



Living with long Covid: some reflections 14 months down the line

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As I write this editorial, it is almost 14 months since I first developed COVID-19 symptoms and my journey with long COVID-19 continues. In their guideline on long COVID-19 NICE/SIGN define post-COVID-19 syndrome as signs and symptoms that develop during or after a COVID-19 infection, continuing for more than 12 weeks, and not explained by an alternative diagnosis. More information about long COVID-19 can be found in the blog written by @jakesuett and me in September 2020. Data from the Office for National Statistics in April 2021 estimated that 1.1 million people in the UK reported experiencing some form of long COVID-19 symptoms. Despite this, the UK Government continues to focus on the outcomes of COVID-19 being binary: dying or surviving. [Box 1](#) provides details about some useful sources of information on long COVID-19.

Everyone's long COVID-19 journey is different; recovery is not linear with many relapses along the way. Fourteen months on, I am better than I was but still not fit enough to return to work and need to be careful not to do too much. My ongoing symptoms include:

- ▶ Breathlessness—e.g. after having a shower or walking short distances.
- ▶ Brain fog—unable to read for more than 15–20 min or concentrate on anything for more than 30 min.
- ▶ Headache.
- ▶ Fatigue.
- ▶ Poor temperature control and hot flushes.
- ▶ Deterioration in my eyesight—potentially due to steroids.
- ▶ Tingling in face
- ▶ Swollen glands.
- ▶ Nausea.

I am one of the lucky ones—I was reviewed at a (virtual) long COVID-19 clinic in February 2021. As suggested by the NICE/SIGN guidelines, I had some tests ordered to rule out any organic causes for my symptoms. The blood tests showed that I had developed type

2 diabetes. A brain MRI indicated I have had a stroke at some point.

Nowadays, there is an expectation that most illnesses can be cured; this makes it more difficult when there are no answers. As a patient group we struggled, and in many cases, are still struggling, to get access to the tests we needed which exacerbated this situation. This is perhaps not surprising in the middle of a pandemic. I always felt slightly uncomfortable fighting for access to tests when I knew the NHS was at crisis point but as a registered nurse had some knowledge as to where to turn for help. This was particularly helpful when I was rung with the results of my tests following my long COVID-19 clinic appointment. Having been told I had developed type 2 diabetes, the advice was to 'go on a low sugar diet' and have my bloods tested again in a few months. However, I was able to reach out to friends for advice as well as referring myself to the diabetes nurse at my GP practice. I am now on a low carb diet and have been prescribed metformin that would not have happened if I had just followed the initial advice. Getting advice about my stroke has not been so easy. Over 6 weeks down the line, I am still awaiting my referral to the stroke clinic.

On an intellectual level, as someone who has spent much of their nursing career promoting evidence-based practice, it has been interesting having a new disease and observing as information about potential treatments emerge. People within the long COVID-19 community were willing to try almost anything in an attempt to get better. A scene from the recent TV series *It's a Sin* struck a chord—someone who thought they had AIDS/HIV in the mid 1980s ringing a hotline and asking whether a list of potential cures, including drinking bleach, would cure him.

As a registered nurse and editor of Evidence Based Nursing, I found it challenging when other people with long COVID-19 appeared to me to be 'grasping at straws' and trying any treatment that was available despite a lack of evidence to support it. I understand this is a reaction to the lack of available treatments as well as many people being told by the medical profession their symptoms were 'all in their head'. But, on occasion, it made it difficult being part of these groups. Going forward, we need robust research to identify treatments for long COVID-19. An international multistakeholder forum has recently produced a list of research priorities for long COVID-19. Governments are beginning to allocate money for research into long COVID-19—for example, in the USA, the NIH has put US\$1.15 billion aside. These are definitely steps in the right direction but more needs to be done worldwide to care for those of us with Long COVID-19.

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Box 1 Useful sources of information about long Covid

- ▶ NICE/SIGN rapid guideline published in December 2020.
- ▶ The NIHR review of evidence: living with Covid-19—second Review (March 2021).
- ▶ Paper in nature in April 2021 provides a summary of how post acute Covid-19 (long Covid) can affect different organ systems.
- ▶ Paper published in March 2021 describing the range of signs and symptoms experienced by people with long Covid via a social media survey.

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