



Long COVID

Case Study

“ Going from being an independent person to becoming disabled is a lot to process and I have felt alone out there because of the waiting lists. ”



 @longcovidlucy

Lucy is a Barnet resident in her early 30s, spoke with Healthwatch Barnet about her experience of living with Long COVID after contracting COVID-19 in March 2020.

Lucy worked as a sign language interpreter however, her illness meant she has had to stop working, leading to a significant impact on her life.

I am not able to process two languages at once at the moment and because I suffer from chronic fatigue, I just don't have the energy to be processing.

I have had to move back home from my rented accommodation because I could not afford to stay there. I also could not look after myself and remain independent. So for things around the house I rely on other people to help me, they do the shopping, cooking and cleaning. Sometimes on bad days, I have help bathing too.

I am not able to work so obviously that has affected me financially and mentally because I was self-employed, have my own business and worked full time but now, I am not able to do that so it has been a huge life-changing event from being very independent to relying on people around me for support.

Although Lucy experienced Long COVID symptoms early on in the pandemic, she did not receive a diagnosis until November 2020.

A lack of knowledge on Long COVID has been highlighted by Long COVID patients, Lucy discussed feeling the need to conduct her own research about Long COVID as a result.

‘ Initially I went to my GP because I had continued breathlessness and I thought it was my asthma. It took a while because they thought it was my asthma and Long COVID was not a thing. It was only when a doctor herself was suffering from it, she said there’s a new condition called Long COVID.

At the start, I got told things like “if you find any research let us know”, it was all quite self-led. Now I think there is more awareness obviously and I’m under a Long COVID unit, but I did not get referred to that Long COVID unit until maybe March 2021, so it was a whole year later until I got any kind of real support. ’



Like other Long COVID patients, receiving appropriate healthcare support such as a referral to a specialist Long COVID clinic or community health support and their associated waiting times has been difficult for Lucy.

“ That November 2020 when they discussed Long COVID, I got referred to a respiratory specialist but I was never seen by the specialist because my referral in the end got cancelled. It kept getting moved due to the lockdowns and I just got a letter saying that your referral has been cancelled. I did not bother to chase up on it because I was under the Long COVID unit, and I was just tired of chasing everything myself. ”

Lucy also received referrals to other healthcare providers however the lack of communication and coordination from these services has proved strenuous, particularly for a Long COVID patient experiencing chronic fatigue.

“ UCLH referred me to Barnet and then the East Barnet community clinic. I had an initial assessment with them but they basically said they felt I was too unwell to be seen under them and they didn't know why UCLH had referred me. ”

So that felt quite upsetting because I thought Barnet was going to give me more rehab like physio, get me back on my feet and since I've had a UCLH review, they said they don't know why East Barnet had said that, so I feel a bit confused.

This is what is quite hard and communication just gets confused, so I have to chase up East Barnet and then they say they need to get the go-ahead from UCLH. I'm at UCLH and East Barnet said that they would keep my name on file, but I'm not at the moment being seen by them.

Once I decided to give up work and move home, I think it took a lot of pressure off and it has allowed me time to rest. They kept saying I have to pace myself but I could not while I was trying to work and pay rent.

Also, I created my own Instagram profile and that has created a real online community of peers who are also going through the same thing. Because it's been so long, I think you just start learning your own coping mechanisms. I have had friends online that I have made who have said their local place has like a peer hub, but I've never known anything here in Barnet.

Through being online I have also become part of the Wren project. They are offering a 'listening support service' for people with autoimmune disorders. They adapted their service to support people with Long COVID temporarily. I've been waiting seven months for counselling from Barnet and I'm still on the waiting list. I'm receiving support from the Wren project tomorrow and it'll be every other week because I've been waiting for mental health support obviously, but I can't seem to get any.



Reflecting on her experience as a young person with Long COVID, Lucy outlined improvements that would have improved her experience of receiving support from healthcare services, including better communication between different hospital departments, early access to healthcare services, a greater understanding of Long COVID by healthcare professionals and a local peer support offering.

“It is hard if I am being honest. At first in 2020 I felt so alone and things like “if you find any research, let us know” made me feel like I had to be the expert and advocate for myself, which is hard when you are not well. It is not easy, I feel like I have to constantly advocate for myself and it’s a lot of energy. Going from being an independent person to becoming disabled is a lot to process and I have felt alone out there because of the waiting lists.

Since I have been with UCLH, again I am really grateful for the NHS and I don’t like putting things down because we’re so privileged in this country, but I have had to chase up for my appointments and I have had to chase for letters. It has not been easy, and I have had appointments where they say, “oh we will put a letter up within the next two days” and I still do not have it and I have to ring up and ask for it. At the same time, I appreciate it because I know how busy they are.

I kind of feel like although it is diagnostic and they are doing tests, there is no pastoral support. Peer groups as well, having something in the area and mental health support would be really helpful.

Healthwatch Barnet
Independent Living Centre,
c/o Barnet & Southgate College
7 Bristol Avenue,
Colindale
London NW9 4BR



020 3475 1308



info@healthwatchbarnet.co.uk



@HWBarnet



Facebook.com/HealthwatchBarnet



@HealthwatchBarnet

healthwatch
Barnet

www.healthwatchbarnet.co.uk