Long Covid Case Study

I moved my established rehabilitation, women's health business on-line just before lockdown, not because I was at risk from Covid but some of my clients were. I was fit and healthy, strong, and able at the start of 2020. I managed to continue teaching simple Pilates on-line at the start of my illness - I'd do it with the help of my husband – he'd help me downstairs and set up the computer, but I'd crash out afterwards. I don't know how I did it – it must have been on adrenalin and the residual strength I had from before Covid – I can't do that now – and my studio has not opened again.

I started to feel unwell at the start of the pandemic in March 2020. I didn't realise it was Covid at first - it was before we knew and understand much about Covid-19, and before testing. I started to feel ill with a scratchy throat, but then I got worse so I went into isolation in the bedroom at home so I didn't infect my daughter and husband. I wasn't hospitalised but I think I might have been if it had been later in the pandemic. I had a feeling of a tight hat on my head, like a vice, a temperature, debilitating fatigue – I couldn't stay awake. I had a feeling of breathlessness; a bit of a cough and I was worried about it getting worse; on the news I could see ambulances queuing up outside hospitals. Like others we didn't have any information, luckily, we'd bought in a supply of medicines, and a pulse oximeter because of my background in health. 111 told us that as I was breathing I didn't' need help, my husband's a first aider and did observations on me every twenty minutes, I could only breath if I lay over the end of my bed. I've blocked out a lot of what happened in those days.

By 14 days I was tired and weak but getting a little better. I thought it would just take time to recover but I found I couldn't even go downstairs to sit in the garden – I didn't have the energy. This went on for another few weeks, and eventually I managed to convince a GP to come to see me – I couldn't pick up a glass of water without using two hands or being helped. I couldn't brush my hair or get dressed.

When the GP did come to see me, he asked to meet in the garden. I had a blood test there. My daughter had started to be ill then too, but the GP couldn't see her because he hadn't done a risk assessment for her, only me.

The blood test came back negative, so I was told to 'try harder', exercise more and I'd get better. But I couldn't do more, and I didn't get better. I don't remember much more detail of that time now – my brain has shut it out.

Not long after the GP's visit my daughter become worse, she was debilitatingly ill, only my husband stayed well. My daughter had a high temperature, a bit of a cough at the start – I was too weak to help her but my husband cared for her. Later she had to crawl to the toilet and kept fainting in the shower. We isolated her for 14 days. As she started to feel better my daughter and I tried to go for short walks for about twenty minutes with our sausage dog – the first time we were so exhausted that I literally didn't know how we would get back. We did got back but were exhausted. I tried this again and again, but it didn't make any difference – I would feel so tired I'd have to sleep and sleep to feel better.

One day I went to my GP's surgery for another blood test. The nurse asked me how I was - she was the first person I'd seen outside the home – I was so pleased to have contact with someone – I burst into tears. I replied that I was fed up with being ill, but she interpreted this as depression and suggested this to me. I tried to explain that I wasn't depressed simply fed up with being ill and not

able to do what I normally do – I'm a mover and a doer normally, and I was fed up with not being able to do that. I tried to reason with her that my daughter felt the same way and that I just felt fed up not depressed. She said that she thought my daughter was mimicking me and said that if I tried a bit harder, she'd get better. At this point I didn't know what to say - she made me feel like a failure. I went home and my husband says I hardly talked for three days, I just slept and cried. Then I went on-line, I'd not thought to do that before, and I found all these people who were sick and not getting better, just like us. This gave me the strength to fight on.

Later I complained to the GP practice and got a letter suggesting the nurse misread my body language because I was wearing a mask.

I decided to try to pull my daughter and myself out of this slump by doing some light exercise in the garden, but my daughter soon became grey and pale with pains in her chest and had to stop, not long afterwards the same thing happened to me. We then found we were confined to bed for 8 months. We couldn't even cut our food or lift our glasses to drink.

Fatigue, breathlessness, cough, brain fog, were the ongoing symptoms I experienced - I didn't have pain. I could think things, but I couldn't answer questions – I couldn't make decisions. I'm sure I had TIAs, I'd get the wrong words in conversations, my arm felt strange as if it was floating off to the side. But no one was interested, and we didn't get help from anyone. I'd only get dressed once a week, I couldn't do household tasks, I couldn't help my daughter who couldn't stand, she kept fainting and passing out, she'd crawl to the toilet and sometimes pass out in the shower.

The symptoms didn't really change for me – cough, breathlessness, fatigue and weakness. Things felt really heavy too - even moving the laundry basket. I also had horrific heart palpitations and dizziness, so bad I couldn't stand.

It's about 18 months since the long Covid service started near me and I met them in a zoom call. They grilled me for an hour and a half and at the end said 'thanks very much' – I was exhausted. I never heard back from them until I complained and then they send me some leaflets about brain fog – that was all. It was insulting.

Now I'm pacing myself, I knew about pacing before from my work. My expectations over the duration of this illness have become less. At the start I thought I'd fully recover, but now I know I can't do too much exercise. I'm grateful not to be stuck in bed just looking at the same view, I can get dressed most days, I wash most days, I brush my teeth every day. I can't cook or do tasks around the house and my husband remains my full-time carer and does the lion's share of our parenting.

I can do my adaptation of 'wild-swimming' now – I just get in the sea, I can't swim very far but just being in the water helps and I can move my arms and be with other people. My mental health got bad in August 2021 when I realised I might not get back to how I was, so it helps my mental health to 'swim' and I meet other people – a group of older ladies, all different shapes and sizes. It also helps me adjust to my changed body shape since Covid: I can't move enough to change my shape, but I can wave my arms around and stand in the water with others.

I got reinfected with Covid twice – in March 2022 and February 2023. Each re-infection has made me sicker – it's pulled me back to the same symptoms, inability to find words, inability to read a book, it's hard to be on screen and the fatigue and brain fog worsen. Since my last reinfection I've been in bed until two weeks ago. This level of reinfection feels like I'm just layering up damage in my body. Now I need to think about how I stop being reinfected. I am learning to cope with the isolation if that's what it takes – a one-step removed from society kind of lifestyle.

The NHS has given me nothing. They are probably very frustrated with me, but I can't engage in these fatiguing hour-long conversations. I had a cardiology appointment and follow-up recently. The nurse took my blood pressure and I had a massive change from sit to stand – that's the first time anyone's seen that. The cardiologist said there's not really anything else he could do. But, I've seen private specialists and got game-changing drugs from them.

I feel it's unfortunate I got ill so early, and then I probably fell through some of the gaps. When I've tried to get into the service it isn't what I need, I don't need hand-holding or to be part of data collection processes. People don't want to hear more about improvements in the field I know about – you just get treated as if you've got health anxieties, rather than simply being a well-educated person who's trying to help themselves along the way and share what you've found out. I feel that the knowledge I've accumulated could help nurses to know more, we should be able to share knowledge from lived-experience.

People don't understand because they haven't had this level of experience. I struggle with seeing people getting Long-covid after subsequent infections – and when I relay that people think I'm scare-mongering and obsessed – but I'm not I just don't want people to go through this.

I need to focus on me and my daughter now. I have to learn how to create a new version of me, and so far, I have done that through my research and trying to provide help for people in a different way. I want to learn from this experience and ultimately take that away from Long-covid to other things.

How can nurses help me do this?