Witness Name: Natalie Rogers

Statement No.: 1

Dated: 17 June 2024

UK COVID-19 INQUIRY

WITNESS STATEMENT OF NATALIE ROGERS

I, Natalie Rogers, will say as follows: -

1. I make this statement for the purposes of Module 3 of the Covid-19 Public Inquiry. I make this statement on the basis of my own knowledge or belief. Where something is outside my own knowledge, I will refer to the source. I am happy to give oral evidence to the Inquiry in Module 3 to expand upon the matters set out in this statement or address any other issues arising.

2. I provide this statement in accordance with the Inquiry's request dated 16 May 2024.

3. This statement is structured as follows:

   A. Overview of personal circumstances and background
   B. Long Covid Diagnosis and access to treatment
   C. The impact of Long Covid

A. Overview of personal circumstances and background

I. Background which has led to providing evidence to the Inquiry

4. I make this statement to the Covid-19 Inquiry to give an example of how those with Long Covid in the early days of the pandemic were regarded by healthcare services and the impact that the lack of consideration for long-term

sequelae had. There was plenty of evidence that viruses (e.g. Spanish Flu, MERS, SARS-CoV1) cause long-term sequelae, yet the narrative put forward by the Government and healthcare services did not consider long-term harm from infection as being a possibility. When raising the alarm about longer-term sequelae, people were met with a pervasive narrative – that they cannot still be ill from Covid-19 unless they were so critically ill that they could die; that they will recover and be fine. This narrative made it difficult for people, myself included, to be acknowledged. We were made to feel invisible.

5. It is important for those with Long Covid to be seen during the course of the Covid-19 Inquiry, and to be validated. Preparation for future pandemics must recognise that there is a possibility that people will suffer long-term consequences and will need support. Even though there are significant papers on Long Covid now, the narrative that people cannot suffer long-term harm from Covid-19 persists. At best it is regarded purely as a post viral syndrome from which people can fully rehabilitate themselves. This needs to end. Policy makers must acknowledge that Long Covid is a serious condition, that it can impact anyone; young, old, fit, healthy and that it does warrant a sufficient level of research funding to both understand and treat it. People are still contracting Covid-19 and suffering long-term health issues as a result. We cannot just wish it away.

II. Overview of personal circumstances and acute Covid-19 infection

6. I am a deputy headteacher. I contracted Covid-19 in March 2020. At the time I was employed in a Lancashire state school as an assistant headteacher and teacher of mathematics. The majority of our students were in receipt of free school meals, with a substantial number living in poverty. During lockdown we made a huge effort to continue to provide essential services to children and families in need. I believe that I was infected whilst attending or travelling to my workplace for the purpose of distributing food parcels. I was led to believe that I was not at significant risk from Covid-19: I was an extremely fit and active teacher deeply committed to my job and my family. I was worried about Covid-19 as my daughter has asthma, having previously had pneumonia as a child. I took sensible precautions, but I had no idea that Covid-19 would be anything more than mild and flu-like to anyone who was not elderly or otherwise vulnerable. There was simply no information provided

by the Government or anyone else that there was a risk of long-term harm to your health from a virus.

7. I was severely ill during the acute stage of my Covid-19 infection. It started on 29 March 2020 which was a Sunday. The first symptoms came on quite suddenly in the evening, I felt achy, shivery, and exhausted. I spent the next two weeks in bed and self-isolated. My daughter was also subsequently unwell with similar symptoms of acute Covid-19. Neither of us were able to get a Covid-19 test. Despite this, I was advised to stay at home rather than being treated in hospital. I was terrified for my daughter as she had asthma and felt completely incapacitated as a mother knowing that my daughter was also unwell with the virus. I was also concerned for my own health. Fortunately, my daughter recovered after ten days, but I continued to suffer from severe difficulties breathing, experienced crushing chest pain, lung problems, intense sinus pressure, extreme muscle/joint pain and was unable to walk to the bathroom without difficulty

8. During the first 10 days of being acutely infected with Covid-19, I tried to call NHS 111 on several occasions. This was complicated by the fact that I could not get a PCR test as my symptoms did not match the three published symptoms of Covid-19 at that time: fever, cough, and shortness of breath. As I never developed a cough and did not have a fever, this appeared to cause confusion to the call handlers. However, I was struggling to breathe, had chest pain and my lungs felt like they were burning. I got passed from the NHS 111 Covid-19 line to the NHS 111 non-Covid-19 line, I seemed to fall in the gap between the two. This involved me being directed to call back as once I had been directed to one service it was not possible to be re-directed to the other. Often, I would be held in a queue for so long that I gave up trying. At no point did I get to speak to a clinician. I was advised to shelter at home and recall being told to only seek medical care if I stopped breathing as I did not meet the threshold for hospitalisation, which apparently encompassed being unable to draw breath and having lips that are turning blue.

9. Attempts to get medical advice during this time were exhausting and futile. It took so much effort and energy to try and get through to a 111-call responder. I would spend hours trying to get through; all the while worrying about burdening the NHS when it was under pressure. I would come off those calls

questioning myself and questioning whether I really had a right to be asking for healthcare, whether I was sick enough to merit it. Although I did not know this at the time this was the start of years of being and continuing to be chronically ill with Covid-19.

10. By mid-April 2020, the initial symptoms, that is crushing chest pain, struggling to breathe all the time, and burning in my lungs started subsiding but by early May 2020 they returned and further symptoms developed. Occasionally I had slightly better days but as soon as I tried to get on my feet, I ended up back in bed with a new onslaught of symptoms. I experienced cold shaking sweats while simultaneously my head felt like it was on fire despite my body being cold. I also suffered from extreme muscle/joint pains, tingling sensations, and intense sinus pressure among other symptoms. I have never been a migraine sufferer but the pain in my head at that time was excruciating; feeling as though my brain was being crushed by my skull. I took a combination of Ibuprofen and Co-codamol but these did not scratch the surface of the pain I felt.

11. On 4 May 2020, I had been unwell for 37 days. I called NHS 111 due to my ongoing and seemingly worsening symptoms. I was given an appointment at the Covid-19 Hub near to where I live. I was given a blood test, the results of which later came back normal, but my blood pressure was very high, such that the clinician thought the device was broken. The clinician advised me to rest, keep moving but not overexert myself until I felt recovered. My body felt like it had been poisoned. At this time, I still had not received a positive Covid-19 test so I had no way of proving that I had Covid-19. A discussion was had as to the likely cause, during which I stated that it seemed too much of a coincidence for me to be suffering symptoms following a viral illness and for it not to be Covid-19.

12. Shortly after this, on the evening of 22 May 2020, my chest felt particularly tight but it was the first time I had fallen asleep properly after several nights of insomnia, profuse sweating, chills and vivid dreams so I did not think much of it. However, in the early hours of 23 May 2020, I was woken by intense pain in my left chest/shoulder and all down my left arm. I felt extremely sick and dizzy. I contemplated ringing an ambulance but was too exhausted to do so. At this point, I decided I would either wake up or I would not. When I woke

on the morning of 23 May 2020, I could not move my arm at all and had such an intense headache that I slept all day. I spent the rest of the weekend feeling very unwell and unable to use my left arm. After regaining some strength on 25 May 2020, which was a bank holiday, I called NHS 111 as my GP's practice was closed. After liaising with NHS 111 over the phone for two days, I was eventually able to be seen at the Covid-19 Hub on 27 May 2020. It was difficult for me to stand up for any length of time, and I struggled to concentrate on conversations and process information. It was incredibly hard to have to explain what happened and seek help when I was so ill. At the Covid-19 Hub, a nurse practitioner took bloods and, did a Covid-19 test. I was later advised that blood tests did not show abnormalities and that the Covid-19 test was negative. This was unsurprising as it was now almost 2 months since my initial infection.

13. Following continued intense chest pain and a high heart rate, I called my GP on 29 May 2020 and was referred back to the Covid-19 Hub's urgent care triage tent. I attended the Covid-19 Hub on 29 May 2020. During the consultation, I was questioned by healthcare practitioners about whether I was suffering from anxiety, which I denied. I am a robust person with a difficult job in public service and I am used to dealing with multiple challenging situations including child protection issues. The idea that I was anxious about a virus or manifesting my symptoms was so wrong. My medical records show that it was also suggested during this appointment that I was experiencing symptoms of menopause. I felt that this was dismissive and did little to truly understand the systemic and devastating impact my symptoms had including on chest, heart and lungs. I was unable to fill my lungs and got light-headed when I tried. I experienced stabbing chest pain, shingles like pain in my chest and back, fatigue, being unable to stand, muscle pain in legs, freezing cold feet, tachycardia, vertigo, distortion to my sense of smell, sinus pressure, sore eyes, headaches, nausea, visual disturbances, mental confusion (including inability to speak, form sentences and memory loss). A resting ECG was completed; the results of which are recorded in my medical records as "116-123, anxiety?". Further blood tests were also taken, and I was referred for a chest x-ray. After this appointment, I felt defeated, especially in my efforts to seek advice because the way I was responded to made me feel like I was accused of being someone who wanted to be medicalised. This whole experience was atypical of me, I would have been at work if I could have

been, and all I was trying to do was to get someone to explain what was happening to me.

14. On 18 June 2020, I had a Covid-19 antibody test which excluded Covid-19. I have since learnt that women do not mount the same antibody response and do not always have a positive antibody test more than two months after initial infection. However, at the time this led me to further question whether I could possibly have had Covid-19.

B. Long Covid diagnosis and access to treatment

I. Diagnosis

15. In the months after this, my symptoms continued and I also developed further symptoms, including but not limited to gastro-intestinal issues, severe indigestion/reflux, tachycardia, an internal juddering sensation, heart palpitations, vertigo and other balance disturbances, enhanced sense of certain smells/phantom smells, visual disturbances, sore eyes and cognitive problems including difficulty reading and with speech.

16. I first became aware of the term Long Covid from social media. On 27 June 2020, I joined the Long Covid Support ("LC Support") Facebook group. I came across the Facebook group because I was desperately searching on the internet to find out why I was getting worse and not recovering.

17. LC Support began as a peer support Facebook group in May 2020, registering as a charitable company in May 2021 and with the Charity Commission in May 2022. The charity provided me with support and information on Long Covid and finding this group was the first thing that provided any sort of relief that I was not going mad. The Facebook group provided a forum for stories of those going through similar experiences to be shared. For everyone in those early days, the online support groups were a lifeline. I was spending days, months, lying in a dark room being unable to do anything. Knowing that there were other people experiencing the same debilitating symptoms was validating for me and in many ways reassured me that I was not alone. I had my family with me caring for me throughout this period when I was unable to care for myself, but I know that some people in the group did not have that support. Being part of the group helped me to understand what was

happening to me. Knowing that many people were similarly affected made me more determined to find answers.

18. On 18 and 30 June 2020, I had two further consultations at the Covid-19 Hub to discuss my ongoing symptoms. These followed a patient-initiated telephone request by me. On these occasions, the GP that I spoke with indicated that Covid-19 was the most plausible explanation for my persistent symptoms. I was referred to Cardiology due to ongoing tachycardia and received an echocardiogram on 27 July 2020. Despite these investigations, after five months since initially contracting Covid-19, I still felt like I was a long way from being back to who I was before. At this point I continued to suffer from significant deterioration in my physical abilities and diminished cognitive function. I notified my GP of this in writing on 29 July 2020 because I wanted them to understand my current condition and I also wanted there to be some form of record of my symptoms which were otherwise unrecorded. I decided to write to my GP because when the receptionist called on 24 July 2020 to check up on me, I was quite taken aback and was unable to formulate anything constructive in my head.

19. On 24 September 2020, after receiving advice from the Cardiology department and my GP that my ongoing symptoms were most likely attributable to Long Covid, I again wrote to my GP to update them on my ongoing persistent symptoms. In this letter, I highlighted that the biggest issue for me continued to be chest pain. This came on suddenly after exertion and after eating. It was an intense, crushing pain, leaving me short of breath and feeling dizzy. It usually passed if I sat/lied down and rested. By exertion, I generally mean a very short slow-paced walk. That was the upper limit of my activity, and I felt exhausted and needed to rest for the remainder of the day afterwards. Most days I also experienced what feels like a brain zap, where my whole visual field seemed to judder and distort, causing me to lose balance – this also involved an intense flash of light. My general cognitive ability/processing speed continued to be noticeably diminished.

20. On 13 October 2020, I received a call from my GP about my letter of 24 September 2020. I was formally diagnosed with post-viral fatigue syndrome, suspected Long Covid by my GP, and on 14 October 2020 my GP sent a request for a Long Covid Rehab Pathway referral. The GP who I had spoken

with previously was honest about her limitations in understanding the condition, but she was willing to ask for tests.

II. Long Covid Services

21. Shortly after the referral, I received a phone call about the referral from the Long Covid Service run by the Respiratory Physiology team of my local NHS Trust who advised me that they would visit me the following week at my home. After preliminary assessments, the respiratory physiologist said that it was most likely that I was hypercapnic during my acute Covid-19 illness, based on the severity of the breathing pattern disorder that I had developed. It was the opinion of my respiratory physiotherapist that I would have been treated in hospital under non-pandemic protocols. I believe this would have also been the case for many others who received the advice to shelter in place despite the severity of the symptoms they experienced.

22. My Long Covid Clinic is not like others are understood to be. My Trust were quick to respond when Covid-19 was initially considered to be a respiratory virus, so the service was set up within the existing local respiratory physio team. This meant that the respiratory physios would then come out to see you. They were great and I cannot fault them.

23. Despite weekly visits from the respiratory physiologist to work on the dysfunctional breathing patterns I had developed during the acute phase of my Covid-19 infection, by 15 January 2021, I had still not been able to progress with rehabilitation beyond breathing exercises due to my elevated heart rate on minimal exertion. It is noted in my GP record on the 1 March 2021 following a 24hr ECG that I had inappropriate sinus tachycardia on minimal exertion, although this was not followed up by the surgery at the time.

24. The Respiratory Physiology Team had first focused on my dysfunctional breathing patterns but then looked at getting me mobile. It quickly became apparent that I had various symptoms involving muscular skeletal pains and post-exertional malaise ("PEM") in additional to my respiratory symptoms. On this basis, the Long Covid Service decided to add an Occupational Therapist to my care. The Occupational Therapist conducted a cognitive assessment and worked with me to develop methods whereby I could conserve energy, and thus reduce the impact of tachycardia. For example, this included adding

a stool in the kitchen and the bathroom. We then started to work on gentle incremental exercise. After first becoming ill in March 2020, it was only a year later that I was able to walk at all outside the house. This was initially the equivalent distance of a few houses up the road and back again. I practiced exercise tolerance. Gradually I worked from that to walking around the block. Now, four years after the initial infection, I am still only able to walk short distances on flat ground and continue to experience significant pain.

25. As a result of the cognitive assessment carried out by the Occupational Therapist, I also began working with a Speech and Language Therapist from March 2021. I initially worked with them on a weekly basis. I continued to work with them until April 2024 due to ongoing suffering from receptive and expressive dysphasia, auditory processing disorder and memory impairment. They also supported me with dietary advice as my ability to swallow had been affected.

26. Overall, the most useful advice I got was from the Occupational Therapist who insisted that I needed to take things slowly, pace and celebrate small wins, instead of getting frustrated by the glacial rate of progress. Through my involvement with LC Support and by working with the Occupational Therapist, I became acquainted with PEM, Post-Exertional Symptom Exacerbation ("PESE") and how to manage these using energy envelopes,[1] pacing[2] and heart rate monitoring.[3] I have since gotten a Fitbit and ensure not to exert myself beyond a heart rate of 100, which initially meant walking very slowly and very short distances followed by sitting down and resting. In doing so, I was able to avoid bringing on a lot of symptoms and big crashes. I still suffered from underlying muscular skeletal and cognitive symptoms while also working on the breath work for my chest pain, but I was able to maintain a level of stability.

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[1] The Energy envelop theory suggests that by maintaining expended energy levels within the envelop of perceived available energy levels, people are able to better sustain physical and mental functioning while reducing symptom severity and frequency of relapses.

[2] Pacing is a strategy and rehabilitation approach that balances rest and activities in daily life to manage symptoms such as fatigue and post-exertional symptom exacerbation (PESE).

[3] Heart rate monitoring is a rehabilitation strategy that can be used by people to self-manage symptoms when living with Long Covid. Heart rate monitoring involves the use of wearable devices to monitor your heart rate to more accurately pace daily activities and monitor the body's responses to exertion.

27. Running parallel to the assistance I was receiving from the Long Covid Service, I continued to correspond with my GP, and they referred me to various secondary care pathways including Cardiology, Neurology and Respiratory. I received these investigations because I pushed for them after learning more about the condition through my involvement with LC Support and by keeping abreast of the Long Covid research being published. I did not push for them through a desire to be medicalised but through a desire to understand and treat my condition both for myself and others.

28. Upon referral to a neurologist, I undertook an MRI which showed neuro-inflammation. The neurologist believed this to be the cause of my intense migraines and other neurological issues and prescribed me medication, which I continue to take. I was sent for various cardiology and respiratory tests throughout 2021/2022, including an ECG, echocardiogram, cardiopulmonary exercise testing, full lung function and bronchial challenge testing. These tests show that I have significant inappropriate sinus tachycardia (180bpm during a gentle stroll) as well as cardio vascular limitation and myocardial ischemia evident on high intensity exercise. They also record that my VO2 peak indicates low fitness for my age which I find surprising given that I have always been so active. There are also issues with my peak flow and hyperinflation of my lungs. Structurally my lungs and heart are normal.

29. During the bronchial challenge, I was required to inhale a powder, I failed the test. The person administering the test said that as I was not typically asthmatic, I should not have failed it. They became quite cross at the fact that I did not progress to the next level of the test and seemed to suggest that I was not trying hard enough. I did not undergo any further investigations stemming from the conclusion of this test but I did subsequently notice in my medical records that there was a referral to an asthma service which I missed as I was not aware of this at the time. Having checked back through all modes of communication, I can find no record of the results of the bronchial challenge test anywhere nor of the subsequent referral to the asthma service other than it being recorded as a missed encounter in my medical records. I do have the original letter inviting me to attend the bronchial challenge test on 1 June 2022. On the whole I cannot complain about the number of investigations that I have received, however the results of these have not always been effectively

communicated and the big picture that they present has perhaps not been adequately considered.

30. What I have learnt from these various investigations is that I do not have any significant individual organ impairment. Whilst I understand why medical pathways are set up to eliminate this, I never considered myself to have any. Long Covid is, by definition, a diagnosis of exclusion. However, once all alternative diagnoses are excluded you are left with a label but no answers. Patients are not looking for a label or to be medicalised, they are looking to get well. In order to achieve this when dealing with a novel disease we need a novel approach. Four years into this, I have learnt that my body no longer responds to exertion as it did previously. The tests back this up. I have also learned that, however determined I may be, I cannot simply exercise my way out of this. What I don't fully understand is the underlying pathophysiological mechanisms and how to halt or preferably reverse the damage. A lot of research exists that points to plausible explanations and this now needs to be leveraged to develop holistic clinical pathways appropriate to this novel disease.

31. By April 2024, the Long Covid Service had exhausted the tools at their disposal to assist me with managing my energy and my cognitive issues. They decided to discharge me and advised me to contact the Service if I needed additional care.

32. Compared to many other people, I stayed within the Long Covid Services for much longer. Many services are set up quite differently. For example, a lot of people receive a six-week rehabilitation programme only. The only reason I was retained within the service over all this time was that the appointments became more spaced out. Another reason I stayed with the service for such a long time was because the service evolved from offering local respiratory physiotherapy, and I was then placed with Occupational Therapy and provided with a SALT by that service.

33. Unfortunately, the relatively positive experience I had with the Long Covid Service in my area is not common. I have been fortunate to encounter allied health professionals who were very open minded and willing to learn about the condition but many with Long Covid have struggled to access

appropriate care, diagnosis, and treatment. Through my involvement with LC Support and, hence, researchers and clinicians with a specialist interest in Long Covid, I was empowered to both advocate for myself and to educate those who were wanting to learn.

III. Long Covid Symptoms

34. At 12 months since my initial Covid-19 infection, my persisting symptoms were tachycardia, elevated blood pressure and cognitive issues including significant difficulty with spelling, difficulty structuring sentences/stutter when speaking, memory impairments, reduced processing speed and executive function.

35. I continue to suffer from Long Covid, four years after my initial Covid-19 infection. For the past two years, my most significant issues have been around mobility (significant muscular skeletal pain) and ongoing cognitive issues (short-term memory loss, reduction in executive function/working memory/processing speed). Having not succeeded with getting any advice from specialist referral with regards to the mobility issues, I participated in a Long Covid research trial looking into Long Covid related muscular skeletal issues. As part of this I had a Dexa scan which identified severe osteopenia bordering on osteoporosis, which the clinicians leading the study (as yet unpublished) identify as being accelerated in people with Long Covid compared with the general population.

IV. Messaging on Long Covid

36. As I explained above, it was only when I found LC Support that I had some sort of relief that I was not going mad. The stories of others going through the same experiences, in terms of their symptoms and struggles in getting clinicians to understand, were a lifeline for me.

37. There was limited, and to the majority seemingly no, public health messaging about Long Covid throughout the course of the pandemic. I found out about Long Covid through social media and thereafter joined LC Support, through which I continued to learn about the condition. I did not see or know about the Department of Health and Social Care's public messaging campaign in October 2020 until after the fact while doing advocacy work for LC Support

and engaging with policy makers. By which time Long Covid was a widely accepted patient named condition; the term first having been used on social media in May 2020.

38. There also needed to be better public health messaging about the symptoms linked to acute Covid-19 infections. Due to the limited three cardinal symptoms that health messaging focused on, many did not recognise that they were suffering from Covid-19 and those who suspected so were not able to access tests.

39. The disturbing attitude to Long Covid evidenced by Boris Johnson in October 2020, when he scrawled "BOLLOCKS" on a box grid which summarised findings of an NIHR report on Long Covid commissioned by Sir Christopher Whitty was insulting. It captures how people who know nothing about those living with Long Covid made and continue to make the assumption that we have chosen to car crash our lives by inventing some sort of illness to get attention. This is how we have been portrayed.

40. Healthcare services failed to acknowledge Long Covid as a complex, whole body, chronic condition as they operated on the premise that Long Covid was respiratory based, a view which prevailed quite far into the pandemic. Healthcare providers were limited and could only refer an individual to existing, siloed secondary care pathways. The diagnostic testing available was not tailored to Long Covid and many assessments undertaken would therefore go on to generate negative or non-conclusive results. This further compounded the disbelief encountered from healthcare providers about Long Covid. Even to this day there is a narrative that Long Covid is psychological which is simply not supported by the multiple research papers indicating physiological changes. I further note that people with Long Covid are not permitted by the NHS to donate blood which to me shows the reality and is a stark contrast to the minimisation that people with Long Covid experience.

41. The system failed to consider developing research and was slow to implement clinics with multi-disciplinary teams. At the moment we have a service that was inadequately set up which was prematurely placed in the remit of rehabilitation and works off NICE Guidelines from December 2020. Despite two reviews being conducted by NICE after the initial publication of

the Guidelines in December 2020, they have not been substantially amended since then, despite all the research that has been happening. As a result of this, all research undertaken to this date has sat completely separately to the clinical pathways in place. Importantly, there remains a lack of funding for comprehensive clinical trials on Long Covid, akin to the RECOVERY trial set up for acute Covid-19.

V. Work with LC Support

42. My personal experience and my work through LC Support have led me to understand that the healthcare system's approach to dealing with Long Covid does not offer comprehensive and consistent care for those affected.

43. Having joined LC Support in June 2020 and personally benefited from the peer support offered, I was keen to do more to support the organisation reach its key goals. I started attending virtual meetings in November 2020 with others from the group and got involved with research and advocacy. Doing these things with other members from LC Support gave me purpose and a belief that I still had something to give. I was, at that time, feeling so cognitively debilitated but with LC Support it did not matter. It did not matter that I could not get a sentence out without stopping, that I was stuttering trying to find the words and often would say the wrong words, or that my emails took forever to compose and were full of mistakes. My work with LC Support gave me an arena in which I could practice communicating, a skill I had previously been fortunate to take for granted. It is through this that I got involved with the PHOSP research study and met people outside the charity, including policy makers. We also set about registering as a charity as it was becoming increasingly clear to us that a lot of people would be affected.

44. I increasingly became comfortable talking to people and not being self-conscious about the fact that I could no longer speak as I previously did, process information or respond as quickly as I did. If a meeting was going too fast, we collectively would stop it and say that adjustments needed to be made. It gave me hope at a time where I had lost all hope for myself. If I had not gotten involved with LC Support and growing the charity, I would not be back working now.

C. The Impact of Long Covid

I. Personal Impact of Long Covid

45. Prior to having Covid-19, I had been fit and healthy. My hobbies including mountain walking and climbing. I was an outdoorsy person. I loved spending time with family and friends by going on long walks, bike rides and musical nights out. I was also working full-time and was very passionate and driven in the job I did.

46. I was mostly bedbound for the first 6 months of my illness. Walking to the bathroom would leave me breathless and exhausted. I also experienced dizziness and vertigo due to extreme tachycardia and dysautonomia. It took a further 6 months of working with a respiratory physiotherapist and occupational therapist to be able to walk the few houses to the end of my street, an activity which would leave me exhausted and needing to rest.

47. Since having Long Covid, I get fatigued very easily. I have to walk more slowly and quickly feel as if I have run a marathon. I now get various respiratory issues whenever I have a cold and have to use an asthma inhaler on an ad-hoc basis. For the first three years, I would have to rest for most of the next day even after minimal exertion. When going upstairs, I would have to pause halfway before continuing. Once I reached the top I needed to sit and rest, whilst I waited for my heart rate to settle back down. I would also experience increased chest tightness and high heart rate whilst walking and have to walk slowly otherwise I become short of breath. To this day I still have to pace and manage my energy otherwise I experience debilitating symptoms. One of the most beneficial insights into maintaining a new baseline has been gaining an understanding of PESE. Knowing that over-exerting would cause a symptom crash has enabled me to better manage some of my symptoms. However, like many people with Long Covid I have learned to live with some physical suffering, for example, I know walking will cause me fatigue and pain in my legs, but I still do it.

48. The impact of Long Covid on my mobility hit home for me in October 2023, when my husband took me away to a log cabin which we have previously visited near Cairngorm Mountain. My husband drove me to the base of the mountain where there is a small garden area. From there you can access the

foot of the path we had previously taken up the mountain. I looked up to the snow covered top (4081 feet) and remembered making snow angels up there. I asked my husband how we had reached the top; whether we would take the funicular part way and he reminded me that I used to hike the full track myself. After four years of rehabilitation there is no chance of me walking even the lowest slopes of this mountain. It is my goal to be able to hike it again. The significant decrease in mobility I have experienced affects many aspects of my life, but I have learned to gradually lessen the impact by not over-exerting myself and pacing. I am yet to be able to rejoin my friends for our Sunday walks, and the hope is that I eventually get to the point where I can.

49. Long Covid also affected my eating which became slower and more effortful as well as causing dysphagia. As mentioned above, I was assessed by a Speech and Language Therapist to have reduced muscle function with regard to swallowing. On their advice, I try to have small amounts of high calorie foods often, graze through the day and reduce the oral effort needed by having soft moist food or fluid nourishment. During the first couple of years of my Long Covid, I had to ensure that I was well rested before eating and have the opportunity to rest after doing so. The evening meal was the most difficult as I became progressively more fatigued as the day went on, meaning that I often had to stop eating part way through the meal.

50. I now use a shower seat as standing in the shower is difficult due to orthostatic intolerance. I find that relaxing in a salt bath gives some reprieve from the muscular skeletal pain that I experience on a daily basis, mostly significantly in my knees, hip and back but also in my wrists, hands, and ankles. During the first two years of my illness, I also experienced a lot of chest pain and tightness, which baths helped with. After a bath or shower, I will need to rest before being able to dress myself. I find that if I pace myself, I can avoid having a relapse of other symptoms such as dizziness, vertigo, pins and needles, head pain and PEM. For a considerable time, the tachycardia affected me at all times of the day and on all days, but this is now better controlled.

51. Since having Long Covid, I struggle to find words, have greater difficulty formulating sentences and processing information. I frequently lose my train of thought and cannot complete sentences. For this reason, I was referred to

speech and language therapy. I have learned to manage these issues better than when I first became unwell, although due to receptive and expressive dysphasia, I require people to speak more slowly and break questions/instructions into smaller manageable chunks to allow me time to process and respond. People that know me are aware that my response may be delayed or that I may have to return to a question later once something has come back to me. I find it upsetting when speaking to people who do not understand my condition and presume that I lack understanding or intellect. These issues affect me at all times of the day and on all days. The cognitive issues become more pronounced as I become more fatigued and there is a cumulative effect as the day goes on. I try to manage this by pacing activities, but this means I am limited as to how much I can engage with other people during the course of a day.

52. I now find reading and understanding complex information difficult as I am only able to concentrate for short periods of time, can't remember what I just read and take longer to process information. I therefore have to break tasks down into bite-size chunks or request that information is presented to me in short sentences/bullet points/using clear straightforward language. When reading information from a page or screen, I quickly become fatigued and then struggle to focus, the surface appearing warped and the words blurry. When returning to tasks I often do not recognise what I wrote previously. For some time, these issues were significant and the only thing that I could do was rest as attempting to continue with the task resulted in my vision becoming increasingly distorted and me getting a headache. In a situation where several people are having an animated discussion, I end up not contributing because by the time I have formulated what I want to say the conversation has moved on. I found the cognitive issues particularly challenging in my previous job as people would talk quickly at me, conveying a lot of complex information in one go and would expect an immediate response.

II. The Impact on My Family

53. My husband has effectively become my carer. During the first two years of my illness, he would bring me my breakfast and put everything ready for my lunch before leaving for work. He would then prepare a cooked meal in the

evening. I would either heat my lunch up or if too tired I would snack. However, I frequently forgot that I had put things on to heat and would end up burning the kettle or saucepan dry. Simple meals that could be heated in the microwave were preferable, although sometimes members of the family would return to discover that I had put something in the microwave and forgotten all about it. They had to request that I did not turn on the oven or hob as I frequently left the oven on or even worse left the gas on without lighting it. Now that I have returned to work, I am conscious that this is only possible because he continues to take sole responsibility for the household chores and for supporting our youngest son with his studies.

54. My husband summarised the profound impact that my illness had on my family in his statement in support of my application for personal independence payments. He said:

> *Since becoming unwell with Long Covid, Natalie has become almost completely reliant on her family members to function on a day-to-day basis. As her husband, I have had to re-evaluate how to manage a full-time job whilst being the main person supporting the family with everyday chores to enable us to function as a family unit. I get up earlier in the morning (6am) to ensure things are organised for my son and wife before I leave for work; I cannot rely on Natalie to be responsible for sorting out my son ready for his school day. In the evening when I return from work, I usually find that Natalie has not been able to do very much towards helping out with activities such as cleaning, shopping, washing etc. so this is all left to me and my son. Due to the nature of my job, I always have work to complete in the evenings and at weekends, so I find that my days are even more extended – after cooking, clearing up and sorting out anything that needs doing with my son, I have to sit down and complete marking and preparation for my job. This means I am regularly working past midnight.*
>
> *Before Natalie got Long Covid, we were much more of a team in terms of sharing the load equitably. My son has had to become much more independent and will look to me to support him with homework and studies as when his mum tries to help out it can leave her mentally exhausted and frustrated. Natalie having lost her job has put an additional strain on the family; I have had to manage the finances much more carefully and take on this responsibility completely independently. Before Natalie became ill, we would divide up jobs that needed doing and this has obviously had an impact on both my son and myself. I have had to attend parents' evenings for my son on my own, make relevant medical appointments for him, drive him to*

> *places he needs to be etc. as I know Natalie just cannot cope with these responsibilities since becoming ill.*
> *To all intents and purposes, I now feel like I am effectively acting as a carer for my wife; I cannot rely on Natalie remembering to do simple things such as monitor the kettle when it is on the stove, turn taps off when the bath is running etc. I have to build in time to assist Natalie getting in and out of the bath and dressing etc. Simple conversations can become much more drawn out as I have to patiently wait for Natalie to construct sentences and find the appropriate words; this can become frustrating for both of us. My son finds this particularly difficult, as the patience of a teenager can become quickly tested. He has had to become understanding of his mum's situation and will also be vigilant around the house when his mum may have forgotten to do something.*

55. At the start of the pandemic, I quickly found myself unable to do anything to care for my family. I had to lay there and accept that as a mum, I could no longer be there for my kids, during one of the scariest events of their lifetime. My youngest child was 13 years old at the time and he would come to my room every night to tuck me in and say good night instead of the other way around. My daughter has significant health vulnerabilities and I had to accept that I could no longer care for her personally, nor did I even feel well enough to oversee her medical care. This was profoundly difficult and upsetting for me as a mother. I did not have anything in the tank to communicate and explain to my children what was going on with me. When I did eventually surface months later, there was an occasion where I was downstairs, my son had done something and I corrected him about his behaviour. We had an argument and he broke down, recounting that he spent the last six months not knowing if I was going to die and here I was telling him off which was hard for him to process. I had not realised the full extent to which my children were affected until that day.

III. Impact on my employment

56. Long Covid has had a significant impact on my career. Prior to getting ill in March 2020, I was a healthy, successful school leader working in a fast-paced environment. I was signed off as unfit for work from March 2020 to April 2021 and I attempted a phased return to work in April 2021. I just about coped doing 3 days working every other day in an adapted role whereby I was permanently based in the same office with limited physical movement and was able to pace

how I managed my workload. Unfortunately, I could no longer teach and went from being a GCSE Maths teacher to someone who had to sit and do written calculations for basic mathematical questions due to the cognitive dysfunction I suffered from.

57. I would spend all the time that I was not in work (evenings, in-between days, weekends) resting in bed – mostly sleeping. I also napped in my office at lunchtime. Despite being exhausted and in constant pain I was desperate not to lose my job. Sadly, working was too much and caused me to have a massive relapse in October 2021 that took me months to recover from. I was signed off as unable to work due to Long Covid in October 2021 and in February 2022, was eventually forced to give up the job that I loved as I was unable to work without significant adjustments.

58. My battle to remain in work was further compounded by a lack of understanding of Long Covid both on the part of medical professionals and employers. My sickness review meetings at work were hampered by the fact that the doctor's surgery would often write 'post-viral fatigue syndrome' on my fit for work notes despite my clinical diagnosis of Long Covid and being under the care of a Long Covid Service since October 2020. By August 2021, my fit for work notes still stated that I had post-viral fatigue syndrome instead of Long Covid – 10 months after being clinically diagnosed with the condition. I believe this description as "post-viral fatigue" minimised the daily impact of the disease and the use of the word "syndrome" suggested to a lay person that it was lacking substance or not real. I am concerned that there has not been adequate guidance to employers on Long Covid, the daily impact of Long Covid, how disabling it can be and the necessity to make reasonable adjustments for those with chronic long-term conditions. Again, although there has been much good work here by organisations such as the Society of Occupational Medicine, Royal College of Occupational therapists, and others; this has not been adequately driven by policy makers.

59. In April 2023 I was fortunate to secure a new job as a deputy headteacher. I have been able to manage in this new role as my employer has been incredibly supportive in terms of accommodating reasonable adjustments that enable me to work better. I am also implementing a lot of helpful strategies provided by my Occupational Therapist and Speech and Language Therapist.

If there is a lot of information, I find it helpful to make notes that I can refer back to. I make use of assistive technology, including voice recognition and read aloud software to assist me at work. I also have PA support to assist with the scheduling aspects of my role. No longer having a teaching commitment means that I am able to pace my workload. My husband also continues to do all household chores (shopping, cooking, and cleaning). Without him I could not work.

D. Conclusion

60. Having previously been a hardworking lively sociable person, Long Covid completely altered my life, taking away my career, my independence, and above all, my identity. I would encourage this Inquiry to centre those people who continue to suffer directly from Covid-19. In my view there is a risk that future pandemic emergencies will make the same mistakes unless urgent attention is paid to those who have suffered direct harm from SARS-CoV-2. It is an unhappy truth that people continue to contract Covid-19 and continue to develop Long Covid without adequate surveillance, mitigations, public health communications or treatment. The only way people learn about the long-term harms of Covid-19 is by knowing someone with Long Covid. That is a failure of public health and the opportunity to learn must be taken.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: **Personal Data**

Dated: Jun 17, 2024