

## **How I Learnt to Live with Long Covid by Sally Pilcher**

Hi – I am Salli Pilcher, a Mum, a wife, a daughter and I am an Associate Director of Nursing working for North Cumbria Integrated Care Trust in Cumbria, I am DNS by background with 25 years working in community services, I am a Queen's Nurse, a member of the Community Nursing Exec Nursing Committee and I am also a Long Covid sufferer – a functional long hauler, a title that I inherited in 2020!

Whilst I wasn't the fittest woman in the world and have had back problems on an off throughout the years, I was an active woman, played lots of golf in our Ladies scratch team, enjoyed walking, cycling and generally being an active mum to a teenage son.

Five years ago, we were enjoying a full-on week of activities at Centre Parks

Four years ago, I had been on the golf course all day with the girls

Three years ago, I had just completed a 6-mile mountain bike trail round Sherwood Pines

Two years ago, I had just finished an 8 ½ mile hike in the mountains and valley of Eskdale in Cumbria

In March 2020 year I caught covid – the day before the first National Lockdown

It started off as a mild infection, but by day 7 I felt like I had been hit by a bus. I was not admitted to hospital, but I had a temperature more than 39 degrees, I had a cough, was breathless, had widespread muscle and joint pain, sit to stand was a struggle and one day I was stuck on the floor with all my back in spasm for 90 minutes. Walking was painful and very limited due to breathlessness and fatigue... I was isolated, frightened and anxious and had an overwhelming sense of guilt, not being with my team at the start of this pandemic.

I know now, as a middle-aged woman, a bit overweight, with five or more symptoms in the first week that there was strong possibility that I would develop what is now known as Long Covid, but at the time, I was a new statistic, new benchmark in a world of unknown.

Right from the start I had good support from my GP, Occupational Health and a physio – I was probably one of the very lucky ones in a world where it was becoming impossible to access primary care. I live in a rural area and am a patient at a very small GP practice. My GP rang me every other day, my physio whom I have a longstanding relationship with due to a chronic back injury that I sustained as a student nurse many moons ago, gave me exercises to do over the phone and my Occupational Health Nurse was amazing. I was on a strong cocktail of drugs, Diazepam, Codeine, then Gabapentin, co-codamol and Naproxen. On day 12 when I was given a PCR test and when it came back as negative, despite them all saying they were convinced it was a false positive – the guilt and fear that my peers, colleagues and manager would not believe me was overwhelming. My presentation at the time was not typical of the emerging covid symptoms but we now know that widespread joint and muscle pain are part and parcel of the covid symptoms, and that the virus can exacerbate previous conditions, but we didn't know that not back then. I felt vulnerable and paranoid.

I had a return-to-work plan and tentatively returned to work at week 5 – not because I was well enough but because I felt I had to – pressure and an expectation I had put on myself, but also because I had had that negative PCR test. I had been advised not to drive too far, have flexi start times as required and work from home where possible – but I was also a senior nurse and needed to be visible and accessible

I struggled emotionally and physically for the next few months – I was in pain, I was using TENS at work, I had overwhelming brain fog, I was breathless, had days of awful fatigue especially in the mornings and evenings. I was anxious and emotional, I was exhausted, not sleeping for the pain and felt vulnerable. I was still on 3600mg of Gabapentin, Naproxen 1g and Codeine and paracetamol – looking back now I should not have been at work – I was responsible for Nursing across two DGHS covering Surgical, ICU, Theatres, Cancers as well as a portfolio of Community Services. Those spring and summer months were a blur.

Whilst I got really good support from my family, friends, immediate team and colleagues – not all of them really understood what I was going through. I wore an emotional mask and still do to some extent, only letting it down in private. I tried to be the best mum, really pushing myself every day to do normal things. I look back on pictures of those months and see someone smiling back at me – subtle things show the challenges – walking poles on a short walk, riding in a buggy on the golf course when I would join in a few holes with my son and hubby. But behind the smile was pain, exhaustion and a knowledge that not long afterwards I would be home, crumpled in a heap in pain and not able to put one foot in front of another. On work days I was in bed by 7.30 pm.

I was getting worse rather than better – more fatigued, more pain, less sleep, more anxious and paranoid and we were also going through a restructure at work, and I didn't want to be seen not to be coping. I have always been strong, capable and determined, I didn't want to fail. I was draining every ounce of resilience I had – I had yet to learn about pacing – I thought recovery would come from pushing myself, getting on with life, but it was doing just the opposite.

My back pain eased but left me with horrendous nerve pain down my right leg – weird sensations and pain – deep relentless bone pain, pulsing burning pain and also at times this feeling of water pouring from my knee to the point where on more than one occasion despite me knowing it was not feasible, I would roll up my trousers to make sure my leg was not wet. Pain was worse at night, relentless, sleep depriving. If I sat for too long or was active for too long it went into overdrive.

My GP, Occupational Health Nurse and Physio kept telling me I had post covid myalgia and fatigue – the phrase Long Covid had not been introduced at this stage. That it would get better in time, hope for Spring 2021 – that was devastating, how could I survive another 8 months of this. I read as much as I could, they sent me articles but often relating to ME, MS, other neurological post viral effects. There was one study in Canada on health workers following the last SARS outbreak that related to what I was experiencing – but it was like trying to piece together one of those Perspex jigsaws – that has no picture, trying to fit together pieces to make sense of what???

I had MIR full Spine, Hip and Knee X-ray, Ortho review – no cause for my nerve pain other than post covid myalgia. All my bloods came back negative. But on the 20<sup>th</sup> of June Occupational Health called me for my antibodies test– they came back positive –at least I had an answer, I'd had Covid. The sense of relief and validation was overwhelming. One comment that someone had made around me not having covid had haunted me, now I knew I had it, I strangely felt so much better psychologically, I burst into tears with the occupational health nurse.

After reading one article around post infection autoimmune response and talking to a close physio colleague about her experience of RA which she said was very similar to my symptoms, I spoke to my GP, and asked whether she would test me for RA and consider a short sharp course of steroids – she did the blood test but asked me to find more evidence around post covid and steroids – when I challenged her, I broke down in tears and said but there isn't any evidence she inferred my anxiety was exacerbating my symptoms and when I asked for a medication review she said there was nothing more she could add and to try TENS again....

I was at breaking point, So I started to look for alternatives. I have been desperate for my sports and holistic therapist Kerry to start work again – she had been my go-to alternative person with my back issues over the years, but she was isolating with her husband who had a long-term condition – I kept messaging her and eventually she offered me an alternative – socially distancing one to one TaiJi lessons. What could I lose...?

Turning point in my recovery number one– I am sure that you are all aware that TaiJi is an ancient internal martial art, slow movement with intention with many health and wellbeing benefits, not least because my outside classroom was in her garden overlooking Wasdale, Scafell and Great Gable in the Western Lake District. When we were no longer able to mix in people's gardens, we practiced on the shores on WastWater – in a deserted Valley. She introduced me to mediation and helped everything quieten down. I had and still do have one to one session with her each week, as well as joining her group Zoom session on a Sunday morning. The benefits are difficult to explain in a

sentence but its like re-programming your body, resetting the norm, calming everything down. It also helps practicing outside in one of the most beautiful valleys in the world – my natural health service.

Spending time in Wasdale – which is only 10 minutes from home, reconnected me with the outdoors and the beauty of the place I call home, but had not appreciated fully until lock down and led to another turning point in my recovery. A family staycation picnic with our inflatable kayak, which I couldn't physically sit in for long without my leg pain going into overdrive, led me to swim in the lake alongside my son and nephews. It was cold but within a few minutes I realised my body felt different, decompressed, pain free and supported – it was just an amazing feeling after 5 months of near constant pain.

I came home and after a few days and feeling the benefit after another tentative swim posted on Facebook – tongue in cheek – did any of my friends' fancy trying wild swimming. One of my colleagues and now a very close friend Zoe or @mummaZee, replied "Yes", I typed "When?" She typed back – "15 minutes at the lake, I will just switch the iron off" – so we did. Fast forward 17 months and we have swum three times a week often four times, right through winter in the deepest lake in England. Again like TaiJi I could wax lyrical about the evidence base and literature around cold water, wild swimming – improving stamina, core stability, muscle tone, mindfulness, decompression of joints, exercise with low anaerobic tolerance, nerve calming – but most importantly it works for me, the pain subsides, usually for a few hours to a couple of days and the mindfulness and feeling of wellbeing was and is overwhelmingly positive, even after some of our most brutal and cold swims – We are now swimming well over a mile three times a week and in August this year I achieved my covid goal set last year, of swimming the length of Wastwater, 3.1 miles.

At one of my Physio appointments in late August, hearing the benefits that TaiJi and Swimming were bringing, my physio Steph tentatively suggested referral to the Physical Health Psychology Persistent Pain Team - tentatively because she didn't want me to feel that my pain was all in my head! She felt that it could offer me more tools to add to my belt of things that could tone down the nerve pain and help me cope with the uncertainty of what was feeling like running an endurance race, with no finish line – what was now becoming increasingly labeled as Long Covid.

The Service had just come into my new revised community portfolio, so I made contact with the CD of the service and discussed what she thought. She was really enthusiastic, said that she had a Senior Psychological Therapist, with a professional interest in the emerging Long Covid agenda, that they were offering this service to staff, and she arranged a referral via OCC health.

Breakthrough number three Lucy - our sessions started and Number one Lesson, was why things hurt. She sent me lots of reading, lots of stuff initially was too simple for me, didn't relate to Long Covid, often again related to other chronic conditions and some of it felt a bit patronising, but she recognised that it always came with those cavies. The one ted talk that I could really relate to was by Lorimer Moseley – Why things hurt? How your brain remembers pain.

She listened to me, believed me, coached me, encouraged me, challenged me and we debated lots.

Lesson Number two was a revelation – Pacing! I had been pushing myself hard, trying to drive my improvement – what I needed to have done all along was to pace, pace and pace some more! I kept an activity journal, started to understand what I could do and what I couldn't. I found out that Pacing is really hard when you are competitive and driven like I am!

She shared professional webinars with me that were coming through the Long Covid route, she helped me deal with my anxiety of failing to beat this thing and helped me to lower my emotional mask. She unleashed me!!

I talked about my feelings to my family and friends, I talked openly with my hubby, son and mum, I was open and honest at work which unlocked a huge amount of support especially from my close team and I started to be more honest on social media – I opened up on Facebook and twitter about my #Longcovid – sharing the good days, the bad days and the really shit days!

Next Breakthrough Fiona - I found a new GP – someone who had come into my practice who I had worked with before, again another game changer. She believed me, but was also clued in to the emerging national guidance, she was willing to take risks.

The first consultation with her was at the end of her surgery, she was with me an hour, she took my bloods, she requested a CT scan of my chest, and Echo and because of my unresolved doubt that all the pain in my leg had been as a result of a blood clot she arranged an USS of my femoral vein. I asked if she would check my vitamin D – all came back NAD apart from my vitamin D which I was significantly deficient in – 20,000 u three times a week were prescribed.

She introduced an inhaler for me, and suggested a short sharp course of steroids, no evidence base or measurable metrics – but she thought it would be worth a go. I shared my story about my previous ask about this with her – she shrugged and said she was a GP coming up to retirement and whilst we could only evaluate it subjectively it was worth a shot! They gave me a boost – at first it was like every single symptom of covid had returned, my joints ached and so did my muscles, but by the end of the week's course the nerve pain had been turned down several notches.

Then came Barbara – early in 2021 a respiratory physio specialising in the emerging long covid clinics contacted me on twitter, she sent me articles on anaerobic thresholds, how to assess whether you are breathing correctly (I had wrongly assumed since I have been breathing for 48 years that I was doing it correctly, how wrong was I) and she gave me an hour of her time. We spent time chatting on zoom, and told me I had breathing pattern disorder, hence the air hunger I was experiencing and suggested I ask my team for a formal referral into the Long Covid clinic for lung function tests! My first appointment is next week.

I went away and wrote a plan on a page – underpinned by a more detail plan

- Breathing
- Heart Rate
- Sleep
- Exercise
- Pain
- Pacing
- Fatigue
- Medication
- Work
- Investigations
- Threat: Drive and Soothing
- Emotions
- Short-, medium- and long-term goals
- Acceptance.

My following consultation with my GP involved me spreading out my plans of the couch in her treatment room and taking her through it step by step – she thanked me for helping her retire on a high!

My Psychological Therapist set me some homework in February to send an email or set up a survey monkey for family and friends to ask them What I have done well in my long covid recovery, what positive progress they have noticed and what could I have done better – I left it to the last day of the three weeks I had to do this in – I wasn't sure I was ready for the response – but it was overwhelming 6 A4 pages of feedback.... Which I still use now on the days I am struggling

## **So where am I now?**

I have swum right through winter– in the dark in the snow, ice, wind and rain – its exhilarating. My swim buddy is amazing and now a very close friend – she also has fibro myalgia and gets Significant benefit from the cold. The only complaint during the summer months is that the lake is not cold

enough and we have to swim for much longer to get any benefit – but now we are into our second winter, its colder again now, the pain relief is back, and I have reduced my gabapentin and only take my naproxen on bad days – usually when I am overdue a swim.

A few months ago, I knocked my right leg while swimming in devoke water on a rock – the nerve pain went into overdrive again and was disproportionate to the little scratch that was on it – I had to check that it was still attached to me and at this point I remembered this ted talk, Lorimer Moseley – Why things hurt? I laughed, breathed and talked my brain into a more sensible approach to the pain it was telling me I was in!

TaiJi continues in the open-air classroom – I am getting more benefit the deeper I get into this ancient practice – each time I think I have ‘got it’ Kerry throws in another dimension, and I realise like Long Covid, TaiJi is going to take me a long time to master.

My sleep has improved (thanks to a meditation course) and on the whole my pain is controlled – after one failed attempt to reduce my gabapentin which resulted in cold turkey symptoms because I went at it too fast, I have managed to get that down to 300mg– so long as I don’t sit for too long or don’t do too much – it’s a very fine line and balance that I still have to manage.

I still struggle to pace, I am competitive and want to beat this thing, but thankfully boom and bust scenarios are getting less as I learn to live with the symptoms of chronic fatigue

I have a standing desk at work and a specialist chair which has made all the difference and I walk at lunchtimes with my PA and Quality Matron when diaries allow.

I continue to post my journey on social media and have been able to help and support others suffering from Long Covid even if every person’s experience is different, even if it’s only listening to others or signposting them to services. I joined a great focus group run by Drs in Distress that connected Nurses with Long Covid from around the Country for reflective discussion and support - We are really lucky in North Cumbria to have such well-co-ordinated Long Covid services now – but it’s not the same elsewhere and I have heard stories from other nurses who have been left to founder, not had support from occupational health and are still at home, losing hope.

Driving is still difficult – it’s the fixed position for so long and the action of using the foot on the accelerator, but I am working on desensitising the nerves (top tip from neuro physio who swims with us occasionally). Biking is still off the agenda – it raises my anaerobic threshold way to high – to above 180 bpm, but paddle boarding is on it – only for short periods as the nerves in my right leg go off on one, but good for stability and hopefully will help with driving in the long run.

I am back playing golf well again, but with a buggy (like an old lady – but needs must if I am going to get back to a sport I love) and I need to build in a rest day afterwards as I am still really tired. In September we went on an overnight golf break that my mum had bought my Hubby and I for Christmas – we booked the date as late in the season as we could to give me time to recover – but two days off golf left me physically drained for the next two weeks.

I have been discharged from all of the services, I have a staying well plan and crafting and cooking are my soothing activities that bring me joy without expending cognitive or physical energy.

I know I am making progress, sometimes I need to stop and reflect at just how far I have come – but I am not there yet. It still feels less like completing that Perspex jigsaw with no picture to guide you – but still feels like a long distance marathon without a finish line and although I could sense it is getting nearer, in recent weeks I have been struggling to come to terms with the fact that I may be left with these symptoms and the nerve pain, myalgia and fatigue may be my long term condition – and that is hard at the moment and is making me emotional again!

However, I have the tools in the box and I need to use them – not let my routines or activities that bring me relief slip – because when they do the pain and the fatigue is not far behind them

### **My top tips would be -**

- Be open and honest
- Ask for help early
- Make reasonable adjustments for staff in your team if they are suffering from Long Covid and talk openly about the challenges
- Keep an activity diary – know what the triggers are to feeling good or that result in boom and bust and energy drain
- Build consistent professional relationships with people who believe you, are consistent and whom you can build trust in – it's difficult in today's post covid world where General practice and services are under so much pressure but it is still possible – I now proactively email my GP and let them know my progress so when I ask for advice they are really receptive
- Keep an open mind – one size does not fit all, everyone is different there are many tools in the tool kit, they need will all be different and be required at different stages in their recovery
- Mindfulness, breathing and meditation is the most under rated and powerful tool in the toolbox
- Think wider than just the traditional pathways and solutions – be open to trying different things
- Pace, pace and more pacing... Pushing yourself pushes you further from your destination

### **So what do I hope from sharing my experience here and on Twitter?**

*It can be easy not to share, I have felt exposed sharing my experience, I have agonised as to whether I am doing the right thing and if I am quiet on Twitter I am usually having a bad week, I feel anxious now doing this, but whilst some people let you know that they disapprove of you sharing your journey, not by what they say but by what they don't say, the majority of the feedback has been overwhelmingly positive and encouraging, and most importantly has helped others.*

I had to navigate my way through fog over the past 18 months, I had no map and no GPS – but thankfully I had some great health professionals within my organisation to help me, and some great alternative therapies, family and friends and the great outdoors #mynaturalhealthservice. I don't want anyone to have to go through that, and whilst we are getting more geared up for recognising and helping people with long covid, there are still may gaps and some people are still floundering. Not only with Long Covid, but with other long-term conditions which are similar – from which we need to use our learning from Long Covid to improve those pathways too.

I had the benefit of being a senior nurse, I can be assertive, can access and interpret research, I can hold my own, fight for answers and for access and have been able to explore options and have the financial means to access options outside of the traditional box – my TiaJi and Wild Swimming journey hasn't been cheap, swim wetsuits come with a hefty price tag and I now have more neoprene than my brother has lycra. But despite all this - I felt helpless, despondent, frightened, a failure and struggled to make myself heard or believed in the early days.

What if I was a 78-year-old lady living isolated at home without the internet, what if I was a middle-aged woman with learning difficulties, what if I was a passive individual or didn't know what to ask who to ask or was too frightened to ask.

Much of the media around this focuses on people who were once active and in work and are now housebound, in wheelchairs or home O2 – it's not always the case, my experience represents the middle ground, the functional long hauler - but it's still a long and lonely haul.

We need to help our practitioners to listen, really hear, recognise the symptoms of long covid, know what they can access, know what they can do to help patients and to give them confidence. But most importantly to give Long Covid sufferers HOPE.