

Disability patient testifies to Global Workers' Inquest into COVID-19: "The pandemic is a mass-disabling event"

Anne Patrick
25 March 2022

The following testimony has been submitted to the Global Workers' Inquest into the COVID-19 Pandemic by Anne Patrick, who suffers from an auto-immune condition known as "dysautonomia," a group of medical conditions caused by problems with the autonomic nervous system. Its impact on bodily functions including heartbeat, breathing and digestion is similar to that experienced by those with Long COVID. A growing body of scientific evidence has found that dysautonomia may explain the persistent symptoms observed in Long COVID-19 patients, such as fatigue and hypoxia (low blood oxygen levels).

Anne discusses how the pandemic is being experienced by people with serious pre-existing illness and warns of the huge toll in long-term disability being left by Long COVID. Anne's name has been changed for privacy.

I want to explain what the pandemic is like for me, a disabled person living in Britain. In doing so, I hope to make people, especially able-bodied people, aware of the problems they may face if they become disabled due to COVID-19 infection.

From my perspective and that of many disabled people, the "Freedom Day" lifting of public health measures means a new level of imprisonment. For others, those who go on to catch COVID, it will mark their last few days, weeks or months as able-bodied.

Over a decade ago I caught a bad flu which damaged part of my nervous system. Since then I've been living with post-viral symptoms nearly identical to those of Long COVID, including profound fatigue, brain fog, tremors, nausea, fainting, heartrate issues, blood pressure drops, dizziness, stomach pain, weakness, as well as problems with thinking, standing, and sometimes breathing.

The broad medical term for the dysfunction behind these symptoms is 'dysautonomia', and it affects a large proportion of those with Long COVID. The nervous system is involved in the immune response, and I now struggle to recover from infections. Due to this, a serious heart condition and medication I take which further dampens my immune response, I do not feel that I can afford to risk death or further disability by going places the airborne virus is circulating—in shops, buses, trains, pubs, events, people's houses, and so on.

Like most people, I miss socialising, but unlike most people I fear I may be excluded from it for much longer than necessary. In the last two years, most of my visits to buildings other than my house have been to hospitals and doctors' offices. There have been far fewer of these than necessary since critical appointments continue to be cancelled or postponed for long periods.

Some may be surprised to learn that pain, even acute pain, does not

automatically qualify a person for urgent investigation or treatment in Britain. For the routine investigation I needed for my pain, the National Health Service (NHS) waiting time in my area even before the pandemic was a year and a half. With a private specialist during the pandemic, I had the same procedure done within two weeks.

Two of my friends have died during the pandemic, not from COVID but from complications caused by lack of access to medical services. One was able-bodied, early thirties, and died from undetected and untreated cancer. The other was in her early forties and disabled. Despite collapsing repeatedly at home, the pressure of the pandemic on the medical system meant that she was consistently refused care at the hospital and sent home where she suffered her final collapse. Finally admitted into emergency room, unconscious, doctors examined her properly at last and discovered that she had a systemic infection which could have been easily treated with intravenous antibiotics. It was too late. She never woke up.

Unfortunately, Prime Minister Boris Johnson's false mantra of "personal responsibility" has infiltrated even medical settings. During my own medical visits, I have encountered doctors who refuse to wear proper masks, or who refuse to wear masks at all, even the basic surgery type. Recently, it was necessary for me to be unmasked during an appointment. The doctor examining my face wore a ventilated mask, which protects the wearer but is designed to allow their breath to escape unfiltered. He treated me to multiple lectures on why it was inevitable that everyone would catch COVID even as I pleaded with him to change his mask, explaining over and over what my health conditions were and that I was a carer for a vulnerable elderly relative.

At another appointment, an obstetrician-gynecologist without a mask examined me in a closed room for a full forty minutes and then went on to see a queue of pregnant women, many of whom were wearing poor-quality cloth masks. At an inpatient appointment, someone in the bed next to me began to display COVID symptoms yet remained in the small general ward; I was partly sedated and unmasked after a procedure.

How does my "personal responsibility" to protect myself apply in any of these circumstances? And what about the elderly relative I look after, who leads a fulfilling life with mild cognitive problems but who cannot be expected to remember to wear a mask or follow necessary protective measures? How can any member of the public keep themselves safe when the medical system is either unavailable or unsafe itself?

When the pandemic began, there was a consensus in my neighbourhood that we were all vulnerable to COVID and we created

a basic mutual aid infrastructure to support each other because there was nothing else in place. It was strangers who brought my medication from the pharmacy, delivered food to the elderly, swapped educational books among the kids, policed the door-to-door “NHS” scammers, and helped out when people were having their power supply threatened or needed food from the nearest food bank. It was wonderful to realise that we weren’t alone.

I was incredibly fortunate that my partner had a job that could be done from home. It may sound strange, but some of my quality of life actually improved in 2020. Rather than spending time alone at home due to dysautonomia symptoms, my partner was now there to keep me company, friends were socialising online more, and there were events, gatherings and courses I could attend virtually. My everyday levels of anxiety also reduced. Previously, I had carried my phone into every room in case of a medical emergency, but now I could feel sure that my partner would find me in time if, for example, I fainted or experienced other urgent health problems.

Unfortunately, throughout the pandemic, the government—not just Westminster, but the devolved governments too—have been working against this growing awareness of our interdependence, constantly pushing the rhetoric that it is only the disabled who need to fear COVID. This has been a global message, often using the health insurance phrase “pre-existing conditions.” This message is a lie.

Apart from the millions dying, between 10 to 30 percent of people who contract COVID will have lingering symptoms and an unknown proportion of them will be disabled permanently. Yet more unknown numbers now have heart or lung damage from COVID. The pandemic is a mass-disabling event. The Office for National Statistics (ONS) reports Long COVID as affecting around 1.5 million Britons, nearly half (45 percent) of whom report having had Long COVID for at least a year. Since these figures are based on extrapolated data from a survey of very limited questions to a specific group, we have no way of knowing the true long-term disability toll.

Another ONS survey just released says that one in 100 British primary school children has Long COVID, defined as having symptoms for three months or more following infection. That estimate includes all primary school children, not just those who’ve had COVID. The same rationale applies to secondary school children, where the incidence of Long COVID rises to one in 37.

All these studies were conducted before the outbreak of Omicron, a much more virulent strain. The studies are also limited, not only because of the lack of accurate or available testing but because they only include those with pre-defined, newly occurring symptoms. They also exclude worsening symptoms. For example, since I already have many of the same symptoms as Long COVID, even if these deteriorated significantly after a COVID infection, I would not be counted in the data. This means that the actual prevalence of Long COVID is underestimated overall, and more so within the disabled population. For governments and local authorities to put children into crowded classrooms with minimal to no precautions is obscene. Beyond that, schools are the vectors of infection for the entire community.

The mental pressure on the disabled is extreme. By stressing repeatedly that only those with “conditions” die, I feel as if my government has sanctioned my death as necessary. It has been distressing to hear that message repeated or the dangers dismissed, especially by those close to me. Early in the pandemic, the NHS introduced something called the “clinical frailty scale” for use when hospitals are overwhelmed by a surplus of patients and a scarcity of

resources. It was a scale which predetermined who might live and who would probably die—if not from COVID, then from critical resources being withheld for “healthier” people.

I was shocked to find that I might not meet the criteria for care if I went into hospital with COVID. The framing of the tool has changed but the frailty scale is still in use, a constant reminder that the most vulnerable are the first to pay the price of decades of NHS cuts and privatisation.

I am so careful in everything I do now. My hygiene is impeccable and fearfully performed. Every minor infection or new symptom comes with more anxiety. Will I be able to get an appointment to treat it? If I need to travel for my appointment, will it be possible to keep myself safe the whole time? If I go into hospital, will I get COVID?

With the removal of basic public health protections, I feel only despair.

The government will do nothing, so surely the public will need to act in its own interest. I worry about how long it will take for people to realise that. The official lies are relentless and we’re all so tired already. Now, with the threat of a wider European conflict I’m scared that the resources desperately needed to fight the pandemic will go instead towards needless war and profiteering.

I can’t possibly convey the experience of long-term illness in a few sentences, but I want readers to be aware of the risks of COVID damage. Over the last decade or so I’ve lost financial autonomy, relationships, the possibility of having children, and the freedom of using my body and mind as and when I choose. I have lost jobs explicitly because of my disability, something which is perfectly legal in Britain.

By far the worst part of dysautonomia has been losing my clarity of thought; I’ve taken two weeks to write these paragraphs. I would like readers to understand that the risk of disability from COVID is vastly greater than the possibility of death. The risk of this future is what you are being exposed to by your governments and employers. It’s the risk your children are being exposed to in their schools. The situation is brutal, criminal, and ultimately unsustainable. It must be stopped.



To contact the WSWs and the Socialist Equality Party visit:

[wsws.org/contact](https://www.wsws.org/contact)