathy, show love and care, really.

But one thing about being a family and friends that stood out for me, is also taking care of their own mental health. Because being a carer - informal carer, especially - could be very, very hard, because you're 24/7 there, helping, supporting. So: remember to just take a step back. Some time to just rest and focus on yourself could be very important.

**PAULA:** Yeah.

**AMY:** Yeah. What a great conversation, guys. That was brilliant.

**PAULA:** Yeah, this was really interesting. Thank you so much for just everything we shared there today. It's been really helpful for me, really helpful for so many people out there. So yeah, thank you very much, both of you. Thank you, Amy and Ada.

**AMY:** Thank you.

**ADA:** Thank you.

**[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

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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.

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#### **ADDITIONAL CREDITS**

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

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