

Dear Senedd,

I became ill with Covid19 on March 20th 2020.

I am still ill, still struggling to care for myself.

Last March, we were all told that if we weren't at death's door we were to stay at home and look after ourselves.

So like hundreds of others, that's what I did.

I had viral pneumonia. There was no advice available but luckily I knew what to do. I managed to treat it with steam inhalation and postural drainage, despite being barely able to get out of bed.

In May, I had a serious relapse. The virus was occupying my red blood cells. I was breathing fine but it wasn't having any effect. To me, it felt like I had altitude sickness. It would have been more accurate to describe it as like carbon monoxide poisoning.

At the time, according to what information I could find, the only treatment being given to people with severe breathing difficulties was ventilation. I knew I didn't need ventilation, but some oxygen would have been helpful. However it was impossible to get through to the local GP surgery to find out if it was possible to arrange for home oxygen.

Luckily, I have a brilliant homeopath who told me to take Carbo Veg, a remedy I have in my lambing kit and use quite often on new born lambs that aren't breathing. It saved my life.

The virus left my red blood cells after a week, and moved on to my heart. I started getting palpitations. One night these were so bad I felt faint, even lying down. I phoned 111 for advice. They decided to send an ambulance. The paramedics decided they needed to take me to A&E.

In A&E, despite my ECG showing frequent ectopic beats, I was told that as my chest Xray was clear there was nothing wrong. I was just a bit "anxious" about lockdown. This was despite the fact that by May research was already starting to emerge that the damage caused to the lungs by Covid19 does not show up on Xrays.

But no-one in A&E believed I had the virus.

No-one took my history.

I had by this stage had 30 or 40 distinct symptoms, but in A&E they were still reciting the 2 or 3 symptom mantra.

I was shocked that there was no curiosity, no desire to learn.

I was shocked that they relied completely on tests and were not interested in symptoms.

When I expressed concern at their assumption that I should call a neighbour to take me home, concern that I could pass the virus on to my neighbour, I was escorted from A&E to the phone for taxis and left there.

In June I started to improve slowly but in July the fatigue started.
I was barely able to walk.
This has been the case ever since.

In August I had a complete relapse.

After my experience in A&E I decided that however ill I became, I did not want to go to hospital. I couldn't face being gaslit again.
I decided that if I was going to die, I would rather die at home than in hospital.
I warned my son and daughter that I might not make it.

I had a number of close calls over the following weeks.
Thankfully my homeopath, with her quick and accurate prescribing, got me through those weeks and I am still here and gradually recovering.

During the Autumn, I tried to get support from Social Services.
I phoned to ask if this could be arranged. I was asked what help I needed. I explained I was struggling to look after myself and mentioned that there was 6 months worth of rubbish and recycling piled up behind the door. I was told rather curtly that they don't put rubbish out.
Brain fog, one of my symptoms, meant I couldn't think quickly what else to say. The person on the other end of the phone didn't try to help me. The call ended and that was that.
I still couldn't cook for myself.
I still struggled to wash myself, my clothes and my bedding.
I still had no income.

In November and December, I tried again to get a phone appointment with the GP.
I wanted blood tests and I wanted to be referred for online physio.
Each time I managed to get through the hoops on the surgery's phone system, I was too late for an appointment for that day.
Each time, I explained that I have Long Covid.
Each time, I asked the receptionist if I could arrange an appointment for another day.
Each time, I asked if there was a Long Covid clinic in the area.
Each time, the answer was negative.

Like thousands of other Long Haulers, I have had to be my own doctor, nurse, physio, nutritionist, researcher and house elf.

I love the NHS but years of underfunding has left it beleaguered.

I am in awe of how staff on the front line are coping with the tidal wave of cases needing intensive care.

But I am shocked at the lack of interest in Long Covid.
I am shocked at the lack of support.

I am shocked that Wales is not setting up any Long Covid clinics.

We need, urgently, multidisciplinary clinics dedicated to the diagnosis and treatment of Long Covid.

Because Covid19 affects every single organ and system in the body, these clinics need to take a holistic approach.

The clinics need to include not just doctors, nurses and physios but also homeopaths and acupuncturists. These practitioners are experienced in looking at the whole person and seeing how pathology in different organs is interacting across the body. This is vital in understanding this unusual and devastating virus.

We need a Universal Basic Income for everyone. Financial worries mean people are pushing themselves to go back to work before they are ready and are then relapsing. Brain fog, a common symptom, means applying for any benefits is nigh on impossible, especially when it is difficult to access any support to do this.

Yours sincerely.

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