

#### London

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## COVID-19

## Long covid: the doctors' lives destroyed by an illness they caught while doing their jobs

Unable to work or to play with their children, forced to sell their homes or facing insolvency—doctors with long covid deserve more support from the government and the NHS, writes **Adele Waters** 

## Adele Waters freelance journalist

When Kelly Fearnley first stepped on to a surgical ward as a doctor at Bradford Royal Infirmary in August 2020 her head was still buzzing with delight at having finally achieved her dream of qualifying in medicine.

As a mature student she had financed herself through a medical degree by working shifts as a pharmacy assistant. Now, aged 34, she was ready to get stuck into her foundation training.

Early months were spent dealing with emergency surgical patients but by autumn, as the second wave of covid-19 struck, the hospital opened several covid wards and she was deployed to work on one of them.

She remembers: "I walked onto the ward full of covid patients to find only plastic pinnies and flimsy blue surgical masks. I'd expected long sleeved surgical gowns and FFP3 masks. I remember asking a senior nurse where the other masks were. She replied, 'These are the ones we're using now.'

"I spent 10 hours a day for five consecutive days surrounded by infectious patients so I was subjected to high viral loads on a ward with no ventilation and an absence of respiratory protective equipment.

"It was essentially a covid soup."

The next week Fearnley tested positive for covid-19, and three weeks later she became severely unwell. She hasn't worked since. Because of long covid, Fearnley has been forced to relinquish her provisional registration and is currently not able to work as a doctor.

"I'm living with my dad—which is obviously not where you want to be at 37 years old—and my ability to earn a living has been taken away. I've opted to take a 12 month career break in the hope of recovering sufficiently to return to training, but my long term career is at risk.

"All my plans to work, save, and buy a house have been shelved."

Fearnley co-founded a support network in August last year with fellow doctor Shaun Qureshi after meeting others in the same position on social media. Long Covid Doctors For Action (LCD4A) campaigns for greater recognition of long covid and its impact on doctors' health and careers.

"Some doctors have been forced to sell their homes and a growing number face financial destitution," she says.

## One in 25 healthcare workers affected

Members of LCD4A include doctors who have been dismissed by their employer on capability grounds, those who have applied for ill health retirement decades early, and others who have lost their places on training programmes. There are GPs who have been expelled from partnerships and doctors whose work contracts have not been renewed. An increasing number of employers are refusing to make necessary adjustments to allow doctors to return and work at a reduced capacity.

"Doctors must have adequate protection at work," says Fearnley. "SARS-CoV-2 is airborne. It is outrageous that three and a half years into this pandemic, staff and patients are still, knowingly and repeatedly, being exposed to a level 3 biohazard."

Long covid, also known as post-acute covid or post-covid syndrome, is an umbrella term for a diverse range of more than 200 symptoms<sup>1</sup>—including fatigue, heart palpitations, joint pain, and respiratory problems—that last longer than four weeks after an acute covid-19 infection and are not explained by an alternative diagnosis.<sup>2</sup>

There is no official number of cases in the UK but the most recent estimate (March 2023) from the Office for National Statistics points to 1.9 million people currently living with the condition—some 2.9% of the population.<sup>3</sup> Globally the estimate is  $10\%.^4$ 

Likewise, there are no precise figures for how many doctors—or even healthcare workers—currently have long covid. The ONS data estimates that up to 4.41% of healthcare workers have acquired long covid.

## "Shockingly low" protection

To find out more about the impact of long covid on the medical profession, the BMA joined forces with LCD4A last year to survey doctors with the condition. Some 603 doctors responded to the survey (though not all of them answered every question), carried out during December 2022 and January 2023.

The results<sup>5</sup> reveal that almost one in five (18%) were no longer able to work. While more than half (57%) worked full time before the onset of their covid illness, that proportion had dropped to one in three (31%). Nearly half (49%) of respondents had lost income because of long covid.

The findings, published in July,<sup>6</sup> also show the lack of protection that many doctors faced in their

workplaces. "Shockingly low" numbers of doctors had access to respiratory protective equipment such as filtering facepiece respirators, the report says. Just 11% of respondents say they had access to FFP2 respirators and 16% to FFP3 respirators around the time that they contracted covid-19. The report points out that GP surgeries were initially left outside the formal NHS supply chain, forcing them to secure their own equipment from commercial suppliers.

The BMA will refer to these findings in its submissions to the ongoing covid inquiry<sup>7</sup> as part of its lobbying to get doctors living with long covid improved financial and wider support. David Strain, chair of the BMA's board of science, tells *TheBMJ*, "These are doctors left at risk and let down during the pandemic, and they're still being let down with a lack of support."

## Loss of enhanced sick pay

*The BMJ* is aware of scores of doctors with long covid. One of them is Alexis Gilbert, a public health consultant for

the Yorkshire and Humber Health Protection Team, who is unsure how he contracted covid-19. Like many doctors who describe their pre-covid state as fit and active, Gilbert says he went from "climbing mountains and working long weeks on-call to being unable to feed or wash myself or even hug my children. Long covid is the annihilation of planning for the future, as you never know what will trigger the next crash."

"I've been bed bound and unable to work for eight months," he tells *The BMJ*. "I have two young children and I'm worried about our finances when my sick pay stops in October. I hope I can get back to work but right now that feels like an insurmountable challenge given the lack of treatments and the level of physical and cognitive function that I have."

During the covid-19 pandemic the NHS suspended its normal sick pay rules for all hospital staff so that those unable to work because of long covid continued to be paid. That enhanced provision ended, however, in September last year when all staff reverted to standard sick pay, as set out in their contracts, giving them a further six months on full pay and then six months on half pay.

This means that anyone who remains off sick with long covid will have been in receipt of half pay from March 2023 and facing no salary from September. There was no special leave provision for GPs at any stage.

One salaried GP in west London who wanted to remain anonymous told *The BMJ*, "I haven't been paid for almost two years. I have a job but I'm not working and there is no plan for me to return. I'm in career limbo."

Charities that provide financial support to doctors in need have seen a sudden rise in demand. The Cameron Fund, which supports GPs and their dependents, says 2022 was "an exceptionally busy year" with an increase in applications from GPs off sick with long covid. During the first half of 2023, it has seen a 67% increase in enquiries for assistance compared with the same period last year. Likewise, the Royal Medical Benevolent Fund has helped 11% more doctors in the 2022-23 period than usual.

## **Occupational disease**

Long covid has taken a significant toll on doctors' lives, their sense of wellbeing, and their ability to carry out day-to-day activities. "Life is absolutely miserable," one consultant told the survey. "Every day is a struggle." Rachel Ali, a 43 year old GP from Devon, was fit and well before getting covid but that all changed when she became ill with the virus on Boxing Day 2021, after working on Christmas Eve. "Long covid has completely upended my life," she says. "I can't do things with my kids, I can't do things with my partner. I can't drive for more than half an hour. And I can't work. And I really want to.

"Fatigue is so different from being just tired. I've got kids and was a junior doctor for a long time—so tired, I can do. This is when nothing works. My brain stops working, my mouth stops working, I'll be mid-sentence and not know where I'm going with it. I'll be unable to get out of a chair to go to bed because I don't have the energy to stand up. It's like your legs are empty."

Is there any sign of help for these doctors? Both the BMA and LCD4A have set out five demands (see box 1), among them a call for long covid to be considered an occupational disease to help doctors and other healthcare workers access support and financial aid.

#### Box 1: Five demands from the BMA and LCD4A

- Financial support for doctors and healthcare staff with post-acute covid
- Post-acute covid to be recognised as an occupational disease in healthcare workers, with a definition that covers all the debilitating symptoms that people with post-acute covid experience
- Improved access to physical and mental health services to aid comprehensive assessment, appropriate investigations, and treatment
- Greater workplace protection for healthcare staff risking their lives for others
- Better support for post-acute covid sufferers to return to work safely, including a flexible approach to the use of workplace adjustments

In March, the Trade Union Congress made the same call<sup>8</sup> and in November 2022 the Industrial Injuries Advisory Council, which advises the government on which diseases should be classified as work related, recommended that health workers with long covid be able to claim industrial injuries benefit.<sup>9</sup>

There is no sign yet that such a move is on the cards. The Department of Health and Social Care (DHSC) tells *The BMJ* it recognises that long covid can have a debilitating impact on people but adds, "The evidence in relation to making long covid an occupational disease is at present insufficient, given continuing uncertainties around its definition, fluctuating nature, and range of symptoms."

Doctors recognise this will be tough to achieve. "I think part of the refusal to admit that covid and long covid are occupational illnesses is purely political. It's a protective action by the government to avoid being held responsible for the occupational illnesses of so many people, healthcare workers as well as other patient facing workers," says Ali.

## Gaslighting and lack of support

Improved access to physical and mental health services is also on the BMA and LCD4A list of demands. Doctors have faced significant barriers in getting medically assessed, investigated, and treated, and almost half of doctors surveyed by the BMA and LCD4A had not been referred to an NHS long covid clinic. One doctor tells *TheBMJ*, "My GP is helpful but what is lacking is a medical professional with a special interest in long covid overseeing my care. I feel I'm having to do it all myself."

Others tell *TheBMJ* they have often struggled for medical colleagues to take their symptoms seriously and have even felt "gaslighted" by them (see case studies). "GPs are being gaslighted themselves,

by having hordes of their referrals refused," another London based GP tells *TheBMJ*. "GPs are at their wit's end with what's happening to them because they have these patients that they're desperately worried about that they can't do anything with because nobody will see them. No one will accept their referrals."

A spokesperson for DHSC says, "We are backing our world leading scientists with over  $\pounds_{50}$  m to understand better the long term effects of this virus and make treatments available.

"NHS staff are able to seek support for long covid from their GP or one of the 100 specialist clinics available nationwide. The NHS has also committed  $\pounds_{314m}$  to support people with ongoing symptoms of long covid."

For doctors such as Fearnley that simply is not good enough. "After risking our lives to save others, now disabled, we are being managed out of the door with no support system in place," she says.

"I contracted this illness caring for covid positive patients because my employer failed to provide me with adequate respiratory protective equipment. There should be more of an effort to support healthcare workers. At a time when the country needed us, we stepped up, and it's not right that now in our time of need the country steps away."

#### The GP: "We've been left to rot"

Kerry Smith, 51, was working as a part time salaried GP before she developed long covid.

"Before I got ill with covid, I was rarely off sick and running half marathons. On top of working six sessions a week as a GP, I had a wedding florist business that I did at the weekend. I also had a young family so I was a really busy, active person.

"I'm not that person anymore. Day-to-day I can do very little. After my acute infection, I improved physically but I started to notice that my brain was not right. I would leave the front door open in the middle of the night and the gas cooker on. I couldn't remember who I worked for, the names of any people I worked for, or what my practice was called.

"When occupational health told me I wasn't fit for work, I felt I had no choice but to leave. That was in September 2021. Now I'm on Employment Support Allowance and Universal Credit. The difference is huge—I'm living on about a third of my previous income.

"'ve massively reduced my outgoings and have managed to get by with support from the Cameron Fund. But with bills to pay and the cost of living going up massively, it's not sustainable. I will be hit by increased mortgage rates in January next year, when my fixed deal ends, so I'm going to have to sell my house and downsize.

"It feels like long covid has been swept under the carpet but I would like it recognised as an occupational illness so that I can get some form of compensation for my life, which is totally not what it was.

"Getting covid was an occupational hazard. There are still a lot of us who got covid-19 in 2020 because there were no vaccines then and we didn't have proper personal protective equipment and we are still really unwell from it.

"I feel completely let down by the NHS. I told my GP that we've just been left to rot. As doctors, we are people who hardly ever take any sick days—we're more likely to say we're fine and go back to work—as we're very driven people. We have been badly let down."

#### The hospital consultant: "NICE guidelines are not fit for purpose"

Asad Khan, 47, was working as a respiratory consultant before he developed long covid. He has not worked since November 2020.

"I have had to become my own doctor, researcher, and advocate. If I hadn't taken matters into my own hands, I would not be alive today. In September 2021 I was close to death.

"I contracted covid-19 after one week on an acute covid ward. I've since been diagnosed with mast cell activation syndrome (MCAS) and postural tachycardia syndrome (PoTS) and I experience a range of post-covid symptoms with fluctuating intensity, including urticaria requiring immunosuppression, difficulty remaining upright, bladder incontinence, cognitive impairment, and fatigue.

"I've paid to access different treatments privately, such as apheresis and anticoagulation—and, yes, I did see improvements and am keen to explore their potential for other patients in the NHS.

"Despite the complexity of my case I don't have a consultant overseeing my care. My GP has been very supportive, but her hands are tied because of the lack of support from specialists and the absence of pragmatic guidelines.

"'ve now learnt to avoid NHS doctors in general. I'd heard of gaslighting happening to lay people but I didn't expect it to happen to a medical professional. If I suggested certain treatments, I was dismissed. If I suggested certain dietary approaches, I was ridiculed. One doctor refused to accept that my urticarial rash was part of long covid. At one point I was told, "Remember you are the patient." What does that say about how we view patients? I was also made to feel that by falling sick I had suddenly lost my medical knowledge and all credibility.

"'ve been told by fellow medical professionals that there is no such thing as long covid, that it's psychological, that it's just a matter of a slow recovery, and that there is no evidence based treatment.

"Yes, there may not be any licensed treatments but that does not mean that we cannot offer symptom control to patients. Symptomatic treatment of MCAS with antihistamines, and PoTS with beta blockers, can make a huge difference to quality of life.

"Part of the problem is that there is no helpful national guidance for doctors to follow. The National Institute for Health and Care Excellence guidelines are not fit for purpose. They don't contain any specific recommendations for low risk treatments to help people feel better.

"We have to be a bit more agile in our practice. In the absence of guidelines, doctors should be empowered to offer time limited trials of low risk treatments to patients."

# The emergency medicine doctor: "My granny stopped us from becoming bankrupt and homeless"

Sarah Mason-Whitfield, 47, was working as an emergency medical doctor at Lewisham and Greenwich NHS Trust when she became ill. She has not worked since March 2021.

"My 6 year old daughter started to get panic attacks during lockdown. I remember being in my scrubs about to leave for work and her saying to me, 'Mummy, everyone's been told to stay at home because it's not safe.' She knew I was deliberately seeing covid-19 patients when everyone else was being told to stay at home and she was watching me do the exact opposite.

"I was working as an emergency medicine doctor—I was the clinical lead for a team of GPs, running the front end of the hospital. We saw everyone that arrived and stratified them. Sometimes I was working 70 hours a week—on one stretch I worked 28 days in a row.

"I couldn't have been more 'frontline' if I'd tried. I worked in two rooms—one for covid patients and the other for non-covid patients. There was no window, the ventilation didn't work, and none of us wore full respiratory protection equipment. I had massive exposure.

"When I went off sick in March 2021, I felt so desperately unwell. I didn't get better and a few weeks turned into months and then years.

"I live with my partner and daughter but I was the main breadwinner. When I got sick, our outgoings were £6000 a month. Today, my partner has had to become my full time carer. We rely on state benefits including Universal Credit and Personal Independence Payment, which add up to £1300. We have sliced down our outgoings but we've still got our mortgage which is £2000 a month.

"Last winter we couldn't afford to heat the house properly—we had frost on the inside of our windows. We limited our heating and hot water to 30 minutes a day so my daughter could have a bath. We faced selling our house and relied on various extended family members to support us financially, including my 98 year old granny. If it wasn't for her, we would have been homeless and bankrupt within three months.

### FEATURE

"I have also received grants from the Cameron Fund and the Royal Medical Benevolent Fund. Just recently, after months of struggle, I've managed to qualify for ill health retirement because of my specific cognitive problems.

"Before getting covid-19, I was physically fit and my cognitive tests were in the superior range. Now I have to go up and down stairs on my bottom and I can't even do my daughter's maths homework. My cognitive domains are low average to impaired, which is in the learning disability range."

 $\pm 10$  donations to the Cameron Fund can be made by texting 'HELPGP' to 70085. Donate to the Royal Medical Benevolent Fund at https://mbf.org/donate

#### Commissioned, not externally peer reviewed.

I have read and understood BMJ policy on declaration of interests and have no relevant interests to declare.

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