

# Episode 5 – Women's Health

## NOTES

### WHO'S HERE?

This episode features regular host Paula Leask (CHSS Community Coordinator).

The featured guest this week is Dr Amy Small, who you may recognise as our other regular host! Amy is a GP and medical consultant for Chest Heart and Stroke Scotland, and has been living with Long Covid since 2020.

### WHAT ARE WE TALKING ABOUT?

This episode deals with women's health, and how Long Covid can affect fertility, menses, and women's lifestyles. Statistically, Long Covid affects many more women than men; Dr Small outlines why this might be, and how women can experience symptoms differently to men. Key points include:

- Long Covid affects more women than men, in terms of numbers. This might be because women are more comfortable accessing care, but it does seem to be more absolute than that.
- COVID affects ACE2 receptors, which are on all our cells but particularly concentrated in the lungs and the ovaries. This high ovary concentration might partly explain why women are more often affected.
- Long Covid is also suspected to be an autoimmune condition, which women are more prone to than men.
- Long Covid symptoms can affect menstruation, and can often be similar to symptoms of the menopause or perimenopause.
- HRT or testosterone treatments might be helpful in some cases, especially around fatigue and brain fog, as well as menstrual disruption.
- It is important to consider women's health as part of the whole picture, and to be open and honest about "women's issues" in the public eye. Women's health doesn't only matter to women!

### FIND OUT MORE

- You can find support through the CHSS Advice Line: 0808 801 0899
- Amy mentions the Balance app and website in this episode. You can find the app and discover more at [their website](#).
- Amy also mentioned the [Dr Louise Newson Podcast](#). This women's health podcast covers a range of conditions and experiences – you might want to start with her episode on [Long Covid and changing hormones](#).

- [This article from Women's Health magazine](#) covers the broad issues of gender and Long Covid.

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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, Amy. Thank you very much for joining us today.

**AMY:** Hi, Paula. Good to be back.

**PAULA:** Thank you for your time. So, this conversation today is going to be about women's health and Long Covid - what that feels like, what that means and what information is out there, and how can people access it? You know, to get their best possible support for that recovery, for the here and now, and to help them move forward.

So we've looked at stats, we've looked at different data, and it's showing that more women in numbers than men are affected by Long Covid symptoms. Could you just share a little bit about that: what you know, and what you felt in yourself?

**AMY:** Yeah, I mean, it's something that we're seeing both in my role as a GP - I'm seeing a lot more women coming forward with Long Covid symptoms - and also in a lot of the patient forums, and even in our own Chest Heart and Stroke Scotland patient participation group, you know, we're seeing that women are disproportionately represented in these groups. And it was actually the patient participation group that had asked us to include this in our podcast, because actually it's something that... there's not so much written stuff out there. And it's something that I think we're still just sort of gathering data on initially.

It's really hard to know, you know, why women are more affected. You know, I guess one of the things is: is it just that women are coming more forward than men? You know, women are much more used to healthcare, right from young age, where we might go to the GP for contraception, through to our pregnancies, through to being the traditional caregivers to young children. Women naturally access healthcare far more than men do from a very, very young age.

So, we're more comfortable with that. We know how it works. We might have a maybe stronger relationship with our GP, even if we haven't had a chronic disease before, we probably will have come across them to a certain extent, for all the things I've just mentioned.

So: is it that women are presenting more, and actually there are lots and lots of men out there who've got it who just aren't coming forward for whatever reason? And that might be what we would have said initially, but I think there's more and more evidence now coming out to show that women *are* disproportionately affected. And that's a really good question as to why.

So, we're getting some data now coming through about the fact that Long Covid may be an autoimmune disease, for example. So, what that means is: your body essentially starts attacking its own cells. So it starts to malfunction in a way that, initially the body thinks: "Oh, there's an alert, there's COVID! I need to fight the COVID!" And then the body still thinks there's COVID there, so it's constantly fighting it and inadvertently attacking its own healthy cells. And that's what an autoimmune disease is.

So, is it because women generally are more predisposed to autoimmune disease? And we're not quite sure why that is. Some people think it's because we've got two X chromosomes - men have an X and a Y chromosome - and is it because we carry so much more genetic data in having those two X chromosomes, and therefore there's more areas in those X chromosomes for to go wrong?

There is also other evidence that covid affects our ACE2 receptors. Now, what are ACE2 receptors? This is something I have to keep going to look up, because it falls out of my head as quickly as it goes in! But, essentially, all of our cells have ACE2 receptors on them. And what we've learned is that COVID attacks those ACE2 receptors, and ACE2 receptors basically help our cells function normally. And we have loads of those ACE2 receptors in our lungs, which is why with COVID, predominantly initially we thought it was just a respiratory illness, but also we carry loads of those receptors in our ovaries.

So, as we have a lot of those receptors in our ovaries, you know, we are wondering: actually, is COVID directly attacking those bits of the body – ovaries included - which means that women are disproportionate being affected because they've got high numbers of those receptors on their ovaries?

So that's one of the big questions that hopefully, in time, research is going to start to unpick and help us to understand, you know, why women are, in numbers, seemingly more affected by Long Covid than men.

**PAULA:** That's a really great way of explaining it, thank you for that. And I think in years to come, actually, research is still going to be done, there's still so much learning in this. I mean, when a couple of years ago, we were in the midst of our pandemic, and it's now there, following after, that people are still feeling the symptoms. So Long Covid is very much present, why is it still present? And it's important to ask these questions and get the answers.

You were speaking about women and ovaries. So, I've heard from my number of friends and other people reading their stories, that periods can be affected. So, some women are saying their periods completely stop; some people are saying in their cycle has changed, which can

be quite alarming for people. Again, that's the uncertainty and how to manage that. And there's an emotional side, and that worry that's connected with that. Can you maybe just talk a bit more about that, Amy?

**AMY:** It's really interesting you say that, because I've had the same thing with friends who wouldn't necessarily class themselves as having Long Covid, but will tell me that their cycles have been, as you say, either completely disrupted and they've not had a period in months - which by definition *is* Long Covid, because it's any one symptom that lasts more than four weeks - or others, as you say, who've had disrupted cycles.

So, what we're seeing more and more now is that a lot of the symptoms of Long Covid also mimic perimenopause and menopause. So if we're talking about cycles, and we're talking about, you know, irregular periods... but also other things, like brain fog. And if you speak to anyone with Long Covid, they will tell you that brain fog is one of the most debilitating aspects of their Long Covid, along with the fatigue. And also, a lot of menopausal women, Long Covid aside, will tell you that brain fog's a real issue for them - that they're losing words, they are forgetting ingredients when they're baking... That's a classic one that I keep doing! They are, you know, burning, putting things in the oven, forgetting about them, you know.

And that's really, really distressing for people. And so, lots of Long Covid people are saying this, and lots of menopausal people have been saying, "well, I've been feeling like that for years with a menopause, you know, is it not just the same thing?"

And so, again, when we're looking at these ACE2 receptors and how your ovaries are affected, etcetera, etcetera... You know, actually, is COVID tipping non-menopausal women into perimenopause and tipping perimenopausal women into full blown menopause?

And this is something that's just really fascinating from a scientific perspective, you know, actually, what is going on here? And can we unpick a lot of this - for women particularly, obviously - with Long Covid, through looking at perimenopause and menopause and how that's affecting them?

So right from the younger women who are being affected, and I think we've got to remember that Long Covid stats show us, ONS stats show us, that 85% of people affected by Long Covid are of working age. And so, a huge percentage of those women are going to be women who are still fertile, for want of a better word: women who are still having, or should be having, regular cycles.

So actually, you know, this is a huge percentage of people that are affected. And that's something where the research is going to have to go, to see, you know, what is going on here and why are women being more affected?

**PAULA:** And I think that's why it's so important in a scientific world to be listening to the people affected, because there's all that science involved, but actually listening and saying,

how is this affecting you? What is it doing to you? And the whole range of symptoms, and bringing it together. And actually asking people to come forward, share your feedback, be part of research trials, is where all that data is going to be gathered - is going to help the masses that are living with long covid.

If someone's feeling like this, someone's period has stopped, they're going through different things, but their cycles changed. Emotionally feel distressed, but their body, like I said, is going on... things are feeling a bit different. Where could someone get help for that? Where's the best place to seek advice? Where's the first port of call?

**AMY:** So I think, being a GP, I would say the first port of call for this would be your GP.

So things that can be really helpful is: if you start to keep track of your cycles, keep track of your symptoms. There's a brilliant app called the Balance App, which has been created by Dr Louise Newson, who's a menopause expert, and she also has an interest in Long Covid and menopause. And she has her own really good podcast that's worth a listen and some really good resources on her website.

But the Balance App can be really useful for women to download, to track their symptoms and help them to work out what's going on. Because quite often, if you're feeling a bit brain foggy and you're not feeling great, it's actually difficult to tease it all apart and work out, you know, what part of my body isn't quite working well? And you know, actually sometimes being able to name those things, track those things, see: is there a pattern? If you are having periods, is there a pattern to your symptoms? Does actually all your brain fog get worse just around the time of your period or just before it, as your hormone levels fluctuate?

So again, that can be also really helpful for you to take that information to your GP, you know, writing down all your symptoms, writing down everything that's going on. Because when you get there you've got that sort of pressurized ten minutes, "Aah! got to speak to the GP and get it all out there!" - often a lot of these things fall out of your head. And so I think being prepared for your consultation can be really helpful.

And I think also raising a question with a GP, you know: would HRT be helpful for me and even sometimes, would testosterone be helpful? These are treatments that we're seeing that can be quite helpful for people, obviously, with menopausal symptoms. But now, should we be pushing a bit further, should we be looking to try some of these relatively safe treatments with women who have Long Covid, who are experiencing the typical menopause-type symptoms with their Long Covid?

I think people are investing an awful lot of money in rather experimental stuff - plasmapheresis, hyperbaric oxygen treatment, all these things that can be potentially quite risky. And we know that on the whole, hormones are pretty safe, and that increasing evidence out there shows us that hormonal treatment is pretty safe.

So, you know, hearing stories of women who have found the brain fog really tricky and they've gone on to HRT and they've replaced the oestrogen and stuff, but actually they're

still not quite there... Some of those women have then gone to have a look at their testosterone levels and have shown that the testosterone levels are low, and then have added testosterone in on top of that. And then, actually, their quality of life and mood and other things like libido that we would expect to be improved with testosterone have got better. So, I think, you know, there's a lot out there that we still don't know, but I think we can afford to look a bit more into this and keep open minds.

I think if you go to your GP and you're not sure where they sit with all of this, sometimes it can be worth looking at a GP practice website. Quite often it will tell you what GPs' interests are. If there's anyone on there that admits to having an interest in women's health, then it might be worth actually approaching that with that particular GP, who might have been looking at this in a bit more detail than others who have other interests in medicine.

And then there's also lots of resources on the Balance website. And some people, of course, may choose to go privately to seek other help where that's appropriate.

But I certainly think as a clinician now, it's something that I'm a lot more open minded to, and I certainly will explore this more with my patients as they come to me. And I would hope my colleagues would do the same.

**PAULA:** That's really helpful, hearing that. I think, as well, when you're saying to be prepared for your doctor's appointment: have a journal, keep track of your symptoms. And my friend actually has an app in her phone, where it tells her she's going to get her period, it's due in a few days, so it'll come up and go ping! and she's like, "Oh, a few days' time."

So I think actually, when you're keeping track of things, for example, you could say: "Okay, but I'm starting to feel this, this is... it's coming up for that time." And then it's relatable. Write it down, take the information, because we've all been to a GP appointment where we have all these things we want to say and tell, and it's not till we leave the door that we think, "Oh my goodness, this is what I wanted to bring up!"

So, being prepared for your appointment, writing things down: what do you want to say? And your GP probably - like you're saying, you're the GP as well, you know these things, so you're the person to listen to! - you're going to say: "What have you noticed about your symptoms? How often are they happening? When are they happening? When are you feeling these things?"

I think if people come armed for that information, the conversation and communication will happen right there and then, and that support process will happen much quicker. So, thank you for that. It's been really helpful listening to that.

**AMY:** Pleasure. Yeah. I mean, it's such a difficult mix of symptoms and stuff that's going on. And I think also, I mean... We were chatting, you and I, before the podcast was recording about how, you know, maybe it's something that people haven't always been comfortable talking about publicly? And I think generally people are better, I think organisations are

getting better about, you know, menopause policies. You're seeing a lot more about it being discussed at government level.

You know, in Scotland, now that the Scottish government released the Women's Health Plan back in September 2021, you know, looking at how we need to really look at women's health and really look at differences and see where women are more affected. And just reading through that health plan made me realize like, you know... On average, it takes eight years to diagnose a woman with endometriosis. And the level of funding that's gone into that has been pitiful. And the funding for a lot of conditions that affect only men has been much, much higher. And we do still live in a patriarchal society.

And I think it is changing, but I think it's not going to change unless we keep banging that drum and keep standing up and saying: "Look, this is really affecting us, to the point where we're not able to work, you know." And again, I think that's the thing about Long Covid, and when I talked about the fact that 85% of people with it are working age... People are losing their livelihoods because they can't work!

And actually, this is where: you know, actually, do we try a bit of HRT? Do we try a bit of testosterone - in those where it's appropriate, of course, you know, and that has to be a discussion with an appropriate clinician? But if that is the difference between someone not being able to work because their brain fog is so awful and other things are going on with their bodies, and them being able to make a living and contribute to society, I mean: wow, what a difference!

But I think we're still, sadly, a long way away from these sorts of conditions being high priority by policymakers, by the people that hold the purse strings. And I think that's why all of this is going to take a long, long time to come out.

But I know that, you know, even within our own organisation, Chest Heart and Stroke Scotland, you know, we have a women's health group, we're looking actively about how women's health is affected, in particular, by all the conditions that we manage. And I'm hoping that, you know, all the things that we're doing at various different levels will trickle down, you know, and eventually women will get the health and the care that they deserve, alongside every other human being on the planet.

**PAULA:** Absolutely. I totally echo what you're saying. I think women's health being highlighted is at the forefront of people's minds. And I think what's important to remember is: thinking of women's health. It's not just for women to be aware of. It's for men, you know, everybody around. It's not just relevant to women.

**AMY:** Exactly!

**PAULA:** It's relevant to every other human being. For example, men's health, it's not just relevant to me. It's relevant to everybody around, you know, because it's important when we have understanding, that drive of compassion levels up, that empathy levels up. And when we're talking about menopause cafes and things in our organization, to start to see that happen in these cafes, these support groups, it's incredibly important, because it's giving people a safe space.

For years, women have not been able to voice their feelings. They're thinking: "Oh, I can't say this to my bosses. Is that okay? You know, I'm not feeling good. Can I take time off because of that?" Yes, you can. You absolutely can.

And it's important that people know that organisations have an awareness. What's happening now is people trying to implement change, policy, and have that compassion there for everyone within their own organisation. That's a way of moving forward. But as you say, there's so much work still to be done. We still need to bang that drum as loud as we can, but we're moving forward. And I think that could only be a good thing to change.

We're all human beings. We're all just trying to get by. We're all doing the best that we can. And I think it's just important to remember that we're looking out for each other. People are everything.

I always think, you know, we always have our own selves. We have this amazing inner strength, but actually, when you're supported by others, it's even stronger.

**AMY:** Yeah.

**PAULA:** And that, that's so important. So, what you've shared today has been so helpful.

And I think, you know, ending our podcast, just to put it out there to everybody listening – whether it's themselves, a friend, a family member - give us feedback, because we want to create this, we're doing this for you. It's so important we're aware of what's going on, how we, as an organization can create positive changes and give a sense of space and purpose to people. Because it's so important with people living with long-term health conditions that they get the support, but it's about moving on.

For example, my job of a community support coordinator is about people living with their long-term health conditions. But up until that point, it's all been quite medical, until the appointment. But then, there's a point where people have to come in front of their condition to move forward with their life, still living with it, but actually making peace with who they are and living with the condition, but moving forward.

So, it's been so good to speak to you - could go on for ages! It's just so interesting, what you've got to say, and you share it so well. And I think what's lovely is that you're a GP, so you have all this knowledge and that... actually some of the lived experience, and you have a

huge amount of compassion. And I think even without having Long Covid, it's absolutely there in abundance with you, and what your mission is in your life: to help others live their best possible life. Thank you so much.

**AMY:** Thank you for having me on today. It's been brilliant.

**PAULA:** 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 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](mailto: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.

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## 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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