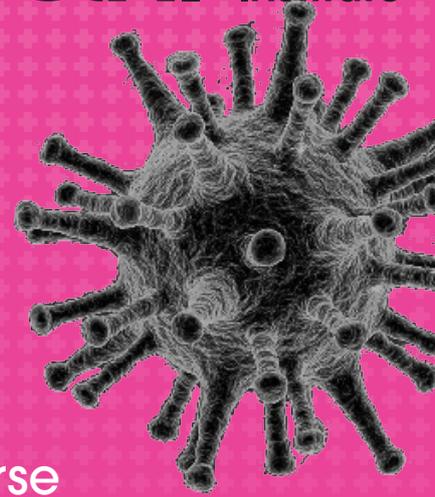


Long Covid-19

BLOG

‘Who Am I Now?’

By Sue Nightingale, QN, General Practice Nurse



I am a Queen’s Nurse, a General Practice Nurse (GPN), and in October this year I will have been Nursing for 38 years and hope to make 40 years.

I would like to tell you what happened to me after contracting Covid in March 2020. But first a bit more about me.

I am 56 years old, living in Birmingham, from an Irish family. My mother was left with four children to raise after my father left and we had to grow up quite quickly. I wanted to be a missionary when I was at school but had to leave to get a job and support the family. I was not particularly looking at nursing at that time. However, when I was almost 18, I went to Ireland to care for my grandmother and decided I would apply for nursing when I returned home 6 weeks later. I was offered the training as a SEN in 1984, I then converted in 1991 to RN. I am a mother of two beautiful girls: Isobel aged 26 and Daisie aged 23.

I have been Nursing for 38 years having worked in Secondary Care for 12 years on various wards then in ITU/Burns and Trauma for 9 years, was then given the opportunity to work in Primary Care as a junior GPN. I moved practices to gain more experience. I am a Nurse prescriber and after 16 years in one practice moved to my current practice. I have been a student mentor, and GPN foundation course mentor. We have large Nursing team, and I was planning to semi-retire in 2020. 23 years later I am now semi-retired and work 2 days a week as a Diabetes Specialist Nurse in Primary Care. I also do a lot of voluntary work in the community.

I have had the opportunity to work in India, Brazil, Kenya, Poland, France and Italy which has given me huge life experiences but allowed me to take my skills and adapt them to any situation. I have met Pope Francis. I always wanted to be patient facing and have really enjoyed primary care and the relationships you develop with your patients and their families. I set up and ran a bimonthly cancer care drop-in in my own time to support patients and their families along their cancer journey. I developed with a colleague a Medical Alert Card (MAC) to allow patients with complex needs better access our surgery. I am now currently working towards restarted the drop in’s post-Covid. I have been part of the Covid vaccination programme from the very beginning as I felt I needed to help prevent others from getting Covid and also play my part.

In February 2020 I and a group of friends travelled to France to do a 25-mile sponsored walk through the Pyrenees to raise money to take children to Lourdes at Easter. We had a great weekend and although I was not the fittest of people, I was able to complete the walk and felt a great sense of achievement. We had little idea of what was to come once we returned home.

Less than a month later we received a frantic call from my daughter to say that the University was closing, and we had 3 hours to collect her and her belongings before the lockdown began. I was at work on a Friday afternoon and had to ask permission to leave. Luckily, she was only in Wolverhampton, a few miles away. We managed to secure a lockup for her belongings, and we settled over the weekend as we were then heading for a national lockdown.

I was at work on 25th March 2020 when the first symptoms started. We were told at work that only the receptionists needed to wear masks at that time, and we continued to see patients in the very early days of the pandemic. I began with a dry cough during the day and then developed a temperature of 38.8 by the evening. I still felt okay in myself but was then isolating at home for the next 10 days, my husband and daughter were both home, and we kept apart from each other as

much as you can in a 3-bed semi. Still feeling well, although still coughing the fever had settled and I was preparing to return to work.

On 3rd April I woke at 5am in the morning struggling to breath, my cough had got worse and was now persistent with sputum, my temperature was 39, and I felt dreadful, I was beginning to get short of breath, I sat on the side of the bed to calm myself and try to rationalise what was happening. My oxygen saturations we 91%, my lungs felt like they were already full and could not get more air in. I don't know how long I sat for trying to calm my breathing. After some time, I managed to get downstairs, I was then shivering, barely able to speak and trying to find a reason for the sudden change.

I phoned 111 who were not the most helpful and said just stay at home, drink fluids and take paracetamol. My husband came into the room and sat as far away as he could. I was struggling to speak and was leaning forward to try to get more air in my lungs. I then rang 111 again and asked to speak to a doctor. I remember a lovely ANP who spoke calmly to me and said they would send a paramedic to assess me. By this time I was in tears which made things worse and I was very scared.

The paramedics arrived, two young men who were very calm, came in with all their PPE on, it was quite surreal. My husband sat watching what was happening. The paramedics did lots of checks including ECG and my oxygen was 90% my chest was congested, I was tachycardic and temperature 39.5, however they advised after a long discussion to stay at home if I could. I looked to my husband for help and he said, 'if you go to the hospital, we won't be able to visit!' The Paramedics suggested I contact my GP for some antibiotics for a secondary infection and left reassuring me to call 999 again if I got any worse. They stated that home was the best place at the moment.

I took their advice although I was still very scared. I was trying to remain professional while feeling out of control. After a while I managed to ring the GP who prescribed antibiotics and a Ventolin inhaler. My husband phoned my sister who went and collected them from the pharmacy. I was exhausted but restless. I managed to take a couple of tablets and some water and spent the night on the side of my bed struggling to breathe. This continued for the next five days; I barely moved from my bed, I could barely take any medication and struggled to take the inhaler, my husband would give me drinks to try to keep hydrated, I ate nothing. My whole body felt under attack. I had pains in every muscle and joint, when I say pain it was nothing I had ever experienced. I began having what I call hiccup breaths, every now and then my body would take a big hiccup to catch up with the breathing that was now very shallow and rapid. I think I may even have stopped breathing and maybe those hiccup breaths helped. I do not know if I slept. After five days of this I was so weak and in so much pain, trying to breathe was zapping all my energy. I remember thinking how much more can my body take. I messaged one of the GPs I worked for and asked for advice, she suggested I go to the Emergency Department.

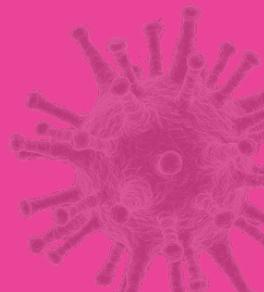
I asked my husband to take me as I knew how busy the ambulances were by now.

I arrived at an empty waiting room and was seen in what I can only describe as a cupboard with enough room for a bed and a computer, I was seen by a male nurse, he did an ECG, BP, oxygen sats, pulse, and asked me about my symptoms, not making any eye contact and being very dismissive. I felt that I was wasting his time but didn't have the energy to say anything. I was taken to another cubicle and seen by a doctor in full PPE who sent me for a Chest X-ray, and he confirmed I had Covid. I knew that already, and they would be admitting me for further scans and treatment. I remember the huge relief that I would be able to get help to breathe. Another doctor came and took blood with another junior doctor; he was so busy chatting that he got blood everywhere. Again, I was too exhausted to say anything.

I then saw another more senior doctor who said my Ferritin levels were very high: 'often seen during acute infection' but other bloods looked okay. He asked me to do the step test, which at that time was the new tool to see if patients desaturated. I struggled to do the step test, but I managed, and my saturations did increase to 95%. I was then seen by then a Respiratory Consultant who was totally dismissive and said as you can maintain your saturations above 90% you can go home and if things deteriorate come back. You will either start to improve or you will be back. I just wanted help to breathe. I could not believe what was happening. How sick do I have to get?

I was in shock at this point and hadn't the energy to challenge them. They said you can leave when you're ready. I eventually

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rang my husband, and he came back to collect me. While I was waiting, I was thinking, 'They are sending me home to die. I am not sick enough to be here so I will have to take my chances.'

Over the next few days, I stopped eating, barely drank, and stopped all meds. What was the point, I struggled to swallow and was still struggling to breathe, I thought my lungs would just give up. I stopped passing urine, I had not left my room for days, I asked my husband to open my bedroom door to check I was alive, he said, 'I listen at the door', and I snapped back, 'Who can hear a dead person?' In the long dark hours of night, I wrote letters to my daughters and husband and told them how much I loved them.

I was praying that if God had more work for me to do, he would help me now, I prayed for all my family and most of all my girls. I cried I would never see them again, my lovely mother who I had not told I was poorly so as not to worry her. Well, I was in God's hands now, I have had a good life and done many wonderful things. I would not see my girls marry or have children. The days were a blur and I had not washed or brushed my teeth all my energy was to breathe, and the pains were exhausting me. How much more will my body take.

By day 15 I noticed my breathing start to ease very slightly, I could take a deeper breath, I managed to pass a little urine, I remember looking at myself in the mirror and not recognising myself. I felt numb despite all the pain. My sister had told my mum and she texted me; I was in tears as I didn't want her to know but was so grateful at the same time, I felt unloved and like a leper in my own home. My husband kept a distance, not just because of Covid but because he didn't know how to help, and he was obviously scared too.

Then my daughter started to develop mild symptoms not surprisingly despite us trying to keep separate. Thankfully I was able to tell my husband how to help her. I was scared for her too as knew things could change so quickly.

I continued to pray that I would get stronger and eventually I was able to start drinking and eating a small amount. I lost two stone in weight, which on one hand was great as I was overweight but was equally shocked as this caused muscle wasting in my legs and the pain in my feet and right leg was excruciating. I would literally have to crawl up the stairs at night and dreaded going to the toilet as we only had an upstairs toilet. Slowly I was able to take some pain relief.

Over the next 8 weeks I began to improve, the chest began to ease so I was able to take slightly deeper breaths, I was able to lie down and finally get some sleep, I slept for 14 hours straight with my husband checking on me every few hours. I had warned him not to just leave me I was so scared I would not wake up once I finally slept. He eventually woke me up. I felt exhausted still and not refreshed but felt my body needed the rest.

I continued to improve, and my daughter was also improving; after her initial infection she was troubled by the fatigue. Together we would lie on her bed and just chat then fall asleep.

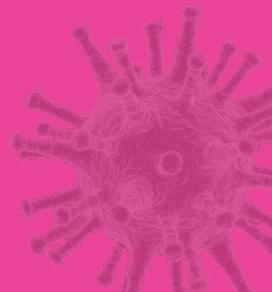
After a month I asked my husband to take me to see my mum, I just cried with relief, she was shocked by my appearance and upset I had not told her I was ill, I told her how scared I was and didn't want her to worry as I obviously wasn't sick enough to be in hospital.

At times I thought I would end up in a wheelchair. That I would be dependent on others. I would lose control of my life or maybe I was too busy before and this was God's way of slowing me down.

After 8 weeks I spoke to work who had barely contacted me throughout my sickness. They told me to take as long as I needed, the nurse in me was thinking who would look after my patients. I would try to return to work. That need for normality and not letting others down pricked at me. I was worried because my memory was awful and felt that doing something familiar would help. The brain fog was really annoying. We had agreed a slow gradual return.

I had lost my confidence to drive or go out alone. In November 2020, I was driving home one day from a shop I knew well not far from home; I was coming out of a side road, and I just went blank and pulled out. I was hit by a speeding vehicle.

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The other driver jumped out of her car shouting at me, 'What was I doing?!' I said, 'Calm down, you were speeding, let's just pull over and discuss it'. I checked the damage to her car, forgot to check mine. We exchanged details and then I drove home, all the time feeling like I was on the outside looking in. Feeling I was the only person on the road and my reactions were definitely slower, so I avoided driving unless absolutely necessary.

I began doing 2 hours for 2 days initially and then would go home and sleep for 4-5 hours. Building up to doing 4 days over the next few weeks. I was still having a lot of pain, breathless on exertion especially stairs or slight incline. This was in the June, and I was due to semi-retire in the August. I decided I would take a month off completely before returning 2 days a week. As I was literally working and sleeping. I felt much better for this complete break and felt then I had gone back too soon. I was able to catch up with friends for coffee which was about all I could manage in a day.

In September I started working 2 days a week, Monday and Thursday so I had time to recover in between. I was still working remotely but wanted to go into work rather than work from home to give me incentive to develop a routine.

I have had several relapses which have set me back and have been convinced I had Covid again but tested negative. The relapses are now decreasing in frequency as I can pace myself better. Another hard lesson to learn, feeling I just wanted to be normal again.

In December 2020 we started the Covid vaccination programme and I was determined to do my part to help protect people but also to give back a little as I felt for my colleagues in secondary care who had been through so much. My first shift was a split shift and by 12 midday the pain in my feet was unreal I persevered and by the end of the shift could barely walk. When I got home I sat on the sofa and cried. It took 3-4 days for the pain to ease enough for me to stand more than 20 mins. I returned to the clinic the following week and just did 3 hours shifts which although painful were more manageable. I soon learned that sketched trainers were the best thing to wear and now live in them.

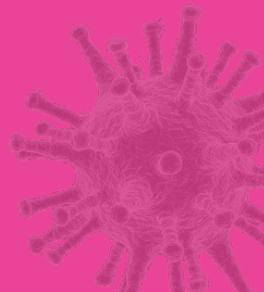
I was eventually referred to the Long Covid clinic by my GP; my first appointment was in July 2021! I had a driving test done to ensure I was safe to drive (ironically more than 6 months after my accident). Thankfully I passed with flying colours. I remember breaking down while doing the written test, as my family were making fun of my memory loss and I was heartbroken as I didn't want to be like that. I struggle to read more than a few sentences; I was an avid reader before, my poor vision and memory made reading impossible, despite eye test and new glasses my vision has a mind of its own.

I was referred to physio, MRI, bloods, Chest X-ray, Psychologist, speech and language therapist, weight management and neurophysiology. I am awaiting respiratory appointments and due an EMG and gynae referral due to having a heavy bleed after 2.5 years of no periods. I have looked at POTS and ME groups. I hope that my symptoms will eventually settle, or I will adapt around them. I do not know what is post-menopausal and would I have had some symptoms due to this. I am able to stand now for longer periods without the excruciating pain in my feet. What I do know is it is real, and it has stopped me doing what I love and being who I am.

My first appointment with the Long Covid clinic seems promising, we discussed every symptoms at length. I acknowledge the improvements I have made but still have to deal with daily symptoms like fatigue, insomnia, loss of taste and smell, muscle and joint pain, paraesthesia to the left foot, blurred vision, memory loss, gastric problems, persistent dry cough and wheeze. Shortness of breath on exertion. Choking when sneezing and swallowing difficulties. Lack of concentration.

I have lots of symptoms some of which I can explain, some I can't and are difficult even to describe. I am not the person I was either physically or mentally. I have lost my taste and sense of smell, yet sometimes smell things that are really awful to me and can't get out of my nose for hours. If I do not have my daily antihistamine I choke when I sneeze, very scary at times. I have no appetite; I eat to survive not to enjoy. I can walk a maximum of 3 miles but in great pain. I have lost confidence and am more anxious than I have even been. I struggle on a daily basis with my memory although my brain fog has lifted after I took part in a silent retreat, just me and God, and my brain was on overdrive, but it seemed to help. I still have crash days and sleep excessively; I find limiting my sleeping helps in a strange way until I crash again. Almost like my body needs to recharge without the benefit of feeling refreshed.

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When I look back, I feel so lucky to be alive, I feel that my experience has been shared with so many who were left out of hospital and survived. I realise that the hospital staff would have seen the sickest possible patients and I would have seemed minor to them now. I have tried to prioritise what I want to do and spend more time at home and in the garden. I have tried to move forward and put it behind me and move forward as the new me. I went to Lourdes (France) at Easter 2022 on a children's pilgrimage trust 5 days caring for children and the team. I was very anxious but felt with the support of the team who new part of my journey I would have to try. It went very well, I had early nights once the children were in bed, I missed breakfast so I could have extra time to get ready, mornings are the worst. I was overwhelmed being back in Lourdes and doing what I love. It took me a week to recover, sleeping 16 hours then 14 and so on until I began to feel normal again. Stupidly, I had planned to return to work on the Monday but had to phone in sick.

In May 2022 I will be helping with an adult pilgrimage. I am hoping that I will be able to manage my symptoms to be able to support this group too and we have shift patterns so I can plan my rest periods better. It will be my first big challenge after 2 years living with Long Covid. I have to believe I can do this.

I have been helped by the Long Covid support group set up by the QNI and on Facebook, hearing other people experiences helps to reinforce what I went through. I have been able to discuss and encourage others to seek help for their own peace of mind. I encourage my patients to seek help. I was very saddened to hear from a patient that his GP told him there was no such thing as 'Long Covid', that same GP having been on ITU and on CPAP, was just unbelievable. My faith helped me in my darkest hours in the still of the night when every breath felt like my last. I thank my daughter Daisie, my mother and sister who have believed me and still support me in my recovery.

I still speak to my psychologist as the fear sometimes takes over and struggle to deal with these feelings as a glass half full type of girl. I have started to read again; I do not retain it for long but at least it's a start. So for now I take advantage of the good days and rest on the bad days. I am definitely changed and do not jump into things. I do not want to overload myself but have time for the new me. The relapses are much less troublesome and with each investigations giving positive news I plan to continue for now and hopefully 2023 will be able to plan my future better.

Share your story, no two stories are the same as everyone journey and symptoms will differ and I am blessed to be hear to tell my story and hope that it helps others. Writing it down really helps me to resolve some of the negative feelings and move forward. Do not feel it is all in your head. It is good to speak about your journey in order for you to process everything and accept a new chapter.

I hope that Long Covid is recognised as a condition, better acknowledgement, as many will suffer symptoms for years to come. There may be no cure, but we can help each other to understand and slowly heal.

Thank you!

Sue Nightingale QN
April 2022

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