

Post-COVID Syndrome (Long COVID): The continuing effects in Havering and responding to resident engagement

Focus groups held 28–30 May 2024

Following two earlier surveys of local people who are living with Long COVID, in May we ran four Focus Group sessions with local people living with Long COVID to find out about their experiences in greater depth, including:

- their symptoms
- how they found dealing with healthcare professionals and
- what support they felt they needed

The sessions were held at:

- 1 – Hornchurch, in person – 11 participants
- 2 – Harold Wood, person – 2 participants
- 3 – Video conference, morning – 6 participants
- 4 – Video conference, evening – 2 participants

Themes explored

What symptoms have had the most significant impact on your ability to do day-to-day activities and your quality of life?

Can you tell us about your experience with accessing services to help you with your symptoms (this includes local services)?

- How did you find out about these services?
- What has worked well for you?
- What has not worked well for you?

What further support or services would help you manage your symptoms?

Do you think a peer support group would be beneficial? If yes, why do you think so? If no, why do you think it would not be beneficial?

Impact on day to day living

1. Participants experienced symptoms of Long COVID, including fatigue, brain fog, and muscle weakness, impacting their daily lives and work routines.
2. They highlighted the importance of adapting work practices, such as writing things down and working from home, to manage the cognitive challenges associated with Long COVID.
3. They described struggles with general fatigue, difficulty concentrating, and physical exhaustion, affecting activities like watching TV, socialising, and even simple tasks like walking the dog.
4. They emphasised the significant impact of Long COVID on their energy levels, sleep patterns, and overall quality of life, leading to challenges in maintaining their previous levels of activity and social engagement.
5. Despite the difficulties faced, participants expressed resilience and determination to continue working and managing their symptoms, showcasing a strong will to overcome the obstacles posed by Long COVID.

Accessing services

1. **Misattribution of Symptoms:** Participants mentioned that their symptoms were attributed to other conditions like menopause or depression by their GPs, leading to a delay in recognising Long COVID as the underlying cause of their health issues.
2. **Lack of Awareness:** Participants expressed frustration over GPs not fully understanding or acknowledging Long COVID as a legitimate condition, leading to dismissive attitudes and inadequate support.
3. **Diagnostic Process:** Participants highlighted difficulties in the diagnostic process, with GPs often suggesting tests for other conditions first before considering Long COVID, causing delays in receiving appropriate care.
4. **Limited Treatment Options:** Some participants mentioned being prescribed antidepressants as a standard treatment, even though it might not address the specific symptoms of Long COVID, indicating a lack of tailored treatment options.
5. **Access to Specialised Care:** Participants faced challenges in accessing specialised Long COVID clinics or services, with delays in referrals and long waiting times contributing to their overall struggle in receiving comprehensive care for their condition.

Further support needed

1. Participants faced challenges in accessing specialised medical care, including rare blood disorder testing, and expressed the need for at-home support services due to disability.
2. They highlighted the positive impact of the Long COVID team's holistic and non-patronising approach to care, which significantly improved their condition and quality of life.
3. One participant shared a complex experience with Long COVID symptoms exacerbated by COVID vaccination, leading to various health issues like body tremors, high blood pressure, and challenges in maintaining good health and work performance.
4. Another participant expressed a need for better coordination between other medical professionals and GPs in understanding the impact of exercise on Long COVID recovery and overall health.
5. A participant expressed feelings of guilt for seeking mental health support through IAPT, feeling undeserving compared to others with severe depression, highlighting the importance of recognising and addressing mental health needs regardless of severity.

Peer support group

1. One participant mentioned that the groups were focused on anxiety and depression, not covering their Long COVID symptoms. Another emphasised the importance of a positive approach in peer support, highlighting the risk of unproductive cycles when individuals with the same symptoms gather without professional guidance towards positive outcomes.
2. On the other hand, some participants valued the framework of the Long COVID clinic and believed in the profound effect of peer support in finding a way forward. They suggested that sharing non-mainstream information and experiences within a peer group, such as acupuncture and therapeutic practices, could be influential in moving forward and finding recovery.
3. However, mixed feelings were expressed about peer support. One participant had self-referred to IAPT and participated in Zoom meetings but felt like a fraud because the focus was on severe depression, which they did not feel they were experiencing. This led to feelings of guilt for taking a spot from someone who might have needed it more.
4. In summary, the participants' feelings about peer support groups range from scepticism and concerns about group dynamics to appreciation for structured support programs and the value of sharing experiences for mutual recovery. Most participants felt that a dedicated peer support group for Long COVID patients would be beneficial.

Some participants' comments - 1

"This COVID is a very strange disease, isn't it? It's affected a lot of people, some very badly as we know and yet other people almost shrug it off within 24 hours. It left me within four days and I was perfectly alright but someone I know went down with it and she suffered for 12 months"

"When I spoke to my GP about my fatigue, they put that down to the diabetes, that I'm diabetic now, so they say, "Oh you're now tired because you're diabetic," so kind of ignore the possibility of Long COVID. People who have had the virus for a long time tell of loss of smell and I have no smell whatsoever."

"If we go to our GP's and find that we've got to wait three to four weeks for an appointment and then we're told that we need a triple appointment, which is actually only 15 minutes ... I try very hard to squeeze what I can say in but the reaction is '*I haven't got time to do it now*' and the attitude is '*You are wasting my time*' "

"I think part of the problem is that COVID didn't exist as a thing until the end of 2019. Doctors have been trained to take some symptoms and say "You've got that"; and if they can't do that, they're really in bother because the doctor's job is to give you a medication or whatever and then you're going to get better. With Long COVID, they can't do that, so they find themselves, I believe, in a very difficult situation"

Some participants' comments - 2

"I had a physiotherapist show about me three weeks ago now how to breath, and it's changed my previous score from three or four seconds to 30 seconds, which is life changing. It's not been like a little step, it's been a leap forwards with recovery, because obviously now the fatigue levels have dropped. I'm probably 50% back to being where I was before and not only strength wise its massively changed my life"

"I got discharged about a year, year and a half ago: I went for my appointment, and I didn't know it was the last appointment. I got there and I gave him this long list of stuff I'm still suffering with. He went "OK well, we'll test you for everything. Nothing we can do, so we'll just discharge you" and then you are back to where you started"

"Every day is a different day, there's no warning, I mean you literally wake up each morning and you don't know how you're going to feel. Some days you can't even get out of bed. My kids and my husband, who's at home, have to literally treat me like I'm completely disabled"

"I would absolutely love physio or some sort of massage or anything in that sort of genre. But nothing has ever been mentioned about that, just psychology stuff. They call it Cognitive Behaviour Therapy (CBT) but that's not going to help me now this far down the line"

Some participants' comments – 3

“I get headaches that feel like after going 10 rounds with Tyson Fury. It's horrendous on some days and some days it's manageable. On other days it's like I'm just not getting dressed, which I hate doing, because I feel like I'm not achieving anything in life”

“Another thing I find is I get very short of breath still and so they put me in contact with the ENO, which is the English National Opera; they run a course for six weeks to try and teach you how to breathe properly – they teach opera performers to sing and where to sing from and how to use your diaphragm and your lungs and all that”

“I think for me, the biggest symptoms are really the brain fog. I didn't even know there was such thing as brain fog. I just thought I was getting super old, I thought “Is this what getting old is all about?””

“Like the brain fog today, I didn't pick up on until others have just said as well. So it is the constant waiting and the constant chasing. It's the having to go to so many different types of specialties”

“When I did IAPT, I actually felt a bit of a fraud, because there was a waiting list and the other people were severely depressed where it was impacting on their life. I thought I'm not depressed like them, I'm taking someone's place because the people were so severely depressed. And I'm not”

Some participants' comments - 4

"The first time I went to the supermarket, I didn't know where I was. I almost had a panic attack, and I couldn't find anything, and I had to ask an assistant. In the end, she gave up and just came round with me because I couldn't find anything. I just wanted to get out and get home. It was a really strange experience to go in the supermarket"

"Another thing I found as well (and I know this probably sounds probably quite stupid), I get socially fatigued quite easily. I'm OK to mix with people for a very short space of time but actually having to be social and interact for long periods of time, I find quite wearing, quite tiring and I find towards the end of my workday I'm a bit like "Just go away and leave me alone", I just don't want to talk to people, don't want to be smiley, happy and nice and all that sort of thing. That is not me; it's just I'm tired and I just want to go home"

"Long COVID isn't recognised as a disability. It's not covered under the Disability Act. I've had many arguments within my workplace as I have a long-term illness. I'm quite lucky that my line manager is very helpful, however I've had to go backwards and forwards to our occupational health, HR, etc fighting to be listened to in work because it's not recognised as a disability. So for those that are in work, and they are struggling, you are covered under the Equality Act. So therefore that's how you should be treated equally"

Long COVID support – posters

Havering Long COVID Support

Experiencing symptoms weeks or months after having COVID-19?
Is it Long COVID?

What you told us* about your Long COVID symptoms?

Fatigue



Low mood



Brain fog



Breathlessness



...and many more symptoms including loss of taste and smell

Accessing support for your symptoms

See your GP who can check you over and may refer you to a **specialist Long COVID service**, social prescribers and/or health coaches.

Local services available include:

Mental health & emotional wellbeing

e.g. Talking Therapies, Age UK activities, Mind in Havering activities

Physical health

e.g. Yoga, Tai Chi and community walking groups

Employment / financial support

e.g. Havering Council services and schemes to provide advice and information.



www.havering.gov.uk/longcovid

*In 2023, Healthwatch Havering, Public Health and Havering North PCN invited residents to complete a survey about their Long COVID symptoms and experiences

Long COVID support – posters

Havering Long COVID Support

What you told us* about your Long COVID symptoms?

Fatigue



Low mood



Brain fog



Breathlessness



...and many more

Getting support for your symptoms

See your GP who can check you over and may refer you to a specialist Long COVID service

Get local support for your:

Mental health & emotional wellbeing

Physical health

Employment / financial support

Scan below for more information



www.havering.gov.uk/longcovid

The next steps...

- Continue to share the Long COVID support poster with residents
- Explore pilot peer support programme – in discussions with Peer Partnership who has develop a model for people with Long COVID
- Training for primary care – BHR Long COVID Service to deliver more widely

The full report...

Post-COVID Syndrome (Long COVID): The continuing effects in Havering

... is available in two volumes:

Volume 1 – **Focus Group discussions: report**

Volume 2 – **Focus Group discussions: Full Transcripts**

<https://www.healthwatchhavering.co.uk/news/2024-08-05/post-covid-syndrome-long-covid>