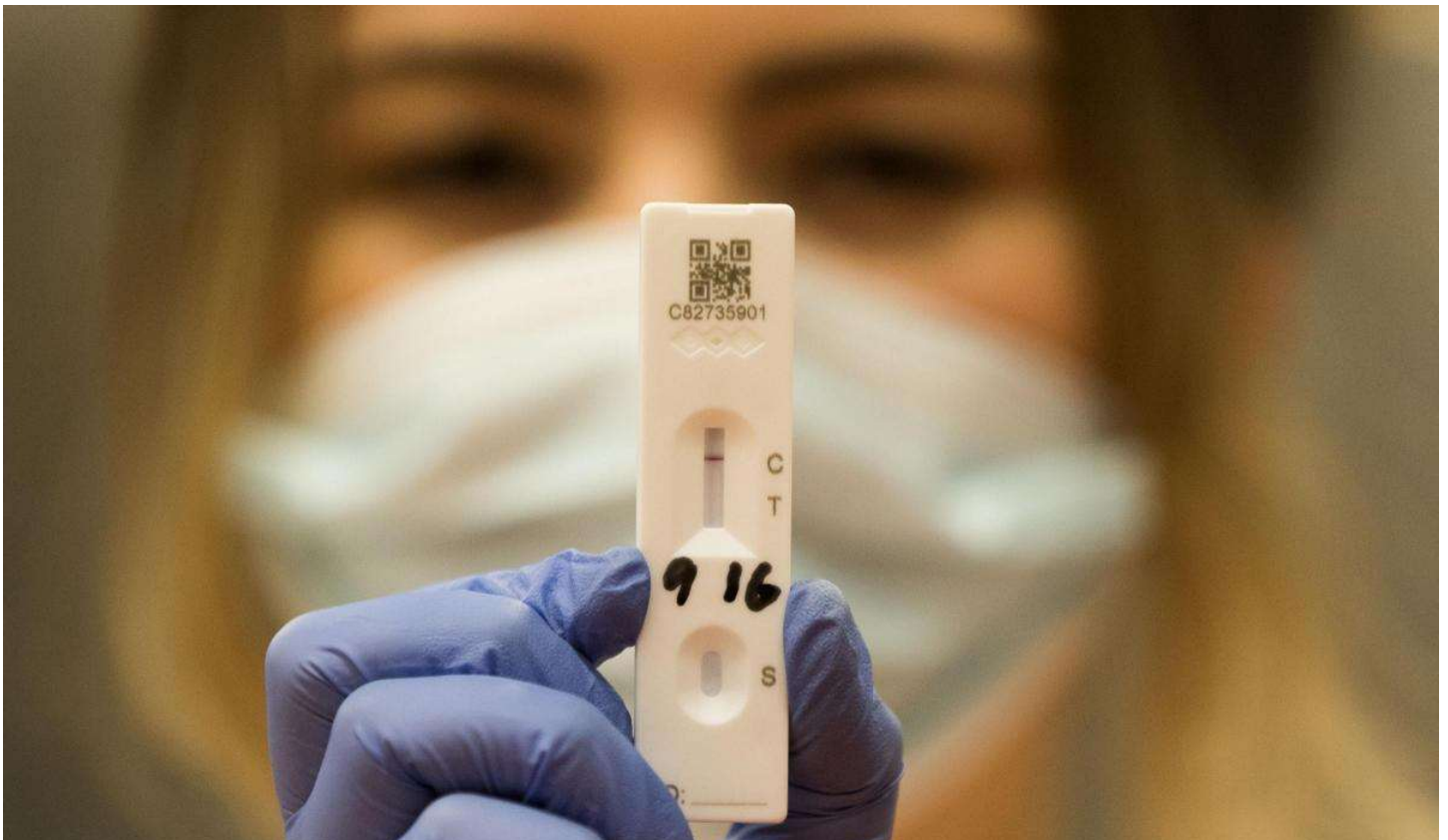




PREMIUM

Long Covid: Patients say treatment in Wales is lacking

3 hrs ago



Some people are still struggling with the effects of Covid two years after testing positive. Picture: Huw Evans Agency

BY TOM CARTER



PATIENTS suffering from Long Covid have criticised Wales' response to the disease, saying treatment is severely lacking.

There are an estimated 83,000 people living with Long Covid in Wales, according to self-reported

However, patients living with Long Covid have told *The National* that the treatment they have received in Wales has not been good enough, with several being forced to turn to private healthcare.

Sarah Sutton, 43, first tested positive for Covid in March 2020, a week before the first lockdown.

“Initially I thought it was sort of ok,” she said. “I felt a bit rough for the first few days, and then I started to feel a little better towards the end of the first week.

“But then by about 10 days in, my partner called an ambulance because I couldn’t breathe.”

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For the past two years, Ms Sutton has suffered from constant fatigue, migraines, breathlessness and heart palpitations as a result of Long Covid. She has also struggled with brain fog - neurological symptoms that have affected her memory and left her unable to remember entire conversations.

“You are constantly a bit breathless, and it gets a lot worse if you try to do anything,” she said.

“My life bears no resemblance to how it used to be. I was a full-time community midwife, on top of bringing up children and my social life. Now, I shower twice a week, I wash my hair once a week if I’m lucky.

“It’s just changed everything.”

Ms Sutton says that the treatment she was offered for her symptoms was sub-standard, and has forced her to pay for private healthcare out of her own pocket.

“It’s been very frustrating,” she said. “I have had to drive everything myself, which is exhausting.”

She is now paying for a private cardiologist, after being discharged by an NHS cardiologist only to be told a year later by a GP that her resting heart rate was abnormally high.

Similarly, when Ms Sutton was eventually referred to a neurologist for her neurological symptoms, she was told that they couldn’t help her.

“When I saw a neurologist, he just told me that he didn’t even know why I was here,” she explained. “He said, ‘we’ve agreed that we’re not going to see people with long Covid.’”

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Georgia Walby also contracted Covid in March 2020, and has likewise been forced to turn to private healthcare to treat her Long Covid.

“I shouldn’t have to be funding my own treatments, I shouldn’t have to be spending my energy finding my own treatments.”

Ms Walby is a member of Long Covid Wales, a group campaigning for the introduction of specialist Long Covid clinics in Wales. The 54-year-old says that Long Covid patients turning to private healthcare in Wales is a “very common scenario”, thanks to long waiting times for specialist services in the NHS.

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“I’ve been on a waiting list to see an immunologist for nearly 18 months now,” she said. “I was told it would be at least two years when the GP put me on that list, and I’ve not heard a thing about that referral.

“It’s really common - people are waiting over a year to see a cardiac specialist. The result is that people are having to dig deeper and pay to go private because they’re scared.”

“If your heartbeat is completely erratic, you don’t want to wait a year to see a cardiologist.”

Ms Walby says that specialist Long Covid clinics, like the 69 currently operating in England, would speed up referrals and ease the worries of patients by not forcing them to spend years waiting to see a specialist.

“It’s scary, having a new illness where nobody really knows what’s going on,” she said. “So just allaying people’s fears is not a small thing.”

Dr Emma Kavanagh also believes that Long Covid care in Wales needs to be more cohesive. The Swansea-based psychologist and author has had Long Covid since early 2020.

The intense fatigue, headaches, chest pain and shortness of breath meant she couldn’t work for a year, and when she was finally referred to an occupational therapy service at the beginning of 2022, the experience was underwhelming.

“The crux of their advice was just to rest,” said the 43-year-old. “But I’ve been resting for two years, and I’m self-employed so it’s not something I can do anyway.”



Dr Emma Kavanagh, left, and midwife Sarah Sutton have both experienced Long Covid.

Using her medical expertise and reading the latest scientific research on Long Covid, she was able to “cobble together” a treatment plan that her GP was willing to try, and her condition began to improve.

“But the only reason I could do that is because I’m a doctor in psychology, and I’ve spent half my working life reading academic journals,” said Dr Kavanagh.

“For somebody who isn’t comfortable in that environment, there is nowhere else to turn.”

Covid treatment in Wales is run through rehabilitation pathways administered by local NHS health boards. These rehabilitation programmes are funded through the Adferiad programme, which was announced by Health Minister Eluned Morgan in June 2021 in an initial £5 million package of funding.

“We believe our approach of treating, supporting and managing people through our unique service model is the most efficient and effective way of achieving the best outcomes for people experiencing Long Covid,” said a Welsh Government spokesperson.

“People with Long Covid may experience a wide range of symptoms and will be directed to the right investigation, assessment, treatment and rehabilitation to meet their specific needs.”

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The Adferiad program's six-month review, conducted in February, found that only 3.5 per cent of people referred to Long Covid rehabilitation services in the previous year were referred onward to secondary care.

Additionally, Freedom of Information data obtained by *The National* from all seven Welsh health boards has revealed that their rehabilitation pathways are currently supporting less than 1,500 Long Covid patients in total.

That is despite the ONS estimate that there are 83,000 people living with the condition in Wales.

While some health boards have seen high numbers of referrals, others have not. Powys Teaching Health Board has had just 12 people referred to its Long Covid pain and fatigue management service this year.

The figures reflect a patchwork system of care, with some health boards setting up new services specifically for Long Covid, and others folding treatment into existing services for chronic pain and fatigue.

The ad hoc approach extends to the way patients access these services. Of the rehabilitation pathways run by Wales' seven health boards, only one allows patients to refer themselves to its Long Covid service directly.

All other programmes require patients to be referred by their GPs, and some even require a separate "individualised assessment" before patients are accepted onto the rehabilitation scheme.

This is despite the fact that the Bevan report found that patients being allowed to refer themselves was "essential" to ensuring equal access to treatment.

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The Welsh Government said that the current system allows patients to "access the services they need, as close to home as possible", and that patients requiring specialist support will be referred "via their GP or healthcare professional."

However, patients have told *The National* that it has created wide disparities in care for patients in different parts of the country. And research conducted by Betsi Cadwaladr, the only health board that allows self-referral, has found that only 16 per cent of their referrals come from GPs.

"It's completely patchy," Ms Walby. "It's literally down to the attitude of your GP and how much they know about Long Covid."

"Even if you've got a GP who is informed, what they can do is limited because of the system in place. If they feel you need to see a specialist then you're just placed at the end of a long waiting list."

“There needs to be a real concerted understanding of Long Covid that can then be pushed out to all the local treatment centres - because the methods that are being used there aren’t working.”

If you are concerned that you might be suffering from long covid, a list of symptoms from the NHS are available [here](#).

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