

Please find below my submission for the inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales

Submission: Name xxxx

This month marks my 8-month Coronanniversary

Prior to getting ill with Covid Symptoms I was a very fit, active and healthy xx-year-old with no underlying health conditions. I was a Pilates Teacher & Artistic Director, Teacher & Choreographer of a Youth Dance Company. I'm a married mum to teenage daughter and a dog owner. I was always a very busy person and then on 1st May I developed Covid symptoms and from this point on it's been a rollercoaster of symptoms, relapses and recovery, darkness and hope. I've experienced a multitude of symptoms and have never felt so ill.

I haven't been able to work for 8 months.

I had very little prior experience with health care providers.

By July my symptoms worsened and I developed cognitive impairment, tremors, stunted & slow speech, brain fog, memory issues, dizziness and other cognitive issues alongside worsening fatigue. I contacted my GP and had 2 face to appointments between July and September who sent me to hospital twice. In July with suspected stroke and admitted for 3 days to hospital and had loads of tests, another in September with chest pain to rule out heart problems. Diagnosed with Costochondritis.

I needed support from my husband to write info about my symptoms to my GP before the appointments and also support talking to my GP as my cognitive function was not good enough to explain myself. Also getting past the recorded message and the receptionist, acting as a gate keeper and asking lots of questions was very costly in terms of my low Covid battery, it left me exhausted. I think if it wasn't for having support from my husband, I'm not sure if I would have been able to get the appointments with my GP.

Although I found my GP supportive, and felt listened to, they did admit they couldn't do anything for me, and as someone who felt as ill as I did, this was unnerving. I turned to peer support groups for help and support on Facebook, such as Long Covid Support and Long Covid Wales, which I found invaluable.

It was in July that I was diagnosed with Post Viral Fatigue Syndrome, probable Covid - I developed Covid before community testing was in place and my antibody test 11 weeks after onset of illness also negative which I understand is common.

I have been referred to the neurology outpatient physiotherapy unit at C&V UHB. but only telephone appointments which are not much help and they clearly don't know what to do with me! I have residual I think nerve damage in shoulders and under armpits that mean I can't get back to teaching Pilates yet. In the two telephone appointments I spent a lot of time on the phone educating about long Covid, it was exhausting and not helpful to me but I guess helpful to them. If the physio was working in a long COVID clinic they would have some idea of how to work with me because I wouldn't be their first LC patient. The LC clinics we so desperately need will help staff to build expertise.

Due to my neurological problems, I went to see a neurologist privately, as my father had and died of MS and I wanted to rule out anything like that. He suggested I'd suffered encephalitis (inflammation of the brain), prescribed amitriptyline for nerve pain and referred me back to the NHS for a brain scan to check for any brain damage. He assumed that any damage due to Long Covid would be like damage from any other virus, and would heal, but Covid is a novel virus so we just don't know. I have no idea when or if I will have a brain scan.

At 8 months I am slowly improving bit still have no idea when I will be well enough able to return to work.

My Long Covid experiences of health services in Wales, both NHS and private, stress the need for one stop diagnostic and rehabilitation services that Long Covid clinics would provide here in Wales.

Between 10-20% of people with Covid go on to develop Long Covid. In time there will be many more of us, not able to work, or function properly for many months. L.C It is affecting many NHS workers, placing a further drain on already stretched NHS resources. Presently there is no cure, little recognition of L.C, a patchy picture of Long Covid Clinics (none in Wales) and very little funding for research, let alone any medical treatments. Come 2021 there could be many thousands of people with Long Covid.

Thank you for reading.

Kind regards,

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