Community Engagement

Post-COVID Syndrome (Long COVID)

The continuing effects in Havering

October 2023

Healthwatch Havering is the operating name of
Havering Healthwatch Limited
A company limited by guarantee
Registered in England and Wales
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What is Healthwatch Havering?

Healthwatch Havering is the local consumer champion for both health and social care in the London Borough of Havering. Our aim is to give local citizens and communities a stronger voice to influence and challenge how health and social care services are provided for all individuals locally.

We are an independent organisation, established by the Health and Social Care Act 2012, and employ our own staff and involve lay people/volunteers so that we can become the influential and effective voice of the public.

Healthwatch Havering is a Community Interest Company Limited by Guarantee, managed by three part-time directors, including the Chairman and the Company Secretary, supported by two part-time staff, and by volunteers, both from professional health and social care backgrounds and lay people who have an interest in health or social care issues.

Why is this important to you and your family and friends?

Healthwatch England is the national organisation which enables the collective views of the people who use NHS and social services to influence national policy, advice and guidance.

Healthwatch Havering is your voice, enabling you on behalf of yourself, your family and your friends to ensure views and concerns about the local health and social services are understood.

Your contribution is vital in helping to build a picture of where services are doing well and where they need to be improved. This will help and support the Clinical Commissioning Groups, NHS Services and contractors, and the Local Authority to make sure their services really are designed to meet citizens' needs.

'You make a living by what you get,

but you make a life by what you give.'

Winston Churchill

Community engagement

Under Section 221 of the Local Government and Public Involvement in Health Act 2007, Healthwatch Havering has a statutory duty to ascertain the views of health and social care services and to make them known to the commissioners and providers of those services so that they can be taken into account in the development, commissioning and delivery of services.

We do this in a variety of ways, such as surveys, interviews and focus groups.

We also participate, with other Healthwatch organisations across North East London, in the Community Insights System, which gathers views and comments on health and social care from people across the area. Intelligence gained from Community Insights is used directly in, or to inform, many of the surveys and other public engagement events that we carry out.

The results of our community engagement are shared with Havering Council, NHS North East London, NHS and other provider organisations and Healthwatch England.

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What respondents told us - *continued*

Executive Summary

This report examines the effects of Long COVID on people in Havering, building on an earlier report by the Healthwatch organisations in Barking & Dagenham, Havering and Redbridge.

For this report, people (including some of those who responded to the 2022 survey) were invited to answer questions on their experience of Long COVID. The questions examined whether people felt their symptoms of Long COVID had got better, stayed the same or worsened; if they had been formally diagnosed; what symptoms they had experienced; whether their lifestyle had changed; what services and support they were aware of and whether they had availed themselves of that help; and whether their physical and mental needs had been met.

Responses to those questions revealed a range of experiences, from feeling much better to much worse, from receiving the support they needed to having no support at all.

Many of those living with Long COVID reported experiencing both devastating mental stress (fatigue, tiredness, “brain fog”, anxiety) and physical difficulty (breathing difficulties and breathlessness, smell and taste problems, lack of energy). This confirms known clinical indicators of Long COVID.

This report concludes that clinicians need to understand more about Long COVID and also the support available for patients living with Long COVID. Some patients might also benefit from better networks within the community aimed at addressing the Long COVID and by enabling them to share their experiences for mutual support and understanding.

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Introduction

The Coronavirus (COVID) pandemic emerged onto an unsuspecting world in early 2020, when reports of a high level of infection by a previously unknown virus circulating in the Chinese city of Wuhan first came to attention. By late March, infection in the UK had reached a sufficiently high level to warrant unprecedented action by the government effectively to close society by imposing the first of several periods of lockdown: "stay home, stay safe and protect the NHS" [1].

There was, inevitably, an initial period of confusion until things settled down into what would prove to be a then unforeseen period of disruptive pandemic – even now, three and a half years later(September 2023), the effects of the pandemic remain, and the fifth round of COVID vaccinations is underway.

Inevitably, the initial focus was on dealing with the totally unforeseen (and unprepared for) pandemic and the fatalities that it led to. No human immune system had previously come across the coronavirus responsible for COVID and there was thus little, if any, natural immunity to an infection, so that those regularly in contact with the viral infection or who had compromised immune systems were particularly susceptible to its fatal effects. Although the rapid development and deployment of several vaccinations made a big difference, it gradually emerged that, whilst most people who survived infections were able

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[1] Prime Minister Boris Johnson, addressing the nation on 23 March 2020.

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to recover fully, a significant minority continued to suffer symptoms of infection, some very severely, although no longer actively infected by the virus.

Those longer-term symptoms were accorded the designation of Post-COVID Syndrome, popularly called Long COVID. For ease of understanding, the Syndrome is referred to in this report as Long COVID.

Long COVID

The NICE guideline (initially published in December 2020, updated in November 2021) covering the management of the long-term effects of COVID has included the following clinical definitions within its definition of 'Long COVID' (National Institute for Health and Care Excellence, 2021):

- ***Ongoing symptomatic COVID-19****: signs and symptoms of COVID-19 from 4 to 12 weeks*
- ***Post-COVID-19 syndrome****: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis.*

Long COVID not only has an impact on the individual but is suspected to introduce an additional burden to the wider population including the NHS.

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Long COVID in Havering

In August 2022, Havering Council published a Health Needs Assessment (HNA) of Long COVID [2] to understand the local needs associated with Long COVID. Within the HNA, an estimate from the UK Health Security Agency (UKHSA) for Long COVID cases was provided. UKHSA estimated that, as of March 2022, 7,230 residents in Havering were expected to have Long COVID and 1,265 residents would require NHS support.

The effects of Long COVID vary widely from person to person. For some, it is merely an inconvenience: a persistent cough perhaps or some loss of taste (e.g. coffee or tomato ketchup tasting bitter); for others, the long-term effects of symptoms remain debilitating and distressing.

It has been estimated [3] that, in all, since COVID was first recognised, just over one-third of the population of Havering has been infected at least once by COVID. The incidence of infection has varied by age group, broadly as set out in the following table:

Age range	Population	Percentage infected
Under 20	63,900	31.1%
20-49	102,700	42.4%
50-69	60,900	31.0%
70-85	27,300	21.8%
85 and over	7,000	32.0%

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[2] See https://www.haveringdata.net/wp-content/uploads/2022/10/Havering-Long-COVID-needs-assessment-Final.pdf
[3] See https://coronavirus.data.gov.uk/details/cases?areaType=ltla&areaName=Havering

Origins of this report

In 2021/22, the three Healthwatch organisations in Redbridge, Havering and Barking & Dagenham, in collaboration with the NELFT Long Covid Clinic at King George Hospital, and NHS North East London carried out a survey [4] across the three boroughs to ascertain the patient voice to help shape and develop services in this, then new, clinical area. The survey was developed in collaboration with the NELFT Long Covid service and BHRUT Clinic, with a focus on inequalities and deprivation. The Executive Summary of that survey is set out in Appendix 1 to this report and its findings are referenced in some of the following sections.

In April 2023, Healthwatch Havering was approached by Havering Council's Public Health Service and the Havering North Primary Care Network, who wanted to build on the findings of the 2022 tri-borough survey by finding out the current situation in Havering. The outcome was the survey now reported, which ran from late-July to mid-September 2023.

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[4] See https://www.healthwatchhavering.co.uk/sites/healthwatchhavering.co.uk/files/Post%20Covid%20Syndrome%20final%20report.pdf

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Methodology

The survey was conducted online using a question-set derived from that used in the tri-borough survey. The questions were updated to take account of the passage of some 18 months since the tri-borough survey was carried out and to reflect the focus on Havering alone.

Results

The survey yielded 113 complete responses from Havering residents (and a few more from outside Havering). In addition, there were partial responses from which it has been possible to extract data for use in this report.

Among those responding to the survey were 23 of the people from Havering who had responded to the tri-borough survey. Based on the number of people living with COVID estimated in the HNA, it appears that around 10% of the number of residents estimated to be living with Long COVID in Havering responded to this survey.

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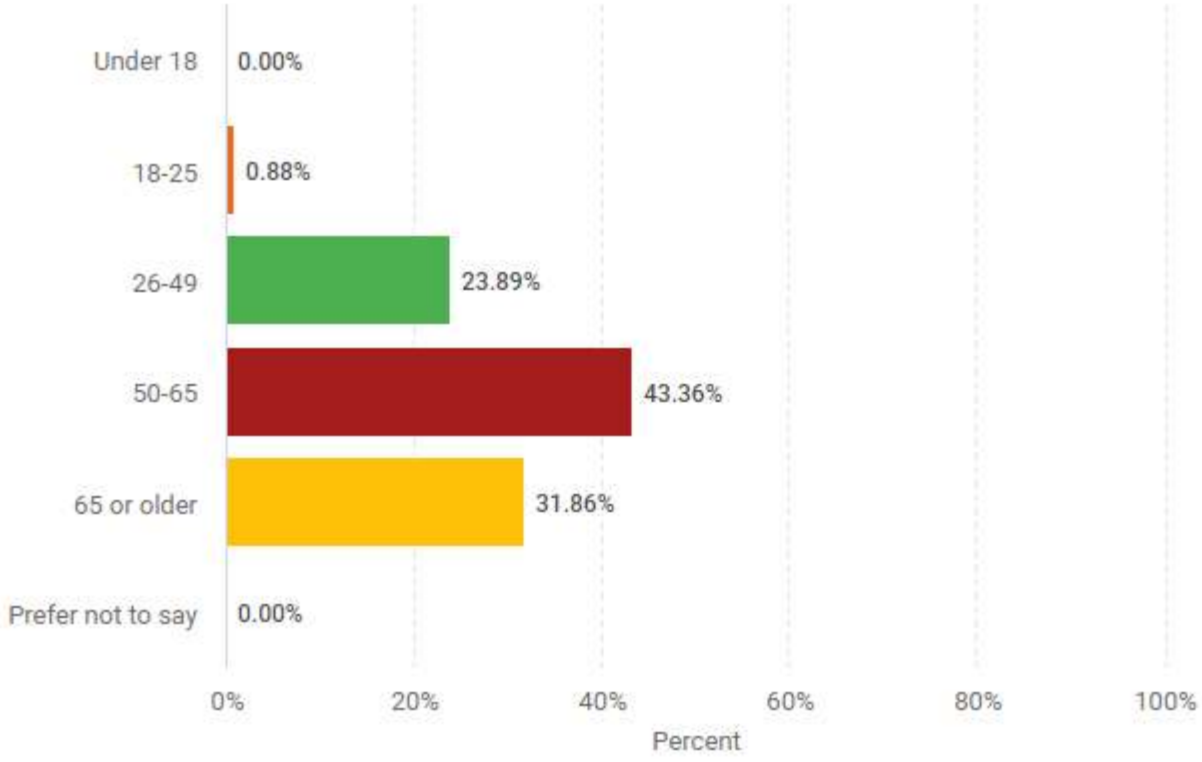
Demography of respondents [5]

Age groups



The ages of respondents differed from the broad age groups in the borough – about 19% of the borough's population is under 15 years of age but no one in that age group responded to the survey while 32% of respondents were over 65, against 18% of the borough's population:

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[5] References to the broader population of the borough are taken from the Havering Data Intelligence Hub, based on the 2021 Census - see https://www.haveringdata.net/population-demographics/#/view-report/63aeddf1d7fc44b8b4dffcd868e84eac/___iaFirstFeature/G3

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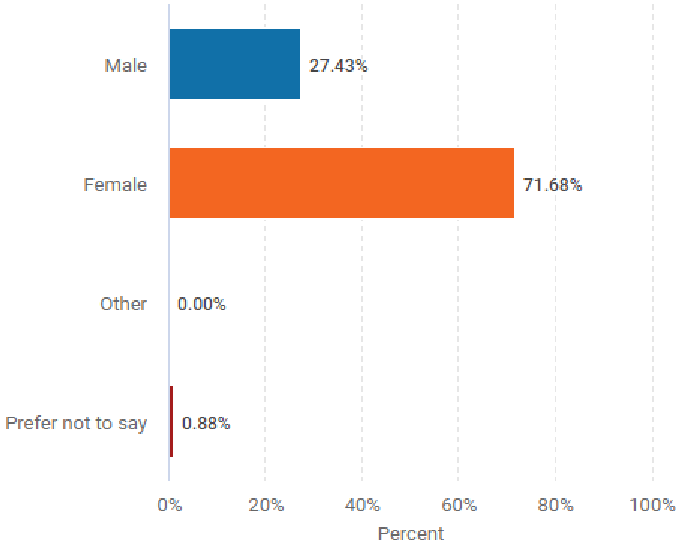
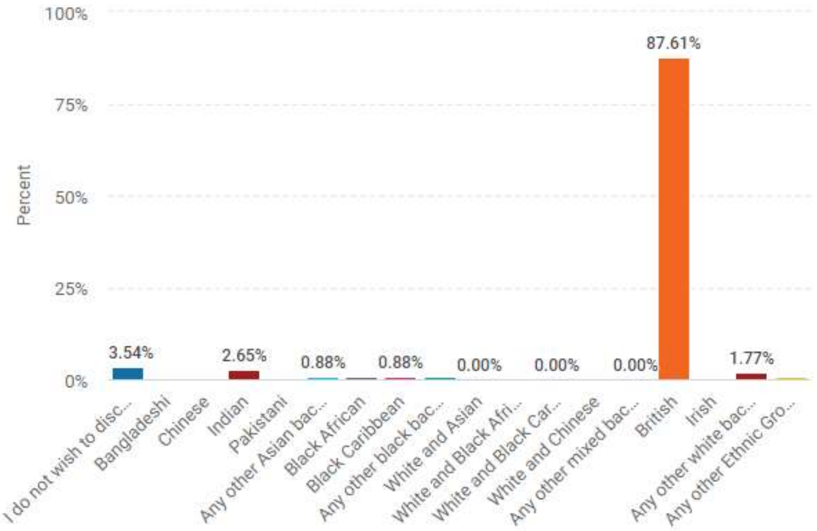
Gender

Slightly more females than males reside in the borough, but more than twice as many females as males responded:



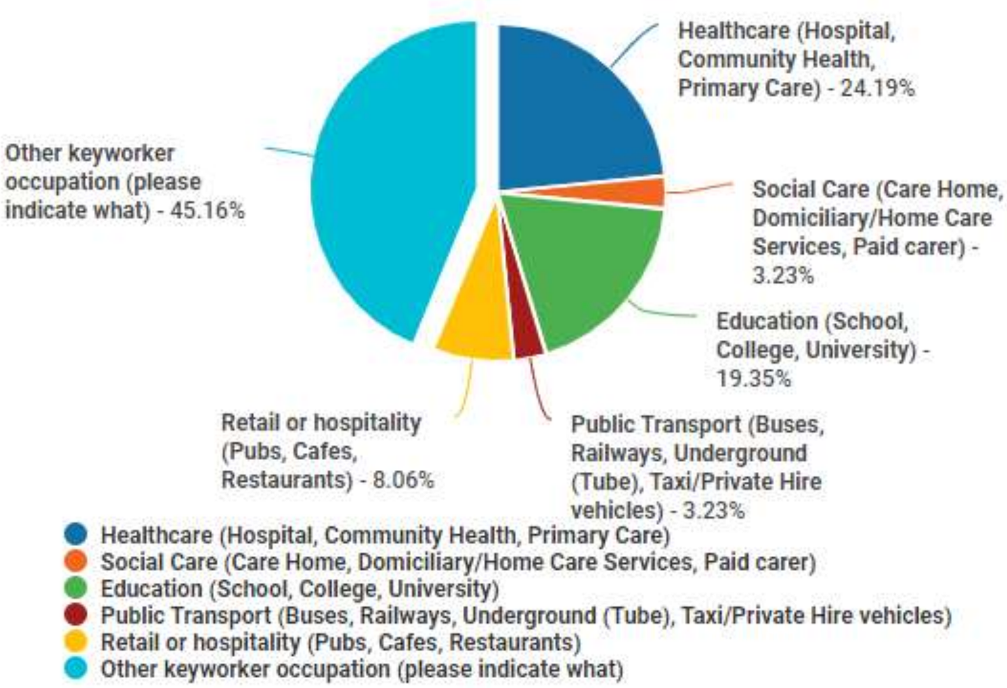
Ethnicity

Some 75% of Havering's population is of white British ethnicity: inevitably, therefore, most respondents were also white but the proportion was somewhat larger, at nearly 88%. Other ethnicities were broadly representative of the general population.



Employment status

Most people complied with the “stay home” instruction during the lockdown periods, but a significant minority of people were designated as “key workers”. They were able/required to continue to attend for work and were inevitably more exposed to risk of infection than the population-at-large. We asked respondents to tell us whether they had been keyworkers and, if so, in what sector. 62 respondents – slightly more than half the total – declared that they had been “key workers”:



“Other keyworker occupations” reported included**:**

- Police officer/Prison officer/Court staff
- Council staff
- Construction wor
- Civil servant
- Royal Mail worker
- Haulage worker

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Location

Respondents were asked to indicate their location by providing the first part of their postcode:

Postcode	Location	No. of respondents
RM1	Central Romford	17
RM2	Gidea Park	6
RM3	Harold Hill/Harold Wood	42
RM4	Havering-atte-Bower	1
RM5	North Romford/Collier Row	7
RM7	Rush Green	10
RM11	Hornchurch/Elm Park	9
RM12	Hornchurch/Emerson Park	8
RM13	Rainham	7
RM14	Upminster	6
		113

Although it would be inappropriate to infer too much from the data, it is noticeable that about one third of respondents gave an RM3 postcode as their location: RM3 covers the Harold Hill and Harold Wood areas, which include the areas of greatest deprivation in the borough (and some of the greatest deprivation nationally). By contrast, areas where there is least deprivation are RM2, RM4, RM12 and RM14, which a total of 21 respondents gave as their postcode.

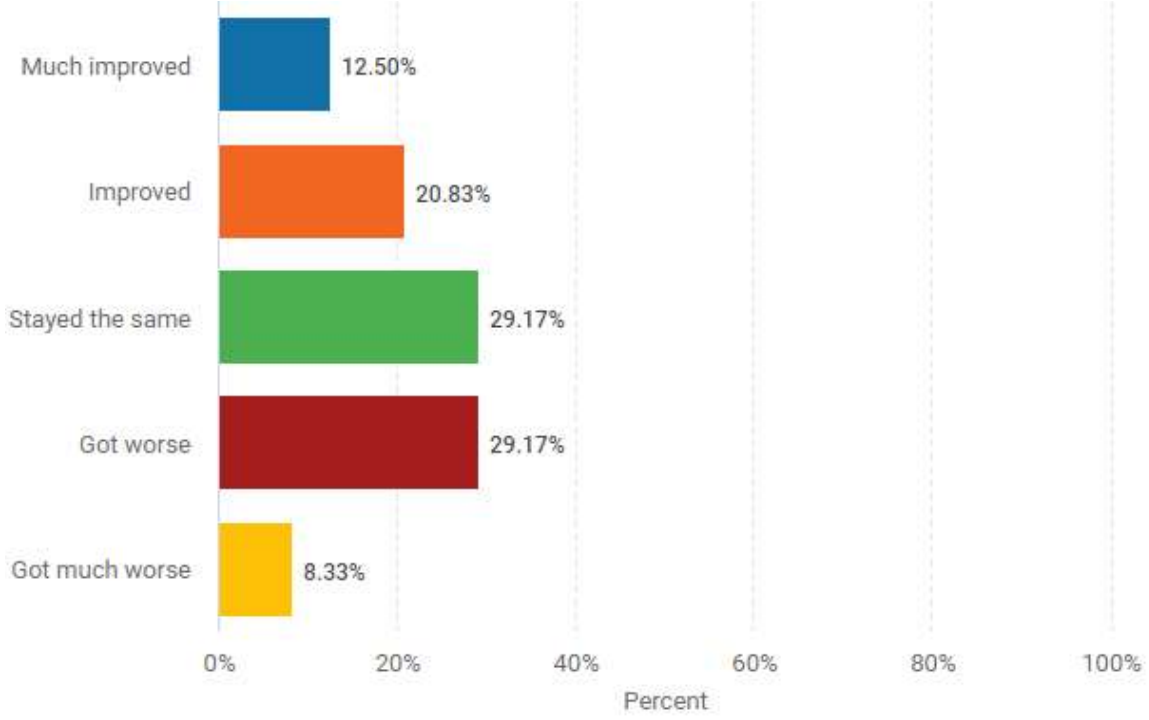
What the respondents told us

Respondents to the survey were asked a series of questions designed to obtain from them details of how they had been affected by Long COVID. They were given opportunity to add comments to the set responses asked for.

As noted earlier, the effects of Long COVID vary widely, and this is reflected in the survey results.

Appendix 2 contains the full set of comments we received: the data which follows contains selected comments to illustrate the nature of the views of respondents. In both the main report and Appendix 2, comments quoted are indicated by an arrow (➢).

We asked the 23 respondents who had participated in our previous survey whether their condition had improved, stayed the same or got worse. They told us they had:



About a third (33.3% = 8) of respondents who had previously participated reported an improvement in their condition. Just over 29% told us there had been no change; and for 38%, the condition had worsened.

Respondents' comments included:

- I originally had further investigations and was told my condition would be monitored on a 6 monthly basis. In 2 years I have been monitored only once. My GP doesn't know why I still feel breathless, and have pain in my throat, the results from the original tests didn't reveal exact reasons why I continue to feel unwell

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- I had breathing difficulty. With careful instructions, my condition has significantly improved.
- I have attended 10 sessions run for people with long covid syndrome which has helped me to do breathing exercise, working according to my pace and taking plenty rest. I have gone part time working (60%) to allow rest.
- My memory has got worse plus constant exhaustion, breathlessness has not improved.
- I'm constantly exhausted want to just sleep. My body is not the same
- I have brain fog my memory has got lot worse
- Still suffering with the majority of the symptoms I've just had to learn to cope with them better
- My lack of mobility has increased. My anxiety is worse and so is my memory. Some days I literally ache from head to toe.
- It took a long time, but after 10months I improved
- I still have the same issues and problems as I did then. The various tests and doctors' visits have been unable to identify why (apart from confirming they are long covid symptoms) and nor how to treat effectively
- Nothing much has changed; my symptoms are not really any better and I am struggling mentally with the debilitation caused by my symptoms.
- I'm more depressed about my tiredness.

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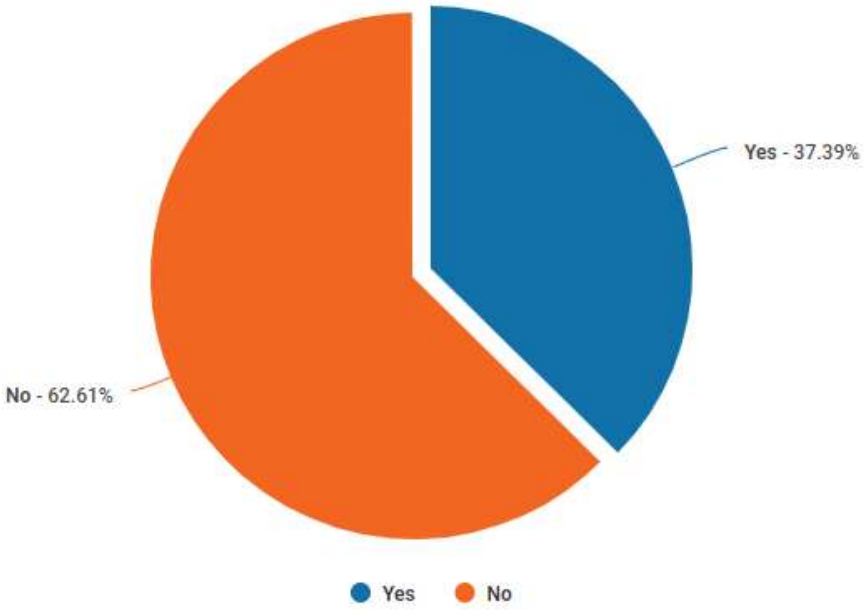
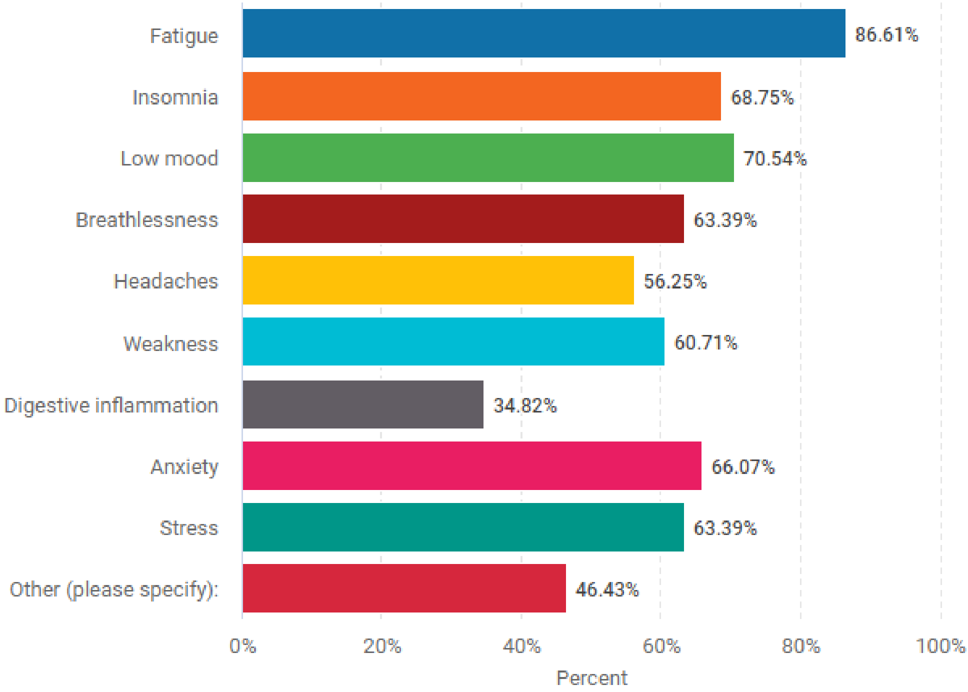
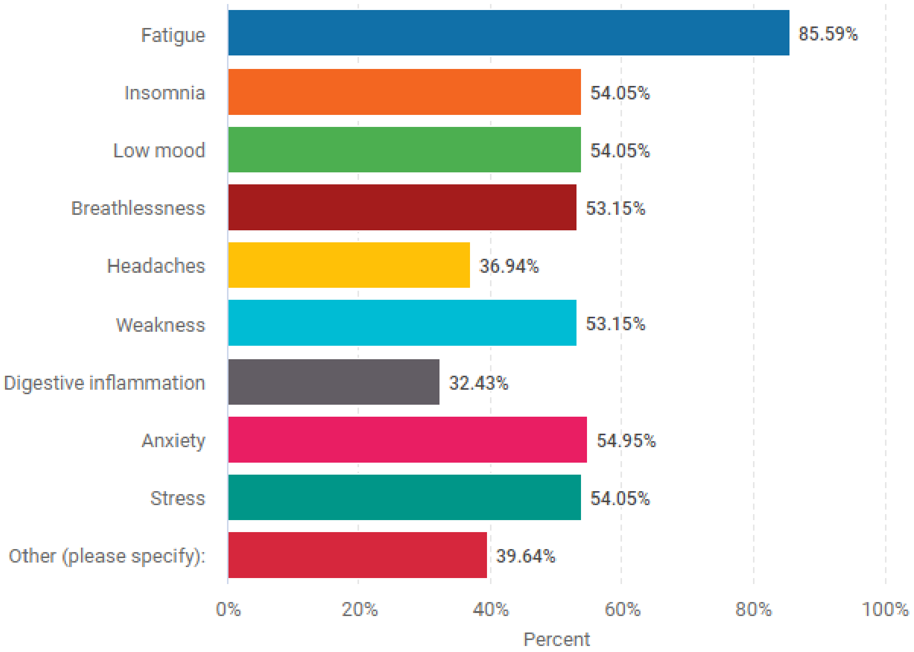
We asked respondents whether they had been formally diagnosed with Long COVID by a doctor. They told us:



We asked whether they had experienced any of the clinically recognised symptoms of Long COVID. They told us:



We then asked if these symptoms had continued for six weeks or more. They told us:



We asked what other symptoms respondents had experienced. They told us of a range of symptoms; the following table shows how many times particular terms were mentioned in the responses:

Key word	Times mentioned	Key word	Times mentioned
Fatigue	32	Memory affected	18
Pain in various parts of the body	31	Sense of smell affected	15
Tired	24	Breathlessness	14
Brain fog	23	Anxiety	12
Breathing	23	Memory	11
Taste affected	21	Smell	11
Persistent cough	21	Dizziness or vertigo	9
Taste	17	No energy	7
Struggle	16	Exhaustion	5

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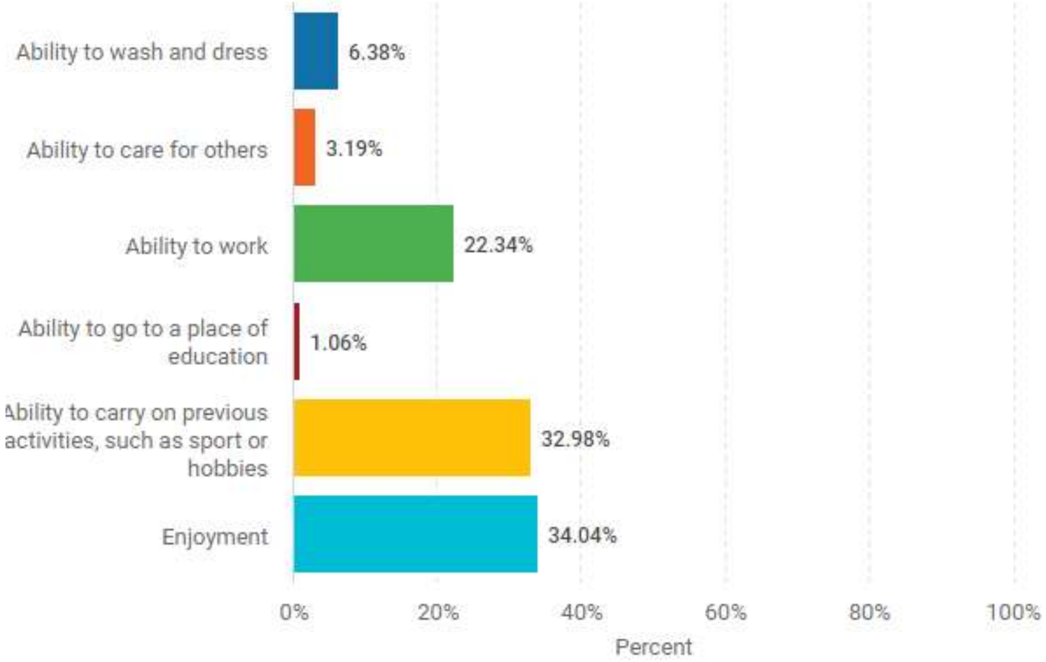
The term "brain fog" was mentioned by many respondents. While not a recognised medical term, and varying from person to person, it clearly has a debilitating effect on those who feel that they are affected by it. It was associated with feelings of exhaustion, fatigue, tiredness and dizziness. "Brain fog" is mentioned further on in this report – it is clearly a significant symptom for many people living with Long COVID.

We asked whether they felt that their lifestyle had changed since developing Long Covid. Most respondents told us it had:



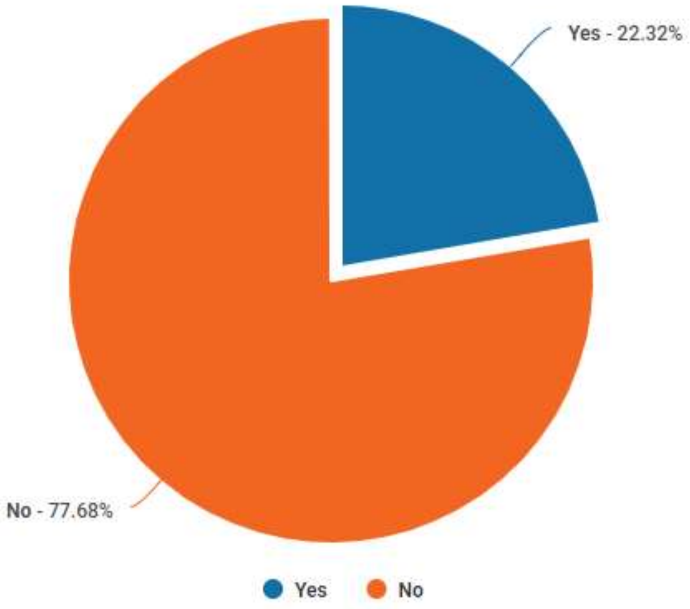
We asked how they had been affected:

Comments were sorted and categorised by the response options; the following table shows some of the comments we received:

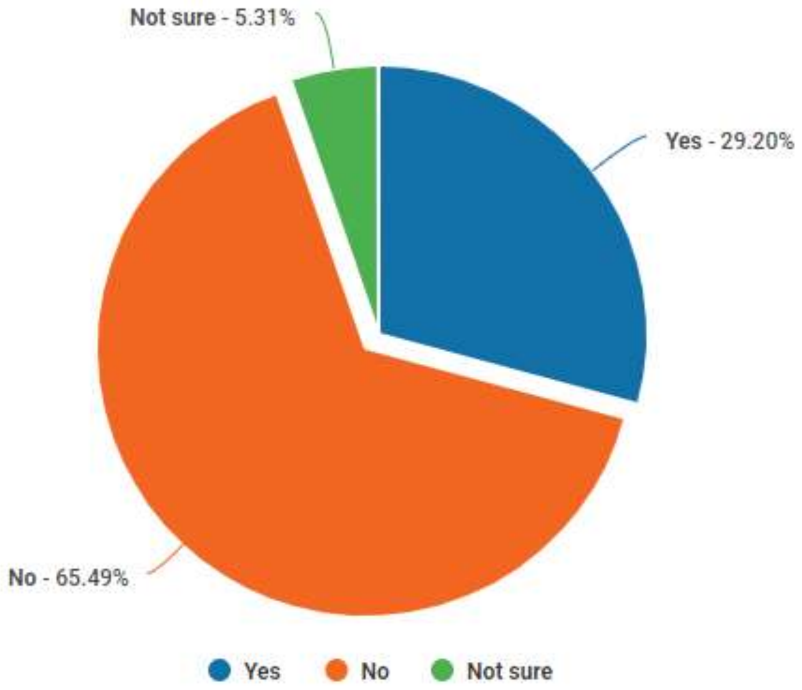
Ability to wash and dress	Ability to work
➢ I find I can't plan to do more than a couple of days out each week. Sometimes I can't get shopping ➢ I struggle every single day. My husband helps me shower and dress I go to work where I have to plan my route as I need to drive	➢ Work is a struggle now and have had very low attendance at work, which has made me nearly lose my job. As well as struggling with money due to lack of income. ➢ I had to cut down working hours which has a huge negative impact in overall quality of life including my career aspiration, finance, caring responsibility, and social engagement/ activities.
Ability to care for others	Ability to carry on previous activities, such as sport or hobbies and enjoyment
➢ Can't carry things. Too weak to cook for family and self. Can't open jars etc. Cleaning difficult Had to have walk in shower fitted ➢ I am not able to do more than one task of housework in one day, e.g. cleaning the bathroom /kitchen or hoovering. I used to be able to do at least two of these in one day, but now I just get to fatigued doing one of them.	➢ Continuous breathlessness which causes pain in the throat and chest prohibits me from cycling and swimming ➢ I have lost interest in many things and find it hard to motivate myself due to the fatigue ➢ I have been affected with the ability to work, carry out hobbies and activities and it

- Looking after my mum with dementia and my own children has been impacted.	has impacted on my enjoyment. I have found the headaches/migraines crippling and often end up in bed, under the duvet where it is dark. Due to lack of energy and breathlessness, I have not been able to exercise or the things I enjoyed doing outside - Secondary to my fatigue, breathlessness and frequent headaches, I have found it difficult to wash/dress on occasions, work has been far more challenging, despite now working from home, my previous activities and hobbies have been severely affected and this in turn has adversely affected my mood

We asked if respondents were aware of services in the community for people suffering from Long COVID. They told us:



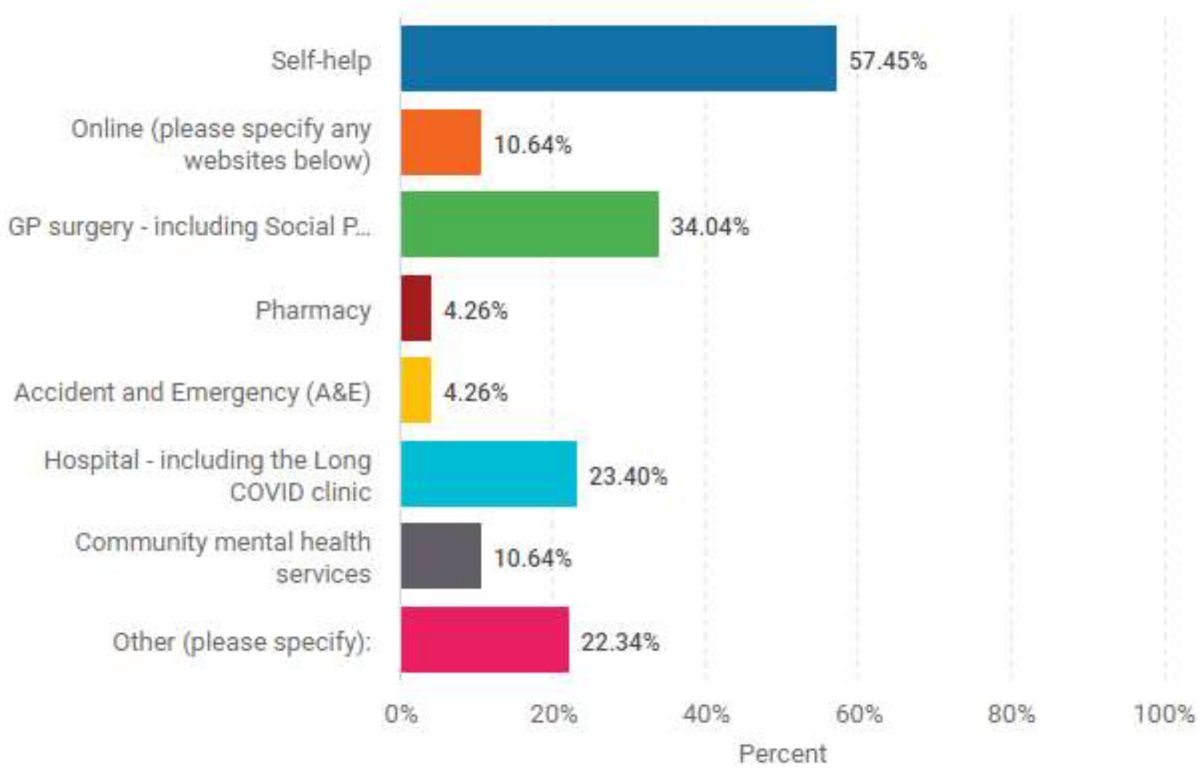
We asked if respondents had been referred for support for Long COVID. They told us:



We asked those who were "not sure" why that was so; their comments included:

- I have been referred to talking therapies and the gym but feel more support is needed.
- GP referred, but I am unaware what to expect.

We asked what services respondents access for ongoing support for Long COVID:



We asked what "other services" respondents had accessed.

Comments included:

- Online support group
- Many and varied websites, but mainly NHS websites
- Online Long COVID on Facebook

We asked respondents to give details of their experience of seeking support for Long COVID. What they told us included:

- Referred to long covid clinic which has been a great help. Recent prescribe medication seems to be helping with breathing. Still feeling very low
- The long covid team has been very helpful.
- Saw an advert from Havering Council for Covid support. I phoned, got help and had weekly sessions with counsellor over the phone. This helped me tremendously with coping managing my anxiety. Flowed by joining a group each week on improving my breathing
- Attended living better with long Covid from NELFT - 9-week course, it was very good
- GP was very helpful and supportive. … It would have been nice to see professionals in person where my state of health could properly be assessed - say a full day appt instead of a 6-week online course of 1-hour sessions. It seems that test are called for and if things come back ok (like they often do with LC) there is nowhere to go with my symptoms.
- It took 2 years before anyone took it seriously and referred me. Mainly then ruling out other illnesses then when seen by long Covid clinic referred to online support sessions to manage my symptoms. Have been discharged from that as finished the course. Feel in limbo now as some of my symptoms are not improving and because of lack of balance and cough I can’t take up the exercise sessions. If

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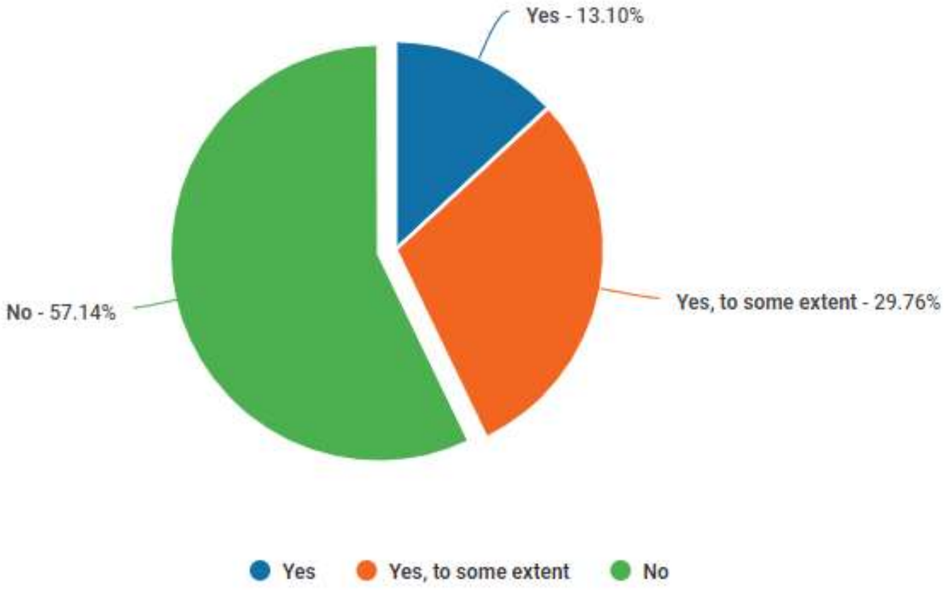
it wasn't for my allotment, I would be really upset though still stressful in case I have my plot taken away due to not keeping up with its maintenance properly. Nowhere to go from here other than trying to keep going the best I can.

We asked respondents if, in the support that they had received for Long COVID, their physical support needs had been met.



Comments included:

- Doctors don't listen
- My appointment with the consultant was cancelled on two occasions and so I haven't had a proper consultation as yet. My symptoms are ongoing and have not been addressed.
- I have learnt correct breathing techniques.
- I did a 12-week trial at the gym and I found that really helped my breathing

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- Breathing exercise has helped me, however, myalgia and fatigue still affecting my day-to-day functioning.
- Unable to help with my fatigue- had to manage on my own
- I got COVID 3 times. About two weeks after my 3rd time, which was in February 2023, my throat started hurting with severe cough. I could not get a GP appointment, but rather got a nurse appointment who had one look at my throat and prescribed anti biotics. When I told him about getting COVID 3 times the last of which was just 2 weeks ago, he seemed to be amused rather than relating both. The cough and hurting reduced but came back again at which point I fought to get a GP appointment. He said he can give anti biotics but it looked to him as if the infection was on its way out. He also did not give any thoughts about me getting COVID 3 times. When pressed he said to do a blood test and chest x ray which was clear. I feel like there is a lump in my throat on the right side still.
- I am still struggling massively. The only support is online group sessions.
- As mentioned above, during this journey there has been extremely little recognition that there is a direct correlation between Covid and digestive problems/suffering.
- Didn't know there was support in my community
- Only help is CBT to help mentally deal with life after long covid. No other help other than a long list of tests that show nothing. Left to your own devices after that. I’m 3 years in,

have now been diagnosed with long covid/ ME/Fibromyalgia. Again no help for any of that. There is no help or cure. I cannot do a lot of things I used to be able to do and am sometimes incapable of looking after myself but no offer of home care help or anything. It seems that as Covid is no longer a pandemic, people still seriously suffering, like myself, are forgotten.

- It was good to talk to someone other than my own GP and for him to confirm that it was Long Term COVID which I was suffering from. At least then I knew what I was dealing with.
- Still suffering- symptoms seem to be improving but still impacting me for periods of time.
- The biggest physical issue has been the difficulty to walk at times and this hasn't been resolved. I also still suffer from memory loss at times and these have knock on effects in my personal life I decided this year to retire from work. There were many reasons I decided to do so, however having long COVID was one
- I was referred to the long covid recovery course, but it was very focused on breathing. I had little breathing difficulties but felt that fatigue and insomnia (causing headaches) issues were poorly covered in the course.

We asked respondents if, in the support that they had received for Long COVID, their mental health support needs had been met.

Comments included :

- I have been referred to Talking Therapies.
- Ongoing help for sleep issues and anxiety physically worn out.
- I was shown several ways to combat the stress and anxiety.
- Meditation methods were introduced.
- Had to come to terms with my own limitations on my own
- Just talking to others that are suffering also helps
- As mentioned previously, I have not had any advisory or counselling support.
- I struggle to get to counsellors I need a psychiatrist with my help and I suffer with PTSD as well from past health issues as well

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- Hard to get face to face with doctors
- I've resigned myself to the fact this is my life now. I have no choice but to struggle on, mainly for my children and grandsons Still winds me up and I end up upset and crying. What else can I do?
- The wait times for support are too long. My workplace will look at support me
- Self-support: I try to keep active and socially engaged despite feeling awful at times
- I have some brain fog and memory issues which I worried about but learnt some techniques to cope which has eased my anxiety.

We asked if there was anything else they would like to tell us about their experience or the support they had received. Replies included:

- My GP has supported me as far as he can (in my opinion). The system overall has failed me, I am still unwell, I have no confidence in the NHS providing information on an outcome. I am just left to get on with it.
- I feel like I have been left to deal with it on my own now after being discharged. My doctors haven't asked me how I'm doing. I've had to emails, texts or calls from the long covid team. Feels like they have said there's nothing we can do bye now.
- I would like to start by saying the long covid team are fantastic and very good at communicating with me. I've

felt supported throughout and as I continue to heal from this pandemic, I hope the support continues.

- It was an eye opener to share the experience of others who have gone through the different stages of different episodes after COVID like myself.
- I feel that GPs are very dismissive when being asked if long COVID may be the cause of my problem.
- All the staff in the LCC and the therapists have been very nice and empathetic, it just seems there is nothing for them to offer. It feels like the clinic and courses are box ticking exercises and they really don't know what to do with us. From online forums it is very apparent that services differ around the country and there is no standard approach to treating the symptoms - e.g. some clinics will prescribe anti histamine treatments while King George's will not consider this at all.
- Have lost confidence in GP as it took so long to be believed and the '8am lottery' to get a phone appointment is a farce - waiting 40 minutes or more to get through and be told to try again tomorrow which isn't helpful when you start work at 8am! Generally only get to see the nurse practitioner in the end anyway. Once you have done the online self-management courses then you are cast adrift to keep managing by yourself which does not totally help if not all your symptoms are covered
- Only help is CBT to help mentally deal with life after long covid. No other help other than a long list of tests that show

nothing. Left to your own devices after that. I'm 3 years in, have now been diagnosed with long covid/ ME/Fibromyalgia. Again no help for any of that. There is no help or cure. I cannot do a lot of things I used to be able to do and am sometimes incapable of looking after myself but no offer of home care help or anything. It seems that as Covid is no longer a pandemic, people still seriously suffering, like myself, are forgotten.

- Breathlessness improved after 5-6 months with lots of practice of diaphragmatic breathing, relaxation. Other ongoing symptoms could be overlapped with chronic fatigue syndrome which I have suffered with a long time, or newly diagnosed rheumatoid arthritis.
- I was disappointed in that I felt that the course was very locked into the breathing aspect of long covid and seemed to assume that most people would suffer from breathing problems. The focus on this was such that it felt as if other symptoms were not covered as thoroughly. Would it not be of benefit to run two courses - one for those with breathing difficulties and other symptoms and one for those who have not experienced breathing difficulties.

Conclusions

Inevitably, the experiences of people vary widely. While many of the symptoms reported are not exclusively related to Long COVID, the shear repetitiveness of the comments of the respondents to our survey suggest that many sufferers from Long COVID experience similar feelings – the following table indicates the incidence of certain key words throughout the responses we received:

Key word	Times mentioned	Key word	Times mentioned
Fatigue	32	Breathlessness	14
Tired	24	Anxiety	12
Brain fog	23	Memory	11
Breathing	23	Smell	11
Taste	17	No energy	7
Struggle	16	Exhaustion	5

Whilst that list is not definitive, it indicates that many of the people living with Long COVID experience both devastating mental stress (fatigue, tiredness, "brain fog", anxiety) and physical difficulty (breathing difficulties and breathlessness, smell and taste problems, lack of energy). This confirms known clinical indicators of Long COVID. That said, it is known that Long COVID is difficult to diagnose, having many symptoms in common with other viral infections and post-viral infection effects.

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It is clear that many people living with Long COVID remain unaware of the possible support available for them, or where to find it. But the replies also suggest that there is an ongoing lack of awareness among health care professionals about what is Long COVID and how to identify it: comments such as:

- “I’ve not had support”
- “Difficult to get a diagnosis”
- “I feel quite let down”
- “Have lost confidence in my GP”
- “My doctor said it’s too hard to diagnose”
- ”My GP stated that long COVID support clinics mainly deal with breathlessness and not brain fog”
- It was the nurse in my GP practice who referred me to the health and well-being coach. My GP has offered no support or advice…” and
- “All I need is a proper diagnosis so my GP can move forward and support me more”

contrast with others such as

- “If my GP had not referred me to support, I would never have known about the help available”
- “My GP has been very supportive” and
- “One source of positivity has been Long COVID Kids charity”

It is hard to escape the conclusion that healthcare professionals (including those at NHS111 and in pharmacies) need to understand more about Long COVID, and how to diagnose it. They need empowering to identify and refer patients reporting the symptoms of Long COVID.to the support that is available for them both clinical for those presenting with symptoms requiring a medical response and non-clinical.

Development of a clear non-clinical pathway may also ensure that residents can readily access support for symptoms such as fatigue, anxiety and “brain fog”. This may be through community groups or networks where they can share their experiences with others having similar experiences, rebuilding their confidence through mutual support and understanding. The worst feeling is to believe that one is alone in experiencing debilitation – knowing that others are “in the same boat” is often a source of comfort and strength for many people.

Acknowledgments

We would like to thank everyone who responded to the survey for being so frank and open with us.

Whilst the various comments quoted in the report are taken from those provided by the respondents to our survey, the interpretations placed on them are entirely the responsibility of Healthwatch Havering.

Appendix 1

The Tri-borough report, July 2022: Executive Summary of Findings

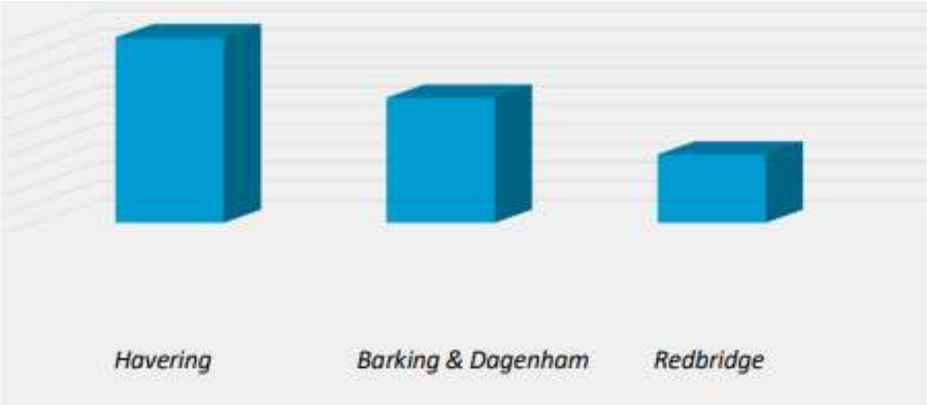
During March-June 2022 169 people from North East London completed our survey on Post-Covid Syndrome. 10 service users gave in-depth interviews and 4 GPs gave interviews. It is important to state that only 29% of the respondents to the Survey were referred for support for long COVID, and only 16% of these had accessed the long COVID service. Questions did not specifically reference the long COVID service and were answered by all survey respondents. 4. Impact of interim findings – service change 5. Executive Summary of Findings 8 The findings, therefore, include a 71% majority of patients who experienced help only from primary care or other services. Access difficulties need to be interpreted accordingly.

Key Findings

General

- A clear majority of respondents (86%) have tested positive for Covid-19, while under half (45%) have been diagnosed with Long Covid
- On impact on daily living, most (93%) feel that their enjoyment of life has been impacted, with three quarters (76%) finding it more difficult to undertake hobbies
- Half of all respondents (50%) say their ability to work has been affected.

Respondents by Borough:



Services

- Respondents are almost twice as likely to seek self-help, than consult with their GP
- Just under a third of respondents (30%) have been referred for support for Long Covid
- Just over half of respondents feel that hospital and community-based services (not including the Long COVID service itself) have not been helpful (54%), while a similar number (54%) say that primary care services have not helped
- Almost a fifth (18%) have self-referred, or found support elsewhere
- A third of respondents (35%) have heard of the Long Covid Clinic.
- Just under three quarters (70%) say their physical support needs are unmet, while 71% indicate that their mental health needs have not been met. This is in the context of a majority of service users (71%) who had not been seen by or have not accessed specific support.

Health inequalities

Although we had a relatively small number of survey respondents who were from Bangladeshi, Pakistani, Black African, and Caribbean backgrounds (8%), it is worth noting that in every area of life, respondents from these communities identified a greater effect on their day to day lives. Particularly of note is in the areas of self- care and caring for others. 33% of service users from BAME backgrounds felt that Long Covid had affected their ability to care for others, whereas 19% of service users from White backgrounds identified this impact. 60% of service users from BAME backgrounds felt their ability to work had been affected; whereas 44% of service users from White backgrounds identified this issue.

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What are people saying – themes in the free text comments

- As the condition is relatively new, many doubt the effectiveness of interventions and some, citing 'overstretched services' are fearful of being a burden on the NHS
- Levels of information on what support is available are said to be lacking
- While some people feel their GP would be sympathetic, others fear that symptoms may be dismissed. The ability to obtain appointments is a key issue
- Participants identified long waits to be referred for support, with many commenting this took one year. Service users also felt that children, or those without a diagnosis, are not eligible. These are findings from comments left in the Survey and not NHSE guidance. There is a pan-London service for children and a diagnosis is not required before referral. These clarifications will be sent to all the survey respondents who left an email address for contact
- We hear that waiting lists for general support have been 'too long', and services offered have been generic, with 'one-to-one' options lacking
- It is also suggested that some packages suggested by GPs, such as a six-week mobility class are insufficient, and therefore ineffective
- Those with caring responsibilities have found it difficult to support themselves and also their loved ones.

Appendix 2

The full responses we received

This appendix sets out in full the responses we received, organised by the order of the questionnaire.

We asked the 23 respondents who had participated in our previous survey whether their condition had improved, stayed the same or got worse. They told us:

- I originally had further investigations and was told my condition would be monitored on a 6 monthly basis. In 2 years I have been monitored only once. My GP doesn't know why I still feel breathless, and have pain in my throat, the results from the original tests didn't reveal exact reasons why I continue to feel unwell
- Breathing is still as bad; fatigue may have got worst but unsure because of brain fog.
- I had breathing difficulty. With careful instructions, my condition has significantly improved.
- I'm not so out of breath
- I have attended 10 sessions run for people with long covid syndrome which has helped me to do breathing exercise, working according to my pace and taking plenty rest. I have gone part time working (60%) to allow rest. I have been taking often breaks and not pushing too much to complete my tasks if I feel tired and have difficulties in concentrating. I have been taking multi vitamins, vit d, C and zinc which, I believe, have been helping me. I have reset my expectations and accepted that it is a slow process and I need be kind to myself.
- My main issue since having COVID is I have to wear a mask when baking as the flour makes me wheeze
- My memory has got worse plus constant exhaustion, breathlessness has not improved.

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- Constant breathing issues, months of antibiotics and steroids
- I'm constantly exhausted want to just sleep. My body is not the same
- Ended up with an 8 week stay in hospital.
- I've only had to go hospital once this year
- I have a Functional Neurological Disorder diagnosis, which made it hard to know what was COVID and what wasn't. The fatigue has gotten worse aches and pains, constantly feeling bunged up and tired. No energy
- I have brain fog my memory has got lot worse
- Still suffering with the majority of the symptoms I've just had to learn to cope with them better
- Feel better than I did.
- I find it hard to leave the house am suffering with anxiety I struggle talking to people I avoid going to the shops being alone has become addictive and I really struggle to attend appointments. Not even being able to go out with my children.
- I have Asthma which turned to COPD and now Emphysema
- I've still got all the symptoms
- Breathing better and exhaustion less
- Bad smells and lack of taste still. Very tired and headaches
- Still no smell and taste after 21 months.
- I had symptoms for roughly 10 months after having Covid and attended a long term covid clinic, just the once but decided to manage the symptoms myself. I feel much better than I did but having said that, I now have a terrible cough and cold.
- Fatigue and tiredness has got worse
- I am struggling with extreme fatigue; I get tired easily and I'm left breathless walking upstairs and can't walk long distances. My irritable bowel syndrome has progressed to a bowel disease and I

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have an urgency to use the toilet, I've now been diagnosed with gastritis I'm unable to control my fibromyalgia I have bladder problems where I wet myself alongside my bowel disease where I poo myself frequently I've got a permanent headache since I first caught covid over 3 years ago and I'm in constant pain

- My lack of mobility has increased. My anxiety is worse and so is my memory. Some days I literally ache from head to toe.
- Still living with breathlessness, fatigue, weakness of muscles, falls, tiredness etc.
- It took a long time, but after 10months I improved
- When I rang NHS111 they said I was wasting time as I didn't have a cough. Covid toe covered in blisters chilblains lost sense of smell. Not got a lot a taste.
- I still have the same issues and problems as I did then. The various tests and doctors' visits have been unable to identify why (apart from confirming they are long covid symptoms) and nor how to treat effectively
- Developed rheumatoid arthritis difficult to separate symptoms is difficult. Worsening of chronic fatigue syndrome.
- Cough has eased but still there still feel tired and congested
- Better energy levels, less severe headaches.
- I developed early menopause but some of the symptoms are identical to long Covid. But I'm only 43 and feel this is too young to be going through this.
- I still suffer from all the symptoms as before bit now have many newer symptoms including body shakes and tremors pain in my lungs and feeling dizzy like I'm going to pass out when I'm standing up

- Nothing much has changed; my symptoms are not really any better and I am struggling mentally with the debilitation caused by my symptoms.
- I'm more writing for my daughter who is under 16. She has issues with heart rate doubling, tripling. On one occasion she passed out. It has been a huge struggle to get her symptoms understood and get her under the right consultant. It is suspected she may have something called PoTS which is linked with Long Covid but there is no NHS consultant in the UK who sees under 16's and I've yet to secure a referral for the NHS doctor we have found for when she is 16 in January.
- I'm more depressed about my tiredness.

We asked what other symptoms respondents had experienced. They told us:

- Depression, insomnia, anxiety, stress, fatigue, dizziness, pins and needles, feeling sick and loss of memory
- Not able to do much without getting tired
- Every week, I don’t feel well. Either a cold or something else – always tired, cannot taste or smell properly, fatigue and aching joints
- Tinnitus, nausea, dizziness, brain fog, inability to focus, pain (especially in chest and upper body)
- Chest pain, brain fog, hair loss, dry lips
- Shake body pain
- Also muscle aches and pains, low level of concentration, repeated chest infection
- I have been having really bad bladder problems this is not on the list but I’ve noticed it’s getting worse.
- Taste and smell took 18 months to return. Occasionally, I still lose my taste

- Liss of smell and taste
- Vertigo
- Chronic cough
- Neck pain
- Incontinence
- Fluid round heart
- Asthma attack like symptoms
- Poor memory
- Loss of taste
- Muscle heaviness, brain fog, short term memory loss, poor balance, incontinence
- Cough
- severe sinusitis
- Stomach & back pain
- Overall pain
- Taste
- Functional neurological disorder seizures
- Taste and smell
- Recurrent cough
- Changes to heart function
- Weakness in legs
- On off loss of taste and smell
- Loss of balance and tremors also my eyes have been affected and overproduction of gunge and resultant cough and brain fog
- Increase in brain fog
- Loss of smell

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- Single parent fearing loose job. word finding. Forgetting what say. Poor spelling
- Brain fog even eye sight was affected.
- Poor taste
- Vastly increased tinnitus
- Mild urinary incontinence
- Poor smell. Poor taste. Difficulty in motivation to initiate tasks. Needing extra short sleeps.
- Joint pain
- Cough
- Have had all of these since I had covid.
- Difficulty walking, memory
- Brain fog, joints pains
- Brain fog, tremors, internal shakes, pains in lungs, nocturnal hypoxia
- Loss of smell/taste, memory loss, nausea
- The dizziness is daily on waking, one of the first symptoms, the blacked-out vision happens at least 3 mornings a week
- Dizzy when turning round

We asked how they had been affected:

- Very tired, brain fog, aches in muscles and joints. Problem with sleep
- Low mood
- Too tired, no energy
- I have a mild COPD and after I caught 2nd dose, Bart’s sent out an anti-viral drug I took for 5 days I have also before Christmas prostate cancer . I now find I am short of breath and get tired in the afternoon

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- My life has been affected in all areas: work, family, socially and planning
- Continuous breathlessness which causes pain in the throat and chest prohibits me from cycling and swimming
- No inclination to do anything, always tired. No energy
- Struggle to lift/carry stuff, struggle to get comfy in bed due to chest pain, seat belt hurts in car generally just feel weak
- Work is a struggle now and have had very low attendance at work which has made me nearly lose my job. Aswell as struggling with money due to lack of income.
- Chronic fatigue, headache, body, misery, unable to live like I used to.
- I have lost interest in many things and find it hard to motivate myself due to the fatigue
- I was housebound. Couldn't do even simple activities such as doing my own shopping.
- I suffer with fatigue and when that comes over me, I have to sleep
- Unusual tiredness, myalgia, repeated infection, and low threshold in loosing concentration have impacted my day-to-day life and work. I had to cut down working hours which has a huge negative impact in overall quality of life including my career aspiration, finance, caring responsibility, and social engagement/ activities.
- Unable to attend the gym twice a week. Unable to swim 3 times a week. Unable to cycle 5 days a week
- Not wanting to go out due to my worsening urine problems.
- it hasn’t, life carries on, I’m lucky to be alive
- One of my hobbies included lifting, which I now get help. My other hobby was having an allotment. Here, I cannot have this hobby much longer as I don't have the strength in my hands anymore.
- Loss of this sense (enjoyment) affects all sorts of things

- And enjoy life and hobbies, mixing with friends etc. it has totally changed my life
- Even speaking for a long period of time causes breathlessness
- I don’t feel like I have the energy to go out and do things anymore and get very anxious.
- Limited for joining in anything, walking
- Ability to carry on previous activities such as sport or hobbies, enjoyment
- I get SOB just doing the usual things. Showering, washing and dressing.
- I can't do anything strenuous
- Constant neck pain for 7 months has been debilitating and restrictive.
- I suffered with breathlessness since having covid in July 2022. ended up as an emergency admission with a pulmonary embolism. I had an 8 week stay in hospital and now have a diagnosis of pulmonary hypertension. I have a significant clot load in my lungs. I suffer from breathlessness.
- I don't go out
- I find I can't plan to do more than a couple of days out each week. Sometimes I can't get shopping
- I have COPD stage 3, am week breathless in constant pain, fatigue and fibromyalgia seems worse now and anxiety is high
- Can't carry things. Too weak to cook for family and self. Can’t open jars etc. Cleaning difficult. Had to have walk in shower fitted
- I currently struggle to train for triathlons due to the asthma attacks I have experienced since having COVID.
- I work in a carer home and worked all the way though COVID-19 to take care of the residents I look after

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- Everything takes so much longer and is a chore. I am less inclined to go out. My confidence has reduced. I am tired all the time. My physical activity is almost zero.
- Disturbed sleep & tiredness
- I lose my sense of taste, get numb toes & stop sleeping when I get stressed. This usually last 8 weeks & has happened multiple times in the last few years.
- Periods of fatigue and sinus issues mean I am unable to carry out activities
- Fatigue, pain and digestive issues means I cannot work, or socialise. Everything is a struggle!
- Breathless at sports
- It would only allow me to select one option, however I have been affected with the ability to work, carry out hobbies and activities and it has impacted on my enjoyment. I have found the headaches/migraines crippling and often end up in bed, under the duvet where it is dark. Due to lack of energy and breathlessness, I have not been able to exercise or the things I enjoyed doing outside
- Secondary to my fatigue, breathlessness and frequent headaches, I have found it difficult to wash/dress on occasions, work has been far more challenging, despite now working from home, my previous activities and hobbies have been severely affected and this in turn has adversely affected my mood.
- All of the above are impacted. Tasks take longer to do either because of fatigue, energy levels or brain fog
- Generally have no energy everything is a struggle even getting up and down stairs
- I now need my husband to do most things for me I cannot go out alone

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- I am not able to do more than one task of housework in one day, e.g. cleaning the bathroom /kitchen or hoovering. I used to be able to do at least two of these in one day, but now I just get to fatigued doing one of them.
- Due to fatigue I just can't do my sewing or art, also everything tastes horrible especially some vegetables and meat
- I caught Covid 2 years ago.... before covid I played intense badminton once a week for 90minutes, I had for over 35 years... after I could hardly walk upstairs without getting breathless. For a year after Covid my at-rest heartrate never fell much below 95... that has now returned to "normal" low 60's
- I stayed in in for three years never left the house but I still got COVID three more times I got it more the fatigue got worse and pain
- Not able to do the things I want to do
- Had a bad fall and damaged lower back so Covid symptoms are only valid with regards to symptoms previously listed. All the above are badly affected through lack of mobility previously had.
- Feel constantly tired, more frequent mood swings/low mood
- I'm very fortunate that I have worked from home since the pandemic. My work is fairly flexible and my place of work have been very accommodating. My concentration and ability to stay awake have suffered. Headaches mean I often sleep at odd hours or not at all
- Have to rest when feeling tired
- Not affected life just carried on.
- No libido. No enjoying going out. Not wanting to go out.
- I've changed job roles due to this!
- My anxiety cause me to have full on panic attacks. As soon as I know I have to leave the house I start to shake then it feels like someone is squeezing my neck so hard then the palpitations start then feels like I can't breath and shaking takes over my whole body and this is the

thought of going out I need the help of my daughter or my mum to help me out the door.

- No interest as tired and breathless
- Just can't be bothered
- I have had to go down to 4 days a week at work as can't cope with 5. Can't have a bath as can't balance to get in and out. Can't go swimming or fell walking and can't spend so much time on the allotment and have already had one of my plots taken away. Can't look after my grandchildren so much or play sports with them
- I have no energy or motivation
- I do not socialise like I used to, I'm breathless more, this is probably due to asbestosis, emphysema, plural thickening and acne rosacea which stops me engaging with other people, this is affecting my mental health and wellbeing.
- Headaches and dizziness. Fatigue
- Brain fog and exhaustion and concentration
- I have suffered all of the above. The pain and exhaustion is the root of my problems.
- For first month or more, light-headedness, frozen shoulders, Difficulty dressing and undressing to avoid ache or pain. Swollen joints (knees, hands and fingers)
- Eating out has lost it enjoyment Tiredness I need to be in bed so early full time working can't rock up half asleep
- No energy to play with children, no enthusiasm for anything
- Not been at work/ can't do sports activities / enjoyment/can't take kids away or day trips to London A few hours out slower paced and exhausted Two years down line - 3-4 hours at computer intermittently Have help if can't manage to do all housework or gardening I pay someone
- Tiredness

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- I had my first bout of Covid in March 2020 and have had severe brain fog since. It has affected my memory, concentration and general ability to do day to day things. I have also developed mental health problems since having Covid. I was also having severe headaches and tachycardia for months after. I have had various brain scans, ECG’s and blood tests but all came back normal. This has resulted in me having a lot of months off of work- I work as a paramedic- as it is extremely difficult to do my job with my health in its current state.
- Extreme fatigue & insomnia has stopped me functioning to 100% in my job and has meant that I have had to get my GP to increase my medication with a non-sleeping pill, sleeping spec
- Intermittently feel unwell. I can feel ok for a few days and then I have a few days of feeling very unwell. The symptoms arrive and depart as though a switch has been turned on and off in my body!!!
- I’ve had to change my shifts at work to do just late turns. I don’t get enough sleep to be able to drive properly on early shifts
- Flat effect. Loss of "get up and go"
- I cannot work I am a different person it has changed my life I am in pain all the time I worry about everything
- I struggle every single day. My husband helps me shower and dress I go to work where I have to plan my route as I need to drive because I’d struggle using the bus due to needing a toilet so I need to stop at a supermarket on route to use the toilet. I have to park a considerable way from the entrance (as havering council won’t issue me a blue badge, I am appealing the decision) then once used the facilities or if I have had a toilet accident change underwear and then go to work. I struggle at work with concentrating, fatigue I ache and hurt all over this affects my mood and my mental health too. I tend not to socialise due to my health conditions and being a burden on others

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- I am no longer able to work at the intensity I once could. I am still on restricted duties, which is depressing
- Has affected work ability to look after my son and also ability to socialise. Before Covid I used to want to and did go out with friends in evenings regularly at weekends but now only a few times a year. Following this I can then be wiped out for 2-3 days.
- I can't look after others Enjoyment is not high in my priority list, I can't work. I'm too tired all the time. I can fall asleep anywhere. If I'm with people the next day I'm wiped out. Life is too much at times.
- I have not been able to work with patients directly, been working off the ward, managed now to finish my MHN course after missing some placement. Had to undergo knee surgery due to falls from weakness of muscles. Still suffering from breathlessness, find it difficult to stay in an un-ventilated place. My mobility is affected now, even worse after my knee surgery. Can't stand for long, can't walk for long and so on
- Can no longer go for long walks
- The symptoms wear me out.
- Have trouble to care for myself let alone someone else.
- All areas have been affected
- Not been able to do as much at my church as I used to. Been unable to go out as often and stay out as long. Not comfortable around a lot of people. More sensitive to noise. Forget people's names quite a lot, even when I've known them for a long time, especially when I'm tired.
- Looking after my mum with dementia and my own children has been impacted.
- I no longer leave home for anything other than doctor and hospital appointments
- My whole life has been affected, work, home life, social life, I still have to work full time, I do work two days from home but by Friday I am

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completely drained, I have no energy when I get home to do any housework or hobbies, I have to plan weeks ahead if I want to go out socially so that I can get the most out of the activities with the least amount of effort.

- All of the above affected. It won't let me tick more than one. Regulating body temperature is an issue so bathing is avoided. My daughter had her worse symptoms on PE days so was advised to stop PE. Exercise endurance tests have been refused so we don't know exactly what we are dealing with from a cardio point of view. As symptoms go on her anxiety and stress levels rise.
- Not as energetic as I was.
- Constant exhaustion no restorative sleep
- No longer go dancing, my fitness has dropped as a result.

We asked those who were "not sure" why that was so; they told us:

- I have been referred to talking therapies and the gym but feel more support is needed.
- I have given some information. But not sure how to join.
- Have had an appointment with GP, on two occasions. Told first time I had Pneumonia, 2 and time may be CPOD. Waiting for Blood Tests and Lung Function Tests.
- I have been referred to musculoskeletal team for physio but long COVID not mentioned.
- My doctor said it's too hard to diagnose
- Still awaiting appointment
- By the nurse at the GP practice, the GP has not formally diagnosed me.
- I've not heard anything
- GP referred, but I am unaware what to expect.

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- I had hospital post covid clinic support which I found out about the clinic Not sure if anything else
- My GP stated that long Covid support clinics mainly deal with breathlessness and not brain fog.
- Telephone conversation only with GP, who may have referred me onwards but I am unsure.
- I have had online support from the long covid clinic and have just been discharged
- I did have some NHS sessions last year with my GP
- Diagnosed but no further help offered. At time GPS didn’t want to know so had to have a private consultation and investigation. A poor NHS service (GP) continues to this day.
- Not been to GP with Long COVID
- Attended some classes and 121 sessions however these didn't really help my underlying issue
- My daughter finally saw someone at UCLH TRACCS from the long Covid team. This was end of June. It's taken 3 years of battling for care to get to this point and also paying to see a consultant in a private capacity for advice who can see her on NHS once she is 16, provided we can get a referral. He is a cardiologist and PoTS specialist. He explained it is early days knowing the link between PoTS and Covid. My daughter was fine before Covid.

We asked what “other services” respondents had accessed. They told us:

- Pulmonary rehabilitation
- I don’t know if I have long covid but since having COVID in July 2022 which lasted weeks if not months I called GP and spoke on the phone as I couldn’t keep and food or water down and such bad diarrhoea just was told to take Co-Codamol take which I have on my prescription.

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- Online help
- Hospital (where I work) claimed to have sent me a letter, that I didn't receive, took me off their waiting list, in spite of my doctor completing all the documentation.
- Self-Routines and rituals
- Pulmonary hypertension clinic.
- Not long COVID clinic: my GP tried to refer me and was too difficult as my primary care was in London (Guys)
- Private food tolerance testing and physiotherapy.
- Breathing problems shown lung damaged from COVID leading to breathlessness
- Various hospital surgeries arranged by local GPs
- I was told nothing else could be done
- Online support group
- many and varied websites, but mainly NHS websites
- I did have support last year which ended
- Private GP and services.
- Online long covid on Facebook

We asked them to give details of their experience of seeking support for Long COVID:

- This has been a struggle as I was recommended physio during initial consultation and then told that I would have to get a referral from my own GP. I feel that I really need reassurance with some of the symptoms I experience but have had to wait over 4 months for a consultation.
- My GP doesn't know what is wrong with me, he relies on information from the results the hospital provides. The hospital has been unable

to identify a particular problem which means I am left in limbo with no confirmed diagnosis. Access to a GP still proves difficult, remote consultation is pointless, as the conversation is just a repetitive exercise.

- Referred to long covid clinic which has been a great help. Recent prescribe medication seems to be helping with breathing. Still feeling very low
- I haven't seemed because I was unaware the professionals could diagnose long covid
- Was part of the long covid rehabilitation for weeks before being discharged. Had OH come to my house to do certain exercises. Used the app that was provided with rehab.
- Initially, I had little support, I had to keep going back to my GP and questioning why I was feeling like this. He did not know what to do with me. This all started from having the first vaccine. I suffered I'll health that did not improve and impacted work and my social life as well as day-to-day life. until 2 years later I was referred to respiratory. I waited 8 months. Once on the covid program I felt less I isolated. And support so far has been good.
- I was put on the extremely vulnerable list as my immune system was totally suppressed due to severe rheumatoid arthritis and emphysema. I first got covid on 1 April 2022 and was given the drug Paxlovid which kept me out of hospital. After several weeks I still felt quite ill and went to my GP, they were very slow in recognising the problem but eventually sent me to the long covid clinic. I was assessed and enrolled for the long covid therapy, after that I was enrolled for the long covid mental health therapy. I am about to start the Pulmonary rehabilitation at the end of this month.
- The long covid team has been very helpful. Received very useful information. But not sure how to get access to the available services to receive needed help.

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- I have found everyone helpful
- The team been excellent and prompt in arranging session, maintaining contact and offering support. I had weekly online sessions for 10 weeks, had telephone meeting with designated team member and my issues been addressed promptly.
- I have not been seeking support as I'm not sure I have post covid, all I can say is I've not felt the same post covid.
- I did on line course which helped and was given a 12-week gym pass which I found was good for my breathing
- Saw an advert from Havering Council for Covid support. I phoned, got help and had weekly sessions with counsellor over the phone. This helped me tremendously with coping managing my anxiety. Flowed by joining a group each week on improving my breathing
- Attended living better with long Covid from NELFT - 9-week course, it was very good
- I have mentioned the symptoms, i.e. fatigue, chronic cough, weakness plus SOB to GP, also swollen ankles and legs. GP wants to run tests first, before comments. I had Covid, started symptoms, March 16, 2020. Before the first lockdown. Spent 3 weeks in bed. I do not think I recovered, properly, from that. I paid for a private Antibody test, in July 2020 and it was proved, I had contacted Covid.
- When mentioning long COVID to my GP it seems they are hesitant to acknowledge it.
- getting a diagnosis of long covid has been difficult. All the medics seem to say that my current condition could be due to covid but don't want to commit.
- Not had any support its4lf....but when I am ill A&E have a record of me going there on oxygen and starts dripping while I'm walking
- As I have other preexisting health problems, I will continue to seek medical help when needed. I have found getting face to face

appointments with my GP difficult indeed I have never met my current GP as my previous practice closed during covid and all patients were transferred.

- Could not get support in havering as my scans were at Guys hospital Was totally presented from being referred as my condition for sarcoidosis in lungs is at Guys and they took over care from queens when I was discharged due to my extended problems and Queen's discharged me when I was still extremely unwell and I needed repeat scans Queen's missed fluid on heart Guys found it
- Went to the Drs after experiencing horrendous coughing fits/asthma attack like symptoms, very quick service with chest X ray, bloods and ECG done in a week, now awaiting referral to long COVID clinic as tests all clear. Given a blue inhaler for when required.
- It took a year to be seen at the long covid clinic. They are able to offer little support.
- None sought
- I've not been offered any post-covid support. I was not even aware there was any available in Havering.
- I have seen my GP for symptoms related to respiratory issues
- This has been a long gruelling journey. I have had every test imaginable but each result has been "normal" leading to the conclusion that I am now suffering from Long Covid. During this journey there has been extremely little recognition that there is a direct correlation between Covid and digestive problems/suffering.
- I saw a dermatologist for the hair loss and said it's called Telegon Effilium due to prolonged fever in the body and I am currently on Metformin for diabetes
- After a year of struggling with symptoms, I was recommended by a friend of a private consultant. I have been under him for around 1 month, but the changes and recommendations have been much

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beneficial than what I had via the NHS and I have for the first time in over a year have hope things will get better

- It was the nurse in my GP practice who referred me to the health and well-being coach. My GP has offered no support or advice and I have not had any information about further advice or support that may be available in the borough. I was referred to a cardiologist who suggested that the breathlessness was secondary to post COVID but this was not followed up by my GP.
- GP was very helpful and supportive. Referral process to LC clinic was involved. Support given from clinic has been minimal with 3 face-to-face appointments since October 2022 and have been offered 2 online courses - one physio for breathing and one for fatigue from Occupational Health. I was also giving access to an app to monitor my symptoms and contact the therapists at the clinic. Both courses were a little disappointing on the fact they mainly offered common sense advice and could not really help with specific issues. It would have been nice to see professionals in person where my state of health could properly be assessed - say a full day appt instead of a 6-week online course of 1-hour sessions. It seems that test are called for and if things come back ok (like they often do with LC) there is nowhere to go with my symptoms.
- I think I have it but not got any help or info
- My GP has concerns about my continuing chest issues and fatigue. He has referred me back to the Respiratory clinic at Queens Hospital to see if they can give me a Long COVID diagnosis, so he knows what he is dealing with and can treat it accordingly. I was originally placed under the care of the respiratory clinic in January 2020 after attending the A and E department with respiratory issues. Resulting in numerous courses of antibiotics and inhalers with a cough for 18 months that stopped within two weeks of having my first COVID vaccination. I was then discharged by the clinic with maintenance inhalers.

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- I went to my doctors for the usual over 70 "MOT" and spoke to the nurse if anything could be done...I got a shrug of the shoulders and told "not much"
- Like I said I just assumed was my Functional neurological disorder worsening
- I want to support for post Covid syndrome for the best that I have to do,
- Had x-rays and CT scans on lungs
- Spoke to my doctor who has referred me straight away! Brilliant!
- I haven't really looked for any help did not realise how bad it was but it has worsened over time now
- I mentioned to doctor I have not been feeling good since I got Covid but it was just ignored really
- My nurse didn't offer anything
- It took 2 years before anyone took it seriously and referred me. Mainly then ruling out other illnesses then when seen by long Covid clinic referred to online support sessions to manage my symptoms. Have been discharged from that as finished the course. Feel in limbo now as some of my symptoms are not improving and because of lack of balance and cough I can’t take up the exercise sessions. If it wasn’t for my allotment, I would be really upset though still stressful in case I have my plot taken away due to not keeping up with its maintenance properly. Nowhere to go from here other than trying to keep going the best I can.
- I have not sought help as I have comorbidities which have been exacerbated as a result of possible Long Covid. I am having investigations which might lead to evidence of Covid involvement in my newest conditions.
- Only help is CBT to help mentally deal with life after long covid. No other help other than a long list of tests that show nothing. Left to

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your own devices after that. I'm 3 years in, have now been diagnosed with long covid/ ME/Fibromyalgia. Again no help for any of that. There is no help or cure. I cannot do a lot of things I used to be able to do and am sometimes incapable of looking after myself but no offer of home care help or anything. It seems that as Covid is no longer a pandemic, people still seriously suffering, like myself, are forgotten.

- I was lucky my GP made referral as I am totally unaware of any support.
- Locum doctor helped after 3/4 months. Had some tests Basically told I've got to get on with it tough
- I fought to get long covid clinic Not sure of other support I community
- I haven't been able to access any help
- I attended a long covid clinic and had a good chat with the doctor but decided to manage my own symptoms. Fortunately I started to feel better gradually after about 10 months
- I have seen several GP's and had various scans, ECG's and blood tests carried out- all of which have come back normal. I am also seeing a psychiatrist and a therapist who are helping with the mental health side of things but my brain fog is still extremely severe after three and a half years. Unfortunately no clinicians are able to give me any answers/ information as to why I have such severe brain fog or how to treat it.
- Poor, just very poor. Having suffered over Christmas 22, firstly there were no available GP appointments and then, even when I had a telephone conversation about Long Covid, it wasn't a definite one, and secondly no further referral evident by even an NHS 'holding letter'.
- My GP is now on board with the fact that I am still unwell after over 5 months. But he says the online and/or in person post covid clinics are oversubscribed and not much good!!

- I have not tried. My wife and daughter are very supportive.
- It took a year to be seen the support I got was online and was helpful but I think it was too little too late
- I have contacted covid 4 times and had some support from the long covid team last year and I believe I have been discharged. I am still struggling with my health and I have been diagnosed with long covid. I do suffer with fibromyalgia too which hasn't settled since I first caught covid over three years ago.
- I am lucky to have private medical care through my employer, enabling access to a psychiatrist, psychotherapist and neurologist, much quicker than through the NHS.
- As above- general support through NHS extremely poor. GPs don't seem to take anyone seriously. Based on discussion with others in the same situation. Just lucky I have private health insurance.
- I've been on a few courses with SPS and whilst they've helped at times in the main there are no answers. No one can tell me what is happening, how I can get better, when I'll stop aching. When the headache I've had since 2020 will stop. No one can tell me if the pain will stop.
- There is nothing much to say, I have been with the long covid clinic since 2021, I have attended all that I was asked to attend. The covid gave me diabetes type 2 and I have passed and still passing through a lot.
- GP investigating my chronic cough not sure if related to covid or heart issue yet
- I have not sought support as I don't believe that my doctor would support this.
- Too short appointments with GP to feel fully heard and understood the range of symptoms. Often attributed to other causes.
- It took a long time to get referred

- The other person I was able to speak to is my GP and consultant with regards to Covid.
- I am under the long covid clinic but the appointments are few and far between
- It was easy to start with but once I did the online courses I was left only with the 'Living With' app. I know there is not much that can be done to eliminate the symptoms so I do the best I can with what I have.
- It has been a battle, there is no other word for it. My daughter's quality of life has changed drastically - she has so many symptoms and I've listed the most severe. Today we are in the unwelcome position of having two cardiologists' opinions, both from well-respected London Hospitals and departments - one linked to Queens saying there is nothing wrong from a cardiology point of view and refusing an exercise endurance ECG and the other saying the opposite but unable to help unless someone refers. In October last year we had an appalling experience when they separated my daughter from me and didn't believe her that she passed out at home. We both felt under immense pressure to prove what is happening, it's been a huge concern and still is. I've paid out just under £1,000 to try and get evidence that will be accepted for what happens to heart rate and the opinion of the private doctor. I have an advocate supporting me raising a concern about aspects of my daughter's care but they take 4 weeks to respond to email if at all and I've been several months trying to organise a date for a meeting to resolve the concerns. It just goes on and on. My daughter via a central London hospital has an appointment for autonomy/neurology as it essentially seems her central nervous system is not working efficiently but this is April 2024 and I'm not going to get her the support she needs for sitting GCSEs. The symptoms she is experiencing are now likely to knock on to the rest of her life because they weren't understood and acted upon in a timely manner.

- I didn't know there was support
- Mentioned several times to GP how body has changed since covid already have another condition so comments were dismissed.

We asked respondents if, in the support that they had received for Long COVID, their physical support needs had been met. They told us:

- Doctors don't listen
- My appointment with the consultant was cancelled on two occasions and so I haven't had a proper consultation as yet. My symptoms are ongoing and have not been addressed.
- Still having the same issues.
- This is an ongoing illness that needs support not just for 10 weeks.
- The support was good once I started to receive it. I am still suffering fatigue and breathlessness bit have been discharged from the clinic.
- I have learnt correct breathing techniques.
- I did a 12-week trial at the gym and I found that really helped my breathing
- Breathing exercise has helped me, however, myalgia and fatigue still affecting my day-to-day functioning.
- Unable to help with my fatigue- had to manage on my own
- I got COVID 3 times. About two weeks after my 3rd time, which was in February 2023, my throat started hurting with severe cough. I could not get a GP appointment, but rather got a nurse appointment who had one look at my throat and prescribed anti biotics. When I told him about getting COVID 3 times the last of which was just 2 weeks ago, he seemed to be amused rather than relating both. The cough and hurting reduced but came back again at which point I fought to get a GP appointment. He said he can give anti biotics but it looked to him as if the infection was on its way out. He also did not give any thoughts about me getting COVID 3 times. When pressed he said to

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do a blood test and chest x ray which was clear. I feel like there is a lump in my throat on the right side still.

- Going to the gym really helped
- Only recently, I have been able tort a face to face, appointment with GP, to voice concerns about my worsening health. Initial appointment, 12 June 2023, was regarding my Incisional Hernia, which kept popping out, due to my constant and violent coughing spells. At last I am getting tests to confirm, whether it's from Long Covid or a general deterioration of my health. It could be both. I only started to get symptoms, post Covid.
- I have waited 5 months for a referral to physio team.
- I've asked my doctor for a diagnosis so 8 can get the support he's refusing
- No support provided
- I am still struggling massively. The only support is online group sessions.
- Not offered any post covid support.
- As mentioned above, during this journey there has been extremely little recognition that there is a direct correlation between Covid and digestive problems/suffering.
- I have had advice about pacing which I presume is all that can be done.
- I am still suffering the same way I was I Jan 2022 and have been discharged from the physio and Occupational health and will probably be discharged from the LCC next week after my telephone appt. I am still waiting for my online brain fog course.
- Haven't asked for help
- I have not had a diagnosis and although I have a twice daily inhaler, I have not had any advisory support.
- Didn't know there was support in my community

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- Waiting for my appointment.
- Have not had any
- I didn’t know enough about it at the time but I can understand now as I have been admitted to hospital for breathing problems and understand it more but I shouldn’t have been able to see doctor more
- I’ve not been offered any
- Received online advice on how to manage my symptoms but it didn’t cover all of them
- Only help is CBT to help mentally deal with life after long covid. No other help other than a long list of tests that show nothing. Left to your own devices after that. I’m 3 years in, have now been diagnosed with long covid/ ME/Fibromyalgia. Again no help for any of that. There is no help or cure. I cannot do a lot of things I used to be able to do and am sometimes incapable of looking after myself but no offer of home care help or anything. It seems that as Covid is no longer a pandemic, people still seriously suffering, like myself, are forgotten.
- Was given a link to read that’s all
- I had no support, or knowledge support was available, or how to access help and support.
- St Edwards Med Physiologist gave me an extensive daily programme of exercises.
- Because I feel I’m still the same two and half years later
- Been told what I need to do to try help self
- It was good to talk to someone other than my own GP and for him to confirm that it was Long Term Covid which I was suffering from. At least then I knew what I was dealing with.

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- My partner has looked after me all through the illness, but the NHS has done nothing for me. Thankfully he has been able to do all that I have needed.
- Some of my usual tasks my daughter does.
- I have never had any investigations into my joint pain just prescribed pain meds and anti-depressants
- I'm now seeing a neurologist for my headaches; I am still waiting to see a pain management specialist and I've not even received a letter for an appointment. The wait times are too long for people struggling everyday
- Still suffering- symptoms seem to be improving but still impacting me for periods of time.
- The pain is constant.
- Knee surgery, which didn't help at all.
- GP currently investigating as only had covid in January 2023 [comment – this answer was given in early August]
- Self-support: breathing exercises work for me
- The biggest physical issue has been the difficulty to walk at times and this hasn't been resolved. I also still suffer from memory loss at times and these have knock on effects in my personal life I decided this year to retire from work. There were many reasons I decided to do so, however having long COVID was one
- Was also pregnant so different support services involved perinatal mental health, health visitors, home start,
- I was referred to the long covid recovery course, but it was very focused on breathing. I had little breathing difficulties but felt that fatigue and insomnia (causing headaches) issues were poorly covered in the course.

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We asked respondents if, in the support that they had received for Long COVID, their mental health support needs had been met. They told us:

- I have been referred to Talking Therapies.
- Have been put in touch with mental health team and having a consultation 12/09/2023
- Still awaiting therapy.
- Ongoing help for sleep issues and anxiety physically worn out.
- I was shown several ways to combat the stress and anxiety.
- Meditation methods were introduced.
- Everyone is so helpful
- Had to come to terms with my own limitations on my own
- Just talking to others that are suffering also helps
- Manage my anxiety and breathing.
- I'm a strong person, and usually do not suffer any mental health issues. Also one of those stoic people, who does not complain, just gets on with things.
- My anxiety has got worse I don't go anywhere
- Face to Face is not possible therefore talking about anything is restricted.
- No support from Havering provided
- I have not needed mental health support
- As mentioned above, during this journey there has been extremely little recognition that there is a direct correlation between COVID and digestive problems/suffering.
- I have been able to chat with the coach which has helped but no additional support has been suggested
- Still waiting for brain fog online course.

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- As mentioned previously, I have not had any advisory or counselling support.
- Been difficult to ascertain this due to overlap of back injury treatment.
- Not needed.
- I struggle to get to counsellors I need a psychiatrist with my help and I suffer with PTSD as well from past health issues as well
- Hard to get face to face with doctors
- Received advice on how to manage but told to refer myself back to IAPT at a later stage if need more help. Haven’t done that yet as bit overwhelmed with everything
- I am still awaiting treatment following referral and assessment for mental health services.
- CBT and online long covid course. Mainly self-help and online chat groups.
- Yet to receive help
- I’ve resigned myself to the fact this is my life now. I have no choice but to struggle on, mainly for my children and grandsons Still winds me up and I end up upset and crying. What else can I do?
- It was offered but I used my life coach instead to help me
- My therapist, GP and psychiatrist have been great in assisting me to manage my mental health.
- I am of the generation that got on with it. It does make me feel down, but I don't bother to ask for outside health. My partner and my friends give me all the support that I need.
- By my wife and daughter.
- I referred myself to a local mental health team this was also on line it was helpful

- The wait times for support are too long. My workplace will look at support me
- No care can take away the symptoms, much as I wish they would.
- I was on medication before Covid to support mental health
- In some ways it's good to know you aren't alone that there are others out there going through the same.
- No mental health issues
- Self-support: I try to keep active and socially engaged despite feeling awful at times
- I have some brain fog and memory issues which I worried about but learnt some techniques to cope which has eased my anxiety.
- I speak to consultant once a week.
- I had appointment with talking therapy but it was just for CBT not for my actually mental health
- Only just learned that there is any help for my mental health issues surrounding Long Covid.
- The lack of support and understanding have caused mental health issues. My daughter doesn't believe anyone can help her and make a difference and that's a hard thing to live with when you are fifteen.
- I've not had support
- GP suggested sleeping tablets

We asked if there was anything else they would like to tell us about their experience or the support they had received. They told us:

- My GP has supported me as far as he can (in my opinion). The system overall has failed me, I am still unwell, I have no confidence in the NHS providing information on an outcome. I am just left to get on with it.
- All teams have been extremely helpful

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- I feel like I have been left to deal with it on my own now after being discharged. My doctors haven't asked me how I'm doing. I've had to emails, texts or calls from the long covid team. Feels like they have said there's nothing we can do bye now.
- I would like to start by saying the long covid team are fantastic and very good at communicating with me. I've felt supported throughout and as I continue to heal from this pandemic, I hope the support continues.
- It was an eye opener to share the experience of others who have gone through the different stages of different episodes after COVID like myself.
- I did the on-line course and found that very helpful
- Everyone has been so helpful
- Support was great. I do realise there are people worse off. But my life has changed completely since I had COVID e.g. loss of hearing in my right ear. I could hardly cope on a daily basis but had to work to make a living, change jobs in fear of getting COVID-19 again. My doctor referred me to the hospital, yet they didn't care. I have to keep moving forward.
- Referrals hospital visits and self help
- Had a lung function test, told my lungs are 15 years older than me, no follow up from doctor no communication
- At aged 81, I'm a bit of a realist, I always think some of my symptoms may be due to ageing.
- I feel that GPs are very dismissive when being asked if long COVID may be the cause of my problem.
- Extremely poor experience when I asked for help doctor was unable to refer me to long covid clinic due to scans done out of havering I believe I have PTSD which has gone undiagnosed I have had a

serious burn due to weakness in arms dropping pan of boiling potatoes on myself No one has offered help with long covid

- I am convinced that COVID has changed my immune responses, I seem to have a weakened immune system and now suffer extreme fatigue whenever I catch a cold which led to more coughs and these take longer to clear up
- I also have fibromyalgia and I feel that the medical professionals have fobbed me off suggesting that it is all secondary to that, despite my needs having changed since having COVID on both occasions. I have been left to cope with it the best I can.
- All the staff in the LCC and the therapists have been very nice and empathetic, it just seems there is nothing for them to offer. It feels like the clinic and courses are box ticking exercises and they really don't know what to do with us. From online forums it is very apparent that services differ around the country and there is no standard approach to treating the symptoms - e.g. some clinics will prescribe anti histamine treatments while King George's will not consider this at all.
- Haven't had support
- My GP has been very supportive and the doctor that I spoke to last at Queens Hospital agreed that my symptoms are more related to long COVID and not asthma, as the consultant was suggesting. All I need is a proper diagnosis so my GP can move forward and support me more.
- Why wasn't everyone checked with mental health during lockdown to make sure they didn't have long COVID or make sure they got outside!
- I feel a lot better but weakness and fatigue is ongoing. I don't have the energy I use to have but age could affect that. I'm better off than a lot of people who suffered a lot more than me.

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- I have changed doctors and I might have to wait 2 weeks but I get to see my doctor
- Have lost confidence in GP as it took so long to be believed and the '8am lottery' to get a phone appointment is a farce - waiting 40 minutes or more to get through and be told to try again tomorrow which isn't helpful when you start work at 8am! Generally only get to see the nurse practitioner in the end anyway. Once you have done the online self-management courses then you are cast adrift to keep managing by yourself which does not totally help if not all your symptoms are covered
- Only help is CBT to help mentally deal with life after long covid. No other help other than a long list of tests that show nothing. Left to your own devices after that. I'm 3 years in, have now been diagnosed with long covid/ ME/Fibromyalgia. Again no help for any of that. There is no help or cure. I cannot do a lot of things I used to be able to do and am sometimes incapable of looking after myself but no offer of home care help or anything. It seems that as Covid is no longer a pandemic, people still seriously suffering, like myself, are forgotten.
- If my GP had not referred me to support, I would never have known about the help available
- The support was useless. I had to chase for everything suggested Was told at one time because I wasn't hospitalised, I didn't deserve anything. I worked the whole of Covid in a school setting. With EYFS and KS1 children. This was the only time I went out. I caught it from the school setting My children who kept a distance from me didn't get it. No one else in my family/household did
- I have overall received great support in dealing with the mental health and physical symptoms of long Covid. Unfortunately no one can give me answers regarding the severe brain fog, and it's severely impacting my life. I wish I could find some answers/ support for it!

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- I would very much like to participate in a survey which will help combat this complaint, but so far have found nothing.
- For too much of the time I am happy to sit at home and do nothing but read and watch TV.
- I feel that I waited too long to get any help and this impacted on my mental health
- I feel quite let down. I know I have fibromyalgia which could have spiked due to covid. But I had contracted covid 4 times. My IBS has progressed to a bowel disease and I struggle to walk long distances and I'm breathless. I wet and mess myself and I'm in constant pain all over and I've had a permanent headache since 9th January 2021 I wasn't like this before COVID. I'm having to fight for a blue badge with havering council and I've got to go to an appeal which is very stressful and is affecting me as I feel I'm not being believed. I'm in receipt of a disability benefit too. All I want is to feel like I used to feel like before COVID
- Poor experience still feel like having to deal with this on own.
- Difficult to get a diagnosis
- Gerry has not been to the GP with his symptoms. He is convinced he has long COVID. I have advised him to make an appointment with his GP.
- Breathlessness improved after 5-6 months with lots of practice of diaphragmatic breathing, relaxation. Other ongoing symptoms could be overlapped with chronic fatigue syndrome which I have suffered with a long time, or newly diagnosed rheumatoid arthritis.
- I was disappointed in that I felt that the course was very locked into the breathing aspect of long covid and seemed to assume that most people would suffer from breathing problems. The focus on this was such that it felt as if other symptoms were not covered as thoroughly. Would it not be of benefit to run two courses - one for those with

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breathing difficulties and other symptoms and one for those who have not experienced breathing difficulties.

- It appears some boroughs receive more support than others like Tower Hamlets and Newham.
- It has been 3 years now and I feel many of the original test could be retaken as symptoms have got worst and the hospital appointments could do with being closer together
- Just what a battle it has been from start to now. Everyone I turn to for support, including Healthwatch Havering says they can't help. One source of positivity has been Long Covid Kids charity. My daughter has missed a lot of school, I've missed a lot of time off work. We are nowhere near knowing answers or how to support her. My focus is getting the referral for January which no one will commit to from Queens, UCLH or our GP. This doctor/cardiologist is our only glimmer of hope, he completely understood what symptoms my daughter was having and how they made her feel and has over thirty years of experience helping people with PoTS. In my daughter's case Long Covid also appears to be playing a role. I would say too that it has been impossible to get her seen in a timely manner when she has her worst episodes and since stopping PE the severity of episodes eased which gives health professionals a false perspective of what is happening now. This is why I believe and one cardiologist, an exercise ECG so important. Queens Hospital have actually 'lost' an ECG and heart scan from Feb 22, another aspect of my complaint alongside it took her fainting/going unconscious to get a halter (the hospital trust do not give them to under 16's) we had to get special permission. Yet, despite her wearing this and having a very bad episode in a London station requiring an ambulance - which took 2 hours to find us by which time she was recovered - I went to 3 important appointments, all 90 mins long and the results shared after. In the appointments I was told 'all was fine' but when I got the paper summary things DID show up, the elevation in beats per minute for example. The whole situation remains a concern.

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- I haven't received support

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Participation in Healthwatch Havering

Local people who have time to spare are welcome to join us as volunteers. We need both people who work in health or social care services, and those who are simply interested in getting the best possible health and social care services for the people of Havering.

Our aim is to develop wide, comprehensive and inclusive involvement in Healthwatch Havering, to allow every individual and organisation of the Havering Community to have a role and a voice at a level they feel appropriate to their personal circumstances.

Members

This is the key working role. For some, this role will provide an opportunity to help improve an area of health and social care where they, their families or friends have experienced problems or difficulties. Very often a life experience has encouraged people to think about giving something back to the local community or simply personal circumstances now allow individuals to have time to develop themselves. This role will enable people to extend their networks, and can help prepare for college, university or a change in the working life. There is no need for any prior experience in health or social care for this role.

The role provides the face-to-face contact with the community, listening, helping, signposting, providing advice. It also is part of ensuring the most isolated people within our community have a voice.

Healthwatch Havering Friends' Network

Join our Friends' Network for regular updates and other information about health and social care in Havering and North East London. It cost nothing to join and there is no ongoing commitment.

To find out more, visit our website at https://www.healthwatchhavering.co.uk/advice-and-information/2022-06-06/our-friends-network-archive

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A community interest company limited by guarantee
Registered in England and Wales
No. 08416383

Registered Office:
Queen's Court, 9-17 Eastern Road, Romford RM1 3NH
Telephone: 01708 303300

☎ Call us on **01708 303 300**

email **enquiries@healthwatchhavering.co.uk**

Find us on Twitter at **@HWHavering**

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