healthwatch
Barnet

Long COVID

Case Study

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Healthwatch Barnet spoke with Joshna, a 62-year-old Events Manager from Barnet, about her experience of living with Long COVID after contracting COVID-19 in January 2021. Joshna's described the impact that Long COVID has had on her.

I've not been out one evening this year, I've not done anything since we were allowed to go out and being invited to birthday parties or engagements or anniversary parties, I don't go but my husband goes by himself. I don't want to be seen by people. I look terrible. I just don't feel up to be being seen, so to speak.

I have two children living abroad whom I haven't seen since January 2020. And like my son, for example, he wanted to go away, him and his wife, and asked could I have two of the children and I said 'no, I definitely can't' because it means mornings, getting up and taking them to school. Mornings are the worst time for me, it takes me a long time to get myself together.

And going back to the going out, I never know from one hour to the next how I'm going to be. I mean, I'm bad, or I'm worse. I've never got a great day or good day should I say, but I could all of a sudden start having flu symptoms, feeling shivery and I'm sure I'm coming down with something again and then within a few hours or the next day, I'm not.

Long COVID has taken a toll on Joshna's mental health, with some people not understanding the complexities of Long COVID and the impact the condition has on patients.

> **It's just everything. I'm feeling very low with it, very, very low. And with family, it comes to a point where you don't want people asking, 'how are you feeling?', you just don't know what to answer anymore. I just say, 'I'm okay, same, fine'. You don't want to burden people all the time about how you're feeling as well. After a while I also feel sometimes that people don't believe me.**
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> Sometimes I get told 'pull yourself together, go out and make an effort' and I just don't have the strength. It's affected me mentally. I don't tell this to the children, but I'm very low and I could cry at the drop of a hat. If I could, I'd spend the whole day in bed but I don't, I make an effort and get dressed but I spend most of my day sitting on the sofa. Apart from cooking, I don't do much. I go out rarely for appointments or if I have to drop somebody off.

Joshna explained the difficulties she has been facing in accessing appropriate healthcare support for Long COVID such as a referral to a specialist Long COVID clinic, leading her to seek private healthcare for her illness. An incident Joshna had with an A&E doctor also highlighted the need for health professionals to be better informed on the symptoms and effects of Long COVID.

“I started to feel unwell on the third of January this year. It started with back pain from nowhere then on the Thursday or Friday, I was helping look after my brother because he’s disabled. He was diagnosed on the third and by Friday, I knew something was up. On Saturday it started with a cough and tickly throat and temperature and that’s when I had my test on the Sunday. I didn’t tell the GP straight away, there was no GP to tell at the time at all, it was during the lockdown. I was positive for COVID, I think about a couple of weeks later I got in touch with the GP and then I called 111 on several occasions and then twice they sent the paramedics.

I was still positive on the 21st of February and I really wasn’t well. They sent another ambulance and the ambulance took me to hospital that time, I had a test in A&E and I was feeling really dreadful. But the doctor that came to see me told me off for being there, he said I was wasting his time even though there were only two other people there, he said this is an accident and emergency. I said ‘I didn’t ask to come, I was brought here by the paramedics’ and he wouldn’t examine me.

I mean, I had a chest X-ray and then reluctantly, he listened to my chest over my clothes and said, 'your lungs look better, your lungs are improving, go home' and that was it. So since then, I've been in touch a lot with the GP and then I went to see a private consultant in March. I saw three consultants, but there's nothing, I was put on various medications.

Many participants including Joshna described having to advocate for themselves and insist on a referral to a Long COVID clinic as their GPs were sometimes unaware that specialist clinics exist. This can be challenging for Long COVID patients who are often dealing with low energy and many other symptoms, without the additional burden of chasing up GPs for referrals and completing laborious forms.

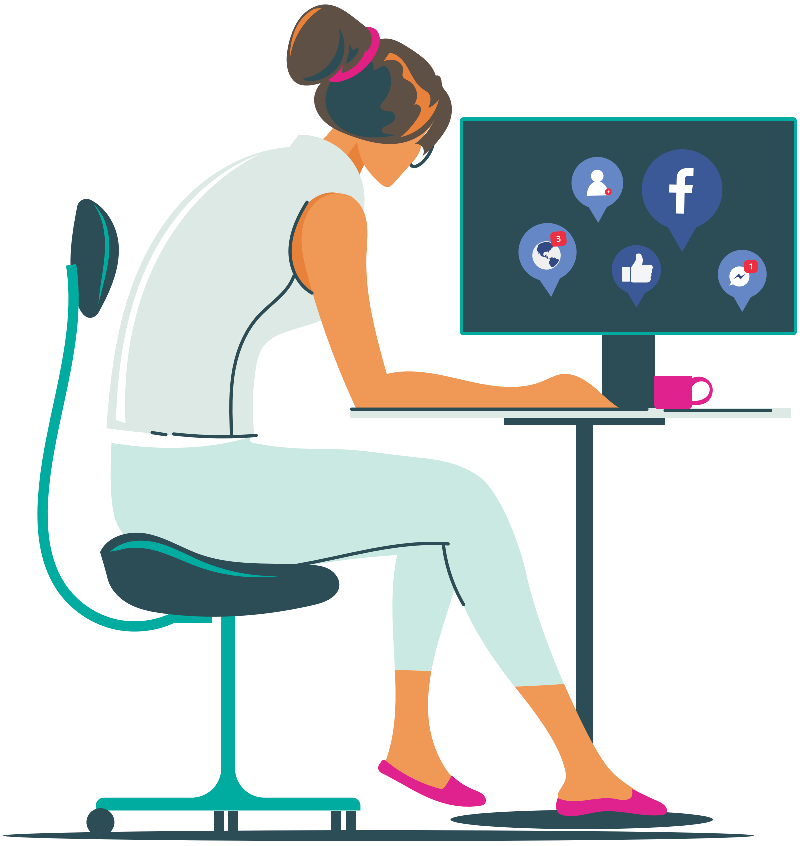
"I asked my GP in March to be referred to the Long COVID clinic and she didn't know much, she asked me if there were any Long COVID clinics. I was told I was referred to the Long COVID clinic and that was some time ago, I had to fill out the forms, the questions about mental health and everything. And now my appointment's tomorrow, and I've had to fill up more or less similar kinds of forms again to take with me. I've had to ask the GP every time for an X-ray, or for blood tests, I was the one who's asking them. I was doing my own private physiotherapy, I had somebody come to the house but it's become too painful to be touched on my upper back. But I've stopped physio now and I just was going to wait to see what the Long COVID clinic does.

The lack of awareness and knowledge of Long COVID amongst healthcare professionals has been highlighted by many participants who have become experts by experience. Joshna felt the need to conduct her own research on Long COVID, saying that her GPs were not knowledgeable on her condition at all, with one GP telling her “What can I say? You’ll get better eventually”.

> **I didn’t go in the end to UCLH because it was just going to be a phone consultation. The private consultant said all the tests I’d had done with him in March, they would have done the same, so I didn’t want to waste their resources. I did ask my GP to refer me to the Barnet one, Healthwatch Barnet had a webinar about Long COVID and that’s when I learnt about it, I learnt a lot of things there and one of those was about the Long COVID clinic in Barnet. The GP should be more knowledgeable and more educated about the whole thing. The GPs were not knowledgeable, not at all, no inkling, nothing to do with Long COVID. Nothing, nothing at all.**

Some participants turned to other Long COVID patients for support due to the difficulties in receiving healthcare support and not feeling heard by healthcare professionals. Peer support schemes within Barnet would provide much needed assistance to Long COVID patients who often feel isolated. Joshna described feeling validated when joining a peer support group on Facebook.

> **I joined a group in March, it's a Long COVID support group on Facebook and they've been amazing. In fact, the first time I joined, the first time I saw the people's symptoms I cried because I was so relieved that it wasn't all in my head.**



Joshna shared that she now considered herself to have a disability due to the mobility issues she has as a result of living with Long COVID. She described feeling very dissatisfied with the Long COVID support offered to her and provided suggestions that could improve her quality of day-to-day life, including being provided with a Blue Badge to ease her challenges with walking:

> **Driving is not a problem, it's the walking. Like I drove today for the first time after a few weeks, so I don't drive a lot because I just don't want to go out. I feel very let down by Barnet because I applied for a Blue Badge so that if I do go out to do shopping, I don't have to worry about finding parking because I can't walk too far. It took a while, I didn't hear from them until I needed to be assessed over the phone, I got in touch and they gave me the number to call for the assessment.**
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> I called and then the man went on about Barnet sending a letter. Then he assessed me on the phone but it was terrible. He was in a very noisy environment and I couldn't hear him properly and his breathing was much heavier than mine, he must have been wearing a headset, I couldn't hear him. Anyway, that afternoon I got an email to say that I was assessed and that I'm absolutely fine. How he could tell that over the phone with all that noise, I have no idea, so I've appealed, and I sent more letters from my physio and my GP. They said the appeal could take until November, and that was about six weeks ago.

Look, nobody seems to know anything. But I wish more people would believe in what we're suffering, especially if we're asking, not me but on the Facebook group, people have been applying for PIP assessments and disability, this and that. I'm in a financial situation where I don't need it, thank God and I would never abuse the system but by asking for a Blue Badge and just some help with mobility, that would be appreciated, if somebody believed me and helped me to get out a bit more.

The other thing I was referred to was occupational therapy to help me with some mobility in my house, I asked the GP and then she referred me. I had a phone call about two or three weeks later and they said, 'You've been referred but we don't know why. We don't understand the letter from the GP.' So I explained, and then she said, 'you might be better off to go privately because there is a three to six month waiting list.' So she gave me some numbers but I didn't call anyone privately, I said please keep me on the list and that was the last I heard.

Regular check-ins from GP surgeries are vital for Long COVID patients as their condition can deteriorate and the lack of energy can make it difficult for patients to contact a healthcare professional. Continuity in care is also important to Long COVID patients as repeating their symptoms to different locum GPs can be a tiresome and frustrating experience.

> “Just before March, it was like when I was in a terrible state, and I really wasn’t well, I sent a long email to the GP surgery and that’s when my GP started calling me herself. Before that, it was only locums who didn’t know me at all calling, or I was in touch with. Then the GP started calling me weekly, only when she realised the state I was in just to see how I am and I would explain, and sometimes I thought was a little better, but I just never know from one day to the next. Then she stopped calling so it was a few weeks ago that I sent a long email again to say I’m not well, I really need help, that’s when I told them about the Barnet clinic. It was another locum, she could hear in my voice the state I was in and then she sent me a paper I had to pick up.”

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