

darts



Case Study

Caroline's Breathe & Connect Story

Breathe & Connect – Caroline’s Story

What is Breathe & Connect?

Breathe & Connect is a programme using singing, breathing, relaxation and gentle movement. It is for people who have Long Covid and other long term breathing-related or health issues. darts developed the approach in 2022 during an intense three-month period funded through Doncaster Council and the Additional Restrictions Grant from South Yorkshire Mayoral Authority.

This period of development enabled darts artists and freelance artists to work collaboratively with each other, and with health professionals, to understand the health and social impacts of Long Covid. The artists worked together, and with groups of Doncaster adults, to test and refine their approach, using their experience of delivering years of singing and dance programmes but adapting the model to respond to the specific needs of Long Covid.

Caroline’s story – the beginning

Caroline (not her real name) told us that she caught Covid-19 on Mother’s Day – ‘...which was a lovely present!’. ‘After about three weeks, she began to feel breathless. As Caroline already has ME, the fatigue she was feeling didn’t feel any different, but after a few weeks she didn’t feel ready to go back to work, so went to see her GP. The nurse practitioner told Caroline to take it slowly and signed her off work for a month.

“It just didn’t get better, so it’s been a really long and lonely process because nobody’s got answers. No one can say, ‘well give it a few months’, so I’ve been in and out of work and meetings with HR and having to go and say, ‘I just can’t do it yet’. That’s been really hard because at a time when you just want the world to leave you alone, you have to kind of engage with everything and have these meetings and go along and say, ‘I still can’t come back to work, I still can’t come to work’. Then you have to deal with the, ‘Well you need to go on half pay’ or ‘You’re going to lose your job’ and all those kinds of things.”

The impact of Long Covid on work and finances

After eight and a half months, Caroline’s employers offered three options. To come back full time for three months, but be off sick and on full pay, to carry on with half pay, or choose to leave. However, they also said that if she chose to stay, they would have to terminate Caroline’s contract as she wasn’t doing her job. Eventually, Caroline made the decision not to go back to work, which felt like a relief initially.

“Foolishly I thought this would take some of the pressure off, but it doesn’t go as you then go onto benefits and masses of hoops to jump through. It’s an absolute nightmare and it knocks you around something chronic.”

For Caroline, this situation became hugely stressful. For a decade, the family had relied on her income to support them and now, on benefits and having to understand the system, they lose a significant amount of money every month.

“You think, how are we going to cope with the kids? It’s been hugely, hugely stressful. Really It’s a time when you just want to curl up and switch the world off because the world is so hard to deal with. Just getting out of bed in the morning is really hard work.”

This stress was on top of the health impacts and fatigue associated with having both ME and Long Covid. After getting up and getting the kids to school, Caroline would have to go back to bed, before getting up again to go and collect them. Throughout this time, Caroline had been in touch with her GP, but they had told her that because she has Long Covid, she didn’t need to speak to a doctor. She was left feeling that she had lots of symptoms that she didn’t understand, but nothing that she could do about it.

Eventually, Caroline received a referral from the Long Covid Clinic, saying, ‘We’ve been trying since July to get your GP to send through an x-ray to get you referred.’ Caroline had no idea that this had been requested or delayed.

“It really does feel like you’ve just been dumped and you’re left to deal with all these symptoms that people don’t understand. I feel like I look ok, but actually I’m not ok. People don’t understand why you’re saying, ‘I can’t do this.’...I see the piles and piles of clothes. I see the mess on the floor. There are four loads of laundry to put away. All those kinds of everyday things that normally you’d take in your stride, and you sit there thinking, ‘I really need to do that’, but I can’t do it because I’ve had to cope with two meltdowns today.”

Symptoms of Long Covid

As well as immense fatigue, Caroline experiences many other symptoms associated with Long Covid – not least the anxiety and depression caused by the situation she has found herself in, and the impact on her and her family. She has been prescribed anti-depressants, has done the Cognitive Behavioural Therapy and anxiety management courses, but is still struggling day to day. Being out of work, and unable to find the energy to meet friends and family, means a huge sense of isolation.

“So you don’t see anyone, you don’t pass the day with anyone, you don’t have any social chit chat, you don’t connect with anybody because it’s an alien world for me. You get weird and wonderful things at random times, so you can be feeling ok and then freezing cold and boiling hot and you think why? You walk anywhere and you get breathless. And the anxiety and depression is really hard to try and manage.”

Finding Breathe & Connect

Following the advice of friends and family that, ‘You need to do something for you’, Caroline had looked around for something that would fit into her day, and with her energy levels. She found that most activity was in the evening, so she couldn’t get there because of the children, the daytime activity tended to be for older people, and anything that looked perfect seemed to be 40 miles away, which wasn’t at all practical.

Through the Long Covid Clinic referral, Caroline was able to access a six-week course run by RDaSH (Rotherham, Doncaster and South Humber NHS Foundation Trust). darts artists delivered some activities during one of the sessions, and Caroline found out more information about Breathe & Connect.

“That’s why the group [Breathe and Connect] was really important to me. It was something that was booked so I knew I had to schedule the energy and schedule the time for it. It wasn’t a come if you feel like it, it was really important to me...The Breathe and Connect group was absolutely fantastic - I can really engage with that.”

Caroline agreed to try four weeks of Breathe & Connect sessions at The Point – darts’ home in central Doncaster. She found the pace and approach hugely beneficial and really valued the time spent in the sessions.

“What coming to your group has really clarified for me is actually having a place where I can just be. I don’t have to have responsibilities. I don’t have to remember things. I don’t have pressure to do things or perform in a certain way. I need a space where I can drop the ‘ought to’s’ and the ‘have to’s’ and the ‘should have’s’. For this hour I am just here. I am just me. I don’t have to produce anything. I don’t have to tick any boxes. It’s just a space where I can be. I’ve felt that really powerfully this week [at Breathe & Connect] when we did the soundscape – I totally lost myself in that. I’ve not felt that peaceful in years.”

Following the sessions, Caroline told us that she felt inspired and able to book onto a weekend music course as a direct result of participating.