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Long Covid – A patient perspective

By Sarah Beasley, a Midway Patient Participation Group member

My first Covid-19 infection was in November 2021. I was unwell for around 2 weeks with a cough, high temperature, breathlessness and fatigue. I gradually improved over the next 2 weeks and returned to work after a month on a phased return. My recovery then plateaued and I was diagnosed with Long Covid in February 2022. I struggled with symptoms of Long Covid throughout 2022, with every day being a challenge but by the end of the year I was able to walk to work and had progressed on to swimming twice a week for around 30 lengths. In January 2023, I had my second Covid-19 infection and was unwell with a sore throat, muscle and joint pains, extreme fatigue and headaches. Following the acute infection, I had more significant limitations to my function including a deterioration in my walking, being unable to swim, having to reduce my working hours to half days and increased symptoms of headaches, brain fog, reflux, vocal difficulties and musculoskeletal pains. Progress throughout 2023 has been frustratingly slow and I have yet to return to the baseline I had reached prior to the second infection.

What is Long Covid?

Long Covid was first recognised in the UK in Spring 2020. Patients tended to have a relatively mild infection (generally not involving hospitalisation), felt a little better at 2 weeks post infection then deteriorated. The following definition was produced by the World Health Organization (WHO):

Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and 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. WHO, 2021

Long Covid is a physical illness with multiple symptoms often affecting the whole body. It is thought to affect around 2 million people in the UK (Office for National Statistics, March 2023). There are over 200 reported symptoms of Long Covid, affecting all major organs. The three most common symptoms are cognitive dysfunction (brain fog), fatigue and headaches. Recent research suggests that Long Covid is a result of the body's reaction to the virus, affecting multiple major organs causing varied symptoms throughout the whole body. There is no consensus yet on the cause of Long Covid but theories include immune dysregulation, microbiota disruption, autoimmunity, clotting and endothelial abnormality, and dysfunctional neurological signalling. It is likely there is overlap between these theories (for more information see Davies et al., 2023).

What I have found helpful

Everyone I have met who has Long Covid seems to have a unique mix of symptoms and to date there is no single treatment or medication that is effective universally. The following is a list of things that have been helpful to me personally, rather than an exhaustive list of treatments.

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Long Covid clinic – I was supported initially by the Long Covid clinic. This included input from Physiotherapists/Nurses to work on monitoring my symptoms, managing my dysfunctional breathing patterns, avoiding the cycle of ‘boom and bust’ and returning to exercise. I also had Speech and Language therapy to manage the symptoms of reflux and speech/swallowing difficulties.

Rest/alteration in working hours – I am fortunate to have a supportive employer who allowed me to change my working pattern to half day shifts, predominantly in the morning. I am then able to rest in the middle of the day and I use mindfulness/meditation/yoga to manage my symptoms and focus on my breathing pattern.

Support from friends and family – I am unable to manage everything I did before I had Long Covid. My family now help more with household tasks, cooking, gardening etc, Friends and family have also adapted to my need to rest during the day meaning holidays/days out need to be carefully planned.

Management of activity – I am slowly returning to walking and swimming activities, using the 5% stretch to increase activity without falling into the boom-and-bust cycle. I also break down household tasks into smaller more manageable chunks and try to have realistic expectations of what I can achieve in a day. For example, I find sitting down in the kitchen using a high stool at the work surfaces/cooker enables me to complete the preparation of a meal then I rest before I start cooking.

English National Opera (ENO) Breathe programme – This is a collaboration between ENO and Imperial College Healthcare team and is funded through donations to ENO. It is a breathing and wellbeing programme for people with Long Covid. I initially did an online six-week course which included breathing control, relaxation and singing lullabies. I now attend the virtual weekly twilight sessions which cover warm up activities, exercises to focus on posture and breath control, learning new lullabies and singing favourites from the six-week course. I also have access to numerous resources on the ENO website and have the opportunity to connect with other people who have Long Covid. I have been lucky enough to sing on the stage of the London Coliseum during a lullaby writing workshop and have attended dress rehearsals of some of the Operas ENO have performed.

Singing in a choir – The choir I sing with have been very supportive and adapted to my changing needs. My vocal range and the pitch/reliability of my voice has changed significantly but the choir has been key to my wellbeing and mental health. I have listened to rehearsals on zoom when I have been unable to sing, attended rehearsals for shorter time periods and used a stool to sit on during concerts as standing combined with singing has been too challenging. I use techniques learnt in ENO Breathe sessions to warm up my voice before singing.

Long Covid Physio video series - these useful short videos explain what Long Covid is and the symptoms/management of the condition. I use this resource with family, friends and work colleagues to help me explain my symptoms and how Long Covid affects my everyday life.

Research projects – I have volunteered to take part in research projects which has kept me up to date with developments in treatment/management of Long Covid and will hopefully benefit people with Long Covid in the future.

The last two years have definitely been challenging with the uncertainty surrounding how long the symptoms will last and what can be done to improve them adding to the complexity. However, with careful planning to use my limited energy levels wisely, I am fortunate to be able to work, participate in family life and enjoy some leisure activities.

References/resources

- 🌀 Davis, H.E., McCorkell, L., Vogel, J.M. et al. (2023) Long COVID: major findings, mechanisms and recommendations. Nat Rev Microbiol 21, 133–146
<https://www.nature.com/articles/s41579-022-00846-2>
- 🌀 World Health Organization Factsheet:
<https://who.canto.global/pdfviewer/viewer/viewer.html?v=JJA37JMFLT&portalType=v%2FJJA37JMFLT&column=document&id=69darire811i718b3aq106mk73&suffix=pdf&print=1>
- 🌀 Office for National Statistics (March 2023):
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/30march2023>
- 🌀 Long Covid physio video series:
<https://longcovid.physio/long-covid-video-series>
- 🌀 English National Opera (ENO) Breathe programme:
<https://www.eno.org/breathe/about-the-eno-breathe-programme/>

Measles Campaign

Measles cases were rising in England in 2023. There were 128 cases from 1st Jan – 30th June, of which the majority were in London, this is now expected to be higher. The vaccination rate is lower than the 95% target set by WHO and as low as 60% in some areas of London. Measles can make children and adults seriously unwell and even result in a hospital visit. There is no medical treatment for Measles and the best protection against becoming unwell is to be vaccinated.

Over 20 million cases of measles have been prevented since the start of measles vaccination in the UK. Over 4,500 lives have been saved as a result (source is [UKHSA blog](#)).

A recent survey conducted among parents of children aged 5 and under could suggest that many parents/carers do not feel an immediate threat from measles, mumps or rubella. Measles was rated as most serious of the three diseases however a large proportion of the respondents to this survey perceived the potential seriousness of each of these diseases as moderate or low. Here are some key findings from the survey:

- ⑤ 90% of respondents were aware that their child was eligible for a free MMR vaccine at both 12 months and 3 years 4 months.
- ⑤ 83% of respondents were aware that two doses of MMR is required for full protection, with 12% who were not aware and 6% of people who were not sure
- ⑤ 72% of people felt they knew how to find out if their child had received one or both doses of MMR with 17% of people who do not know and 11% who were unsure.
- ⑤ 86% of respondents were aware of the concept of herd immunity in relation to the MMR vaccine, with 8% who were not and 5% who were not sure.
- ⑤ 58% rated how serious they thought measles can be at 9 or 10 (promoters), 30% of respondents answer 7 or 8 (passives) and 12% 6 or below (detractors).
- ⑤ 48% rated how serious they thought mumps can be at 9 or 10, 35% at 7 or 8 and 17% at 6 or below.
- ⑤ 52% rated the potential seriousness of rubella as 9 or 10, 34% as 7 or 8 and 14% at 6 or below.

Service barriers:

- ⑤ Many comments were around issues with invitation/reminder and/or late invitation from GP
- ⑤ Accessibility of appointments was confirmed as an issue
- ⑤ Many respondents commented around a lack of unbiased information but interestingly the manner in which information is communicated was identified as problematic
- ⑤ Aside from a small number of respondents who felt negatively towards vaccination, had negative experiences of vaccination or who expressed mistrust in the government or health services, people generally viewed vaccination favourably with many positive comments left

For more information on Measles and/or the MMR vaccine, visit the [Midway Surgery website](#) or go directly to the [NHS dedicated webpage](#). For Information about the measles vaccine for adults [read this leaflet](#).

All in a day's work

Here are some statistics for the work we do – the figures are for the months of October through to December 2023

Available Appointments 6,574
Booked Appointments 6,154



93.6%
Utilisation

Available Appointments 4,112
Booked Appointments 3,775



91.8%
Face to Face

Available Appointments 2,407
Booked Appointments 2,324



96.6%
Telephone

Booked Appointments 6,154
Cancellations 763



9.9%

Booked Appointments 6,154
Did not arrive 94



1.5%

New Registrations
62



Have you heard?

... About [The Sandbox](#)?

[The Sandbox](#) is an NHS-funded service to support children and young people in South Staffordshire and Hertfordshire with their mental health and well-being. In addition to providing NHS-funded support, [The Sandbox](#) is a central place for resources about common mental health issues, with information on how to access additional support or emergency services.



Also in a day's work....



Dr Sam Lad visited Maple School in St Albans, supporting and participating in the 'People who help us week', explaining what a doctor does...

Have you heard?

... About New Leaf College?

New Leaf Recovery and Wellbeing College embraces the recovery approach, based on the principles of individual strength, co-production, choice, hope, opportunity and self-management. This concept is an educational paradigm that promotes strengths and supports people to move from the role of 'patient' to 'student' or 'teacher'. To find out more visit the college's website - <https://www.newleafcollege.co.uk/>



Frequently asked questions

We have gathered several questions our staff get asked regularly.

🌀 **I'm in Spain and not feeling well, can I book a telephone consultation?**

The Surgery is not responsible for your healthcare whilst you are abroad. To get medical attention or medication whilst abroad, book with a local medical service. It is strongly recommended to be covered by a UK Global Health Insurance Card and travel insurance before you go. Once you are back in the UK and home, we continue to look after your healthcare.

🌀 **I've had an accident and need medical attention, what should I do?**

Firstly, is this an emergency, urgent minor injury or can your local pharmacy help??

🌀 **For emergencies, call 999 or go straight to A&E for anything that is life-threatening or any of the following:**

- ❖ Signs of a heart attack – chest pain, pressure/heaviness or squeezing across the chest
- ❖ Signs a stroke – face dropping on one side, cannot hold both arms up, difficulty speaking
- ❖ Sudden confusion
- ❖ Suicide attempt
- ❖ Severe difficulty with breathing
- ❖ Choking
- ❖ Heavy bleeding
- ❖ Severe injuries including severe head injuries
- ❖ Unconscious or seizure
- ❖ Sudden, rapid swelling of lips, mouth or tongue

🌀 **For urgent minor injuries, go to an Urgent Care Centre – our local ones are at Hemel Hempstead Hospital or QEII in Welwyn Garden City. They will look after:**

- ❖ Sprains, strains and suspected broken bones.
- ❖ Injuries, cuts, bruises and anything that may need skin/wound repair such as stitches.
- ❖ Urgent wound dressings

For all of the above, there is no need to contact the Surgery as the appropriate equipment and emergency-care clinicians are available at these services.

If the injury is minor and you are able to care for at home, your local pharmacy can help with pain-relief, wound care and much more.

The legend that is Midway Movers

Following Midway's successful participation at the NHS's 75th anniversary Parkrun, we have kept the momentum going by challenging ourselves to keep as active as possible as a surgery. To add some beautiful virtual scenery, we have used the Conqueror app and completed 10 challenges over 5 months. Virtually, we have explored four continents by, for example, walking Route 66 and the Great Wall of China and received medals for each challenge. The team has walked a total of 14,122kms which is equivalent to walking to the other side of the earth or across the whole of the moon!

It has been rewarding to watch each other's accomplishments and to celebrate these successes together. This collaborative effort has not only improved our physical health but also reinforced a supportive team culture. We hope to continue our journey together and are now working towards the Chilterns 3 Peaks Challenge on the 8th of September for Rennie Grove Hospice who have helped so many of our patients, friends and their families.



If you are interested in getting active through walking, please see below for local groups:

Hertfordshire health walks:

<https://www.hertfordshire.gov.uk/services/recycling-waste-and-environment/countryside-management/hertfordshire-health-walks/hertfordshire-health-walks.aspx>

Verulamium Park walk:

<https://blog.parkrun.com/uk/2022/09/14/introducing-parkwalk-at-parkrun/>

Chilterns 3 Peaks Challenge

<https://renniegrovepeace.org/get-involved/fundraising-events/whats-on/chilterns-3-peaks/>

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Have your say



At Midway Surgery we encourage our patient to provide us with feedback so we can do our best to improve our services and the care our patients receive from us. One of the ways to provide us with feedback is using the Friends & Family Test survey which is available [on our website](#), in the post appointment text message and in paper form at our reception. The written comments are monitored weekly so we can praise our staff when they do well and identify areas where we can improve.

We recently did some analysis on a large number of written comments, submitted through the Friends & Family Test survey, and found that although the vast majority of patients are very happy with Midway Surgery (85% of comments rated us as “Very Good”), one subject which attracted most negative comments was - waiting on the phone when calling the surgery (76% of comments about phone queuing rated us as either “Poor” or “Vey poor”).

We appreciate that it can be very frustrating, having to queue when trying to get through to us. Midway strive to have as many staff as possible available during our busiest times. We have a couple of solutions to help our patient get in touch with us without having to queue unnecessarily.

- 🌀 **eConsult** – you can find [this interactive tool](#) on our website. eConsult can be used for all our services but is especially handy if you have an administrative task to complete. It is very similar to sending us an email, only the information is gathered in such a way that our team can quickly and easily deal with the query.
- 🌀 **Call back** – when in our phone system’s queue, you will be offered a call back service. This means that your place in the queue is retained while you are off the phone. Our system will automatically call you, at the number you were calling from, when you are nearer the front of the queue, leaving you free to get on with your day.

Please also remember that you may be able to receive the care you need by visiting your local pharmacy and/or by calling NHS 111. You can read more about “[Why you don’t always need to see your GP](#)” by clicking on the link.

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Are you finding our quarterly newsletter useful?

If you can spare a few minutes and would like to have a say, please follow the link to [complete a short survey](#) which will help us tailor future releases to our audience. Many thanks in advance from all of us at Midway.