

UK COVID-19 INQUIRY

EXHIBIT NR/14

CASE STUDIES PROVIDED BY LONG COVID SUPPORT

Case Study 1

Name	F
Member of LC Support involvement with LC Support	Yes
Details of the person affected by Long Covid (age, name, sex)	35, female
Summary of experience of Long Covid	<p>I have had long Covid since April 2020 and have been severely debilitated since then. It all started with chilblains in my hands and feet and then developed all the textbook covid symptoms including breathlessness, chronic cough and extreme fatigue and body pains. I was bedridden for months, dealing with pleurisy and constant chest pains. It was hard to get help from doctors (still is) and was given no treatment during all this time except for paracetamol and ibuprofen. To this day, I am still suffering from awful fatigue, both physical and cognitive, neuropathic pains, joint pains, pressure headaches, blurry vision and cognitive difficulties etc. I can't walk unaided for long and need to use a walking stick and wheelchair when leaving the house. This disabling illness has completely altered my life, work and relationships - I no longer recognise who I am. I used to be a very active person with lots of energy, now I am a shadow of my former self.</p>

Impact upon life	<p>I am no longer independent and have to rely on others to do everyday tasks and to go outside. This is tough to experience and to see how I have become a burden for my loved ones. The impact on my partner's life has been significant as he suddenly had to switch to a 24/7 carer role, having to constantly adjust expectations for our future and put his own needs aside. It's hard for my partner and my family to deal with the ups and downs of my illness, there are months in the year when I am still bedridden, and other months when I am able to do a bit more physically but suffer cognitively from the fog.</p> <p>I was able to carry on working from home during these years though I have had to reduce my working hours significantly and stick to a working pattern with rest periods that do not make my fatigue crash. The "brain fog" is the worst, I find it hard to think, write and read and to absorb new information - things that are necessary to my job. Unfortunately, work is coming to an end, and I will soon be without a job not knowing whether I will be able to find employment again in my condition. This is terrifying as being able to carry on working was an important anchor from my pre-covid life.</p> <p>My mental health has been impacted by this sudden loss of my wellbeing and independence, I now struggle with anxiety and low mood on top of all the physical symptoms.</p>
Response from health care professionals	<p>My GP took my case seriously from the start but they were helpless and had no idea what to do to help. I ended up in A&E several times in the first few weeks of illness due to the breathlessness, chest pains and intense headaches. On one occasion I was told that my symptoms were all in my head and that I needed to take antidepressants - no efforts were made to properly investigate my condition and it was impossible to be seen by specialists. It didn't help that community testing was not available when I first got sick which meant I didn't have a positive covid test to show to doctors as proof of my infection.</p> <p>Eventually I had to turn to private healthcare to access a neurologist, cardiologist and rheumatologist and even then, the treatment options I was given didn't help much. I am still trying to find doctors who are literate in post-viral conditions and fatigue but it is not easy and I feel like I should just give up.</p>

Are you aware how/when contracted C19?	I am not sure, though it's possible I caught it in the office at work.
Have you been provided any medical diagnosis of Long Covid?	Yes. I was diagnosed with "post-covid viral condition" in late 2020 and later on with Long Covid. I have also received a diagnosis of post-covid POTS and suspected post-covid small fiber neuropathy.
Summary of treatment / contact with medical / healthcare support	<p>I have been given all sorts of painkillers, from naproxen for the headaches up to morphine patches but none have helped - instead, I seem to have developed sensitivity to medication and serious side effects to several of the meds I have taken during this time.</p> <p>I take ivabradine for POTS which seems to be the only thing that helps a bit without causing major side effects. I have also been given lots of various supplements but it's impossible to tell whether they are beneficial and I am starting to think I should stop and save the expense.</p> <p>Nothing seems to be helping the fatigue, which for me is the most difficult symptom to manage.</p>

Case Study 2

Name	T
Member of LC Support involvement with LC Support	Ambassador
Details of the person affected by Long Covid (age, name, sex)	22, Female
Summary of experience of Long Covid	Caught Covid in July 2021 when I was 19 years old.
Impact upon life	Long Covid has changed my life in every way. I was a professional tennis player at the time of infection and now I rely on a wheelchair. I was bedbound for over a year. I am also unable to work or study and my hopes for a tennis career are long gone.
Response from health care professionals	I don't think that the doctors around me at the beginning responded well. I was told that I was just dehydrated and one doctor even told me that I looked fine so must be fine. I believe that I wouldn't be in this position if I had received the right help early on.
Are you aware how/when contracted C19?	My friend gave me Covid in July 2021 (Delta Variant)

Have you been provided any medical diagnosis of Long Covid?	Yes, I have. I have also since been diagnosed with Peri myocarditis and Sinus Tachycardia.
Summary of treatment / contact with medical / healthcare support	I have since been referred to doctors who have been very helpful and understanding. I get regular tests and checkups as multiple different minor issues keep popping up.

Case Study 3

Name	I
When did you first fall ill with Covid?	3 rd March 2020
When did you become aware that you had Long Covid?	End-April 2020
What did you know about Long Covid before you found out that you had Long Covid?	Nothing, it had yet to be identified and I was initially diagnosed with possible chronic fatigue syndrome by my next-door neighbour, a senior doctor himself.
Did your GP or other healthcare provider know what Long Covid was?	No, I taught them about it.
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	I first heard of Long Covid on Twitter, in correspondence with Dr Eliza Perigo (who first used the hashtag #LongCovid)
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No. Perhaps because I live in Wales and "they do things differently" with a separate government and NHS.
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g., myocarditis etc, and health impairments generally?	Serious, severe and long-lasting. Severe malaise, tiredness, fatigue and muscle pain. Gastrointestinal disturbance: severe irritable bowel. Disordered sleep. Frequent collapses with hypoglycaemia. Autonomic dysfunction, such as gastric hyperacidity, random shortness of breath and tachycardia, hot flushes, postural hypotension. Reduced cognition ("Brain fog"), eventually diagnosed by a Professor of Clinical Linguistics with "specific linguistic retrieval difficulty" which I still have. Miscellaneous neurological symptoms and signs such as paraesthesiae, muscle fasciculation, foot drop, dyspraxia (dropping small items), clumsiness, and eventually diagnosed in April

	<p>2021 with cerebral venous thrombosis requiring treatment with warfarin.</p> <p>Diagnosed in early 2021 with damage on MRI in lungs, liver, pancreas, brain and spleen. Severely disordered immunity, manifest by hypoimmunoglobulinaemia, monocytosis and lymphopaenia, a chronic sore throat and sinusitis. Diagnosed in late 2022 with chronic lung damage (13/25 on the "ground glass" score). Prescribed by GP with an H2 blocker (famotidine) in august 2020 at my suggestion, which I remain on.</p> <p>Prescribed nasal steroids in spring 2021 when diagnosed with sinusitis and oropharyngeal thrush. Prescribed warfarin from April to September 2021 when diagnosed with cerebral venous thrombosis.</p>
How did Long Covid affect your employment or financial circumstances?	<p>I am semi-retired, so my pension has not been affected, but if I had been formally employed I would have to have taken early retirement on the basis of being long-term sick and unable to work. I took early release from NHS Wales in 2019, but have not retired from medicine, I remain engaged in an honorary capacity with national centres of excellence in the UK and Ireland, as well as academically with Cardiff University. Unable to concentrate, read or write scientific papers and participate fully in online and later face-to-face meetings.</p>

Case study 4

Name	G
Member of LC Support involvement with LC Support	Volunteer
Details of the person affected by Long Covid (age, name, sex)	46, Male
Summary of experience of Long Covid	<p>I fell ill during the first wave in April 2020. At the time, I was 42, working full-time, healthy with no underlying conditions and was in training for a triathlon. My initial symptoms were ear pain, fever and fatigue. PCR testing wasn't available to the general public at that time so I did not have a confirmed diagnosis of Covid-19. I self-isolated in my flat by myself for 10 weeks. During this time, I developed further worrying symptoms including POTS which left me unable to stand for any length of time. I also encountered brain fog, insomnia, weight loss (>1 stone), constipation, hair loss amongst others.</p>

	<p>When travel restrictions were lifted, I moved in with my elderly parents so they could take care of me. Again, I developed further worrying symptoms including body spasms, speech loss, tinnitus and hallucinations.</p> <p>During this time, I was in contact with numerous doctors. As I did not have a positive test and I did not present with a cough, they were of the opinion that I did not have Covid. I was diagnosed with anxiety and depression and was prescribed anti-depressants. The relationships with friends and family became tested as they placed faith in what the doctors were telling me and were encouraging me to get out and exercise even though I knew it could serve to make me worse.</p> <p>After 6 months of ongoing symptoms with little help from doctors, I had consigned myself to a life of chronic illness. At that point, I tried to take my own life. I was sectioned and placed on a mental health ward for a month.</p> <p>During my time in hospital, I caught Covid-19 for a second time. My symptoms were mild however I developed a sore, swollen calf which later proved to be Deep Vein Thrombosis. I was given a 3-month course of blood thinners. Within a week of finishing that course, I developed another DVT in the same leg. I'm now on blood thinners for the long term.</p> <p>I'm glad to say I have improved a lot over the last 3 years. I'm back working full time and doing some form of exercise but still not at the level I was prior to Covid. My ongoing symptoms consist of sleep disturbances, tinnitus and occasional brain fog.</p>
Impact upon life	<p>The impact on my life was profound to say the least. Prior to Covid, I was healthy, working full time in a pressurized job and physically active.</p> <p>Having developed Long Covid, I was mostly bed bound for 6 months. I was on sick leave from work for 4-5 months. Without a positive Covid diagnosis, I had a lot of difficulty proving I was physically ill. Instead, the doctors diagnosed me with anxiety and depression. Relationships with my friends and family came under immense strain. This affected my mental health to the extent that I tried to take my own life.</p>
Response from health care professionals	<p>Having caught Long Covid during the first wave, I had real difficulty proving I was physically ill. As PCR testing wasn't</p>

	<p>available to the general public at the time and I did not present with a cough, I was told that I did not have Covid-19. Instead, I was diagnosed with anxiety and depression and prescribed anti-depressants.</p> <p>Over time, I've found that doctors are more accepting of the condition, Long Covid. They are doing what they can to help me in my recovery but there is still little in the way of meaningful diagnosis or treatment. I'm based in Wales therefore there are no Long Covid clinics. A lot of the support provided is in the way of physical rehabilitation which can be counterproductive in some cases.</p>
Are you aware how/when contracted C19?	No. I developed symptoms in April 2020.
Have you been provided any medical diagnosis of Long Covid?	No
Summary of treatment / contact with medical / healthcare support	In the last 3 years, I have had over 130 appointments (and counting) with numerous doctors, clinicians, consultants, physios and psychologists both privately and on the NHS. I have had 2 stays in hospital, attended A&E 3 times and had paramedics visit my home twice. Today, I continue to take 5 types of medication to help manage my symptoms.

Case study 5

Personal information	I, 53
When did you first fall ill with Covid?	December 2020 - around the 10th.
When did you become aware that you had Long Covid?	When I returned to work in the January - I struggled enormously with energy, and cognitively too.
What did you know about Long Covid before you found out that you had Long Covid?	I didn't know much about Long Covid at all. All I knew was Covid lasted about 14 days and then I should expect to get better. Clearly at the start of the illness there was real worry due to the amount of people dying each day from the illness, but I don't recall any talk of Long Covid.

Did your GP or other healthcare provider know what Long Covid was?	My GP was sympathetic and believed me - but at the same point she (nor I) really understood the condition. Do we yet? But she had heard of it and was prepared to take it seriously, although there was little she could offer me other than sick notes and vitamin D.
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	No - not at all.
What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?	<p>It impacted my health in several ways:</p> <ul style="list-style-type: none"> • Energy: my energy levels are much lower than they used to be, and my tolerance to exercise and/or activity is greatly reduced, meaning that if I do too much (and that is nothing like what I was previously able to do) I have energy crashes and am laid low for days at a time. • Cognitive: I struggle to focus, I struggle to find words, I feel disconnected from the world, I struggle to think and process like I used to be able to. • Vertigo • Temperature spikes and dips • Hand-eye coordination has gone out of the window
How did Long Covid affect your employment or financial circumstances?	I was a drama teacher when I got Covid. I had to leave that job as I wasn't able to function in it anymore - I couldn't manage my energy levels, and I couldn't process what was happening in the room fast enough. It absolutely flattened me. So, I had to leave employment. I've done some freelance work over the last couple of years, but it has been small scale and doesn't pay well. This has had a knock-on effect on my husband who has effectively become the sole breadwinner in the house, and he is 66 and wants (deserves) to retire.

Case Study 6

Personal Information	S, 31 years old
When did you first fall ill with Covid?	Wednesday 1st April 2020
When did you become aware that you had Long Covid?	It's difficult to say, however by the end of May 2020, I had been made aware of the facebook group for those who survived covid but never recovered. The awareness of this group, paired with the first news article that made reference to prolonged COVID-19 symptoms sadly confirmed my suspicions of Long Covid. The article can be found here:

	https://www.theguardian.com/world/2020/may/15/weird-hell-professor-advent-calendar-covid-19-symptoms-paul-garner
What did you know about Long Covid before you found out that you had Long Covid?	<p>My knowledge and understanding of Long Covid was non-existent before I had found out I had Long Covid. Due to the multiple hospital admissions within the first 6 weeks of contracting COVID-19, I knew I was not recovering like we were led to believe I should have by this point. I had no pre-existing health conditions prior to COVID-19, I was young, fit and healthy. I had come to the harsh realisation during my last hospital admission in early May 2020, that I remained unrecovered and naturally I was looking for answers as to why this had happened. During my in-patient hospital admission, I found myself asking staff if they were starting to see other patients in a similar situation to myself.</p> <p>Interestingly, the persistent symptoms were unusual at the time and I was the minority in terms of experiencing the persistent painful headache as my main unresolved symptom of COVID-19. I was also the youngest patient on the ward at the time. My earlier introductions to COVID-19, the multiple hospital admissions, the lack of public health messaging of Long Covid and absent knowledge by health care professionals meant that I could only rely on my own suspicions of Long Covid.</p>
Did your GP or other healthcare provider know what Long Covid was?	<p>No, however, my GP also had suspicions of what Long Covid was before there was any official medical guidance. This was based on other patients at the GP practice also experiencing prolonged COVID-19 symptoms. It is worth highlighting, in the absence of medical guidance for health care professionals and my GP's willingness to help and support her patients, she was obtaining information from other doctors via Facebook groups as well as regularly searching for ongoing research or medical articles.</p>
What public messaging had you seen or heard about Long Covid before you fell ill and thereafter?	<p>Unfortunately, as I was part of the 'first wave' of people who contracted COVID-19 at the start of the pandemic, it meant that I already knew I had Long Covid a significant time before any official public messaging. I don't recall the specific public messaging I had seen however I do recall this was around Autumn/Winter of 2020.</p>
Were you aware of the 'Long Covid' video published by the Department of Health and Social Care in October 2020?	<p>Yes I do recall seeing this video, and I also recall not seeing the video for long in terms of when it was aired on the TV as I only saw it a couple of times.</p>

<p>What impact did Long Covid have on your health, please specify symptoms, any particular damage e.g. myocarditis etc, and health impairments generally?</p>	<p>The impact Long Covid has had on my health has been disastrous. I now live with a permanent headache which was the first symptom of my COVID-19 illness back in April 2020. I also live with an intermittent fever mostly over 37.8 degrees. Other symptoms come and go and this includes:</p> <ul style="list-style-type: none"> • Dizziness • Sore throat • Enlarged glands • Nausea • General malaise • Muscle aches • Fatigue <p>Unfortunately, for many, we still don't know the true impact Long Covid has had on our health.</p>
<p>How did Long Covid affect your employment or financial circumstances?</p>	<p>Long Covid had had an intolerable, devastating, and revolting effect on my employment and financial circumstances which haunts me most days. There are no words to truly describe what it is like to be unwell whilst navigating employment which appears to have a structure that works against you, not _with_you.</p> <p>This was made worse by my employer being the NHS, a healthcare organisation responsible for maintaining and caring for the public's health needs, yet unable and unwilling to care for my employment needs which has now changed since becoming unwell with Long Covid.</p> <p>The countless meetings with HR, occupational health, advocacy, raising formal complaints, constant discussion of my health needs not meeting the needs of the service continues to take an irreversible toll on my physical and mental health.</p> <p>I am still not back to my pre-covid baseline in any aspect of my life, particularly when it comes to my ability at work and my financial circumstances.</p>