IPS

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‘With Long Covid, there's a minimisation push’

As Omicron is spreading rapidly across Europe, Covid-19 is still treated as an acute condition only. That's wrong, says Professor Brendan Delaney

What do we know so far about Long Covid, its symptoms, and long-term impact on health. And how is that different from other known viral infections?

The best way of thinking about this is go back to how we started to realise that Covid-19 was not just an acute condition. That was really from the experience of people who caught Covid-19 in the first wave from March 2020 onwards.

In fact, this is implicitly linked with my own personal experience: I had relatively mild Covid-19 in mid-March, which I caught it in the week just before the UK went into lockdown. I recovered quite nicely after two weeks. The next day, I went out on a bike ride. I did about 35 miles and when I returned, I felt great. But the following day was like I've been hit by a truck. I was running a fever again and I was very short of breath.

After this, I was simply unable to do anything for two months. By June, I crawled myself back into work. And even then, I was still unable to get back to it fully. I would spend six weeks signed off sick halftime, still working from home, doing an hour's meeting and then lying down for an hour. During this time, I started getting in contact with people on forums, Facebook, Twitter and asked: Why aren't we better? It was around this time that Elisa Perego, an Italian academic, coined the term Long Covid. Until then, the official line was that Covid-19 was a two-week illness and that’s it. Quite clearly, that was not the experience of very large number of people.

What do we know now almost 21 months into the pandemic?

I think we have a fairly clear idea on the risks. If you ask people after four weeks, about half of them will say they’re not better. They will

say they have some symptoms, persisting breathlessness and fatigue being the most common. By twelve weeks, about ten per cent of patients who had Covid-19 still have at least three symptoms, and half of those will still not be well enough to go back to work and their usual activities. It's about five per cent after three months.

Do we know whether vaccination plays any role in preventing Long Covid or in reducing the likelihood of contracting it?

The best recent study in the British Medical Journal says it cuts in half the chances of getting Long Covid if you've been vaccinated. It doesn't, however, eliminate it. If you wanted to do a back of the envelope calculation, we've probably got 10 per cent of the population who had it, half of those still persisting.

So with the vaccination, you can cut that in half and, let's be very optimistic, you get down to 2 to 3 per cent. That doesn't sound like very much. You can turn it the other way around and 'spin' the political narrative and say 97-98 per cent of people who get Covid-19 are not going to end up with Long Covid if they've been vaccinated. That's all well and good. But if you're in the 2 or 3 per cent who get floored by it, you've got people in their peak working lives who suddenly have a disabling illness.

A study from the UK earlier this year revealed that more than two million people in England were affected in one way or another by Long Covid. That's three per cent of the population. In the US, a study found that 25 per cent of those infected with Covid-19 experienced some form of Long Covid. That was nine million people across the US at the time of the study. All these people are rather invisiblised in the public debate – it's like a second pandemic that nobody is talking about. How should we address this both on the health, but also on the social side?

For a start, this shouldn't come as a surprise. All pandemics have been associated with a long-term tail of people with ill health as a result. If we go back to the granddaddy of pandemics, the 1918 Spanish flu, we had encephalitis lethargica and Parkinsonism in patients afterwards. There have also been long-term sequelae with Ebola and with Zika and a variety of other viral illnesses.

From a policy perspective, it would be naïve to think that SARS-CoV-2 would be different from other various infections. Unfortunately, there is a history of people with complex medical illness after viral illness who've been completely side-lined. It's fair to say that there is a general disinterest in biomedical research, just because it's difficult to get funding in the area.

Moreover, the area has been taken over by psychiatrists and psychologists. Clearly, labelling an illness with clear-cut biological factors as psychological and treating it only psychologically is very wrong and causes a lot of harm to many patients. The UK National Institute for Health and Care Excellence' guidance on myalgic encephalomyelitis /chronic fatigue syndrome has just changed after a lot of controversy and 15 years of work by patient groups. And there are a lot of similarities between the two conditions.

There may well be specific features of SARS-CoV-2 about the way it affects the body biologically, the receptors it uses, the fact that it's looking more and more likely it's driven by persisting inflammation of the vascular endothelium, the lining of blood vessels. That's throughout the body and affects all the organ systems. There's some recent evidence pointing us in the direction of tiny blood clots causing persisting vascular inflammation.

Hopefully, a more focus on biological research will help that wider group of patients with viral illnesses.

Do governments' understand Covid-19 not just as a short and acute but long-term illness?

It's also fair to say – at least for the UK – that governments, lobby groups, and right-wing media have been pushing quite hard the view that Long Covid is not really real.

They suggested that it's a largely psychological illness, that it affects mainly middle-aged women. Perhaps it's menopause. Perhaps it's anxiety. Perhaps it's the effect of lockdown. And the negative talk continues in the background. I saw an interview with Robert Dingwall, a member of the JCVI, the committee on vaccinations in the UK, who's a retired medical sociologist. In the interview, he said pretty much: 'it's not really real, is it?'

He's part of a group that had been talking down the impacts of Covid-19 throughout the pandemic. We need to be aware there's a big patient group and there's a lot of scientists who are interested in the condition. But there's also this minimisation push, in much way there's a similar push to minimise the effect of Covid-19 more generally.

This seems to be a matter of picking 'the science' that fits your political objectives. In my view, it intersects with another conservative talking point on the economy. Whether from France's Emmanuel Macron or German conservatives, we've heard that because we have accumulated so much national debt to keep the economy afloat during the lockdown, we have to increase the working hours to drive it down–

instead of protecting the health of those affected by Covid-19 and Long Covid as well as workers more generally. That sounds like we have learned nothing from the pandemic and just want to go back to the status quo – or worse.

I strongly agree with you on that. I see a lot patients and want to give you two examples of the impacts this can have on people's lives.

Of course, children are less likely to get Covid-19 than adults. But still, if you're a 17-year-old about to do your end of school exams and you've been floored by a condition that makes it very difficult for you to think straight. Once you go back to school, you crash and end up at home in bed for two weeks, that's something that needs a lot of support.

The stories I'm hearing is that schools are told they can have 5 per cent 'mitigation', which means that being unwell allows teachers to give them a 5 per cent higher mark in their exam results. But Long Covid is not recognised as a condition allowing a resit the following year. I said to the parent, what if they had glandular fever? That's a condition we know people have months and months and they often take a year off school. But there's no recognition to do that.

I have another patient in the practice who works for a major supermarket. Their employer, by contrast, have actually been fantastic with her. She has a typical pattern of Long Covid where you get a very high pulse rate when you try and do anything. We call that treatable set of symptoms Postural Orthostatic Tachycardia Syndrome, or POTS. That's one of the major strands of Long Covid. Now, they let her do about 40 minutes of her job, which is stacking shelves. And then she goes and lies down for half an hour. They just extended her working days slightly. She's formed a very gritty, get-on-with-it attitude. It's a combination of a flexible employer plus her needs to work to make ends meet. I've now made her symptoms a lot better by diagnosing her with POTS and treating it accordingly.

Doctors have been pushing recognition and treatment of treatable patterns of symptoms in Covid-19 patients. But it's not going to go away. The cases are accruing and this wave now in Europe over the winter, there will be a lot of sick and unwell people early next year. That's going to have a big effect. And what's going to drag down your economy more: thousands of workers not being able to get back and be productive for a few months, or simple things, like working from home when you can, testing, social distancing, mask-wearing?

I'm wondering, then, what would be a long-term policy and structural solution for those workers suffering from Long Covid, as in the examples you gave?

For starters, recognising it as a long-term condition. And consistent occupational health guidance that recognises both the long-term effects plus the slow, long-term recovery.

From the employers' side, we need flexibility, both in the work that people are able to do and the fact that that may well change over time. Someone may get back to doing a reasonable amount of work and then need to have a few weeks off if they've had a bad spike. Building that flexibility into employment and employment practices is really important for preventing people from being harmed long-term.

If someone's put off long-term sick leave and isn't able to get back flexibly to doing some work, they are financially disadvantaged. Then, anxiety, worry, sleeplessness starts to kick in because of work and the financial situation, which simply makes the condition worse.

Before our interview, I had to think back to the beginning of the pandemic and how the progressive sector of society had a lot of hope that we would rethink the importance of care work, health-related work, essential jobs, the necessity of strong public services. But, looking at the NHS bill in the UK proposed at the moment for instance, we seem to be heading in the opposite direction. Are you rather pessimistic or optimistic?

Certainly, there is a group of people who made sure the pandemic was not wasted as an opportunity to make a large amount of money. And a lot of that was quite fraudulent. I'm still hopeful that eventually that will widely come to light.

Macroeconomically, the problem is that a large part of society is based on the principle of paying rent, also for commercial property. That creates a focus on bringing people in to commute to work and financing those construction of city centres and services around that.

People are quite rightly asking: Why should I spend 15 hours a week commuting into work? It's actually much better and more productive to use technology to work at home and have less time commuting and less expenses. But the political push is that people should stop being lazy and get back into the office.

Restructuring this involves restructuring the way the capital and the return on investment operates. That requires a very hard push and it would take a lot of long-term effort. It would also certainly need to be tied in with green recovery and less energy consumption. But that needs political will and coordination and joining up all those issues about fairness, equity, public services, transparency in politics, green policies, work-life balance. And it's up to progressive parties need to put that whole agenda together.

This interview was conducted by Daniel Kopp.



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