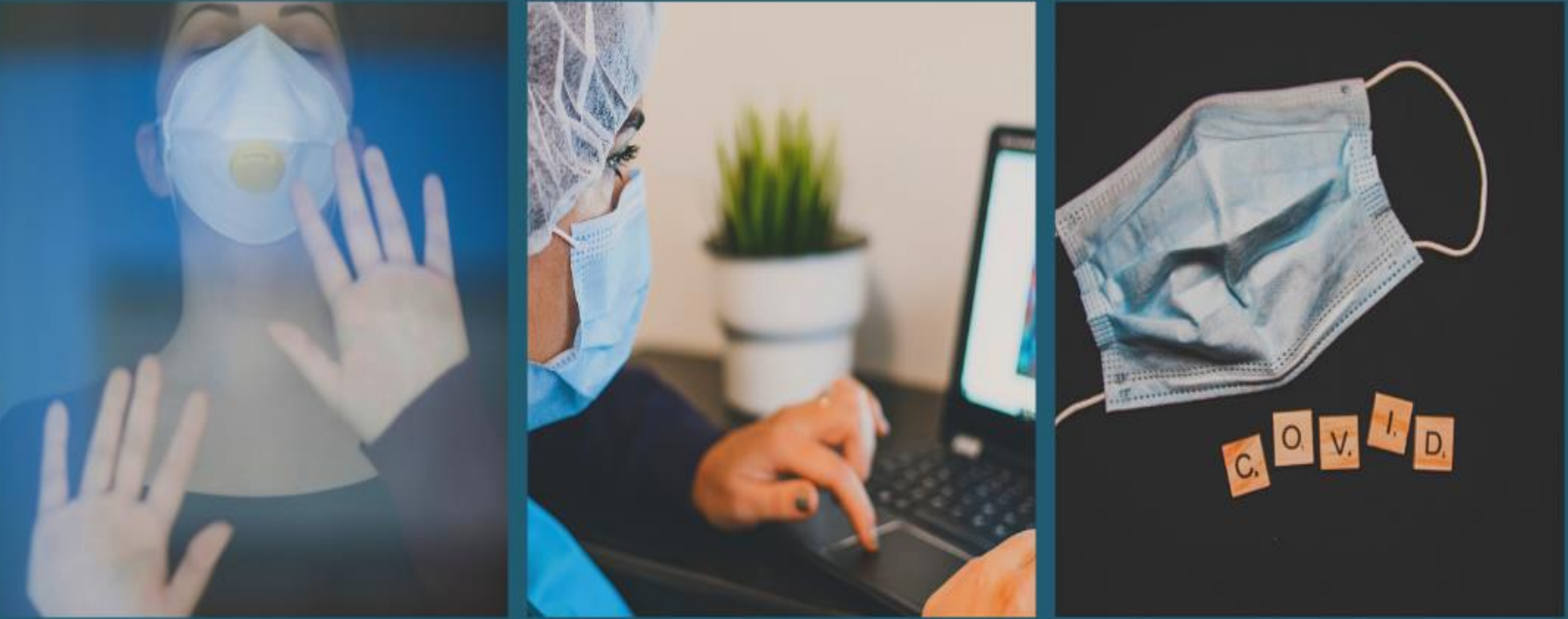


LONG COVID SNAPSHOT REPORT

Feb 2022

healthwatch
Merton

The Context

Long COVID (also known as Post COVID Syndrome) has emerged as another challenge arising from the current pandemic.

Long COVID is defined as signs and symptoms that develop following an infection consistent with COVID-19, which continue for more than 12 weeks. You may experience Long COVID even if you were not acutely ill in the first place. Common symptoms include breathlessness, problems with memory and concentration and fatigue. Not everyone with Long COVID, particularly those who were ill early in the pandemic, will have been tested for COVID-19. https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/

As new services of support emerge and others evolve Healthwatch Merton, along with Healthwatch Richmond, Kingston, Sutton, Croydon and Wandsworth agreed to work together on gathering insight across the 6 South West London Boroughs of people's experiences of Long COVID.

Collectively there have been over 300 responses from people across South West London who shared their experiences on how Long COVID has impacted on their lives, the range and severity of symptoms, the support/help accessed and what else could enable their recovery.

Methodology

An online survey, comparable to the questionnaires used across all local Healthwatches across South West London, invited Merton residents to share their experiences of Long COVID.

The survey was shared via our Healthwatch Merton e-bulletin, a special mailshot, other voluntary and community sector organisations who posted in the news bulletins or/and shared on social media, other social media channels (e.g., Healthwatch Merton, Merton Council, Merton Connected) and also on Merton Council e-bulletin.

The insights shared with Healthwatch Merton between late August and November 2021 and people's circumstances may have improved, stabilised or worsened.

Key Findings - out of the 52 who responded

27%
Had received a diagnosis for Long COVID (also known as Post COVID syndrome)

80%
Stated they had not received support or were unsure

63%
Stated that Long COVID has impacted on their mental health

32%
Stated that living with Long COVID had impacted on their working life

70%
Of the people who shared experiences were aged between 30-59

Profile of people who shared their experiences

♂ **8** ♀ **41**

41 People have an ongoing physical and/or mental health diagnosis

36 Aged 30-59

12 Aged 60+

2 Aged 18-29

33 White British

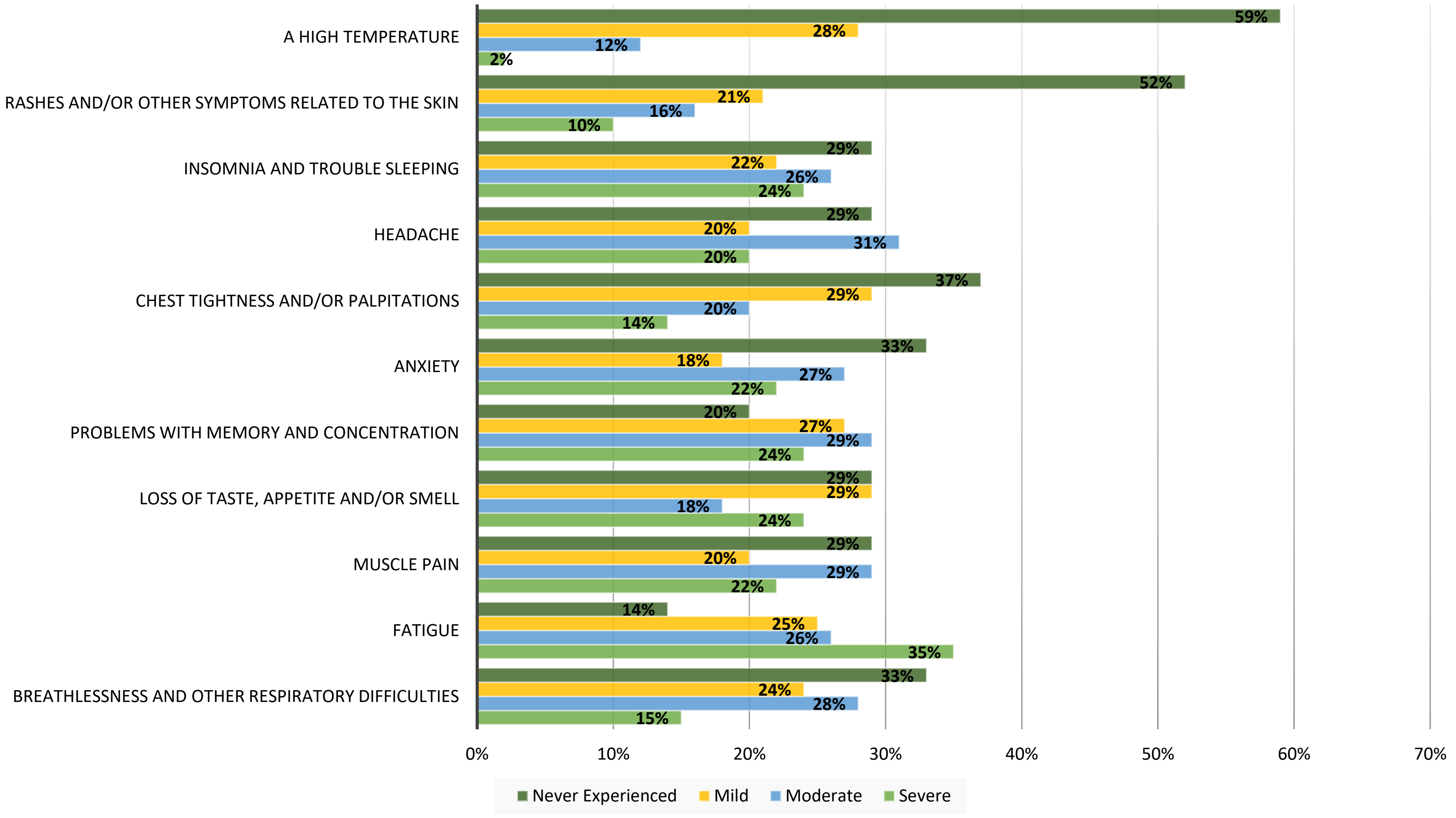
17 Other minority community

46 English is 1st language spoken

4 English not 1st language

3 People did not share information on gender and **2** did not share their age and ethnicity.

Long COVID Symptoms



Main Symptoms people experienced or are still experiencing (%)

Other symptoms mentioned by people in their responses that they have been advised (or believe) may be connected to Long COVID

3 mentioned tinnitus or worsening tinnitus

3 said pins and needles of which **2** mentioned were in the chest area

2 mentioned impact on self-esteem and emotional wellbeing

2 stated hair loss

‘Have been diagnosed with Sinus Tachycardia[1] and have medication for that. Also have post exertional malaise where if I have done more activity than a short, slow walk for example, will get a range of physical symptoms including worsening of tachycardia occurring sometimes for weeks after’

‘Rapid Blood sugar changes, shaking especially of the hands’

‘Profoundly deaf in right ear (confirmed by audiology test); referred to ENT for consideration - appointment Feb 2022’

‘Profound deafness & loss of most of sense of taste occurred a few days after Pfizer VACCINATION January 2021. So, I am not sure that had actual COVID causing them. They persist’

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[1] Sinus tachycardia is a regular cardiac rhythm in which the heart beats faster than normal and results in an increase in cardiac output

‘My skin breaks out into welts when pressure is applied to it (dermatographia)[2] and itchiness. Most skin creams cause a burning sensation and redness’
‘Tonsil’s regrowth due to so much coughing’
‘My immune system can’t seem to fight viruses or bacteria that I have been getting since I had Covid’
‘Reduced normal function in right arm, adverse reaction to low intake of alcohol’
Struggling eyesight
Numbness in soles of feet
Reflux, rapid weight loss

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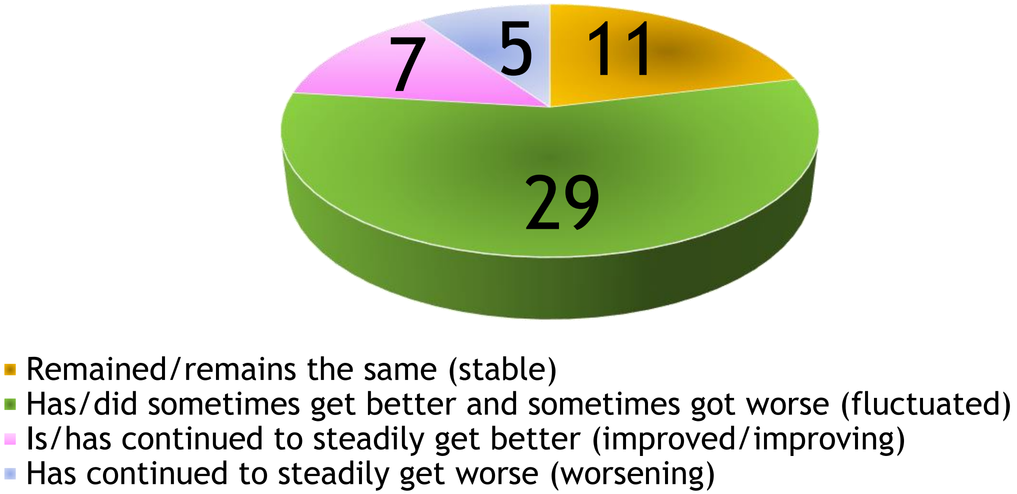
[2] Dermatographia is a condition also known as skin writing. When people who have dermatographia lightly scratch their skin, the scratches redden into a raised wheal similar to hives

Living with Long COVID

The following was highlighted as what best described the peoples overall Long COVID condition

Out of 52 People



Long COVID has impacted on peoples Mental Health and out of the 52 people: -

- 33 stated it has impacted on their mental health
- 19 stated it had not impacted on their mental health

People shared how Long COVID had impacted on their quality of life, relationships, wellbeing, ability to work, etc. and out of the 45 people who shared their experiences 17 mentioned is had impacted on their working lives.

The following comments shared offer a clearer insight into the real impact on individuals and those around them: -

‘Long COVID has made my work life quite difficult. I am 32 years old, I am an administrator/ finance officer and trying to do a full day’s work can be very difficult as its mentally taxing, which makes my home life after work difficult. As I am so tired, this can put a strain on my relationships as I cannot do usual things like go for long walks or carry heavy shopping, this is affecting my mental health and in turn my well-being’
‘Lack of interaction and feel isolated with friends and family due to low energy and increased fatigue and breathlessness, reduced ability to work, long phased return and now having to work part time instead of full time, increased anxiety levels which have never experienced before, weight gain and reduced exercise capability’
‘Left my job as a midday supervisor because of the increase of extra work, cleaning and short of staff and l found it very tiring due to lack of sleep’
‘I have had to work from home as a rule rather than commuting, I don’t have the stamina for going out as often as I did, the major issue is muscular in my right arm’
‘I am regularly taking time off work due to the way my body reacts on different days’
‘I have gone from being a very active sporty person, cycling, swimming, running and dog walking to needing help with daily household tasks and being unable to care for my daughter and do activities and trips out with her. The most activity I can do is a very slow 30-minute walk whereas I used to happily run for an hour’
‘My daughter does not have a life can barely walk or breathe properly has regular brain fog does not venture out anywhere and works limited time from home’
‘Always feel tired, and "brain fog" is very frustrating, this effects my confidence’

‘My anxiety is affecting my everyday life and my head aches are causing me to take tablets daily which is not healthy. I am taking vitamins for my hair loss which has helped but feel it may be deteriorating again. When I walk or do something that is strenuous the tightness in my chest is so worrying and it not going away so I try not to do anything that will cause this but then I am not able to get fitter’

‘I have lost my smell so cannot enjoy eating as much. Food does taste slightly different. But I also have a lesser ability to recognise danger by not being able to smell danger’

Feel I don't have a life like I used to. I just exist. I can't do the things I used to. My body and brain don't work how they used to.

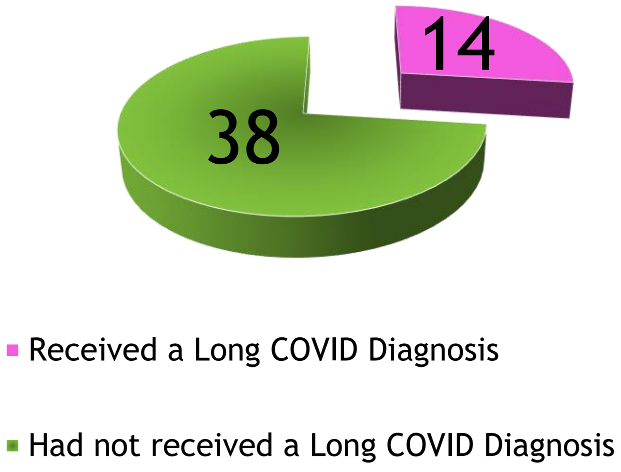
‘I contracted covid over 10 months ago and had mild symptoms except for fatigue. I still have fatigue i.e. I need to rest in bed after eating a meal and I need to rest much more throughout the day than before I had covid’

‘Mostly it is an irritating as it causes itchiness and burning. I have had to try out different face creams and soaps as my usual ones cause my face to burn and turn red’

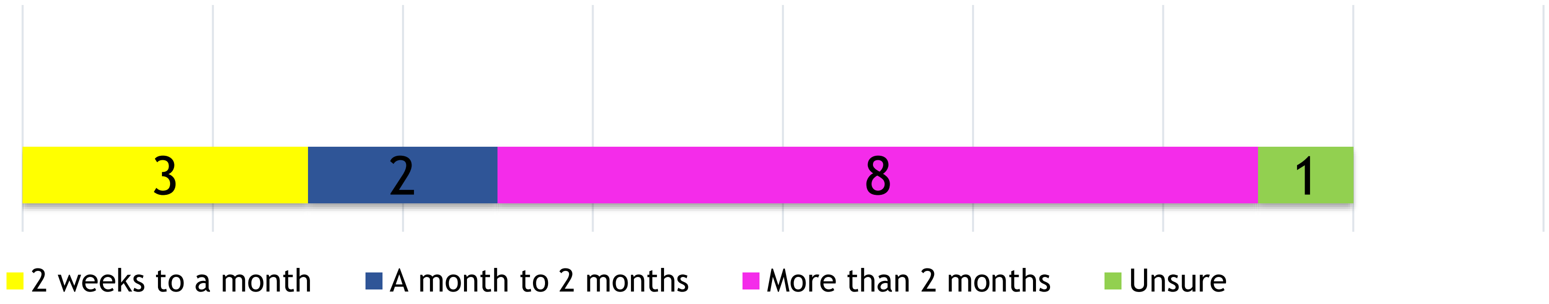
‘The permanent tinnitus is difficult to live with. I have had it since having covid in September 2020. I have to learn to live with it.’

Long COVID Diagnosis and Access to Support

Out of **52** people: -



After a diagnosis was made the length of time the **14** people received support from their first referral was: -



People shared the range of support/help that they had received from the NHS or private care.

10 people shared the following: -

‘Long covid clinic: gave information and some support, did many tests and have some good advice but wasn’t as supportive as I had hoped and did feel like there is still more that could be done to help, I believe the clinic is improving as time has passed. Great support from the GP (eventually): was hard at the start as the GP I had didn’t not believe me but eventually I have now got a go who understands and is knowledgeable about Long covid and has made a difference as just being listened to and believed and investigate my symptoms was a relief and supported and aided my recovery, support from my family and friends: invaluable and has been there at the toughest times to encourage me that I will get there’
‘My doctor has been wonderful, but I have been waiting since June for CBT therapy and still waiting!’
‘Private ENT appointment in July 2020 and have tried smell training. Slight improvement’
‘Finally, after over a year been referred to the post Covid clinic after having to literally plead with the GP. Also had to present my own proof to the GP to get referred to the cardiologist at St George’s as initial tests were inadequate to show the issues of my heart rate peaking after changing posture and during walking. The post Covid clinic person has been brilliant in supporting me mentally and giving me sensible practical advice to benefit me physically which the GPs just do not have time to do at all. She phones me once every week or fortnight and is very helpful, patient and caring when I am in tears, sobbing and distressed. I don’t know what I would do without her as I find it very difficult to open up to family and friends about how bad I feel sometimes. My life has been tipped upside down’
‘Phone consultation with respiratory specialist (still awaiting follow up and diagnosis 6 months later as appointment keeps being deferred. Currently due for end of January 2022). Was put on a different inhaler following the phone consult which helped enormously. I did the ENO (English National Opera) breathe course which did not help at all’

‘I have received support from my excellent physiotherapist whom I was seeing, before I caught covid, for another ailment’
‘Saw consultant about tonsils but nothing about fatigue’
Occupational Health specialist
‘My GP did report my reactions to my first Pfizer vaccination on the yellow card system, My GP has arranged a hospital appointment with Ear, Nose and Throat Specialist in February 2022. She would have arranged it earlier, bit I wanted to see whether I might recover without intervention’
‘Given an inhaler’

People shared the range of support/help that they thought would help. Out of the 32 responses comments included: -

10 believed there was nothing, they were not sure what could be provided, or they were just left to get on with it
5 stated a diagnosis or/and more understanding from their GP
3 would like more understanding and support from work
‘Physio support, how to slowly increase energy uptake and exercise without causing the fatigue to worsen and overall to deteriorate: very hard to get the balance right without doing too much and having reduced energy and having to build up to not again Better long covid links with others: to know that you are not alone and share tips and knowledge that might help Cognitive Behavioural Therapy: to help accept the changes that this virus has caused long term’

Therapy
‘Blood tests etc. - m.o.t. to see if anything wrong’
‘I sought help for my tinnitus within weeks of it first appearing. It wasn't a known symptom at the time, and I was dismissed as being silly when I said I thought it was related to COVID. I have not sought further treatment since no one listened to me and I was told it was a condition that had no cure’
‘I don't think there is anything to help covid fatigue. I go for walks a lot and am quite active every day, but I need to rest in between so much more.’
‘I have not been diagnosed with long COVID but when reading the symptoms, I think maybe this is what it is. I’ve been sent to specialists for my head aches and my chest tightness, but it might be Long COVID. No one has suggested this’
‘I never sought help or support. I read loss and change of smell was possible with Covid and so I just live with it. I don’t think anything can be done about it, so I have not sought medical advice’
‘It feels that help is available only for the most acute COVID cases and for those who are able to carry on living, even if on a low level, no help is available. I went to A&E once and was pretty much told to look myself after myself’
‘A support group’
‘I don’t know what help is available’

People shared their final thoughts on their Long COVID experiences or what else should have been carried as part of our community insight gathering

‘Raise public awareness about Long COVID, there should be more information available on official websites’
‘Asking about experience does not help much. I would rather have this experience ending and have some kind of life’
‘This year covid-19 hit me in Jan did think I get covid-19 not me knock me for six life not been the same any more’
‘Because my symptoms followed Pfizer COVID-19 vaccination rather than an actual bout of COVID (I think; but may have been concurrent), I nearly did not fill in this form. If possible, please try to rephrase the form in a way that encourages severe consequences of COVID-19 vaccination to be recorded’
‘I have not had Covid as far as I am aware but am advised that my reaction to the Pfizer vaccine is identical to Long COVID’
‘My daughter also had several months of having high temperatures after exercising in particular which seemed to stop but I am concerned that if she gets Covid again this could happen again. She is 9 and would love to be vaccinated’
‘It would be nice to have local help as she feels she has just been forgotten about’
‘Does anyone recover their sense of smell from this long ago? It’s now over 18 months’
‘The only treatment that helped with the fatigue and muscle ache was Japanese acupuncture, which was very costly, but worth it to start being able to function a bit better’
‘I contacted my GP to say I was having chest problems and my mental health was getting worse and I was feeling desperate. He didn't even listen. Just said to wait for my referral and try counselling. No help no sympathy no understanding. No one cares about people with long covid’
‘I know this may not be the case anymore, but it would be beneficial for GPs to have more involvement and information from the long covid clinics and teaching to help support people outside the clinic or people that might not be able to go to the clinic’

‘Long Covid wasn’t diagnosed for me but putting the puzzle together 5 months later and looking back, we can see that my anxiety, weight loss, reflux and exhaustion must have been due to having Covid. It’s a scary thing when it’s so unknown so diagnosis is hard. My doctor didn’t diagnose long Covid, after looking online at long Covid symptoms it was us as a family that think I had it.’’

‘I had Covid at the end of March 2020 - before testing was available, so neither it nor long Covid was diagnosed by a healthcare professional. But I found the Covid 19 Yorkshire rehab screen online, and I scored higher than zero for a few symptoms, but none higher than 5 (out of 10)’

The insights shared with Healthwatch Merton between late August and November 2021 and people’s circumstances may have improved, stabilised or worsened.

The next step is to link with all local Healthwatches across South West London and prepare a joint summary report that encompasses key findings across the 6 boroughs and recommendations that will be taken to the South West London CCG Board.

OUR SUGGESTIONS:

- Increase awareness of Long COVID or Post COVID syndrome across the wider community and pathway
- Opportunities for public to meet clinicians or Long COVID leads to gain greater understanding (e.g., series of online webinars, question and answer sessions)
- Promote the Merton and Wandsworth Post COVID service widely and ensure the patients voice helps shape and evolve the service
- A downloadable leaflet listing key Long COVID support services/opportunities Merton residents can access (include services across South West London or and online support that is PAN London or national)
- Explore idea of a pilot or seed fund to empower community sector organisations (across boroughs) who could set up or enhance opportunities that help people living with Long COVID that can make an impact (e.g., peer support groups)
- Joint recommendations with other South West London that could apply across the localities.

LONG COVID SNAPSHOT
REPORT

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healthwatch
Merton

Healthwatch Merton
Vestry Hall
London Road
Mitcham
CR4 3UD

T: 020 8658 2282
E: info@healthwatchmerton.co.uk
W: www.healthwatchmerton.co.uk