Long Covid Case Study

Current situation

Mary is a 57 year old nurse educator and researcher who lives with her long-term partner (Andrew) a retired 69 year old who is now her carer (and chauffeur). They live in a bungalow in a Buckinghamshire village. Mary developed her first covid symptoms on 12th March 2020 – six weeks after starting a new academic job. Mary managed to keep working (from home) for the first week but then crashed and spent three weeks in bed.

Mary wasn't hospitalised at the time of her acute covid infection but probably should have been. As she was able to talk to medical staff over the phone so it was assumed her oxygen levels were within normal limits. She was admitted to hospital for six nights in October 2020 with severe breathlessness and low oxygen saturations and was diagnosed with Post-Covid Pneumonitis during first admission and started on prednisolone.

Mary took her occupational pension (early) in July 2021 having run out of sick pay and was recently awarded Personal Independence Payment. She resigned from her academic role in July 2022 due to ongoing cognitive dysfunction and fatigue. She continues to edit a nursing journal and textbook. Limited attention to detail and working memory means she has employed an editorial assistant to ensure work on the textbook is completed. Mary is also doing her bit to advocate for NHS staff with Long Covid.

Mary has had to learn to pace herself to make the most of her limited energy levels and brainpower. She suspects that she wasn't aware of this for several months which may have contributed to the severity/longevity of her Long Covid. She has to balance the amount of physical, emotional, and cognitive energy used. Failure to do so often results in her having to spend a day or two in bed. She normally has an afternoon sleep (1-2 hours).

Mary is much better than she was but has never returned to her pre-covid levels of health. Her on-going issues include:

- Fatigue
- Cognitive dysfunction
- Moderate to severe headaches (daily)
- Low mood
- Post-exertional malaise and symptom exacerbation
- Occasional sore throat and swollen glands
- Tingling in her face – now intermittent and mostly when she has over done it
- Problems sleeping – although much better than it was – with occasional myoclonic jerks

Mary was experiencing a significant amount of breathlessness which in March 2021 was attributed by the local respiratory consultant to her being overweight. However, despite losing 32 lbs the breathlessness did not improve. Since tests at Harefields Hospital in Summer 2022 ruled out damage to her heart and lungs she was diagnosed with dysfunctional breathing disorder and has been having pulmonary physiotherapy which has improved things dramatically. Following a recent outpatients appointment Mary has been referred for an exercise Echocardiogram and a repeat six minute work test – she scored 61% previously.

Accessing health care has been hard during the pandemic but Mary has managed to access some tests. These are detailed in Table 1. She is still struggling to access care for other issues (see below).

Mary had several long term conditions before she caught covid and was classed as extremely clinically vulnerable. Since having covid she has developed a few more conditions (Table 2).

Table 1: Test carried out and results

Associated with admission to hospital in October 2020	Following appointment in Long Covid clinic in early 2021	At Harefields Hospital – Summer 2022 onwards
• Enhanced CT scan (Nov 2020) - normal • Lung functions tests (Dec 2020) - mild abnormality attributed to me being overweight.	• MRI brain – found white spot on brain – cause remains unknow • Sleep study – two studies showed sleep apnoea but improving • Echocardiogram – described as more or less normal • Bloods – HbA1C raised (see below)	• VQ scan - normal • 7 day ECG - normal • CT angiogram pulmonary scan – normal • MRI heart – normal • NM lung ventilation and perfusion - normal • Lung function tests – normal • Bloods • Sleep study – mild sleep apnoea • Cardio-pulmonary exercise test – normal but spent 3 days in bed afterward

Table 2: Mary's long-term conditions

Pre-existing long-term condition	Details
Asthma	• Well managed - Symbicort turbohaler BD (variable dose – usually 2 puffs BD with additional doses as required) and montelukast 10mg OD (evening).
Allergic rhinitis and chronic sinusitis	• **Seasonal hay fever** managed with cetirizine 10mg OD. Since October 2020 has been taking this all year. • **Chronic sinusitis** since the late 1980s for which she uses a Nasonex nasal spray x 2 per nostril BD as well as taking sudafed when needed.
Hypertension	• Takes Amlodipine 10mg OD and Ramipril 10mg OD • Blood pressure now well controlled • NB stroke consultant wants BP within 130/80 range. • Also takes Atorvastatin 40mg OD due to high cholesterol level – prior to covid dose was 20mg.
Inflammatory bowel disease (probably Crohn's disease)	• Currently in remission and off all medications apart from over the counter peppermint oil capsules BD. • Takes Vitamin D – 20 micrograms BD (prescribed) due to deficiency along with a Vitamin B12 supplement (OTC) • Over 5 years since last colonoscopy (August 2017). • Gluten free diet for 5 years seems to help. • Referral done in Autumn 2021 to transfer care to local hospital. • Told after gastroscopy in June 2022 would be followed up by IBD nurses but this has not happened yet.
Painful hips and neck	• **Painful neck** since whiplash injury in late 1980s. • Physio exercises given in 2011. Rarely has the energy to do these so has a monthly massage to help manage it. • 1g paracetamol QDS normally controls pain. • **Painful hips** for years – particularly bad at night. X-ray in 2019 (normal) followed by MSK physio and exercises. • Had improved pre-covid but is now waking her up at night three or four times a week. • Also sometimes has pins and needles in her lower legs and feet at night.

	• Has seen a one-off physio a couple of times (2021 and 2022). Now waiting for appointment with MSK physio appointment (Feb 2023) for more long term input. • Takes turmeric at night to help with inflammation as advised by physio in 2019.
New long-term conditions	**Details**
Post-covid pneumonitis	• Admitted to hospital via A&E in October 2021 with post-covid pneumonitis and a secondary infection. • Treatment antibiotics and steroids.
Headache	• Moderate to severe headache daily since acute covid infection • Brain MRI in March 2021 carried out because of this which showed a white spot – cause currently unknown – seen by stroke consultant in May 2021. • Started taking aspirin 75mg OD. • GP discourages her from taking NSAIDs due to diabetes so on paracetamol 1g QDS and 30 mg codeine phosphate 30mg 4-6 times a day. • This normally controls the pain moderately well.
GERD	• Gastroscopy in June 2022 showed mild to moderate gastritis. • Now well controlled on Esomeprazole 20mg BD and Famotidine 20mg OD.
Type 2 diabetes	• Bloods in March 2021 showed HbA1C was 58. (Had just stopped long-term steroids.) • Lost 32lbs since April 2021 on a keto and then moderate carb diet and HbA1c is now within normal limits. • Signs of diabetic maculopathy were found at eye test in June 2021 and so restarted medication. Currently taking 1g metformin BD which appears to be controlling ad hoc blood sugars.
Depression	• Citalopram 20mg OD since October 2021. • Increased to 40mg OD in December 2022. • CBT provided via the Long Covid clinic in early 2021.
Carpal tunnel (bilateral)	• Symptoms since February 2022 – maybe due to knitting. • One off appointment with physio in March 2022 – given exercises and advised to wear splits at night. • Often woken at night by tingling and numbness in arms and fingers. • Analgesic drugs for other conditions help.
Problems sleeping	• Ongoing issues with sleeping which have improved over time. • Takes 10mg melatonin at night (imported from North America). • Improved significantly once started on antidepressants in October 2021. • Some evidence of sleep apnoea in earlier sleep studies – results of additional study in November 2022 awaited. • Recently painful hips have disrupted her sleep (see above)
Issues with eyes	• Congenital cataracts – aware of for over 20 years but grew to the extent surgery was needed due to covid or steroids post-covid – surgery on both eyes in 2021. • Dry eyes treated with Thealoz Duo eye drops – on recommendation of optician. • Optician picked up blepharitis during 2022. Now under control with biweekly use of wipes.

Mary's current concerns relate to accessing additional diagnostic tests and associated health care. Recently neurology and endocrinology referrals have been declined. She thought she had

persuaded her GP to refer her to a neuropsychologist for assessment of her cognitive dysfunction but this doesn't seem to have happened. (NB the results of the *Great British Intelligence Test* and *My Cognition Pro* demonstrate a significant decline in cognitive ability.)

Other health related concerns include:

- Not knowing what has happened to her follow up by the IBD nurses
- Why her HbA1c is normal but still developing maculopathy and need to take metformin
- Limited access to care needed due to NHS pressures.

Mary is also worried:

- About the ongoing toll on Andrew of being her carer
- That she is unable to care for parents or look after her nieces and nephews as much as she used to be able to. This has an impact on her wider family.
- Not knowing what her life will be like going forward.

Desired outcomes

- To have access to all diagnostic tests and treatments required.
- Support with navigating health service and accessing additional help such as benefits.
- Advice and treatment provided in a timely manner about managing ongoing symptoms e.g. pain, fatigue.
- To live as full a life as possible.

Likely enablers and barriers to achieving these outcomes

- Support with navigating health service and accessing additional help such as benefits.
- Health care staff with greater understanding and knowledge of Long Covid and relevance of post-exertional symptom exacerbation on treatment and rehab options.
- More Government funding for Long Covid services and research.

Past and current experiences of relevance

Very little input from her local Long Covid clinic (one virtual appointment) which has focused on living with symptoms rather than diagnostic tests and treatment. Workshop on fatigue offered in 2022.

Respiratory physio was unaware of PESE – recommended Mary for pulmonary rehab. Post exertional malaise and symptom exacerbation after her cardio-pulmonary exercise test means she won't be taking up this opportunity.