

Dear Sir / Madam,

Hope you're well.

I was kindly asked by xxxx, to provide oral evidence for the The All-Party Parliamentary Group to inform its recommendations to the UK Government. This meeting was held on 12<sup>th</sup> January by Layla Moran MP, and is available on YouTube and through the APPG Coronavirus Twitter account if you wish to see the discussion.

In preparation for the debate, I prepared answers to questions which may be asked during the debate and I would appreciate it if these could be used as evidence into this inquiry.

"Questions Session One

**1. Briefly, could you tell us your story and your experience living with LongCOVID? How has LongCOVID impacted your day-to-day life?**

- *Thank you for inviting me to be a part of this, I'm honoured and humbled to be speaking in front of you all today. I'm xxxx, xxxx years old, a pharmacist employed in an NHS hospital in South Wales.*
- *Initially became unwell over Easter weekend; feeling dehydrated, lethargic, distinctive cough, pins and needles-type feeling over the top half of my body, feeling drained to the point where I would need to be woken to eat or drink. It was like no other illness I've ever experienced.*
- *After about 10 days I began to feel better, and after my isolation period, I went back to work. I had ongoing chest problems, but this didn't limit me working and over the next two months my cough started to improve.*
- *In July, I had intense stomach pain whilst in work, with my GP referring me to A&E with suspected appendicitis, but my bloods and x-ray came back inconclusive. A week later, still experiencing pain, I had chronic diarrhoea lasting 7 – 8 hours a day. This persisted for 14 – 15 weeks. I still have diarrhoea daily, where I have up to 4 – 5 loose motions and the stomach pain is still there but fluctuates in its severity.*
- *I've also had terrible brain fog, where I can't seem to recall the most basic of words or phrases, doing silly things like putting mugs in the fridge when I go to make a cup of tea.*
- *I also have tinnitus, a constant ringing noise in my right ear which has been there for a number of months and is quite distracting when listening or communicating with others.*
- *I've had painful palpitations which is quite scary, not knowing why my chest is hurting, especially when I experience these at rest.*
- *I used to play football, go to the gym regularly, and since contracting COVID, I've become significantly short of breath, to the extent where I'm noticeably breathless from walking up the stairs at home.*
- *Prior to contracting COVID, I was healthy with no health concerns or co-morbidities, and I've been left with a catalogue of multi-organ difficulties which I'm sure you can appreciate is quite a concern.*

**2. How has LongCOVID impacted your ability to work?**

- *From July to September, I was able to work from home despite being in significant discomfort and experiencing diarrhoea. I was determined not to let my colleagues and patients down during this difficult time.*

- *I woke up one morning in September and broke down in tears, not knowing how long I could go on living like this.*
- *I've been off work since, and I'm awaiting ongoing tests to determine the cause of my multiple symptoms.*
- *At the moment, I don't think I have the mental or physical capacity to be able to fulfil my usual role as a pharmacist.*

**3. When did you become aware that others were also experiencing similar on-going symptoms?**

- *After attending A&E again at a local hospital for my abdominal pain in September, with subsequent tests returning as normal, I was advised that "there was nothing they could do". I returned home feeling quite lost, upset, with no support, diagnosis or suggestion for the pain or diarrhoea that I'd had for 12 weeks at that point.*
- *I decided to search Twitter and Facebook to see if there were others out there who had similar symptoms after initial acute COVID illness. I was amazed to see the amount of people on support groups and threads with symptoms that mirrored mine.*
- *I joined every group that I could find, as these groups were the only places where I could seek support, reassurance and feel that I wasn't alone in my COVID recovery.*
- *It's been eye-opening to see the amount of people who have contracted COVID but are still yet to regain their pre-COVID way of life. I've also noticed a lot of new members joining these groups over the past few weeks or so.*
- *You sympathise with new members seeking reassurance and support, understanding how they felt during a period of symptoms of unknown cause.*
- *Even 9 months after contracting COVID, I'm yet to recover. You see posts from people very early on in their journey and it's saddening knowing what they'll likely have to endure with no answers, diagnosis or treatment. It's 'just COVID'.*

**4. What support has been made available to you and has access to support improved over the course of the pandemic?**

- *The support from other sufferers has been invaluable. This has been my primary support method.*
- *I paid for a private consultation with a respiratory consultant in London who had experience in seeing patients after initial COVID infection. Sadly, he reassured me that my pattern was what he had seen with other patients after infection. Fortunately, I'm financially able to be able to seek support from the private sector; however, my concerns are that there are probably others who won't be able to do this, driving inequalities of care.*
- *My GP has been very helpful, supportive and understanding, but admitting they "don't know what to do", even where prescription medicine isn't alleviating my symptoms. They made urgent referrals to neurology, ENT and cardiology in November; however, I am yet to be informed of a date as to when I will be seen.*
- *I've been fortunate to have had 6 CBT sessions through Health For Health Professionals Wales. The aim of these sessions is to help me cope with living with a chronic illness as I've found it very hard to accept that I'm still unwell.*
- *I've heard of services being offered to help patients like myself with LongCOVID in England, but these are yet to be formally rolled-out in Wales.*

**5. Do you feel there is adequate awareness of LongCOVID, in terms of both the condition itself and the impact that it has on people's lives and ability to work?**

- *No; this was my motivation to share my story with the public and professional media, to raise awareness amongst the public and pharmacists of the problems associated with LongCOVID.*
- *Notably there have been NICE Guidelines published on managing the long-term effects of COVID-19; however, these don't come close to what these patients actually need.*
- *It's such a complex illness, with no real pathology, affecting multiple organs throughout the body. The symptoms fluctuate, so just as you think you're on your way to recovery, you experience something else or have a set-back. There's no pattern which makes it difficult to diagnose.*
- *We must also consider the impact it will have on children that develop LongCOVID. As adults, we can communicate and have an understanding of our issues. It won't be as easy for children.*
- *My personal life has been significantly impacted; the pain is constant and I lie awake at night in pain with no relief. I've lost a significant amount of weight and my level of fitness has drastically decreased. As restrictions eased, I decided to stay at home, not to see friends and family as I was worried about being too far away from a toilet when I needed it urgently.*
- *Professionally, I tried to continue working from home despite experiencing abdominal pain and diarrhoea, but this wasn't sustainable. The fluctuating symptoms, uncertainty of symptoms and general unwellness makes it difficult to provide safe care to patients and even function at a human-level, let alone as a healthcare professional. You feel guilty, seeing how hard it is for your colleagues in the NHS and you long to help them, but physically you're unable to do so. It's worrying to think how many others this may affect as we continue through the pandemic. It's estimated that 1 in 10 people experience ongoing symptoms after 12-weeks; if this continues, we could be left with a LongCOVID endemic which further decimates our nation and workforce.*
- *I'm a xxxx-year-old male with no health concerns. As a front-line worker, I accepted the fact that it was likely I would contract the virus at some point due to the nature of my role. I did not expect that nearly a year later, I'd still be battling with the effects of it.*

#### **6. What more must urgently be done to support those living with LongCOVID?**

- *There is an urgent need for multidisciplinary assessment clinics throughout the U.K. I've been accepted into a few trials due to my symptoms and most of my diagnoses have been determined from these, not from Primary or Secondary Care clinicians.*
- *The involvement of rehabilitation will be important in the recovery stage of the illness; however, a lot of us aren't actually able to recover yet. Understanding the pathology and cause for our symptoms will help to recognise why patients present with these symptoms, and will likely to continue to present over the next few months and years.*
- *A worrying number of patients in these trials are seeing multi-organs affected, not just the lungs. Without large numbers of patients being accepted into research, we risk leaving patients undiagnosed at home with potential organ damage, or worse, organ failure which adds further burden on our NHS.*
- *Unless you have LongCOVID, I don't think anyone quite understands it, that's why the support groups have been so valuable as we all battle this. We are an untapped resource; one of support, willingness to share our experiences and be a part of research, but also very eager to understand what is, and will continue, to happen to us.*

#### **Finance:**

- *As per NHS Employer guidelines we are meant to retain our full pay whilst being unwell due to COVID-related illness; however, I know this is not honoured everywhere and people living with LongCOVID are battling to get their employer to recognise this, as well as trying to recover from their illness."*

I sincerely hope this helps to form part of the enquiry and happy to provide oral evidence if required.