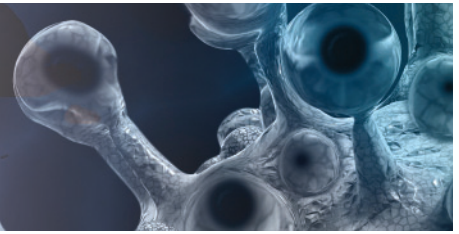


Long Covid

by Geraint Jones



The author, a health-care worker at a hospital in Wales, shares his experiences of Long COVID. This long-lasting illness is still little understood, but new research is uncovering some of the recurring symptoms that many patients experience and suggesting better options for treatment for adults and children.

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Introduction

Long COVID has significantly impacted my life over the past 19 months, consistent with the experiences of numerous other sufferers¹ Over 125,000 participants in one study experienced post-acute sequelae of COVID-19 (PASC) six months after recovery.² The World Health Organisation (WHO) released a clinical case definition for post COVID-19 condition³ in October 2021;

“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARSCoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms

may also fluctuate or relapse over time.”

Long COVID is still not that well understood, despite the Office of National Statistics (ONS) estimating that 1.1 million people in the UK were experiencing Long COVID as of 5th September 2021.⁴ Given the medical community’s previous understanding of post-viral conditions and evolving understanding of COVID-19, the emergence of Long COVID comes as no surprise. The underlying mechanisms are still largely unknown, but hypotheses⁵ include inflammation of autoimmune processes, organ damage and scarring, hyper-coagulability, endothelial damage, microclots or even persistent viral protein in the body.

Long COVID can affect those who were hospitalised with COVID-19 and those that weren’t, and there is growing evidence⁶ that people who experience both mild or severe COVID-19 can go on to experience Long COVID (**Figure 1**). We also now know that COVID is not only a short-

lived respiratory illness.⁷ It is a prolonged illness with serious implications for individuals and society⁸; both now, and the future.

People living with Long COVID can experience many different types of symptoms, affecting many organs in the body, leading to the acceptance of Long COVID being a multi-system illness. Research led by patient-advocacy groups have shown that patients have experienced more than 200 symptoms⁹, whilst a less comprehensive list can be found on the NHS website¹⁰. The National Institute for Health Research (NIHR) has awarded £19.6 million to help diagnose and treat Long COVID¹¹, also releasing evidence reviews in October 2020¹² and March 2021¹³.

The emergence of patient-led advocacy and support groups on social media has really helped keep the illness at the forefront of conversation. Groups such as LongCOVID Support (Facebook¹⁴, Twitter¹⁵), LongCOVID SOS¹⁶, LongCOVID Physio¹⁷ and LongCOVID Kids¹⁸ have been fighting for recognition, equal-access to treatment and shared knowledge whilst being unwell themselves. It is remarkable to see the dedication and power of patient-led advocacy and research.

Personal Experience

I saw the turn of a new decade (2020) as a new chapter in my life; my partner and I were finalising a house move, expecting the imminent arrival

of our nephew, and I was enjoying my role in Cwm Taf Morgannwg University Health Board as HIV & Homecare Pharmacist. I had no idea how quickly my life would change, and how drastic those changes would be.

10th – 13th April 2020, Easter Bank Holiday weekend, are dates I don't think I will ever be able to forget. I had been working on HDU (High Dependency Unit) on Good Friday, ensuring their Mediwell Automated Dispensing Cabinets was fully stocked in case of any emergencies over the weekend, and I remember the sun blazing down as I walked over to my car. I returned home and the first thing I did was lie down on the grass, feeling dehydrated and tired – I wasn't working again until Monday, so I felt like I'd be able to rest properly over the weekend. My partner and I had burgers for tea on the Saturday evening, and despite her enjoying them, I really couldn't face another mouthful of what tasted like rotten meat. Taste disturbance wasn't really one of the most prominent symptoms of COVID-19 infection at the time, but in hindsight, this was the beginning of my long-term illness.

I 'woke' on Easter Sunday; I use this term extremely loosely as I don't recall much from that day. I was lethargic, difficult to rouse, with no appetite and my skin was painful to touch (akin to sunburn), with pain radiating outwards from my bones, and a headache which seemed to sit at the back of my skull. Then the cough started; that distinctive 'COVID cough', becoming breathless very easily. Having

seen patients in hospital with this terrible disease, I was worried for my partner and what I had potentially brought back to our new home, but being so tired, I was never awake long enough to maintain the worry. I laid horizontal on our sofa with my head a few inches from our open patio doors, open due to the blazing hot weather we had that week. In hindsight, that might have been a 'saving grace' as ventilation is now accepted to reduce the risk of COVID-19 spreading¹⁹ as there is consistent, strong evidence that SARS-CoV-2 spreads by airborne transmission. Determined to return to work to support my colleagues during the first few months of the pandemic, I returned to work on 20th April, albeit not fully recovered.

I had been back at work for about ten weeks until, one morning, I woke up with an extremely sore throat. Having been in contact with a patient who was unknowingly COVID-positive a few days prior, naturally I was concerned. I had another test (despite a sore throat not being an indicator for a test at this time), but the swab returned a negative result.

A week later, I was seated at a desk in work when I felt a sharp, stabbing pain just below my ribcage. It felt as if my stomach was on fire and the pain travelled around my abdomen. I was assured that the pain would subside, and after a week of ongoing pain, I sought advice from my GP who quickly rushed me to a local Accident & Emergency Department with suspected appendicitis. Thankfully, it wasn't. However, the following week I was back in

the same Accident & Emergency Department with the same excruciating pain. Although reassuring, it was so frustrating to be told that my scans and blood tests were 'normal' and the symptoms would naturally resolve. If only that was the case...

Instead of resolving, they got worse. Diarrhoea lasting for 12 hours, doubled over in pain, and feeling scared to leave the toilet. My GP was incredible, always accessible, and forthcoming in offering ways to try to alleviate my symptoms. At one stage, I would be taking medication and then within a few minutes, I would be passing them. It had been ten weeks since these symptoms started – I had lost 10kg in weight, I was looking gaunt and grey and unable to sleep due to the pain. One September morning, I broke down in tears wondering what was happening to my body, and how long it would continue. My GP recommended fluoxetine to help my mood; the anxiety and worry triggered by the ongoing and relentless symptoms and the drastic effect they were having on my life.

The prevalence of self-reported Long COVID was noted to be greatest among those working in health or social care²⁰, (see **Figure 2**) whilst another study noted that essential workers were found to have a higher risk of severe COVID-19²¹. Given the circumstances that health and social care workers found themselves in during the early stages of the pandemic, this comes as no surprise; however, it is a concerning statistic as staff look to continue battling through the pandemic.

Investigations and Treatment

In late November 2020, I was experiencing worsening breathlessness and a crushing pain around my chest. Reluctant to attend the same Accident & Emergency Department that I had frequented a few months prior, I sought private advice from a Cardiologist who conducted several tests and suspected myocarditis. I began treatment for this and asked to return for an echocardiogram and fitting of a Holter device, having noted from Apple Watch data that my heart rate had been hitting 190bpm despite no activity. A few weeks later, I was diagnosed with inappropriate sinus tachycardia and commenced on Ivabradine; a diagnosis which seems to be commonly reported, amongst other cardiac issues post-COVID²².

In January, I underwent my first scan as part of the COVERSCAN study, aiming to assess medium-term organ impairment in symptomatic individuals following recovery from acute SARS-CoV-2 infection²³. At this point, I had undergone a myriad of tests and scans, all of which were unremarkable despite my symptoms, so it was quite validating when I was told that there was a reduced lung fractional change in both lungs

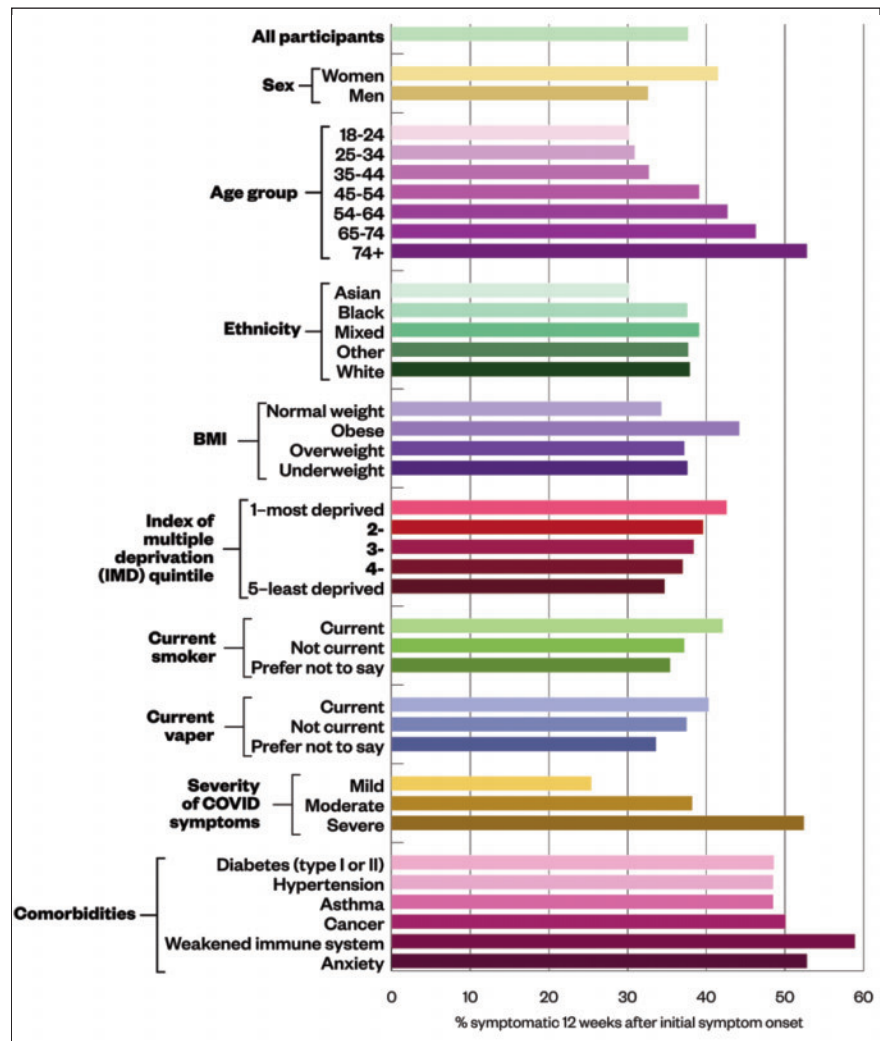


Figure 1. Percentage of major symptoms 12 weeks after initial symptom onset. (<https://pharmaceutical-journal.com/articlefeature/long-covid-the-pharmacy-staff-picking-up-the-pieces-months-after-being-infected>)

and a value indicative of myocarditis. Due to the noted changes, it was recommended that I return for a follow-up scan in June, and upon the second

visit, all findings were normal in the organs analysed.

Thankfully, research and investigations into Long COVID is beginning to catch up with those

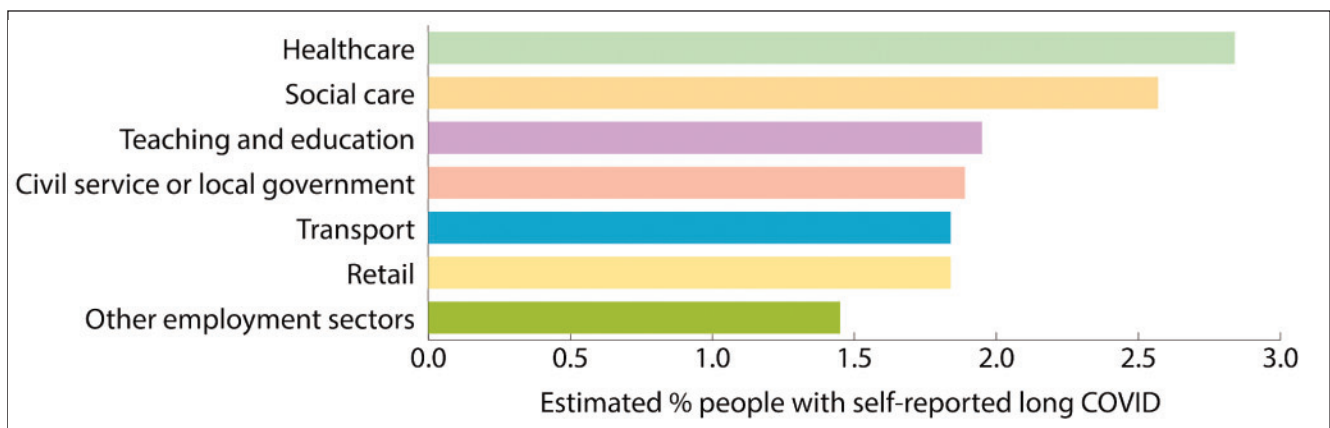


Figure 2. Estimated percentage of people with self-reported Long COVID

affected, demonstrating the importance of patient engagement in research, and how patients can use their experience to help influence outcomes. A recent study²⁴ has shown that plasma samples from Long COVID patients still contain large anomalous (amyloid) deposits (microclots)²⁵, with the authors suggesting that there may be benefits following a regime of continued anticoagulating therapy, helping to support fibrinolytic system function. There is also evidence to demonstrate that prolonged hypoxia could also be a potential cause to some symptoms, notably 'brain fog' and fatigue – a vicious cycle of hypoxia-related inflammation causing a deterioration in capillary function, in-turn accelerating hypoxia-related inflammation and tissue damage.²⁶

As a healthcare professional, there is only so much that journals, research, and textbooks can teach, but those pages will never cover the extent of the difficulties those with a long-term illness face each day. Patients living with Long COVID were subjected to the same mismanagement and advice that those living with chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME) have been fighting against for many years. Debilitating and impactful illnesses that were previously misunderstood have now been brought into the spotlight; notably NICE's decision in August to pause the publication of its updated guideline²⁷ In solidarity, the Long COVID community supported the patient-led CFS & ME communities and encouraged NICE to release the guideline, which they finally did, two months after deciding to pause, in October 2021²⁸ The updated

Guideline provided advice on sensible guidance on activity and energy management to avoid symptom exacerbation and no longer recommending graduated exercise therapy (GET) as a 'treatment' or plan for recovery. The Guideline emphasised the need for early and accurate diagnosis (preferably within 3 months of the onset of symptoms), highlighting overlaps with acute viral infections, like Long COVID.

I am one of more than 45,000 members of the Long COVID Support Group²⁹ on Facebook, a figure that actually seems quite small when you consider that the office of national statistics (ONS) estimate 1.1 million people in the UK were experiencing Long COVID as of 5th September 2021³⁰. It is overwhelming to see complete strangers offering sympathy and support to one another, but worrying to read how many people have similar, devastating symptoms. Even more worrying is the lengths some people are going to in hope of a recovery, purchasing prescription medication from abroad, experimenting with over-the-counter (OTC) and herbal medications (without speaking to health care professionals first), some even spending their savings on seeking treatment abroad due to the lack of Long COVID clinics around the UK. It has been 20 months since my GI symptoms began, and I am still desperate to understand why they are persisting, I purchased a gut microbiome test from Biomesight.³¹ The test provides a snapshot of the gut microbiome and I wasn't surprised to see a 'gut wellness score' of 63.91%. With the help and clever analysis of Ken Lassessen (a mathematician and software engineer with



Figure 3. Author undergoing oxygen treatment in hyperbaric oxygen chamber in July 2021.

chronic fatigue syndrome), we identified ways to potentially aid my recovery which I will certainly pursue and Ken kindly wrote a blog on my analysis.³² I've always been aware of investing time and money to ensure my body 'stays well', but this illness has intensified it! In addition, the number of children who are being diagnosed with Long COVID is very worrying and heart-breaking³³; young people with their lives ahead of them, anxious for their own health. Some even concerned about the health of their parents. This is the reality of 'living with COVID'. It is not going away, so why are we still waiting to help those in serious need?

Despite these groups on Facebook & Twitter having ethical issues in that members (with best intentions) sometimes recommend purchasing various medications online and conducting their own 'clinical trials', I really believe that they have been a force for good, demonstrating the impact of patient advocacy, and empowering individuals to take charge of their own health. I've certainly learned a lot! Without

these groups, I would not have taken part in the handful of clinical trials where I was enrolled as a participant, met like-minded, supportive individuals and been part of helping to support others. We are all certainly desperate for a recovery, back to pre-COVID health; being able to walk upstairs in our own home without shortness of breath, being able to have a few hours away from our beds, not having to schedule the most basic of activities like dressing or showering – activities all dependent on how much energy we have and having the courage to be positive despite the numerous days when we are unable to do these basic activities.

Conclusion

It has been 19 months since I first tested positive for COVID-19 and the effects of the infection are still very noticeable on my day-to-day living. The scary thing is, I'm not alone, and not even *that bad* in comparison to some stories from other patients that I've read and heard. To those affected, those standing in solidarity, those clinicians desperately looking for answers, those healthcare professionals not 'gaslighting' us when we're at our lowest ebb; I truly mean this, thank you.

References

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- 4 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/7october2021>
- 5 <https://www.nature.com/articles/s43856-021-00016-0>
- 6 <https://www.gov.uk/government/publications/wuhan-novel-coronavirus->

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Resources

Long COVID clinics and self-management:

Scottish Intercollegiate Guidelines Network, Health Improvement Scotland, National Institute for Health and Care Excellence and Royal College of GPs. Long COVID: a booklet for people who have signs and symptoms that continue or develop after acute COVID-19: <https://www.sign.ac.uk/patient-and-public-involvement/patient-publications/long-covid/>

Nuffield Health. COVID-19 rehabilitation programme: <https://www.nuffieldhealth.com/about-us/our-impact/healthy-life/covid-19-rehabilitation-programme>

NHS. Your COVID recovery: <https://www.yourcovidrecovery.nhs.uk/>

World Health Organization. Support for rehabilitation: self-management after COVID-19 related illness: <https://www.who.int/publications/m/item/support-for-rehabilitation-self-management-after-covid-19-related-illness>

Long COVID webinars:

All Party Parliamentary Group on Coronavirus: <https://youtu.be/UXakeS4Edac>

All Party Parliamentary Group on Coronavirus: <https://youtu.be/XK5Jz4Yqr8A>

Royal Pharmaceutical Society: <https://www.rpharms.com/resources/webinars/long-covid-what-is-it-and-how-to-manage-it>

Long COVID support groups:

Long COVID SOS: <https://www.longcovidosos.org/>

Long COVID Support: <https://www.longcovid.org/>

Long COVID Support Group: <https://www.facebook.com/groups/longcovid>
COVID-19 Recovery: <https://covid19-recovery.org/>

COVID-19 Long Haulers Support: <https://www.facebook.com/groups/373920943948661>

Advice for employers and employees:

The NHS Staff Council. Management of long-term COVID-19 sickness absences: <https://www.nhsemployers.org/sites/default/files/2021-07/Long-term-covid-absence-guidance.pdf>

Health and Safety Executive. RIDDOR reporting of COVID-19: <https://www.hse.gov.uk/coronavirus/riddor/index.htm>

NHS Employers. Supporting recovery after long COVID: <https://www.nhsemployers.org/articles/supporting-recovery-after-long-covid>

Acas. Long COVID – advice for employers and employees: <https://www.acas.org.uk/long-covid>

Chartered Institute of Personnel and Development. Long COVID: <https://www.cipd.co.uk/knowledge/coronavirus/long-covid>