

Brief Report

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Posted Date: 23 January 2024

doi: 10.20944/preprints202401.1621.v1

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Brief Report

One is the Loneliest *n*: An Autobiographical Report of Long Covid

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Abstract: Long Covid is a debilitating condition that has been well-documented over the past 4 years and shares many similarities with other post-viral chronic illnesses. Despite this, clinicians are not confident in recognising the signs of Long Covid, or effectively managing the symptoms of their patients. This paper presents a single patient case report from a biomedical researcher who has had Long Covid for 2 years; it is written in relatively plain language to be accessible to both patients and clinicians across multiple specialities. The author has had the ability and expertise to keep up with the Long Covid research literature, and from that has cobbled together a management strategy that has alleviated her own symptoms, and those of other people with whom she has shared her protocol. The author's experience of developing and managing her Long Covid is presented here, in the hopes that it may be of assistance to clinicians in identifying and managing Long Covid in their own patients.

Keywords: Long Covid; patient report; symptom description

Introduction

Long Covid is a multi-system, systemic condition that follows on from an acute Covid-19 infection and was first described by patient reports in early 2020 [1,2]. Medical recognition of ongoing health issues caused by Covid-19 infections quickly followed, as clinicians began to see patients who simply “never got better” present with an array of symptoms, ranging from crushing fatigue, cognitive, memory and speech issues, joint pain, constant headaches, dizziness, blood pressure and heart rate issues, immune system dysregulation, new allergies, blurred vision, sensory sensitivities, rashes and hives, menstrual abnormalities, and gastrointestinal disturbance [3]. There is a long history of post-viral chronic illness, with the first formal detailed reports of patients who “never recovered” following illness appearing in the 1930s and 1940s, and the term myalgic encephalomyelitis (ME) established in 1955 [4]. The Covid-19 pandemic is the first time that infection acquired chronic conditions have been reported at such a large scale and proportion of the population, with 10% of all infections resulting in Long Covid, and an estimated at least 650 million people worldwide dealing with this new chronic condition [5].

Despite this prevalence and the extremely high-profile media coverage of Long Covid in the past few years, only 7% of clinicians feel confident recognising the signs of this condition, and only 4% of them feel they can manage and treat Long Covid [6]. The separation of medical care into distinct organ/body systems results in a disjointed and distressing experience of medical care for patients with infection-associated chronic conditions, especially because the number of experienced specialists trained in this field is extremely small (eg. <https://mecfscliniciancoalition.org/about-us/>). The current literature and understanding in the field of Long Covid research is also rapidly evolving and expanding, making it difficult for busy clinicians to maintain up to date knowledge of diagnosis and management options.

Patient-led work has been at the forefront of unravelling Long Covid since the early days of 2020; multiple formal research collectives and individual patients have pushed the science forwards and aided others who have developed this condition. The prevalence of Long Covid and the ongoing rate of infections means there will be a significant health burden well into the future; the author has

written this paper in relatively plain language in the hopes that it will assist both clinicians and patients to recognise Long Covid and offer some effective management suggestions for this infection-associated chronic condition.

Patient risk factors for Long Covid

The author is a cis woman and was 35 [7,8] at the time of her one Covid-19 infection in February 2022. She has a history of mild/subclinical hypermobility [9] and bad hayfever/seasonal allergies [10]. She sustained a sacroiliac joint injury in 2019 during her second pregnancy and has since developed sacroiliac joint dysfunction (SIJD), a chronic inflammatory pain condition [11,12].

Vaccination status/experience

The author was vaccinated 9th January and 1st February 2021 with the Pfizer spike protein mRNA vaccine. She experienced multiple unusual side-effects: flaring of her SIJD for a week post both injections, to the extent that walking was extremely painful; severe gastrointestinal cramps and nausea any time she attempted to eat, for 5 days after each injection; pressure/squeezing headache for 5 days following each injection; extremely disturbed menstrual cycle (menstruation onset 48 hours after each injection; very heavy bleeding for 12 days after the first injection and 10 days after the second, with another very heavy 10 day bleed the month after the second injection. The author was taking the combined oral contraceptive pill at the time; the menstruation induced by vaccination overrode active contraceptive pills). This unusual reaction may be indicative of a systemic sensitivity or inappropriate immune response to the presence of the Covid-19 spike protein, potentially indicating increased risk for Long Covid.

Acute infection symptoms

The acute infection period lasted for 3 weeks, and began with diarrhea, aching swollen glands, sore throat, pressure headache, and extreme fatigue. The author then developed a cough, mild fever, runny nose and stuffy sinuses, severe joint and muscle pain, and constantly elevated heart rate between 120-130 bpm regardless of activity level or postural position. At no point did the author's fever reach above 101°F, and her blood oxygen levels never decreased below 95%. The symptoms were managed with pain and fever medications; there was no ability to access antivirals or other specialised medication.

Long-term symptoms

The author has continued to experience symptoms for the past 2 years consisting of cough, sore throat, unrefreshing sleep, pressure headache, extreme fatigue, hives, severe hayfever reactions, joint pain, joint subluxations, muscle pain, sensory sensitivities, phantom sensations, cognitive, memory and speech issues, covid toes, muscle weakness, tachycardia, heart palpitations, irregular menstruation, vertigo/dizziness, shortness of breath, and post-exertional malaise (PEM) which is the condition in which all symptoms worsen following activity or exertion. See Table 1 for a timeline of when these symptoms appeared, and Figure 1 for examples of hives and covid toes. A plain language description of how the symptoms feel to experience is included, to aid healthcare providers in identifying the occurrence of Long Covid in their patients.

Table 1. Onset, duration, and plain language description of the long-term symptoms resulting from the author's Covid-19 infection.

Symptom	Time of onset	Duration	Plain language description
Cough	Day 2 of infection	4 months	Month 1: wet and productive cough, month 2-4: unproductive, dry cough

Sore throat	Day 2 of Ongoing infection	Dry, scratchy and painful throat, hurts to swallow
Pressure headache	Day 2 of 5 months constant, then 2 days a week ongoing	It feels like a fork is being scraped over the front half of my brain while the back half of my brain is being squeezed in a vice
Extreme fatigue	Day 2 of Ongoing infection	I slept for 16+ hours every day for the first 4 months post infection. If I try to fight or push through feeling tired, I will wind down like I'm running out of batteries and black out from exhaustion, no matter where I am or whether I am lying down. My current sleep baseline is 12 hours a day, with 3-4 days a month needing 16 hours of sleep a day. It feels like I am being drained and weakened, the longer I stay awake past my energy envelope.
Unrefreshing sleep	3 weeks post 22 months constant, then 3 days a week ongoing	No matter how much I sleep, or how well I sleep, I wake up feeling the same or worse as when I went to sleep
Joint pain	Day 2 of Ongoing infection	Deep persistent ache within shoulder, elbow, wrist, and pelvic joints
Joint subluxations	2 weeks post Ongoing infection	My shoulders now pop out of place and back in if I lift my arm too quickly; it feels like a popping then crunching sensation at the shoulder joint, followed by increased muscle and joint pain in that joint. My ribs will slip out of place and I then have a stabbing sensation in my back every time I try to breathe or bend over, until the joint settles back into place
Muscle pain	Day 2 of Ongoing infection	Burning and aching muscles, similar to the sensation following a hard workout, but present at all times
Sensory sensitivities	3 weeks post Ongoing infection	I have become extremely jumpy in response to any sudden noise or movement; it's as if my brain has difficulty filtering out irrelevant stimuli.

			Listening to music, or fast speaking in television/movies, brings on a pressure headache and makes my brain feel like it's full of static
Phantom sensations	3 weeks post infection	Ongoing	Pinching and stinging sensations that feel like I am being bitten by a spider; these usually repeat every 10 minutes in the same body location over an hour or two
Cognitive deficits	2 weeks post infection	Ongoing	Difficulty following conversations; video calls are overwhelming and bring on a pressure headache if they last past 15 minutes; constant mistakes while typing; having my brain "shut down" and feel like it's full of static if I try to engage in high level thinking or conversation for longer than 30 minutes at a time
Memory dysfunction	2 weeks post infection	Ongoing	Complete loss of memory from the 2 months post infection; previous recall ability is severely reduced; reliant on lists and online calendars to remember anything where previously I was able to run science experiments, manage a household, and parent without difficulty
Speech issues	2 weeks post infection	Ongoing	Losing words mid-sentence and being unable to recall them; saying the wrong word in a sentence and not realising, then being incapable of producing the right word even when corrected and making an effort to do so
Covid toes	3 weeks post infection	Ongoing	Swollen, painful, red skin that appears on the edge of toenails and spreads down to the nearest knuckle; this skin then dies and forms a large white blister-like patch before peeling off
Muscle weakness	Day 2 of infection	Ongoing	Shaky and weak; unable to lift everyday objects, frequently dropping household items, burning myself on the oven or

			stove multiple times a day because my hands don't respond like they used to
Tachycardia	Day 2 of Ongoing infection		During illness or times of stress, my heart rate increases to 120-130 bpm and stays there regardless of activity level or postural position
Palpitations	Day 2 of 22 months infection	constant, now in times of illness	My heart constantly skips beats, lurches and does half-beats, and pauses in the middle of beats so that it feels like it's not going to restart
Irregular menstruation	During acute infection	Ongoing	Despite taking the oral contraceptive pill; loss of period during acute illness, followed by extremely heavy 10 day long bleeds every month from March 2022 - September 2022; loss of menstruation starting in December 2022, with 4-6 month gaps between periods for the year of 2023
Vertigo/dizziness	2 weeks post infection	Ongoing	Brought on by sudden postural changes; at its worst I was unable to sit upright without the entire room tilting and spinning around me; daily occurrences of stumbling sideways due to sudden onset dizziness
Shortness of breath	During acute infection	Ongoing	Tightness around my ribs and chest, like an iron band is squeezing me and I can't ever draw in a full breath; worsens with physical exertion
Hives	6 weeks post infection	18 months	Dry, itchy and painful. I was scratching in my sleep until I bled
Severe hayfever reactions	6 weeks post infection	Ongoing, occur every 2 weeks	Itchy deep within my sinuses and nostrils, uncontrollably sneezing every 90 seconds for 36 hours straight, streaming itchy eyes, sudden pressure headache, severe joint pain, muzzy headed and foggy brained. Feel like I've been hit by a truck full of pollen
Post-exertional malaise (PEM)	3 weeks post infection	Ongoing	All of the above symptoms worsen when I over-exert myself mentally, physically or emotionally; PEM also feels like a combination of having a bad hangover,

jetlag, coming down with the flu, and extreme exhaustion all at the same time, on top of the other symptoms worsening



Figure 1. Visual examples of some long-term Long Covid symptoms experienced by the author: **PEM** (A) day 1 one of a PEM episode after 14 hours sleep (B) day 2 of the same PEM episode after 14 hours sleep (C) day 3 of the same PEM episode after 12 hours sleep (D) the author a few months before her covid infection, under similar photograph conditions. **MCAS hives and flushing:** (A-C) MCAS hives (white arrows) (D) MCAS flushing in the skin of arms. **Covid toes (black circles):** (A-B) progression of the red swelling to dead skin blistering observed with Covid toes (C) example of the red swelling (D) example of the dead skin blistering.

At 3 months post infection, the author did not display any organ damage or unusual results other than slightly elevated blood cholesterol in a basic blood panel. She meets diagnostic criteria for postural orthostatic tachycardia syndrome (POTS) [13], mast cell activation syndrome (MCAS) [14], and myalgic encephalomyelitis (ME) [15,16]. The author shows signs of immune system dysfunction; her hepatitis B antibody titres were below detectable levels in May 2022, despite completing the primary vaccine course in 2014, and she has frequent illness at a level beyond her previous experience (in the past 2 years: 4 hand foot and mouth virus infections, 5 sinus infections requiring antibiotics, 3 bouts of RSV, 5 colds, and one influenza infection).

The author has not been able to access specialist Long Covid or post-viral chronic illness care; she is monitored by a general practice clinic and advised on medications by her pharmacist. She is a biomedical researcher who has been able to parse the papers about Long Covid and cobble together some management strategies with the help of her medical team, which are discussed below in the hopes that they will be of assistance to other clinicians.

Management of long-term Long Covid symptoms

The author has been tracking her Long Covid symptoms and management strategies using the Visible app (<https://www.makevisible.com/>). Lifestyle modifications include resting and pacing according to the ME action net guides (<https://www.meaction.net/stoprestspace/>), weekly deep-tissue massage therapy, abstaining from alcohol, and using compression garments. Medications, supplements, and other interventions are listed in Table 2, along with dosing, timing, and the side effects experienced by the author. Changes in symptoms are included, and rationale/references provided for each intervention. Over the past 2 years the author has progressed from moderate Long Covid (FUNCAP55 score of 3.42 [15] at 3 months post infection, house-bound and unable to stay awake for longer than 2 hours at a time) to engaging in scientific work part-time and undertaking

physiotherapy at least 3 times a week (FUNCAP55 score of 4.22 [15]). These interventions have also alleviated the symptoms of 4 other people with Long Covid whom the author shared her management protocol with, and may be helpful for other patients. Thus, a plain language description of the side-effects and symptom alleviation for each is included in Table 2, to assist healthcare workers in managing Long Covid in their patients.

Table 2. Interventions, medications and supplements used by the author to manage her Long Covid symptoms. A plain language description of side effects and symptom changes are included to help clinicians with treating their own patients. Rationale and references are provided for further information.

Intervention	Time of day	Dosage	Side effects	Symptoms alleviated	Rationale & references
Aspirin	7am	160mg	Nil	Cognitive and speech issues, joint pain, joint subluxations, extreme fatigue	Aspirin brings down MCAS symptoms [17], reduces incidence of blood clots, and breaks down Long Covid microclots [18]
Rehydration salts, berocca and creatine	7am	1 litre water with 1 pouch rehydration salts, 1 berocca tablet, 1 scoop creatine	Nil	Vertigo/dizziness, pressure headache, muscle weakness	Bolus fluids alleviate POTS symptoms [19], B vitamins are deficient in Long Covid [20], creatine relieves Long Covid symptoms [21,22]
Nattokinase	9pm	6000 units	Occasional nausea and heart burn sensation; taking 2 hours after dinner helps prevent this	Long and heavy menstruation, extreme fatigue, cognitive and speech issues, covid toes	Nattokinase breaks down amyloid clots and also breaks down Covid-19 spike protein [24], which is known to persist in the body after Covid-19 infection [25]
N-acetylcysteine (NAC)	9pm	1 tablet	Nil	Cognitive and speech issues	NAC is known to reduce cognitive issues in Long Covid [26] and following concussion [27]

Acyclovir	9pm	400mg	Upper left abdominal pain; lightheadedness; nausea; nausea; adjusting dosage helped stop these	Cognitive speech issues, extreme fatigue	and	Herpes virus activation in Long Covid is known to contribute to health issues [28] and acyclovyr has been trialled as a treatment in a small group of Long Covid patients [29]
Metformin	9pm	500mg	Nausea and upset stomach and alternating between diarrhea and constipation for the first 10 days	Cognitive, speech issues, extreme fatigue, muscle weakness, muscle pain, covid toes, unrefreshing sleep, sensory sensitivities, palpitations, and tachycardia	Metformin reduces incidence of Long Covid if given during acute infection [30], and aids in mitochondrial repair and function [31] which are deficient in Long Covid [32,33]	
Ibuprofen	9pm	400mg	Nil	Muscle pain and joint pain	Ibuprofen is an anti-inflammatory pain medication	
Antihistamin e (fexofenadin e hydrochlorid e)	9pm	180mg	Nil	Hives, severe hayfever reactions, joint subluxations, extreme fatigue, cognitive issues, palpitations	Antihistamines are used for the management of MCAS [34] and alleviate Long Covid symptoms [35]	
Multivitamin	9pm	1 tablet	Nil		Long Covid patients display vitamin deficiencies [20]	
Massage therapy	9am	90 minutes weekly	Increased fatigue immediately after, I usually sleep after a massage	Muscle pain, joint pain, muscle weakness, extreme fatigue, cognitive issues	Lymphatic drainage massage alleviates Long Covid symptoms [36], and full body massage alleviates ME symptoms [37,38]	

Thuan Moc	9am and 9pm	Apply directly to hives	Nil	Hives (completely eliminated after a few weeks of use)	Most likely due to the willow bark extract in the cream
Compression socks	All day	Feeling spacey and light-headed	Extreme fatigue, PEM	Compression socks help to regulate blood pressure issues caused by POTS [39]	
Abstinence from alcohol	Constant		Extreme fatigue, joint pain, muscle pain, headache, vertigo/dizziness	Alcohol exacerbates Long Covid symptoms [40]	
Resting and pacing	All the time	Scheduling rest before activity; making sure to sleep whenever I felt tired	Nil	Extreme fatigue, cognitive and speech issues, muscle pain, PEM	Resting and pacing is a well-established management technique for infection-associated chronic conditions (https://www.meactio.net/stoprestspace/)

Discussion

Long Covid is a debilitating and devastating chronic illness; not only does it lead to patients feeling terrible *all the time*, it also results in loss of employment, inability to parent your children, breakdown of marriages, and destruction of your identity and life as you previously knew it. Long Covid patients are at significantly increased risk for suicide (see review [41]) due both to the unrelenting nature of their illness, and the lack of societal and medical support they receive. The author has been extremely fortunate to have both the education and access to understand and trial various interventions for her Long Covid; other patients do not have these privileges and are thus reliant on medical staff to identify and manage this condition. The author has written up her experience in the hopes that it aids clinicians and other healthcare workers in identifying and supporting their patients with Long Covid. Identifying the signs of Long Covid and appropriately managing symptoms from early in the course of this illness spares patients from increased suffering and may help preserve their health until the time there is a full treatment available.

Acknowledgements: The author would like to thank the Patient-Led Research Collaborative (PLRC) for their support in producing this manuscript, and gratefully acknowledges those who went before her for their advice and guidance regarding Long Covid, particularly Hannah Davis, Renuka Dhinakaran, Kristin Houlihan and LongCovidPharmD.

Conflicts of Interest: The author declares no conflicts of interest; there was no funding provided for this work. There was no use of generative AI in producing any part of this manuscript.

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