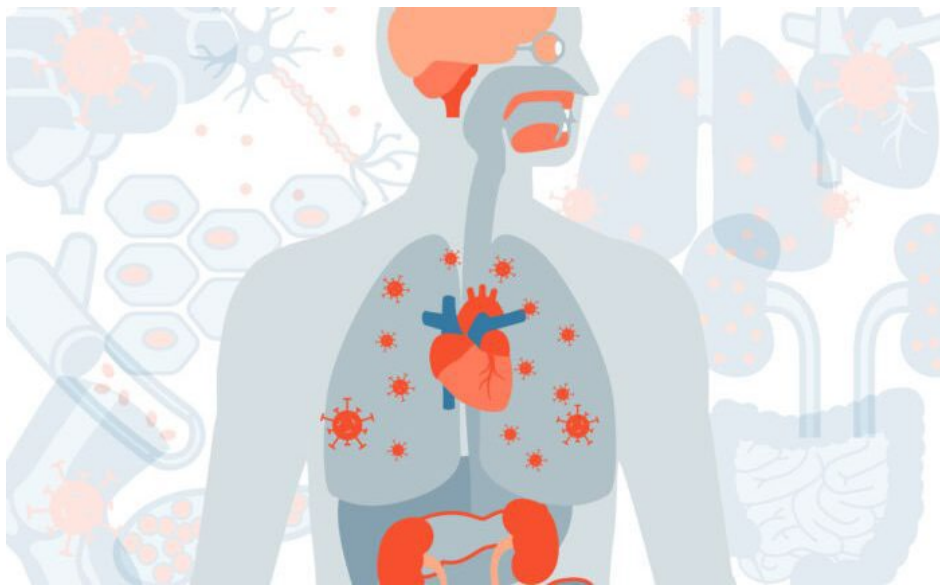


# Residents' Experiences of Living with Long Covid



March 2022

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# Executive summary

Healthwatch Blackburn with Darwen carried out this project between Autumn 2021 and Spring 2022 to gather the experiences of residents suffering from Long Covid. The aim of the project was to understand the range of symptoms people were experiencing, the impact on both their physical and mental health and their experiences of accessing support for Long Covid.

The main symptoms experienced by residents, with a significant impact on their daily lives, are fatigue, breathlessness, brain fog, mobility issues and anxiety. Whilst 56% of respondents' symptoms improved within 9 months, 19% took 10-12 months to recover and 24% of respondents were experiencing Long Covid symptoms for over a year.

Long Covid impacts residents' lives far beyond the physical symptoms. Most of the respondents reported that their mental health had deteriorated because of both the condition and its impact on their lives and relationships. This shows mostly through anxiety and depression, as well as irritability and low mood.

From feedback given from residents, their lives are significantly impacted by Long Covid in many ways: their employment, caring duties, social lives and domestic duties become neglected following high levels of fatigue. For many, it is has become impossible to carry on with lives as normal.

Please find our recommendations for changes which could be made by local services to better support residents living with Long Covid on page 6 of this report.

# Introduction

The National Institute for Health and Care Excellence (NICE) defines Post Covid-19 syndrome and Long Covid as below:-

“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. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.

Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

In addition to the clinical case definitions, the term ‘long COVID’ is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).”

An ONS report in March 2022 states that:-

“An estimated 1.5 million people living in private households in the UK (2.4% of the population) were experiencing self-reported long COVID (symptoms persisting for more than four weeks after the first suspected coronavirus (COVID-19) infection that were not explained by something else) as of 31 January 2022.

Of people with self-reported long COVID, 344,000 (22%) first had (or suspected they had) COVID-19 less than 12 weeks previously, 1.1 million (71%) first had (or suspected they had) COVID-19 at least 12 weeks previously, and 685,000 (45%) first had (or suspected they had) COVID-19 at least one year previously.

Long-COVID symptoms adversely affected the day-to-day activities of 989,000 people (65% of those with self-reported long COVID), with 281,000 (18%) reporting that their ability to undertake their day-to-day activities had been “limited a lot”.

Fatigue continued to be the most common symptom reported as part of individuals' experience of long COVID (51% of those with self-reported long COVID), followed by shortness of breath (35%), loss of smell (34%), and loss of taste and difficulty concentrating (both 25%).

As a proportion of the UK population, prevalence of self-reported long COVID was greatest in people aged 35 to 49 years, females, people living in more deprived areas, those working in teaching and education, social care or health, and those with another activity-limiting health condition or disability.”

As a borough, Blackburn with Darwen was one of the hardest hit areas in the country by the Covid-19 pandemic and services had to develop quickly to support people with Covid-19 and long Covid. As a condition that is yet to be fully understood and pathways still in ongoing development, Long Covid must be treated through a person-centred approach in response to residents' needs and concerns. As such, Healthwatch Blackburn with Darwen decided to undertake a review of people's experiences of Long Covid.

# Methodology

We collected data about people's experiences of Long Covid between Autumn 2021 and Spring 2022 via an online survey. The survey asked people about their symptoms and recovery times, impact on their physical and mental health and their lives more widely. We asked people about the support they had received, gaps in current provision and their hopes for the future. The full questionnaire can be found in the appendix at the end of this report.

We made the decision to collect data online as it allowed us to reach people during a period of uncertainty with varying restrictions and where few in person activities were running. We would have liked to have the opportunity to reach out to digitally excluded people more than we did, however, we are grateful to BwD Council, BwD CCG and voluntary sector partners for sharing this survey widely. We received 101 responses to this survey.

In addition to the online survey, Healthwatch Blackburn with Darwen attended the peer support group established by Blackburn with Darwen Borough Council to gather additional feedback from people in person about their experiences (including those who are digitally excluded therefore unable to access the online survey) and to gather case studies.

## Limitations

One limitation to the survey responses was that 28% of respondents skipped the demographic information section. However, based on the responses received, we were able to gather feedback from residents from a wide range of backgrounds, although it might be beneficial to carry out further research with residents from South Asian backgrounds about their experiences of Long Covid and support accessed. (See demographics information of respondents in the following section).

# Recommendations

To meet the needs of residents living with Long Covid and improve their care, we recommend the following:

**Recommendation 1 - A more comprehensive screening and diagnosis process by GPs** including a review of all clinical history and increased support from GPs including signposting to mental health services, physiotherapy, occupational therapy, rehabilitation, and other community services where appropriate

**Recommendation 2 - Increased promotion and availability of long Covid clinics** in the local area including better multidisciplinary support for people suffering from long Covid.

**Recommendation 3 - Embedding care coordination in the GP assessment process** with the support of Community Connectors, Social Prescribers, BwD Help Hub, and Refresh in the community to ensure a holistic, person-centred approach to supporting individuals with the wider impact on their lives - finance, relationships, caring duties, social activities as well as their physical and mental health.

**Recommendation 4 - Continued provision of a peer-led, clinician aided support group** in the borough. There is a clear demand for peer support and more widespread education on Long Covid and this would support with the issue of social isolation experienced by residents living with Long Covid.

**Recommendation 5 - Provision of self-care information as to what to expect after acute Covid-19** and where to access further medical advice and support via GPs, community services, peer support groups and East Lancashire Hospitals Trust for those residents who were hospitalised.

**Recommendation 6 - Better promotion of 'Your Covid Recovery' website to support self-care** - [When Do I Need To Seek Help? | Your COVID Recovery](#). Many respondents simply wanted a better understanding of how to manage their symptoms and what steps they could take to improve their physical and emotional wellbeing.

**Recommendation 7 - Tailored and targeted communication and education on Long Covid for employers** on how to best support staff members experiencing Long Covid - refer to NICE guidance on [workplace health: long-term sickness absence and capability to work](#). It was clear from respondents that they did not feel that their symptoms were understood by employers and there was a lack of flexible working opportunities whilst in recovery.

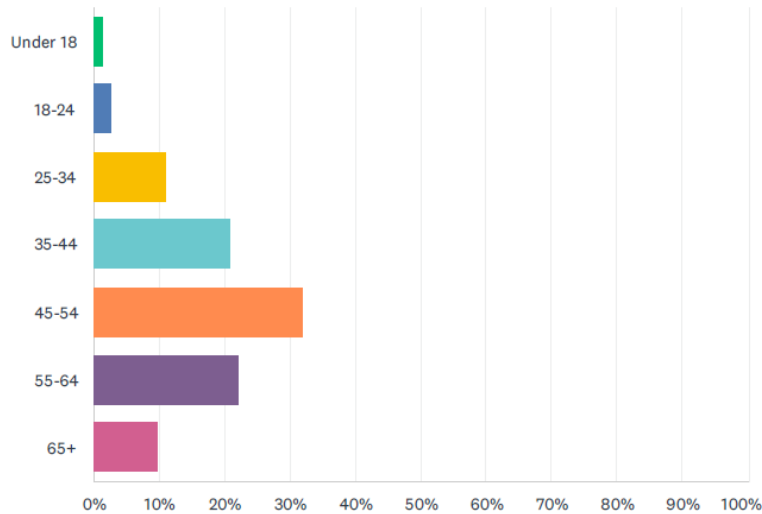
**Recommendation 8 - Local health and social care agencies to consider additional support for residents experiencing Long Covid who may be vulnerable** e.g., older people and people with complex needs including short term care and linking with community connectors and local voluntary sector for support around social isolation and loneliness.

# Demographics

We received 72 responses to the demographic questions in the online survey. Please see details below.

## Q16 What is your age?

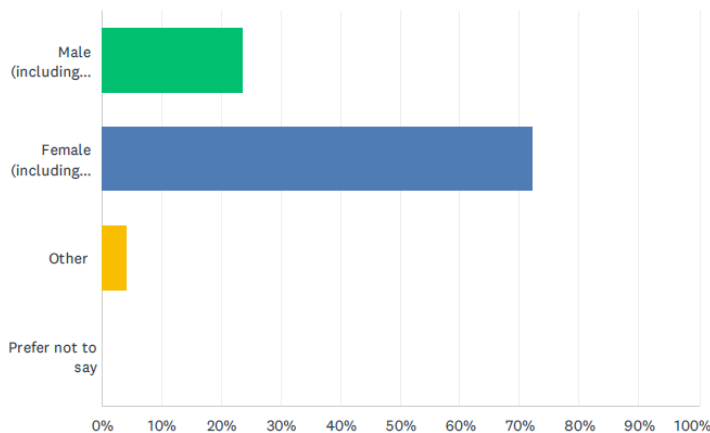
Answered: 72 Skipped: 29



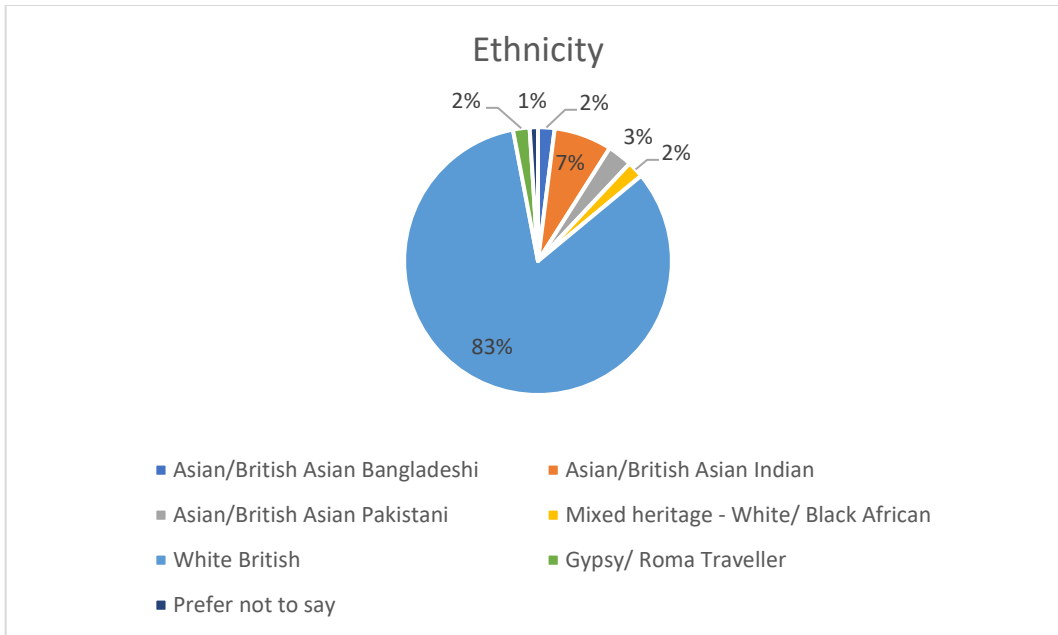
These results are consistent with the March 2022 ONS report ([Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandlife/articles/prevalenceofongoingsymptomsfollowingcoronavirus(covid-19)infectionintheuk/2022-03-01)) which identified that the prevalence of self-reported long COVID was greatest in people aged 35 to 49 years.

## Q17 What gender are you?

Answered: 72 Skipped: 29



Most respondents were female, which, although women are often overrepresented in surveys about health, is consistent with the ONS March 2022 which stated that the greatest prevalence of self-reported long Covid is amongst females.

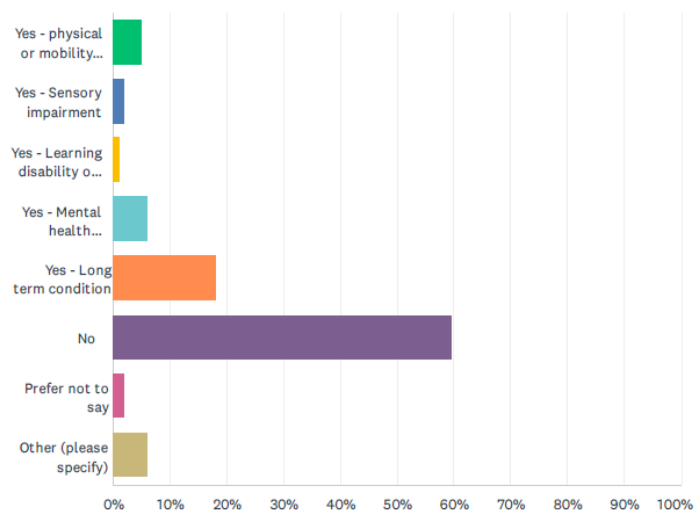


As noted previously, further research face to face with the South Asian heritage community in Blackburn with Darwen would be beneficial to understand their experiences of long Covid and accessing support.

### Pre-existing conditions

Q1 Did you have a disability or long term health condition before the Covid-19 pandemic? (We are asking this question to understand if this may have impacted on the Long Covid support that you received, or otherwise).

Answered: 99 Skipped: 2



Most respondents (60%) did not have a pre-existing condition, however 18% reported having an existing long term condition and 6% experience mental health issues. The 5 respondents who ticked “other” stated:-

“Asthma” - 3 responses

“Slight sensitivity to syncope. Attacks approx every four years”

“Recovering from a Break Down. Previous Alcohol miss use, Full recovery.”

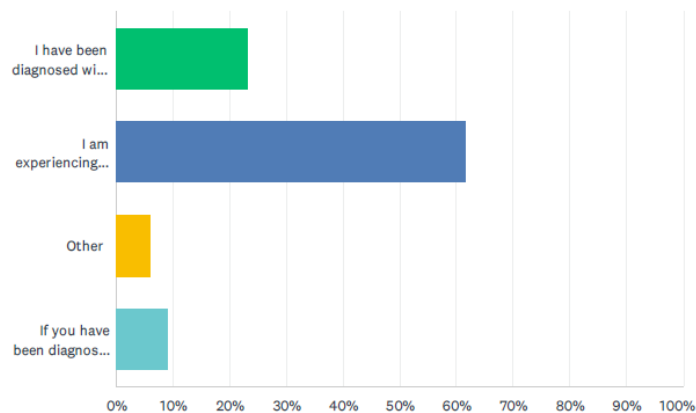


# Key findings

## Diagnosis of Long Covid

Q2 Not everyone who has Long Covid will have been diagnosed with either Covid-19 or Long Covid. We still want to hear from you either way. We want to know what it's like getting diagnosed and whether or not having a diagnosis makes a difference to your experience. Which of the following best describes you?

Answered: 99 Skipped: 2



Whilst 23% of respondents had been diagnosed with long Covid, the majority of respondents (62%) had not received a clinical diagnosis. The 9 respondents who shared further information about their experience stated:-

“Waiting for tests before being referred to long covid clinic. 14 weeks post covid. Lethargy out of breath. Not back at work as yet.”

“All test currently clear. Awaiting results of 24 hour heart monitor”

“I have mentioned it to the GP and they have given a 'query' long covid diagnosis from my history”

“I am suspected of having long covid and have been referred to a long covid clinic”

“Waiting to attend long covid clinic. Referred by doctors practice”

“I’ve felt like my symptoms have not been taken seriously, particularly as I had existing activity limiting conditions”

“There is no joined up approach I am currently under the care of neurology ,rheumatology, pain clinic and none of the appts are until Dec. Reactive not proactive service.”

“I have been referred to the long Covid clinic and have suspected long Covid by GP”

“saw GP and feels symptoms could be attributed to Long Covid but unsure if actually diagnosed”

## Symptoms and recovery

What are the main symptoms you have experienced or are still experiencing?

Please see table below for symptoms experienced by residents and the gravity of their symptoms. The key symptoms which affected residents significantly are: -

- Respiratory issues
- Fatigue
- Mobility issues
- Brain fog
- Anxiety/mental health issues

	NEVER EXPERIENCED/GOT BETTER WITHIN 12 WEEKS	MILD - DID NOT STOP ME DOING ANYTHING	MODERATE - MADE IT DIFFICULT TO DO SOMETHING	SEVERE - MADE IT DIFFICULT OR IMPOSSIBLE TO DO SOMETHING
Shortness of breath & other respiratory difficulties e.g. cough	21.28% 20	13.83% 13	41.49% 39	23.40% 22
Fatigue	8.42% 8	9.47% 9	47.37% 45	34.74% 33
Loss of smell, taste, appetite	38.78% 38	19.39% 19	23.47% 23	18.37% 18
Mobility issues, muscle pain & loss of stamina	8.42% 8	17.89% 17	32.63% 31	41.05% 39
Memory issues or brain fog	13.40% 13	18.56% 18	44.33% 43	23.71% 23
Anxiety and other mental health issues	20.62% 20	30.93% 30	31.96% 31	16.49% 16
Headache	21.28% 20	30.85% 29	25.53% 24	22.34% 21
Fever	51.09% 47	25.00% 23	19.57% 18	4.35% 4
Rashes or other skin related symptoms	67.03% 61	20.88% 19	7.69% 7	4.40% 4

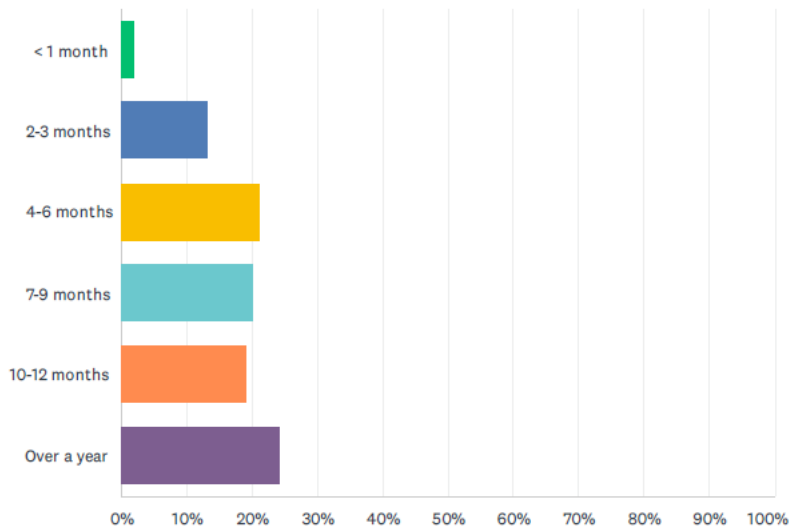
Respondents were also asked to provide any symptoms not listed in a free text box. The following were mentioned several times separately, in a follow-up qualitative answer:

- Tinnitus
- Pins and needles
- Nausea and vertigo
- Hair loss
- Insomnia
- Chest pains
- Reduced eyesight
- Ear pain and loss of hearing
- Vaginal bleeding
- Weight loss

## Recovery over time and Management of Symptoms

Q5 How long have you been experiencing these symptoms?

Answered: 99 Skipped: 2

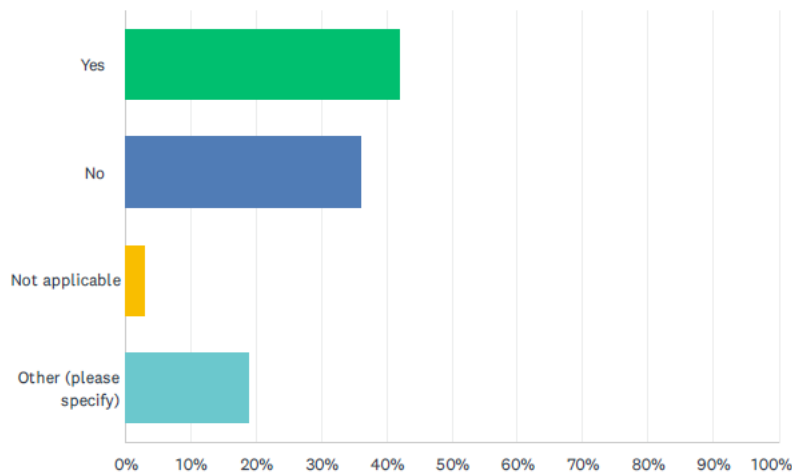


Just over a third of respondents had experienced their symptoms for up to 6 months, 40% between 6 and 12 months and 24% had experience symptoms of long Covid for over a year.

96% of respondents were still experiencing these symptoms at the time of response to the questionnaire.

Q6 Do you feel able to manage your conditions through self care?

Answered: 100 Skipped: 1



Whilst 42% of respondents felt that they were able to manage their symptoms through self-care, 36% felt that they were unable to do so. The 19% of respondents who ticked “other” gave the following feedback: -



“Yes for some symptoms; no for others like vertigo”

“Have to because nothing gets done. Still having CT scans and it is being looked into. But still no diagnosis?”

“Some yes but having therapy for PTSD after being in ICU with Covid.”

“At times, it was extremely difficult but with family support, I have gotten through this stage”

“Mainly, but not always”

“There’s not really anything i can do to get my smell back”

“Not sure as yet, doesn’t feel right, proper diagnosis required.”

“Some days are better than others. Have tried to get some recognition from doctors but getting nowhere”

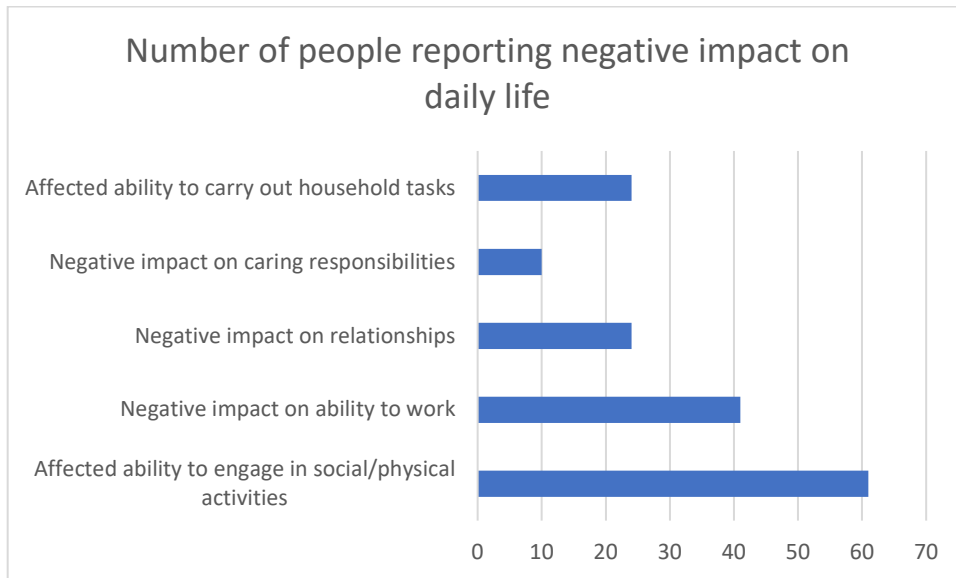
“I have to manage through self care, no help is available from my doctor.”

“Not sure but don’t want to bother doctor as so many are in a worse position than me”



## Wider Impact of Long Covid on Residents' Life and Wellbeing

In the survey, we asked people whether living with Long Covid had impacted on their daily life e.g., quality of life, ability to work, wellbeing, relationships, and caring responsibilities. 93 people responded to state that it had with 8 skipping the question. The responses have been grouped in themes as shown in the table below.



Please find below some of the feedback received against each of these themes from respondents to the survey: -

### Ability to carry out household tasks



“Unable to perform most housework. I can’t manage stairs and break tasks down into smaller parts e.g., making food over several hours”

“I get tired a lot more and physically drained which makes it quite difficult to do some day to day things”

“Can’t do household chores or make a meal for myself”

“Household jobs not getting done, this frustrates my partner so affecting our relationship”

“Housework is having to get left, I have to ask for help with day-to-day chores around the house. I’m too tired to cook properly most days so I’m relying on pre-prepared food I can just assemble, rather than eating quality home cooked food”.



### Impact on caring responsibilities



“As a single parent, falling asleep and the fatigue has had the biggest impact on our lives”.

“No energy for parenting”

“It has impacted my family life and ability to be the parent I want to be”

“I’m unable to do basic tasks and take care of my son”

“I cannot look after my young children alone for any period of time”

“I’ve gone from being an active person capable of caring for myself and my family to someone who needs care”

## Impact on relationships

“My relationships with family are extremely tense because I’m always tired or enduring minor illness”

“Hard to sustain relationship with the man I am dating as I haven’t the energy to go out”

“Friends who you thought were your friends are no longer my friends. Family don’t see you as you anymore”

“Relationships are strained, and I feel myself withdrawing from society”

“I have lost my partner, my job and soon my home. My teenage daughter has become my carer”

“8-year relationship broke down”

“Depending on my wife a lot, lost confidence to do things on my own”

“Family did not understand”

## Ability to Work

“I have not been able to work since December 2021” (feedback 26/3/2022)

“I have just been taken off ESA benefit as I have been deemed capable of work. I want to work for myself part time then build up more hours. I need a bit of financial support to do this though”

“Unable to work for 3 months”

“I am unable to work”

“I work for the NHS but no one recognised long Covid and the effect that it can have on you so I just have to get on with it”

“Work wise my brain fog and fatigue impact my ability to retain and process information. I have to check emails so many times before I send them. It has been very difficult to get out of bed in the morning”

“I haven’t worked for 9 months”

“I had to quit my job as I physically couldn’t manage anymore”

“Brain fog cos me two jobs”

“I am a registered mental health nurse who is finding it incredibly difficult to practice consistently due to ongoing fatigue and exacerbated issues”

“It has destroyed my career, my social life and my faith in human beings. I am in poverty and have lost my independence. I have felt gaslighted by the long Covid clinic who refused to do tests and are treating it as psychological. I have a science degree and know my body.”

“I was off work for 10 weeks but probably should have been more, but work didn’t understand”

“Couldn’t hold down my previous job, returned to a local employer and less skilled work to just keep myself in employment.”

“Even though I work for the NHS, long Covid is not accepted and still goes on my sickness record, and I have been put on Stage 1 so I do my best not to take time off for Covid”

## Ability to Engage in Social/Physical Activities



“Pre Covid I was running about 100 miles a week and cant run at all now due to breathlessness”

“Absolutely no energy, used to enjoy walking, now find it a trial”

“Little enjoyment or joy in life”

“Made me anti social, too tired to do anything”

“I have gained lots of weight because I can’t exercise the way I used to. I avoid certain social situations”

“I feel miserable!”

“It has affected my life, I was once a healthy 21 year old but I do find it difficult to do things I used to. I just want to feel normal again”

“Fatigue takes a toll on normal everyday life”

“I work and sleep with little energy to live life and it’s really frustrating”

“By the end of the week I’m absolutely shattered and takes the entirety of the weekend to recover”

“Constantly tired and feel weary. Constantly short of breath. Working but exhausted and going straight to bed at 7pm”



## Impact of Long Covid on Residents' Mental Health

Q12 Has long Covid had an impact on your mental health? If yes, please tell us more about the impact this has had on your life.

78 respondents to the survey (77%) stated that long Covid had negatively impacted on their mental health. Anxiety, depression and general low mood were the most common symptoms reported out of these replies. 42% reported suffering from anxiety and stress, 32% reported suffering from low mood, 21% were experiencing depression because of long Covid and 5% reported more severe mental health issues including self-harm and PTSD.

“Yes, I feel extremely depressed because I am unable to do what I used to do. Can't mix with people anymore. It's a very lonely illness”.

“It's left me weepy and lethargic a lot of the time. A lot of the symptoms imitate anxiety which is difficult to deal with”.

“Anxiety and depression, social phobias, paranoid”

“I have been diagnosed with PTSD from being in ICU with Covid.”

“I am a different person from pre Covid and it is difficult to cope with having counselling through my workplace.

“Self-harming has increased.”

Mental health is an important aspect of Long Covid. Anxiety especially appears to be not just a consequence of lost function or quality of life but also a symptom of the illness. Damaged livelihoods make it even more difficult for people to remain mentally healthy.

“I intended to work until I'm 70. I don't feel that I am able to do that now.”

“The lack of not knowing what is going on is stressful.”

“Anxiety type symptoms are debilitating at times.”

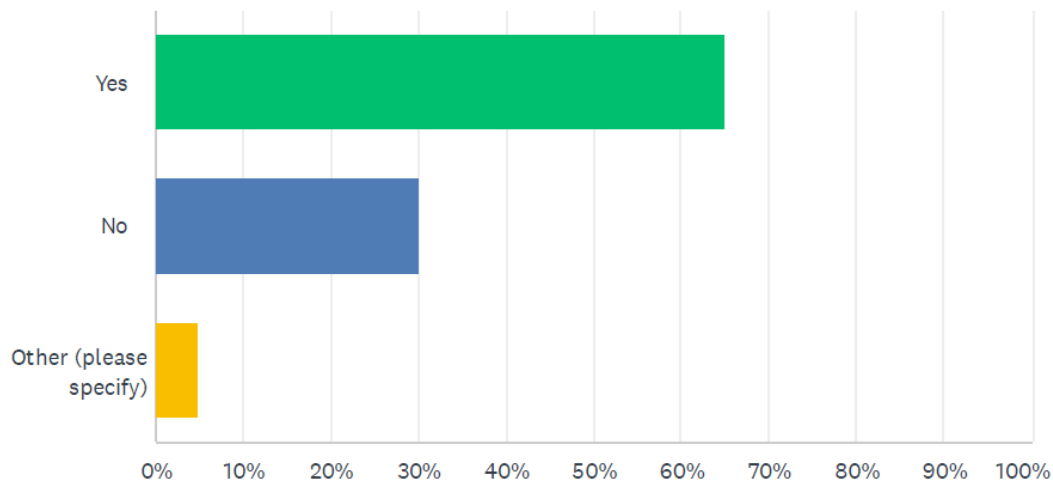
“There's a real sense of frustration at the things you can't do anymore.”



## Access to Clinical and Community Support for Long Covid

### Q7 Have you sought clinical help for long Covid symptoms?

Answered: 100 Skipped: 1



65% of respondents had not sought clinical help for their long Covid symptoms. The five respondents who ticked “other” responded: -

“I have an appointment with the GP in 2 weeks”

“Can’t get to see my gp”

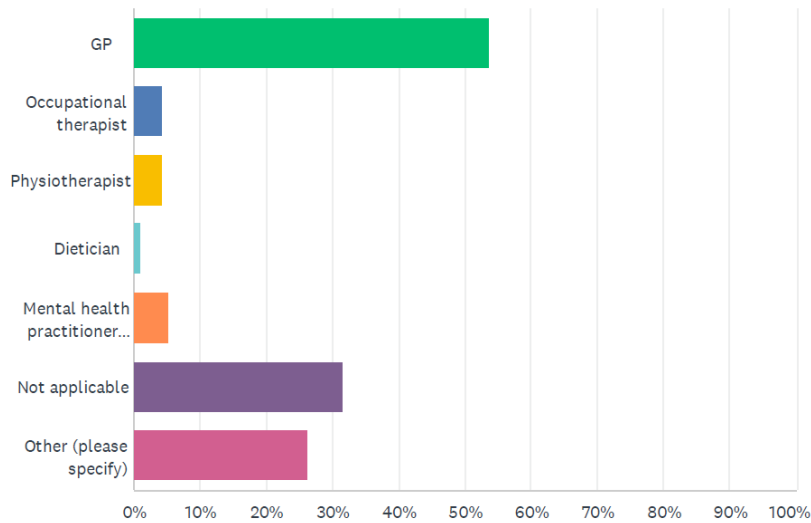
“Currently having more tests, already had an electrical activity response test via GP which showed delays that were not there previously”

“Tried but just get told nothing can be done”

“I had a viral infection 9 years ago now diagnosed with ME/CFS”

## Q8 If yes, who are you currently receiving support from?

Answered: 95 Skipped: 6



Most respondents (54%) had sought support from their GP, with low numbers of people accessing support from other health professionals despite experiencing a wide range of symptoms. The 25 respondents who ticked “other” gave the following responses: -

“No help, cannot get an appointment” - 7 respondents

“Thoracic consultant - 3 respondents

“Cardiologist” - 2 respondents

“Ears, nose and throat department”

“GP has just prescribed pain killers and a link to long covid, I don't feel this is enough support”

“Not been diagnosed but ongoing investigations still suggest symptoms are from having had Covid”

“Waiting for long covid clinic referral”

“Long Covid Clinic”

“Neurologist”

“Family and friends”

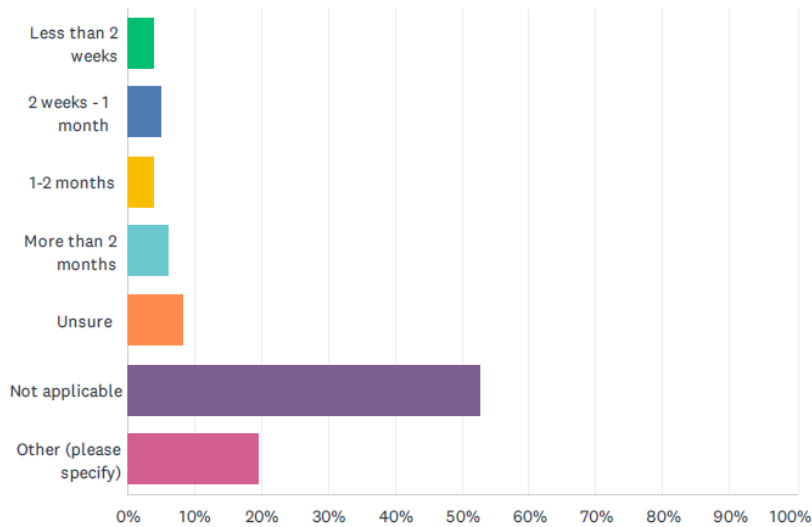
“Self-research”

“Even though GP knows all my symptoms they have not diagnosed long covid or offered support”

“Being monitored by line manager & had previously been seeing occupational health & my GP”  
“Obtaining support for anything at the current time is incredibly frustrating and difficult so currently suffering in silence”

### Q9 If you have been diagnosed with Long Covid, how long have you had to wait before receiving support, after your first referral?

Answered: 97 Skipped: 4



The majority of respondents (53% had not received a clinical diagnosis of Long Covid, however for those who had, the referral times for support ranged between less than 2 weeks to more than 2 months. The 19 respondents who ticked “other” reported:-

“Not been officially diagnosed” - 10 respondents

“No support” - 4 respondents

“GP didn’t think there was a long Covid service”

“My GP had to refer me twice to long covid clinic as they refused referral first time”

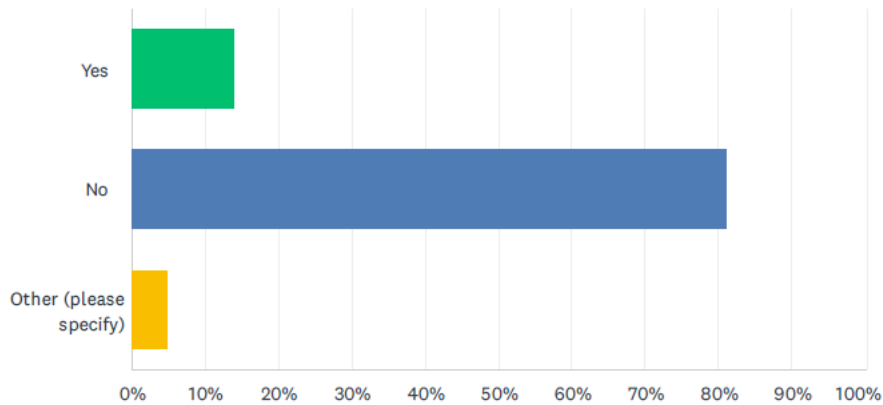
“Diagnosed with PTSD from Covid no support” group for that”

“Would not go to a gp now they are useless”

“saw GP last week -explained not much extra support to be offered at present as most of my symptoms are non-respiratory”

### Q10 Have you sought support from other wellbeing services in the community for long Covid?

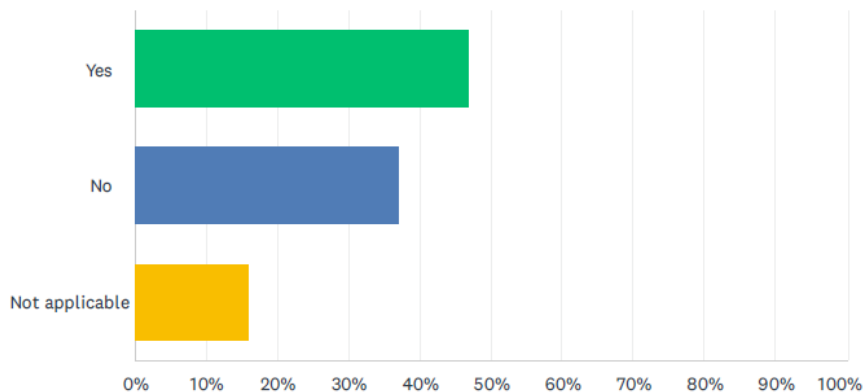
Answered: 100 Skipped: 1



Most respondents (81%) had not accessed support from other wellbeing services in the community for their long Covid symptoms. The 5 respondents who ticked “other” stated:-  
“Have had chest x-ray and blood tests”  
“Self-research”  
“Chinese medicine, ayurvedic medicine - etc”  
“Long covid clinic - on an extremely long waiting list”  
“Not yet but want to be referred to a Long Covid clinic if possible.”

### Q13 Have you spoken to your employer about your experiences of long Covid?

Answered: 100 Skipped: 1



Although almost half of respondents (47%) stated that they had spoken to their employer about their experiences of long Covid, a large number stated that they had not (37%). Most respondents who ticked “not applicable” stated that they were either retired or self-employed, however other comments included: -

“I had to leave my employment due to severe workplace stress.”

“No point as wouldn’t be recognised. Had a sickness meeting because i had been off on 3 occasions even though Long Covid related.”

“If you do probably get sack”

“I did when I returned but it was dismissed”

## Q14 How would you rate the support you have received from the following

	VERY POOR	POOR	AVERAGE/OK	GOOD	EXCELLENT	N/A	TOTAL
GP/community nurse	7.14% 7	19.39% 19	26.53% 26	14.29% 14	11.22% 11	21.43% 21	98
Occupational therapist	2.20% 2	6.59% 6	6.59% 6	3.30% 3	1.10% 1	80.22% 73	91
Physiotherapist	4.30% 4	4.30% 4	0.00% 0	3.23% 3	2.15% 2	86.02% 80	93
Dietician	2.17% 2	3.26% 3	1.09% 1	0.00% 0	0.00% 0	93.48% 86	92
Mental health practitioner/psychologist	3.23% 3	5.38% 5	0.00% 0	3.23% 3	2.15% 2	86.02% 80	93
Other community wellbeing service	6.38% 6	3.19% 3	3.19% 3	5.32% 5	3.19% 3	78.72% 74	94
Employer	12.50% 12	7.29% 7	19.79% 19	19.79% 19	7.29% 7	33.33% 32	96

The responses detailed in the table above reflect the lack of access to other sources of support other than GP or employer by residents of Blackburn with Darwen experiencing long Covid. Whilst 52% of respondents rated support from their GP as ‘ok’ and above, 26% rated it as poor or very poor. Similarly, whilst 47% of respondents rated support from their employer as ‘ok’ and above, 20% rated it as poor or very poor.

“Long covid clinic consultant-very poor, ENT consultant-very good”

“This was my first attempt to get help when I then saw this survey.”

“Not told employer how unwell I am. They have not enquired.”

## What works - both now and ongoing support

### Q15 What would help you now and in the future?

The feedback from the 92 respondents to this survey question fell into four key themes: -

- Support from a dedicated Long Covid clinic (25%)
- More clinical support for conditions (17%)
- Multi-agency support around recovery including fitness, lifestyle, finance and employment (52%)
- Peer support (6%)

#### Feedback gained under each theme

##### Support from a dedicated Long Covid Clinic



“Hopefully after tests I’m waiting for, I will get a referral to long Covid clinic. Last GP didn’t suggest anything just told me I had long Covid”.

“Easily accessible local assistance. I suppose a specific long Covid GP line would majorly help”

“A dedicated long covid clinic that responded to my particular symptoms and up to date research”

“Access to an integrated Long Covid clinic that looks at all my symptoms rather than cherry picking one or two”

“Options to self-refer”



##### More clinical support for conditions



“I would like medical practioners to listen more and do more thorough tests and stop assuming that when they can’t find a cause that means it’s psychological”

“Support from my GP and other professionals”

“Better and faster support from the NHS”

“I want more help with explaining my symptoms and how they will progress”

“Services returning to pre-Covid operationally.”



##### Multi-agency support around recovery



“For government services and bills, for help there. Winter grants, finding a place where you can do something for yourself”

“More empathy, understanding and support”

“Help and support physically and emotionally. To know that I will get better and how to achieve that”

“More information and health support”

“More information on how to manage/get rid of the symptoms fully”

“Understanding by employer and recognition that some days I am so tired and out of breath”

“Looking at more flexible working opportunities and my own work life balance. Looking at support from personal trainer to get back to some form of exercise programme.”



### Peer support



“Speaking to other Covid survivors although I’m getting better from COVID, I don’t feel free from it, I’m not sure I ever will”

“Local peer support group, speaking to people with the same experiences.”

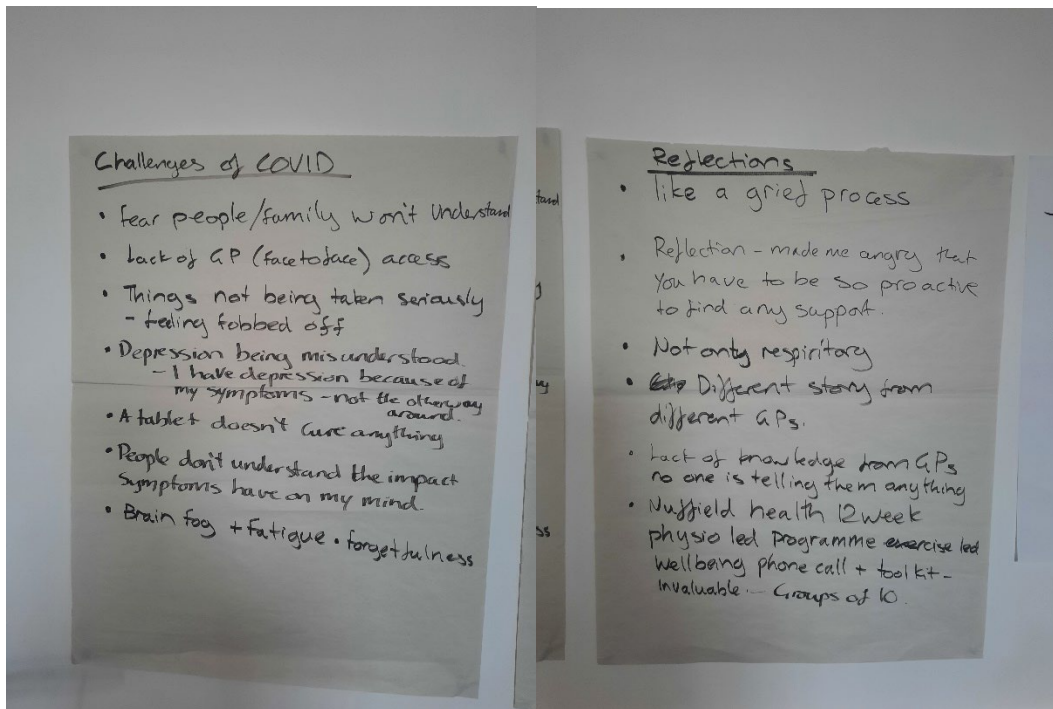
“Access to support groups to share stories and understanding on Long Covid symptoms and living with symptoms. Support/time off work to attend appointments connected with LC symptoms (either medical appointments or support group sessions)”

“A long Covid support group - to listen to other people’s experiences helps you to cope with yours and you don’t feel like you are just crazy. Sometimes just the realisation that the symptoms you have are experienced by others helps you to cope with it all.”



## Feedback from Blackburn with Darwen Council's Long Covid Peer Support Group

Please see feedback below from a summing up session held at Blackburn with Darwen Council's peer support group sessions for residents living with long Covid. The feedback reflects that received from residents to our survey, highlighting the impact on all aspects of people's lives and the perceived lack of help from services to manage symptoms and need for improved multi-agency working to support people with long Covid.





Disagree they don't say it - No one seems to understand it unless they have experienced NOT Much help.

Think there is more people struggling than we know about.

No there isn't. People don't want to talk about it, its like it does what it does.

Financial support - where/how access/ is it enough?

You have to hunt hard for the support.

LC Clinic is too slow & under resourced. Medical support is limited.

Employee support. There are some horror stories about the way employees are being treated.

**EVERYONE IS CLOCKED ON ABOUT LONG COVID. THERE IS SO MUCH HELP AROUND**

Long Hauler Pain Diaries

Definitely NOT!!! from my experience with employers 😞. On the other hand Long Haulers, support groups are our hope to validation.

More education needed of long term effects.

GPs listen but don't have answers. Issuing sick notes is easy but doesn't solve the issue....

Very little help unless symptoms have a vent plan, but even then things which can't be medicated.

No help around apart from this group. More listening needed from GPs/clinical commissioners.

People may not be aware of what's out there, severity of symptoms.

I wish a sense of validation from the NHS to support the NHS workers who have to be the ones to support the people who are suffering. Please let's be real, we need more resources and support for the NHS workers who are suffering.

Support needed for families of those suffering too. They can only understand & support so much.

When tests come back clear, we doubt ourselves more.

We start to convince ourselves of this too! It isn't!!!

**LONG COVID IS ALL IN THE MIND**

I wish!! 😞

Peer support is essential to share the case.

Unfortunately as there is no definitive tests it is difficult to prove so many people may believe this.

**NO IS NOT! But you feel like this as most G.P.S offer no support**

No suitable job! No support every day. Daily and mind.

No, but concerns that healthcare providers can jump to Long Covid diagnosis without exploring other possibilities.

It's not!!!

Exercise is the one thing that has made the biggest difference to my recovery.

Lots of scare stories about exercise & why not to - need clear guidance.

[can't do it at the moment] [long]

Slow & gentle.

# EXERCISE IS A TOXIC TERM FOR SOMEONE SUFFERING FROM LONG COVID

It may be initially but with right support exercise may be beneficial

For some people, but not all, there will be some support available or advice at all.

Disagree  
↓  
We can move in any way we can sitting, lying down, meditation

Yes!  
More informed support needed.  
More covid trained physio/PTs.

would be beneficial if support and exercise was available.

## Case Studies

Please find below two case studies gathered from members of the Long Covid Peer Support group about their experiences of long Covid and support for their symptoms.

### **Mum aged 46, White British**

Was told by GP that had long Covid but that they couldn't really do anything for me. I was really ill for 3-4 weeks and still have symptoms 10 months later. These include coughing every day, headaches, joint pains and serious lethargy. I've had anxiety because of the illness and experienced periods of low mood.

It's impacted on my home life and my ability to care for my children and mother in the way I was able to before having long Covid.

My direct managers have been good at work, but it feels like long Covid doesn't really fit with normal HR processes for dealing with sickness absence. I have periods of being ok but then I might be completely floored for 2-3 days and have to take time off. When I'm asked "how can we help you" I really don't know what to say because there is literally nothing they can do.

I've not been able to access other support because of being busy other than coming to this peer support group. I was referred to a respiratory clinic but didn't really need that support and I'm not really sure what people could help me with.

What would help me now and, in the future, would be better awareness within the community of the symptoms of long Covid and its impact on your ability to function at work and at home and for there to be greater flexibility for people on their journey back to health.

### **Nurse aged 60, White British**

I've been ill now for 19 months so was in the first wave of people to contract Covid. I've been very much on my own for all this time and it's been hard to deal with - I've literally been in "trudge mode" for this length of time. People are really only now starting to listen to us about the impact of long Covid on our lives. I get emotional and weepy easily because of the social isolation I've experienced in this time and am now on the waiting list for MindsMatters which is 16 weeks I think.

I've experienced a significant number of symptoms and several of these are ongoing. The GP didn't really understand it when I first contracted Covid and told me "it's just like flu" and that I might have asthma. After 10 weeks I had to call back to say this isn't going away and I've got neither of those. It turned out that I had also got atypical pneumonia as well as Covid so was put on antibiotics for that.

At the start I had severe palpitations and my whole body used to shake - I was put on beta blockers for these but they gave me pins and needles so I had to ask the doctor to halve the dose which has helped.

I still have brain fog, my insomnia is really bad, I've got tinnitus and my eyesight has worsened significantly. I get the shakes which is the neurological impact and I'm waiting for counselling. I completely lost the ability to remember words or even count. I used to be able to do "killer" SuDoku but I struggled to do easy ones. I used to be able to go for hikes but I get tired walking quickly now.

The benefit of working for the NHS is that they have taken this seriously and I have been on full pay, I wouldn't have been able to cope otherwise because I've had to pay for some treatment like physio privately. I spoke to an occupational therapist but her caseload had been increased by about 250 patients and we agreed that she probably couldn't support me more than I was doing already.

I did get 12 weeks support from "Let's Live Life" which has helped and this peer support group has really helped me socialise again and realise I'm not on my own.

As a nurse, I'm really interested in the clinical studies around Covid and the studies going ahead in Germany around apheresis for viral eradication linked to Covid. I also took part in a study by Swansea University using PrO2 devices to improve respiration - this made a huge difference to me but sadly it was just a short term project.

More widely, I think it would benefit me and other long Covid sufferers to be taken seriously and listened to. I don't want what I've been through to have been in vain.

# Appendix - Full Survey



## Experiences of Long Covid and support

**Long Covid is defined as signs and symptoms that continue for more than 12 weeks and develop following an infection consistent with Covid 19. You may experience Long Covid even if you were not acutely ill in the first place. Common symptoms include breathlessness, brain fog and fatigue. Not everyone with Long Covid, particularly those who were ill early in the pandemic, will have been tested for Covid-19.**

**If you have been experiencing the symptoms of Long Covid (also known as Post-Covid Syndrome), then please share your experience by completing the survey.**

**Your feedback will help us to understand what support is needed for people living with Long Covid and will be used to produce a report to inform the relevant organisations of what you have been experiencing, and recommend how they can design services and support to better meet your needs.**

**If you have any questions about this survey or wish to give us more information about your situation, please contact us at [info@healthwatchbwd.co.uk](mailto:info@healthwatchbwd.co.uk).**

**Thank you for taking part in this survey.**

1. Did you have a disability or long term health condition before the Covid-19 pandemic? (We are asking this question to understand if this may have impacted on the Long Covid support that you received, or otherwise).

Yes - physical or mobility impairment

Yes - Sensory impairment

Yes - Long term condition

No

Yes - Learning disability or difficulties

Yes - Mental health condition

Prefer not to say

Other (please specify)

2. Not everyone who has Long Covid will have been diagnosed with either Covid-19 or Long Covid. We still want to hear from you either way. We want to know what it's like getting diagnosed and whether or not having a diagnosis makes a difference to your experience. Which of the following best describes you?

- I have been diagnosed with Long Covid
- I am experiencing/have previously experienced Long Covid symptoms but not yet been diagnosed  Other
- If you have been diagnosed with Long Covid, or waiting to be diagnosed, please tell us more about your experience.

3. Are you currently experiencing symptoms of Long Covid?

- Yes
- No

4. What are the main symptoms you have experienced or are still experiencing?

	Never experienced/got better within 12 weeks	Mild - did not stop me doing anything	Moderate - made it difficult to do something	Severe - made it difficult or impossible to do something
Shortness of breath & other respiratory difficulties e.g. cough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of smell, taste, appetite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility issues, muscle pain & loss <input type="radio"/> of stamina	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Memory issues or brain fog	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety and other mental health issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Headache	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Rashes or other skin related symptoms

Other (please specify)

5. How long have you been experiencing these symptoms?

< 1 month

2-3 months

4-6 months

7-9 months

10-12 months

Over a year

6. Do you feel able to manage your conditions through self care?

Yes

No

Not applicable

Other (please specify)

7. Have you sought clinical help for long Covid symptoms?

Yes

No

Other (please specify)

8. If yes, who are you currently receiving support from?

GP

Occupational therapist

Physiotherapist

Dietician

Mental health practitioner or psychologist

applicable

Other (please specify)

9. If you have been diagnosed with Long Covid, how long have you had to wait before receiving support, after your first referral?

Less than 2 weeks

2 weeks - 1 month

1-2 months

Other (please specify)

More than 2 months

Unsure

Not applicable





10. Have you sought support from other wellbeing services in the community for long Covid?

- Yes
- No
- Other (please specify)

11. Has living with Long Covid had an effect on your life? Tell us what it has been like and how it has effected you, your quality of life, relationships, wellbeing, your ability to work, complete caring and parental roles and anything else.

12. Has long Covid had an impact on your mental health? If yes please tell us more about the impact this has had on your life.

13. Have you spoken to your employer about your experiences of long Covid?

- Yes
- No
- Not applicable

14. How would you rate the support you have received from the following

	Very poor	Poor	Average/ok	Good	Excellent	N/A
GP/community nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physiotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dietician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental health practitioner/psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other community wellbeing service

Employer

Other (please specify)

15. What would help you now and in the future?

16. What is your age?

- |                                |                             |
|--------------------------------|-----------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 45-54 |
| <input type="radio"/> 18-24    | <input type="radio"/> 55-64 |
| <input type="radio"/> 25-34    | <input type="radio"/> 65+   |
| <input type="radio"/> 35-44    |                             |

17. What gender are you?

- Male (including trans male)
- Female (including trans female)
- Other
- Prefer not to say

18. What is your ethnicity?