Episode 3 – Breathlessness

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 Frances Tait. Frances is the Physical Activity Coordinator for Chest Heart & Stroke Scotland and works with people from a range of backgrounds and experiences to help them get back to activity. This includes people with Long Covid and other breathing issues.

WHAT ARE WE TALKING ABOUT?

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

- Breathlessness can mean rapid, shallow breathing, or a more general difficulty breathing. It can cause chest pain, fatigue, and anxiety.
- Pace yourself. "Stop, rest, recover, redo" should be the mantra.
- Warning signs you should consider talking to a doctor about include: swelling and oedema, breathlessness even when you're not exerting yourself, or a change in your symptoms.
- You can still exercise with breathlessness, but you should be careful. "Functional fitness" – day to day physical tasks – is a key part of recovery.
- Medical professionals can benefit from training on Long Covid and related conditions, and need to understand things like post-exertional malaise (fatigue after exercise). This is an ongoing issue, but we can all push for the NHS and other organisations to focus on it.
- "You can't pour from an empty cup". Care for yourself before you care for others.

FIND OUT MORE

- You can find support through the CHSS Advice Line: 0808 801 0899
- CHSS has booklets available about many topics, including Long Covid Breathlessness and Exercising Safely With Long Covid, which you can download through the links or order online via our website. There is also a page on Breathlessness on our website.
- This video on breathlessness, and others in the series by University College London Hospitals, may help you to find breathing techniques to support your breathing.
- Frances mentions PoTS (postural tachycardia syndrome) in this episode. To find out more, you can read CHSS' factsheet on PoTS, or visit specialist charities like PoTS UK.

- The UK-wide charity Asthma + Lung UK (formerly British Lung Foundation and Asthma UK) has a wide range of support and information available for people struggling with breathing problems.

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. Hi, Amy.

AMY: Hi.

PAULA: Our podcast today is around breathlessness. And here to talk to us is the wonderful Frances Tait, who is our physical activity specialist. Welcome Frances.

FRANCES: Thank you, Paula.

PAULA: Okay, so Frances, could you just explain to us what breathlessness is?

FRANCES: Yeah. Breathlessness, in its medical term, is *Dyspnoea.* For anyone experiencing breathlessness, it's normally an unpleasant feeling of either a rapid breathing or a difficulty breathing. For anyone for long covid in particular, this could be really quite frightening. Some of the people I have supported have described a feeling of anxiety around, where is the next breath coming from? So, it's really important people can learn how to manage their breathlessness and to be in control of that breathlessness.

It can sometimes be associated with chest pain or, you know, tightness around the chest, or a really rapid heart rate, rapid breathing, and can be associated with anxiety as well. So it can have an impact on emotional and psychological health as well.

AMY: I mean, I think living with Long Covid, I can certainly identify with a lot of what you've just discussed. You know, something I - certainly in the early days - really, really struggled with.

What can you tell people living with Long Covid about how to manage it? What can they do to help themselves?

FRANCES: I think one of the most important things is pacing. We've all heard it, we'll continue to say it. It's so important that people living with Long Covid will find their own coping mechanisms and understand that it's okay sometimes to get a little bit breathless. The heart and lungs are going to work when they move; they need to get muscles the oxygen that they need. But it's to understand what is a safe level of breathlessness, and it will be different for everybody. Everybody's got different coping mechanisms.

But it's also about building confidence in... It's okay to get a little bit breathless. Pacing is the key: stop, rest, recover, redo. And that's very easy for someone like me to say it, but it is really important that people can learn their own limitations, be understanding of their own limitations, and work around that.

The Borg scale - or the RPE scale, the Rate of Perceived Exertion - is so important for anyone living with breathing difficulties, and particularly those living with ongoing Long Covid symptoms as well. I've heard many of the people I work with, even in the last six months, say they're so grateful for the understanding of the rate of perceived exertion, because it's really given them some control over the breathlessness and knowing if it's a specific job they're going to do at home - changing the duvet, for one, is a big no-no for many people. It uses up so much energy, so much oxygen, and it is exhausting.

Some people struggle to ask for help, which is another thing, and it's understandable. If people are able to offer help, that's maybe a little bit better, than someone who maybe struggles to ask for help with some tasks at home.

So being in control of your own breathing, knowing what's going to make your breathing more exacerbated, and to try and either avoid that, or to do smaller chunks. You know, do it in smaller bits. It may take a little bit longer, but there won't be the same exhaustion afterwards.

Something simple like having a shower - we know that those living with Long Covid that's a huge task, and it can send some people to the bed for the rest of the day. So, they've made a big effort, they've got up, got dressed, had a shower, and hoped to make breakfast and then just being exhausted.

So again, it's looking at ways to break that down. Perhaps they wouldn't need to have a shower, perhaps they could just wash their face and do their teeth. Maybe have a little bit of breakfast. And it is different for everyone.

It's having those conversations, and just making sure that people know their limitations and not to overdo it. Because it's not always "I'm able to do something". That's one thing, but it's how does my body respond physiologically afterwards? And it can be extremely exhausting for many people. So, yeah, know your own limitations.

Working with that Borg scale, or that rate of perceived exertion: it's a zero to ten scale. It's a simple scale where, zero, you're sitting at rest and you're breathing comfortably. Anyone who doesn't have breathing difficulties such as COPD, Covid, Long Covid - they could perhaps go up to a seven or an eight on that zero to ten scale if they're doing something – changing the duvet or something else that might use that energy.

But for someone with Long Covid, we really do try and encourage to stick with that three, four. If you're getting towards a four or five, that's the time to stop, not get to the seven, to the eight - not to push through it. Like many people think it's the right thing to do. It's the very opposite of pushing through. It's pacing. It's so important.

AMY: There's a big part of acceptance there, isn't it? I think that's the thing that's so hard. Accepting your new level of disability which may be, hopefully, temporary.

That's something I learned through the various forums I was on: that, actually, you could get a shower stool. I hadn't really heard much about shower stools, and it was something I get in my head associated it with people with physical disabilities?

FRANCES: Yeah.

AMY: Maybe not a younger person with breathing disability. So yeah, as you say, having a shower is really difficult.

And it's great to have a medical reason not to change the bedsheets, because I've always hated doing that! *[Laughter]* So now I can just say, well, my long covid stops me from doing that.

When should people worry? When, when, when should they be calling the doctor again?

FRANCES: Just in my experience working with people with breathing difficulties and limitations, there's certainly a couple of things to look out for.

One would be if they were feeling more breathless at rest, is a big red flag not to be ignored. Especially if this is associated with swollen ankles. You know, if the ankles are swollen… if you touch the side of the ankle, take your finger away, the blood circulation should return quite quickly. But if the ankles are swollen and it's taking longer than 4 seconds, and the ankles swelling is a problem associated with the breathlessness, then that's definitely a sign to be contacting GP.

If your breathlessness is exacerbated more when you are doing something of a physical nature, as well. So again, that's a change in the rhythm or the pattern of your breathlessness. These are the kind of main reasons I would refer any of my patients, service users, back to the GP healthcare professional.

And obviously, ongoing screening is so important. It's so important that we're verbally checking in with people before they do any physical activity, during it, and certainly after it as well, because we need to watch for the post exercise fatigue and keep a wee eye on that, so we know what baseline is for individuals. And again, that would change, on a daily basis sometimes. So yeah, they're the things to look out for, I would say, to certainly speak your GP about or your other healthcare professional.

PAULA: You mentioned physical activity there, Frances. Can people still exercise? And what advice can you give to people? Because people can anxiety around that, be quite frightened, but is it still important to move with what you have on a daily basis? But then again, not put too much pressure on yourself?

FRANCES: Yeah, that's absolutely correct, Paula. It is so important that we all move. And physical activity is a preferred wording to exercise, in my book. Movement matters, movement is the key.

So, the answer to the question is yes it is - provided you don't have this increased breathlessness at rest, or the ankle swelling, anything that your GP or other healthcare professional would need an intervention with. It's so important that they have clinical clearance to be physically active or moving.

And again, a lot of the focus with many people living with long covid is functional fitness. You know, it's getting off your chair on your own. It's managing to get your leg over to get into wherever your shower unit is. It's things that we maybe take for granted on a daily basis that uses up a lot of energy.

So, yes, it is safe to focus on still building muscle, you know, building the strength of the bones. Posture is key. Posture is so important - as we all straighten up! - because posture is one that is very obvious in anyone with breathing difficulties. They have this kind of defence mechanism where we round the shoulders, we curve everything forward. And in doing so, it's almost closing the doors of the lungs. Whereas if we sit up tall and straight and you open up the chest, it's opening the doors up.

So, yeah, specific functional movement is absolutely fine, as long as there are no contraindications.

PAULA: Okay. You mentioned the word functional fitness there, Frances. Could you just tell us a little bit more about what that means?

FRANCES: Yeah. Functional fitness is what we use in a daily basis to move around - whether that be moving around at home, walking to your local shops, doing any DIY in the garden. Again, movement is the key. So, functional means we use on a daily basis.

And a very good example of a functional exercise is a sit to stand exercise. There is a way to do it correctly, so that we use the right muscles. I always find, when I work with a new service user, when we talk about the benefits of getting off a chair safely using the right muscles - and more importantly, safely sitting back on that chair - it always raises an eyebrow. Always raises an eyebrow: “I have been standing up and sitting down for years. Surely I’ve not been doing it wrong!”

And it’s not about doing it wrong, but it’s about making it functional. You know, it's pressing your feet into the ground before you prepare to lift off. It's using your muscles and your thighs and your glutes and your hip flexors, and standing up tall. It’s using your breath, your own rhythm of breathing. Normally we would say, take a breath in to prepare, take a breath out as you stand up off your chair. That's not the same for anyone with breathing difficulties. So again, they would manage their own breathing in that way, as long as they’re not holding their breath.

So, yeah, functional is something we use in every day. You know, reaching up to cupboards, wanting to remain as independent and mobile as we can, no matter what age we are. And obviously there’s people have worked with with Long Covid, and they've wanted to return to their spin bike, they've wanted to get into the gym, return to a body combat class again.

Again, pacing’s the key. It is doable for some people, of course it is. But it is that constant screening: how my body’s responding, how’s my breathing? You know, and it’s little bits at a time, small steps at a time.

AMY: Thank you.

I mean, I think I look back and the idea of exercising early on in my illness was just horrifying, and I never could see how I get back to it. But bit by bit, over the last couple of years, I've managed to build it up. And pacing, as you say, is absolutely key.

Initially, I used heart rate monitors to see if I could monitor my heart rate to make sure it didn't get too high, because then I wouldn't get too breathless, and I would manage to recover more quickly. And as time went on, and I managed to kind of get over that hump of deconditioning - because that's always the really difficult one, isn't it? I managed to get back. And I feel very fortunate now that I can do a half an hour body combat class or things, which just feels amazing. And it feels amazing. And it feels like such a huge achievement.

I think I took my body for granted so much before I was ill. A big part of it through the recovery is focusing on what you can do, not what you can't do. You're trying to be in a kind of positive mindset, which isn't easy, but really trying to focus on what you can do. And then now being so grateful for what my body can do. And, yes, I’ll have days where I can’t do it. But then I just think about, well, think about what bits you have managed to do over the last few months - and just trying to remain as positive as possible, because that I think carries you a long way forward.

FRANCES: It's so lovely to hear that, Amy, you're absolutely right. And it is the focus on what you can do, not what you used to do, or even what you would like to do. It is very much in the moment. What are you able to do today? How does it feel today? And it's those small steps.

As you say, Paula, a lot of people will have a lot of anxiety around: am I safe to do that? Is it okay to do that? Everyone should listen to their own body. Know your limitations. Just avoid the boom and bust. There's another terminology we're hearing a lot as well, the boom and bust.

And it's so typical because you have this good day. There's this energy there and you think about, what's all the things I need to do and I have not done. Let me go through that list. And then before you know it, you're completely bust and you've lost two or three days. So again, it's the pacing, it's avoiding the boom and bust.

But, Amy, it's so lovely to hear. And you mentioned the heart rate there as well. And that's why I like to use the Borg scale, the rate of perceived exertion, because again, it gives you a really accurate reading of where you are in terms of your oxygen level sometimes, your heart rate, your pulse. But for many people who can't use these devices or don't have access to them, this zero to ten scale - I honestly am so pleased to hear how it's helping so many people. It's a simple zero to ten number, and it makes a lot of sense. So, it's really good to monitor that.

Again, it's that self-management, isn't it? Managing those symptoms and working towards taking those small steps and hopefully being able to re-enjoy doing activities you did before long covid, maybe just in a different way.

But, yeah, it's little steps, isn't it?

PAULA: I think that's what's really important to remember, is people remember who they are, and what they bring into their life, into other people's lives. I think what's really important, like you're saying, is they still are who they are. They just might be doing things a little bit differently, and that's okay, and be okay with that because everybody else is. And I think that is really important to remember.

FRANCES: I'm really glad to hear that, because I think we need to have conversations. People need to be able to feel free to talk about the difficulties they're having

There's a big element around emotional, psychological health as well. And a lot of people that I support will always say, "but, you know, but what about my daughter? What about my son? What about my husband? Everybody needs me" - but you need you more than anybody else does.

There's another expression: you can't pour from an empty cup. That's so true. You know, it's so important to look out for ourselves, and just try and find ways that can help us to cope with any anxiety - whether it’s sitting still for a minute, doing a little bit guided meditation, it’s different for everyone, isn't it?

But yeah, there's a big element on the psychological and emotional wellbeing also, from any life changing diagnosis. And like you said before, Amy, it’s that acceptance, isn't it? It’s that transition of accepting things are a bit different. And what can I do with this now? How can I move forward?

You know, Chest Heart and Stroke Scotland are here to support as many people as we can. We get new sessions coming up as well to support people living with Long Covid, so anyone who wants to get in touch with that… Looking forward to meeting more people, supporting more people, to know what's out there at the right time and the right level of intervention.

You know, we’re all still learning about the side effects and the long-term conditions for anyone living with long covid. I think it's really important as specialist instructors that we receive up to date training, so that we are keeping people safe for coming to any session that we deliver. It’s all very new and we’re learning as we go along. I think there's a confidence in instructors to be able to deliver the correct level of physical activity intervention based on what we know, and to move forward with that knowledge as well.

And one of the most important things, as I've said, is screening. It's so important that people, individuals, are being screened for their breathlessness, for their fatigue levels, before they start any physical activity, certainly during it, and afterwards as well. And that training would be really helpful, and add to any skill set of a special instructor already. We got cardiac rehab training. We got stroke rehab training. Cancer rehab training is a big plus now, which is great, it’s so good to see changes in the field of cancer rehabilitation as well. And I think it's really important that there's some form of training to specialist instructors as we move forward and support more people living with Long Covid.

AMY: I think it's really important you say that, Frances, because I think even the medical professionals need to be much better about screening for post-exertional malaise – i.e., feeling unwell after having exerted oneself. Because that's something that we didn't get taught at med school. It's something that doesn’t come across our knowledge base a lot of the time.

And I think that's where, you know, you hear these words like deconditioning, which just make my bones shudder, when you're early on in an illness and you're unwell, you know, you can't even go there on the deconditioning when you are just so unwell, anyway. And I think, you know, you see that so much in the Long Covid forums, where people have been told: just push through it, just exercise, you’re deconditioned.

And that's where, you know, health professionals, as you say, exercise experts, everyone needs to understand the screening process for post-exertional malaise, needs to understand how that affects people and how it can make them so much worse.

This is something that people with ME and Chronic Fatigue Syndrome have been living with for decades, but sadly, that hasn't gone out there yet. So, I'm really hoping that through Long Covid, this isn't just going to improve people living with Long Covid, but vast numbers of people living with chronic disease, you know. And if we can all learn about this, then so much more for the better. You know.

FRANCES: I couldn't agree more with that, Amy, and you've probably heard me say this before. I've been saying it for a long, long time, and I will continue to say it for a very long time if I need to.

Healthcare professionals, exercise professionals, we could come together in a beautiful relationship to support as many patients as possible. It's different skill sets, but it's a holistic approach. And again, it's that education, making people aware of how it may affect them, how to deal with that. And PoTS in particular, that, you know, drop of the heart rate, dysregulation of the blood pressure, after standing, for instance… It's being able to communicate that to those living with Long Covid, so they are empowered and understand what is physiologically happening to the body and how can they best manage that.

And I really do believe, in a perfect world, healthcare professionals and fitness professionals, could just work beautifully together. I really, really do. And that is for the benefit of the patient. And we all need to learn. We all need to continue to grow. I think that's important as well, and the more people we can support living with long term conditions, the better.

PAULA: Thank you so much. You can't pour from an empty cup - I think that just speaks to us all. So that's a big statement there about wellbeing and self-care and how important that is.

So, thank you very much. We really appreciate your time and your good energy today. Frances, your advice has been motivating and will be super helpful to so many people. So, thank you so much.

AMY: Thank you very much.

FRANCES: You're very welcome, 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.** 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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