



Experiences of Long Covid

Summary

Background:

Many people who had been ill with Covid-19 have been experiencing long-term effects and symptoms that have affected many aspects of their life. This is called Long Covid or Post-Covid Syndrome. We wanted to understand what support is needed for people living with this condition or the long-term effects of another virus to inform decision makers about what people are experiencing and what further help may need to be put in place.

What we did:

We launched an online survey to find out from people about their experiences with signs and symptoms lasting more than 12 weeks after an infection from a virus. Questions included in the survey covered topics such as the length, type, and strength of symptoms, as well as how they changed over time, how the symptoms affected people's day-to-day life, as well as their mental health and wellbeing. We also asked respondents about the process of getting diagnosed and the support that was provided to them. The survey was open from 22nd of July 2021 to 15th September 2021 and we received a total of 50 responses.

What we were told and recommendations:



For all conclusions and recommendations, see the final chapter of our report. In summary we found a need for the following.

- Increased knowledge and awareness of long-term symptoms after COVID-19, amongst patients and health and care staff, as well as carers and the wider community.
- Development to support should include peer support, more support for managing symptoms and more treatment options.
- Provision of support/referrals should be available if COVID-19 status is not confirmed but based on the symptoms that need support. This may also reduce delays in access to support.
- The uncertainty about how long the symptoms will last and fluctuations in severity, as well as the negative impact of symptoms on a wide range of daily activities and mental health, suggests a need for more holistic support. Nearly three quarters of people said there had been an impact on their emotional wellbeing or mental health.

Thank you to everyone who shared their experience with us and thank you to all staff and volunteers involved in this research and writing this report.

Background

As the COVID-19 pandemic evolved, it became clear that many people who had recovered from COVID-19 were experiencing long term effects and symptoms that they needed to manage. This has sometimes been called 'Long Covid' or 'Post-Covid' Syndrome. Knowledge about this has slowly been developing, but we felt that local services needed to know about the experience of local people to help them understand what support may need to be put in place.

We asked local people who had signs and symptoms lasting more than 12 weeks after an infection from a virus in the last year to tell us about their experiences. As COVID-19 may not have been diagnosed in all possible cases due to limitations on testing and diagnosis throughout the pandemic, particularly early on in the pandemic, we were interested to hear from people about their experiences around anything they understood to be a virus. People may not have been very ill from the virus itself but have experienced symptoms afterwards.

We aimed to understand what support is needed for people living with Long Covid and the long-term effects of a virus to inform decision makers about people's experiences and to recommend how they can design services and support to better meet people's needs.

What we did

Our Consultation Survey

We created an online survey and launched it on the 22nd of July 2021. We aimed our survey questions to be as similar as possible to those used by other South-West London Healthwatches who also launched surveys at the same time. We hope to compare results after the publication of this report.

We advertised the survey via local press and circulation lists, voluntary sector organisations and patients of the Post COVID-19 Assessment Service at St George's Hospital. The South-West London NHS Clinical Commissioning Group (CCG) advertised it on their Long Covid support page as well. We also advertised the survey to staff at St George's Hospital and Wandsworth Council. We closed the survey on the 15th of September 2021.

Who was involved

We received a total of 50 responses to our survey. Almost all respondents (48 of 50) completed the survey for themselves. The other 2 respondents completed the survey on behalf of their child and partner.

Almost all respondents had some experience of COVID-19. Half of our respondents reported that they were experiencing symptoms like Long Covid but had not been diagnosed with it (25 people), and almost half (24 people) had had COVID-19 confirmed with a test. Over a third of respondents (16 of 50) said that they had COVID-19, but not confirmed with a test. This is an interesting response. There may have been external factors to lack of diagnosis, for example, COVID-19 tests like the at-home rapid lateral flow tests were not available during the start of the pandemic. We are aware that people may have had similar experiences and symptoms from other viral infections, and we were keen to hear their story as well, however only 3 people said they had another virus that was causing the symptoms, including 1 respondent who said they had bronchitis.

From this survey, other health conditions did not seem to be a factor in the Long Covid experiences of our respondents. When asked about what other health conditions people currently have other than the Long-Covid type symptoms:

- 14 of the 34 people who responded to this question said they had no other health conditions

- A further 6 people described symptoms similar to Long Covid (tiredness, muscle ache, inability to concentrate), so it is difficult to establish if these people had these symptoms in addition to Long Covid.

Many of the 14 people who did report other health conditions described more than one health condition. Most mentioned were conditions widely known to put people at a higher risk of experiencing worse outcomes from COVID-19:

- 6 mentioned asthma
- 4 mentioned cardiovascular conditions (including hypertension)
- 3 mentioned diabetes and
- 1 person listed obesity.
- Other health conditions mentioned were; breast cancer (1), bowel disease (1), migraine (1), thyroidism (1), depression (2), peripheral neuropathy (2), sleep apnoea (1), and endometriosis (1).

We also asked our respondents if they have a disability or long-term health condition. When answering this question:

- Almost two-third of respondents (34 of 47) said ‘No’
- 6 people said they had a long-term health condition
- 1 had physical or mobility impairment
- 1 had a mental health condition
- 6 people said they had a condition not listed in our survey, which included Type 2 diabetes (1), Lipo/Lymphoedema (1), Asthma (1), Insomnia (1) and Thyroidism (1)
- 2 people were unsure if they have a long-term condition or disability.

The majority of our respondents were women (35 out of 47; 3 people skipped our questions about their gender identity), and the rest identified as men (12 people).

Of the 47 people that indicated their age:

- Nearly half (23 of 47) were aged between 25 and 49 years old
- Just over a third (15) were between 50 and 64 years old
- 8 people were aged 65 -79 years old
- Only 1 respondent was aged 18 -24 years old
- We did not have any respondents who were less than 18 years old or 80 years old or more.

Most of our respondents (36 people) who answered our questions about their ethnicity (47 in total) described their ethnicity as White, out of which 26 described it as White British. Less than third of our respondents had other ethnic backgrounds, including Arab, Asian/Asian British, Black/Black British, and mixed/multiple ethnic backgrounds. You can see the full breakdown of ethnicities described in the table below.

White: British	26	Arab	1	Black / Black British: African	0
White: European	4	Asian / Asian British: Bangladeshi	1	Black / Black British: Caribbean	2

White: Gypsy, Traveller or Irish Traveller	0	Asian / Asian British: Chinese	1	Any other Black / Black British background	0
White: Irish	1	Asian / Asian British: Indian	0	Any other mixed / multiple ethnic backgrounds	2
White: Roma	0	Asian / Asian British: Pakistani	0	Prefer not to say	1
Any other white background	5	Any other Asian / Asian British background	1	Other (please specify): Filipino	2

Our respondents were a self-selected sample of people, reflecting those who heard about and chose to answer the survey online. Due to time constraints and working to a timeline so that we could collect responses in line with other South West London Healthwatches to feed in to plans of local services, we could not expand our work to collect more views. However, we did offer opportunities to people to get in touch if they wanted to take part or share their views in a different way. Nevertheless, these results show less diversity in our respondent sample than we would have liked.

Lastly, 42 of 50 respondents live in Wandsworth. 8 respondents were residents from neighbouring boroughs of Wandsworth (namely, Merton, Richmond, Kingston, Croydon, and Sutton), however we decided to include their responses in this report as they may have accessed health and/or social care services in Wandsworth.

Findings

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Symptoms

We start our findings by showcasing the range of Long-Covid related symptoms that our respondents have faced, the extent to which they were experienced and how they may have changed over time.

Length, type and strength of symptoms

- The vast majority of respondents (42 out of 50) experienced Long Covid symptoms for more than 6 months
- Nearly half (22 out of 50) said they had had symptoms for more than a year.
- Almost all respondents were still experiencing Long Covid symptoms when they completed the survey
- Only 4 of the respondents reported that they no longer have symptoms (and 8 people were unsure).

We asked our respondents to rate a list of symptoms commonly associated with Post-Covid and Long Covid to understand whether they have experienced them and if so, to what extent. They chose from a

scale of 1 (Never experienced it) to 5 (Severe - made it difficult or impossible to do somethings). We received a total of 50 responses to this question.

- **Fatigue:** Almost everyone (46 people, 92%) reported to have been dealing with fatigue to a varying extent, even 12 weeks after their infection. This was the most severely and most often experienced symptom, and 15 people said it made it difficult or impossible to do some things. Multiple respondents explained that they got tired quickly or had to spend long periods in bed.

“I’ve had some periods of having to stay in bed for 3 days without any apparent cause - just complete exhaustion...”

“Very active in the morning, exhausted by 12.00, need to sleep. takes a couple of days to recover properly...”

- **Breathlessness and other respiratory difficulties** were the second most severely felt symptoms by our respondents, with 10 saying it made doing certain things difficult or impossible. One person mentioned having difficulties with doing everyday tasks due to breathlessness.

Other frequently reported Long-Covid symptoms included:

- **Problems with memory and concentration** (“brain fog”) (44 people, 88% after 12 weeks)

“I’m still finding that there are occasions when I can’t find the words that I want to use”

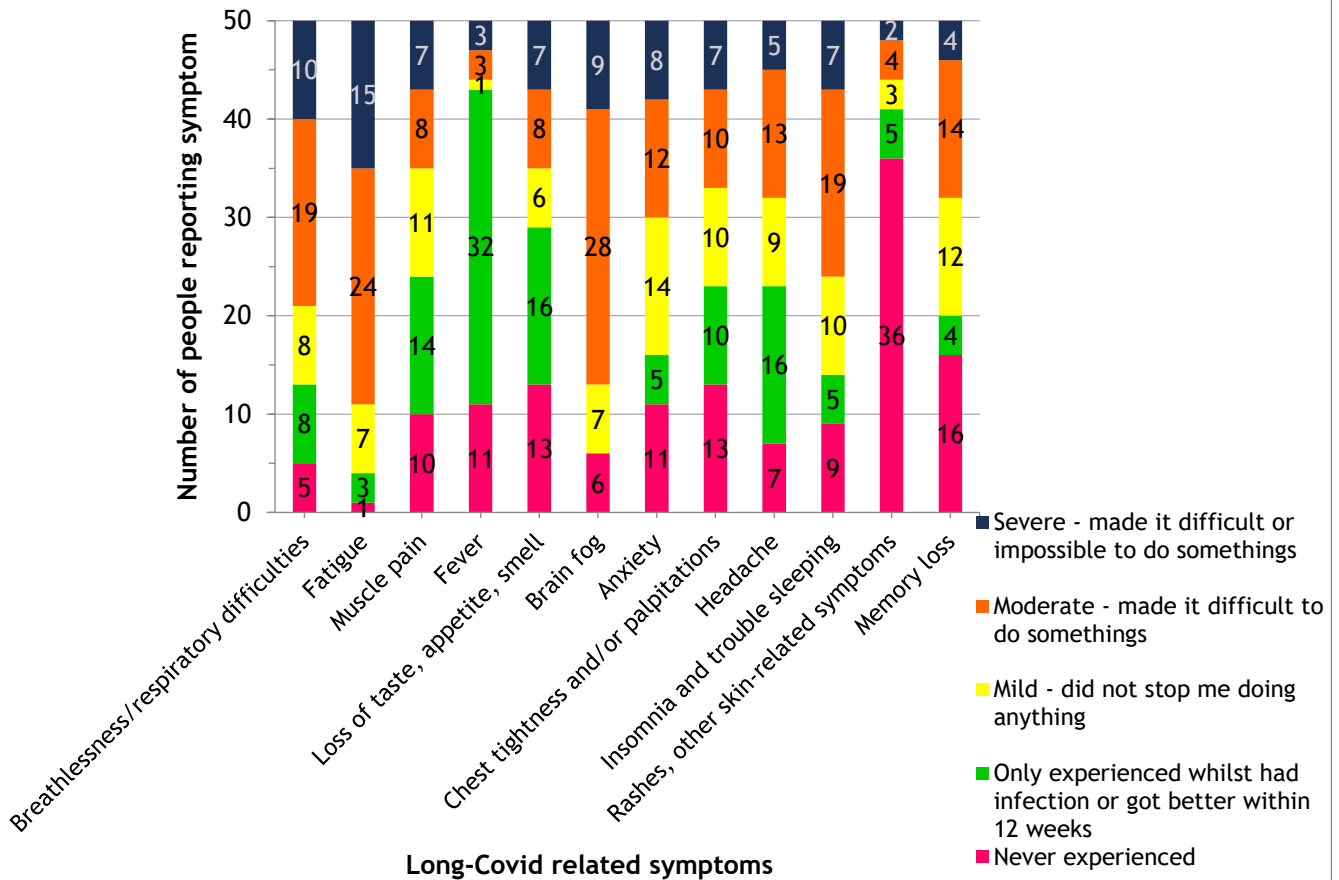
- **Insomnia** (36 people, 72% after 12 weeks)
- **Anxiety** (34 people, 68% after 12 weeks) was the most often reported symptom as mild or moderate.

“Anxiety and panic attacks never experienced before Covid”

- On the other hand, **rashes and other skin conditions were experienced the least**, with 41 people (82%) stating that they either have not experienced them, they only had the symptoms while ill with COVID-19, or that their symptoms got better within 12 weeks.

When asked about other symptoms they had been experiencing, 3 people listed having bouts of **tinnitus** and/or **dizzy spells** and **vertigo attacks** since their infection. **Chronic pain** in the limbs, joints and parts of the face was also reported by a few people, as well as **hair loss**, **sore throat**, **blocked nose**, **sinus pain**, **hearing loss** and **stomach problems**.

What are the main symptoms that you have been experiencing?



Changes to symptoms

All our respondents, 50 people, reflected on how their Long Covid symptoms have changed since they started experiencing them. Overall, the majority of the symptoms we listed were reported to have been improving over time, however sadly many told us that they have experienced no change in their Long-Covid related issues or that their symptoms have been worsening or fluctuating since they first experienced them.

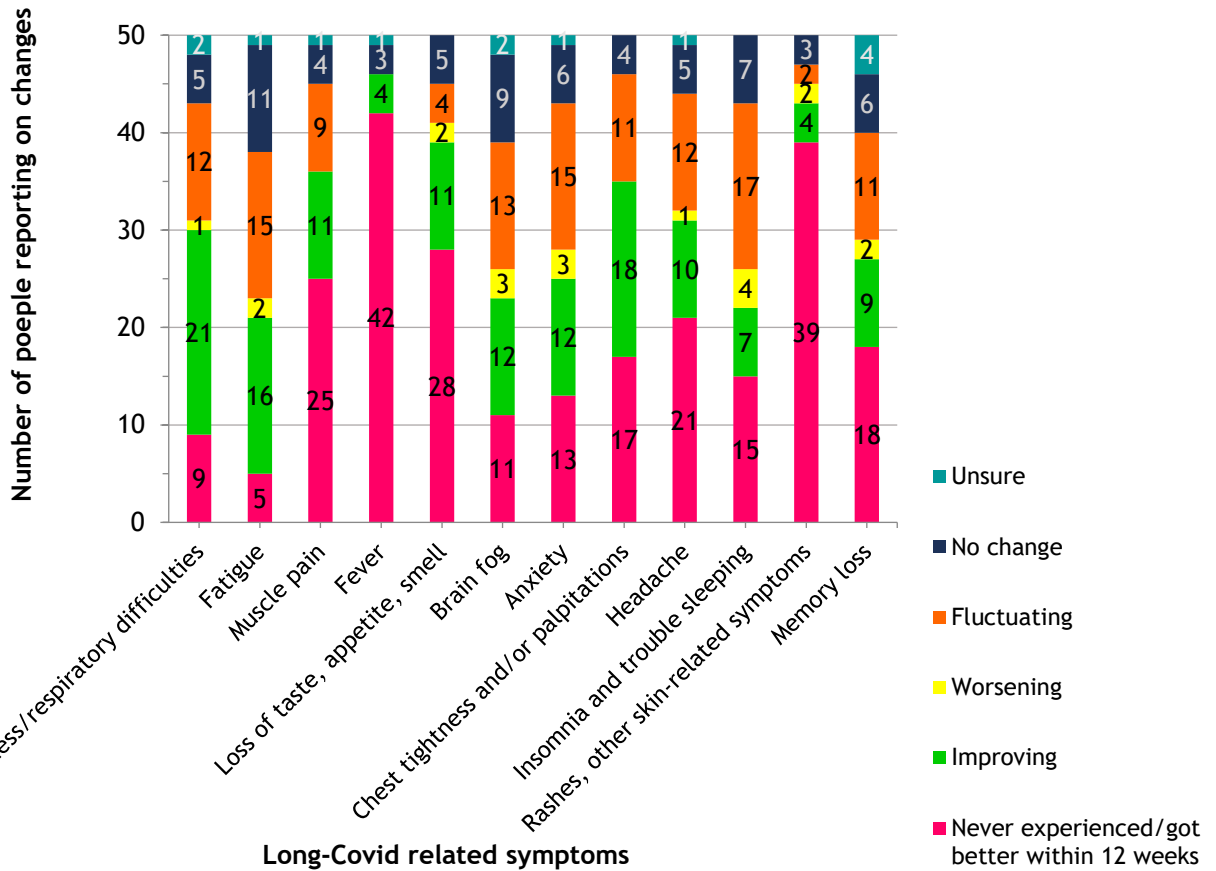
Over half of our respondents were still experiencing:

- Fatigue (28 people)
- Brain fog (25 people)
- Insomnia and/or trouble sleeping (28 people)
- Anxiety (24 people)

They either noticed no change, experienced fluctuations in the above four symptoms or their symptoms worsened.

One respondent commented that they found that skin issues worsened. Another said “The symptoms were not noticeable immediately after having Covid, but started getting worse and worse in the months after having it.” One respondent, who had a range of symptoms, found that becoming pregnant had made her symptoms worse.

How have your symptoms changed since you started experiencing them?



The impact of the symptoms

We invited our respondents to reflect on how Long Covid has affected their lives, and what aspects of the condition they have found particularly difficult to deal with.

It was evident that maintaining quality of life and managing day by day had been, or still is, a real challenge.

For example, one respondent, who was never hospitalised but had suffered several Covid symptoms, had been “very healthy” before the pandemic in contrast to life now.

The below quote demonstrates just how widespread the negative effects of this condition are:

“To start - felt a massive pressure in the back of my head, ..., hearing felt like I had water in them and dizzy. This was in both ears.

A month later, hearing loss in my right ear that fluctuates, headaches and tinnitus & dizzy.

Few weeks after that, vertigo attacks started (felt like [labyrinthitis] sensations). The attacks would have me not working for 1-2 days. I couldn’t go in to work as the attacks would strike randomly.

The tinnitus was so loud.

This all really upset me and no one to help. I got very depressed and cried all the time.

Fast forward a few months. I got pregnant, symptoms got even worse.

It's really effected my job. Out of all the symptoms the vertigo is the worst. As it's unpredictable & dangerous.

My employer doesn't understand & has no compassion. I couldn't do my job and tried.

Also no healthcare professional can help or knows what to do. I feel so unsupported by my NHS doctor - again they have no idea who to help.

It's so depressing.

So this is why I have started looking at alternative medicine”

Changes to symptoms

Respondents had tried to resume normal life, going back to work, and hoped to pick up their social lives but they highlighted how the symptoms had lingered. **Improvements, if they happened, could take a long time.**

For some, a very frustrating aspect seemed to be how, over time, the **severity of symptoms fluctuated** so that almost from one day to the next, or even from one activity to another, individuals could not tell how they would be feeling and could not plan what they could do, e.g.:

“I would be fine going for a cycle, but then be really out of breath walking up a flight of stairs.....sometimes I would be sitting stationary and feel breathless.”

“It took a year before I was slowly able to be more active. But still each time I think I am better and try to live more normally, I relapse and can be out of action for days.”

“Never know from one day to the next how much energy I will have.”

The most difficult symptom to manage

Respondents told us what the most difficult symptom has been to manage. Particular symptoms referred to by those who answered this question were:

- **Breathlessness or a tight chest** (11 respondents)
- **On-going memory loss or brain fog** (10)
- **On-going fatigue** (9)
- **Inability to join in general activity** (4)
- **On-going sleep problems** (3).

Other symptoms mentioned were **dizziness, anxiety, hearing problems, skin issues, loss of sense of smell and taste**. Individuals could be experiencing several symptoms.

Symptoms such as **fatigue, memory loss and brain fog** were very difficult in that they affected all aspects of life, as one respondent expressed it **“The brain fog/memory loss was extremely difficult to manage and was noticed by friends, family and work”** This respondent did feel things were improving with time. Both physical and mental activities could be affected by fatigue, and on-going sleep problems added to the difficulties for some. The quotes below show how hard living with Long Covid symptoms can be:

“It is very difficult to manage the tiredness and brain fog. I struggle at the pace of my job sometimes. I cannot remember things despite being told many times and my anxiety has increased highly ever since having it.”

“The fatigue has been the most difficult to manage. It is not only the physical activities that make you tired but also the mental aspect of your job and this can suddenly take a toll. I have found it also hard to socialise as this is also tiring.”

Breathlessness put great physical limits on those respondents who suffered from it and could be also frightening.

“The worst part is from the respiratory difficulty - it’s frightening. I cannot even do mild activity without becoming breathless.”

“The breathlessness was the most difficult to manage as going up stairs or even talking was a struggle for a few months.”

“The chest [palpitations] and tightness are scary, because it feels like I am having a mini heart attack.” But this respondent did feel that even more distressing than these physical symptoms was the inability to concentrate and memory loss.

Day-to-day life and the impact on others

37 of the 50 respondents also reflected on how living with long term symptoms had an impact on the rest of their lives and those around them.

The impact described fell into three broad categories; relationships and responsibilities, work and managing day-to-day activities.

Difficulties throughout relationships and responsibilities (19 respondents)

Responses referred to relationships either with partners, other family members and friends, or in some cases for all of those. **Tiredness** was a main cause as people had **little energy to socialise or to care for families** as they had before Covid. The sample comments illustrate the disruption to normal living and enjoyment affecting not only the sufferers but those around them.

“Long term symptoms has affected my home.....I don’t really feel as sociable as I was before and is more reluctant to go out.....My children have had to step up a lot more due to this illness.”

“Relationships with friends are strained as my energy levels mean I am not able to meet up or keep in touch as readily as I would like.”

Three respondents wrote frankly about the impact of Long Covid symptoms on their **romantic relationships**:

“Stressful for partner as we can no longer make any plans together.”

“....And with relationships, I live with my partner who is amazing and supportive but I worry that they may also (understandably) be impacted by the frustration and how I’m feeling. I feel bad for them.....and my libido is lower than it used to be too.”

“It hasn’t been listed elsewhere but libido was affected for many, many months...”

Two others summed up the frustration for those trying to run a family, a home and carry out responsibilities towards other family members:

“My husband, who is desperately overworked already, has had to do much more around the house.....My children resent me for being so incapable.”

“My ability to do my job, be a mother, a wife and a daughter (I could not help my elderly mother) has been hugely affected. I’m too tired to want to enjoy doing things.”

One respondent explained how hard it is for other people to understand what is happening:

“I only have half of each day to function properly. Social interaction is difficult and exhausting. Hard to explain to people how I have changed.”

Difficulties in employment/work (13 respondents)

Again, tiredness was a big factor with sleeping problems making this worse, as well as memory and concentration loss and brain fog. Keeping up with the demands of work was a problem and some people had found little understanding from their employer. One respondent said “I don’t think Covid symptoms are recognised and managed by employers”. The following sample quotes give an idea of how difficult work could be with Long Covid symptoms.

“Ability to work has been hard - struggle to match the pace of work. I push myself at work too hard as it makes me feel useless.....I feel guilty taking time off although it is needed.”

“...frustration at being unable to function as well as I did before; the projects I am involved with take so much longer, and need double- and triple-checking to ensure no stupid errors.”

“Can’t work.....It’s a disaster financially.”

Managing day-to-day activities

Other comments showed that daily, active life and enjoyment of life had been severely affected. All kinds of daily activities had been affected. Examples given covered an inability to exercise as before COVID-19 because of continuing breathlessness and loss of smell and taste which made eating food no longer pleasurable - this also affected socialising with others. The section below shows how these things in turn affected mental health and overall wellbeing.

“...I was training twice a day for a triathlon before. I am still not able to get back into regular exercise and tried all sorts of help...”

“It impacted the things I enjoyed doing, such as working out and cycling, for a long time. This in turn impacted my mental health as I could no longer use them as a means to manage my stress.”

Mental health and wellbeing

We wanted to learn whether and how living with Long Covid has affected the emotional wellbeing, mental health, and other aspects of the life of our respondents and those around them.

As many as 35 people out of 47, nearly three quarters, said that their emotional wellbeing or mental health had been impacted. Only 7 people said “No” and 5 were unsure.

“There are lots of days of feeling low. Questioning whether you will ever be the same again, will you be able to keep your job? Also trying to explain to people that you are not well but

them looking at you blankly because they don't know what Long Covid is and think its all in your mind.”

- **Anxiety** was the most frequently mentioned problem by 17 out of the 35 people, ranging from worries about losing their job to (in a few instances) panic attacks.

“Overthinking and worrying almost everyday, sometimes it can be hard to relax. The frustration of not having answers gets to me and the want to feel better but yet the recovery is a very slow process. It has negatively impacted me. This sometimes is reflected onto the household”

“I start to have panic attack for nothing, never experienced before”

- **Depression, low mood, or crying** were mentioned by 15 people.

“It has put a huge strain on my family and I feel depressed and frustrated at being physically inactive and unable to do my normal volunteering and other activity.”

“Get depressed and can't seem to shake it off never been like that before”

- **Tiredness, exhaustion, lack of motivation and appetite** were mentioned by 10 people.
- Other problems, only mentioned by one or two respondents each, were **memory loss, absent-mindedness, difficulty sleeping and irritability or short temper.**

Overall, people have listed a few things about Long Covid that have been impacting on their mental health, including **worries about the physical symptoms and what will happen, and uncertainty.** However, a **lack of knowledge and understanding of Long Covid symptoms, and lack of support as a result, in itself, also contributed to anxiety.**

“It's also hard not having had any actual treatment, timeline or support aside from the advice that ‘it will eventually just go away’ but the uncertainty of that can be tough.”

“I have struggled with anxiety in the past anyway and I have found the uncertainty of living with long covid has added to that challenge. The fluctuation of my symptoms has also made me feel more ‘up and down’ than normal and I think that, combined with the frustration of it lasting so long, has made me suffer with low mood more than before. I do my best to focus on my wellbeing and things that make me feel positive, but it can be harder on the days when I don't feel so well.”

Getting a diagnosis and experience of support

We wanted to explore people's personal experiences of receiving a diagnosis and treatment for Long Covid. A total of 48 people responded to our question about whether they have been in touch with their GP or with a hospital about their symptoms and support needed. The majority of respondents (28) said they did. Of these, 3 were living outside Wandsworth in nearby boroughs.

We also asked them to give us more details about getting or being unable to get their Long-Covid type symptoms diagnosed. 41 of the 50 respondents answered this question, with 5 of the 41 living in neighbouring boroughs of Wandsworth. The respondents reported a range of experiences. Many reported no medical diagnosis, which could be either because respondents had not contacted a GP at all or because a GP could not commit to a diagnosis. In some cases, a GP would make a referral for specific symptoms. A small number were diagnosed by a hospital team or a specialist. A few were referred to Long Covid clinics. Getting a specific diagnosis was rare among our respondents; 13 people (out of 50)

said they were diagnosed with Long Covid, while 25 have experienced symptoms similar to Long Covid, but have not been diagnosed with it.

No medical diagnosis of Long Covid

14 of our respondents who had not received a Long Covid diagnosis said that they had never spoken with a doctor about their symptoms. This was mainly due to either the difficulty in getting a GP appointment or doubting that, even if they did, anything could be done to help them.

“I’ve not been to GP as getting appointment not easy and from what I’ve read they wouldn’t be able to help solve symptoms anyway.”

“I have not been diagnosed by a medical professional with Long Covid, nor have I sought out a diagnosis as I do not believe anything can be done.”

One respondent had only found out about Long Covid symptoms when reading about this survey and realised that symptoms mentioned matched personal experience.

Having Covid in the first months of the pandemic before testing was available was also a problem, as there was no initial diagnosis of the illness. This made it difficult to get a diagnosis for long-lasting symptoms. In the Spring of 2020, there could have been an unwillingness to seek help, as one respondent said:

“I didn’t contact any medical services for 3 months as at the time we were being urged only to seek medical attention if you were dying.”

At times, our respondents said their symptoms were attributed to a condition other than Long Covid. One respondent, reporting continuing tiredness and breathlessness, was diagnosed with depression or anxiety. Two respondents who felt they contracted COVID-19 early in the pandemic were never given a COVID-19 diagnosis but were subsequently treated for other respiratory conditions. One of these was told that now no one will ever know if the illness was COVID-19 so it is unknown whether continuing symptoms are in fact Long Covid. This affected others too with respondents reporting being diagnosed just with “a viral infection” or “a virus” when displaying symptoms associated with Long Covid.

“I haven’t been diagnosed. Had covid after a business flight in November 2019. There have been no tests at the time. ... Every time I say that I am constantly tired I get diagnosed with depression and when I mention being breathless after short or no exercise, they call it anxiety. At least my sense of smell seems to come back slowly.”

“I don’t think it is depression/anxiety. It seems to be my body not coping with something.”

Respondents who did seek a medical diagnosis spoke either with a GP or an NHS or private specialist. A small number wrote of taking antibody tests.

Talking to a GP

18 of the respondents said they had spoken to a GP, many of which resulted in useful consultations. While two respondents had been either prescribed, or advised to take, vitamin supplements by the GP, GPs appeared to often have been uncertain about what symptoms could mean but did try to use the expertise of others to obtain a diagnosis or treatment.

“My GP does not seem to know much about Long Covid and said that as I am under OH [Occupational Health].....they would provide better support.” (This respondent had asked the GP for that referral).

Talking to a GP about Long Covid did not always lead to further support for a variety of reasons. **Some respondents felt GPs could be dismissive**, as in these examples:

“I had a telephone appointment followed by a face to face appointment with a GP who told me that I didn’t have long covid - in his opinion.” (This respondent has been experiencing symptoms for at least 12 months, which included fatigue, brain fog and memory issues.)

“My NHS doctors just told me to wait and I will eventually get better” (This respondent had experienced symptoms for 10 months.)

There were also some respondents who, despite reporting their symptoms to their GP, were **not provided further support due to lack of referral options**. There is more about people’s experiences of referrals and further support later in this report.

Referrals

Some reported that GPs referred them on to other specialists, whilst rarely diagnosing Long Covid themselves. Different specialisms were used to investigate specific symptoms - occupational health, cardiologists, audiologists, ENT departments. Tests included blood tests, such as antibody tests, and X-rays.

Diagnosis at a hospital

Five respondents had been diagnosed with Long Covid at a hospital when attending clinics for specific symptoms, and while some people found them helpful, others thought that a more holistic approach to the condition would be more effective instead of investigating individual or a small cluster of symptoms.

“As I have no evidence of ever having covid, I have not been supported as someone who may have long covid, which is fair enough.....but there is no one who is looking at the symptoms as a whole and whether they are linked.”

Referral to a Long Covid clinic

Responses received throughout our survey showed that although many have been referred to specialist services by their GP, **only a small portion of our respondents have been referred to a Long Covid clinic or been able to access the service.** Only six respondents wrote of referrals to Long Covid clinics at various hospitals. One of these had Long Covid diagnosed over the telephone by a GP, and another had a long-standing appointment at a local hospital where symptoms were discussed but **“they were unable to provide any support for Long Covid and told me to find a specialist clinic.”**

Reasons behind a smaller number of referrals than people expected may be **doctors’ lack of awareness of the Long Covid clinic in Wandsworth:** one Wandsworth resident was told by their GP that there is no Long Covid clinic in the borough, while another was told about 6 months ago that a Long Covid clinic would be opening in Wandsworth and a referral would be made but there had been no news or progress despite the respondent chasing it up. In one additional case, a Long-Covid clinic was discussed but not followed up:

“I went to my GP and she wanted to refer me to a long covid clinic but the referral process was highly detailed, she suggested that I wait further and see how I feel.”

Antibody tests

Five respondents, who had also possibly contracted COVID-19 early in the pandemic, wrote of taking antibody tests. For three of them this was quite a long time after the initial illness, and the tests were negative, meaning continuing symptoms could not be officially defined as Long Covid. One of the five had a private antibody test which was positive. Another, who had been ill in Autumn 2020, took an

antibody test, arranged by the GP, which was positive and was told that the symptoms now experienced probably were Long Covid but that they “**should clear up after a while**”. This respondent did not consider this could be taken as a formal diagnosis of Long Covid.

Private treatment

As well as the one private antibody test reported above, **three other respondents had turned to private medicine**. One had found the only way to receive treatment was to pay for different specialists over a prolonged period. Another went to a private specialist who “**thought might be long covid but not enough research or knowledge to be able to diagnose**”. The third went to an NHS specialist who would not give advice on Long Covid but said that attending a Long Covid clinic was needed. This respondent is looking into finding one privately “**to speed up the process**”. One respondent said that referral letters to private specialists had been provided on request. The comment of a respondent also illustrated **possible health inequalities** as few would be in a position to respond to the situation in the way necessary here:

“For people like me sick in the first wave it’s been and still is a nightmare. My mental health is in tatters and my life has been ruined by this virus. I can’t work, the pain is excruciating and I have had to constantly fight for and pay for all my care. I am lucky in that I had some savings.”

Waiting times

In total, 48 people answered our question about how long they had to wait before receiving support after their first referral, and for some this could be many weeks or months after starting to suffer from Long Covid symptoms.

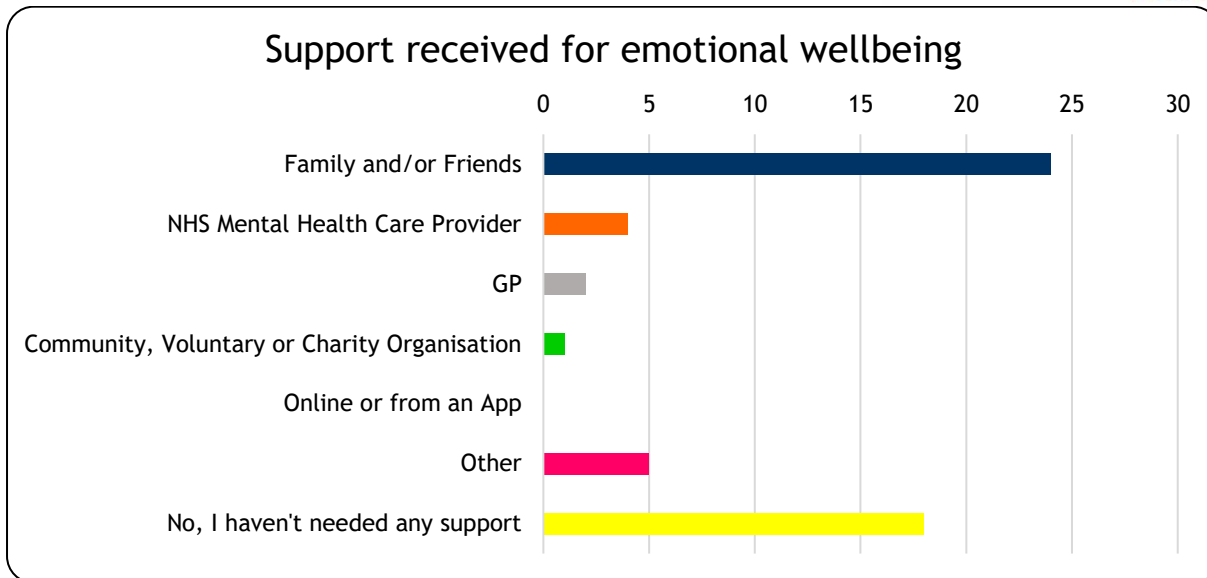
- The majority (**31 people**, approx. 65%) **had not had a referral to support**.
- **5 people waited 1-2 months**
- **5 had to wait more than 2 months** to receive support after their first referral, with **one person having to wait 16 months for a referral to the Long Covid clinic**.
- **6 people waited between less than 2 weeks to up to a month**
- One respondent was unsure of how long they had to wait.

Support with mental health and emotional wellbeing

As previous sections of our report also highlighted, **dealing with Long Covid had a negative impact on the emotional wellbeing of individuals**. Therefore, we wanted to find out what support (if any) our respondents accessed for their mental health.

47 people responded, and chose multiple answer options, to reflect the full range of support they may have received.

- **18 people said they did not require support**
- Those who have received support for mental health have predominantly done so from **friends and/or family** (24 people)
- **4 people accessed an NHS mental health care provider** (e.g., Talk Wandsworth or Community Mental Health Team)
- **2 were supported by their GP**
- **5 people received help from other sources**. These included their **employers, private therapy, and counselling**
- Interestingly, **no one reported receiving support online or from an app**, although one respondent mentioned referring themselves to an online Cognitive Behavioural Therapy (CBT) course (which they have not attended yet).



We invited people to add comments on their experience of receiving support. 10 respondents did so. **Most reiterated how effective the support they received from family, friends and one-to-one counselling was, while others mentioned completing assessments at their workplace, such as Occupational Therapy and a Stress Risk Assessment.** One person said that they have considered going to ‘Staff Support’ but felt they were **not ready to deal with the emotions.** A couple of respondents mentioned **not being able to receive support, despite having a need for it.**

“My family has been a massive support. They remind me of everything and help support me where needed”

“I live alone and it’s very hard to look after myself”.

One respondent mentioned that they had found counselling sessions from Talk Wandsworth helpful for anxiety. Another said they found an ‘Overcoming Worry’ group therapy course before they had Covid beneficial, so they referred themselves back to an unnamed but “fantastic” service for 1:1 therapy for anxiety and low mood, while another was quickly supported with their anxiety by an online CBT course after referring themselves.

Additional support

The majority of people we asked (31 out of 48 people who responded) had not received any additional support apart from through friends and family. Respondents who had received professional help tended to turn to health services rather than social care or community services (people could select multiple answer options for this question).

- 7 people got help from their GP
- 5 received care from a hospital as an outpatient
- 4 people reported needing to seek support from Accident and Emergency departments
- 4 from NHS 111
- 3 got support through their employers or occupational health schemes
- 2 people got support online or via apps
- 2 respondents got help from private healthcare
- One person needed overnight care in hospital
- One respondent mentioned acupuncture
- One received physiotherapy
- One person said they were associated with a trial of a support app at Barts Health NHS Trust and had had conversations about research which has helped.

- No respondents reported receiving support from either social care or community groups/voluntary organisations.

16 people reflected further on how professional help had made a difference. Of these, two people said there was general progress, three people said it had made little or no difference, and one said they were still waiting for treatment.

“It has helped me stay working instead of going sick. There is always a worry that you will be too sick to work and they help provide a balance.”

Of the remaining 10 respondents, four indicated that support was mostly reassurance and three described combinations of advice around rest and exercise.

“With all the hearsay about covid the GP surgery makes me understand about it better and what to expect.”

“Their advice means that I give myself time to improve and try not to overdo things as there is no cure except pacing myself.”

“It helped reassure me that they [NHS 111] said the same as my GP and didn’t feel my symptoms were too severe - but I didn’t receive any other help apart from that.”

Specific treatments were only mentioned by three respondents:

- One mentioned a private neurologist and balance therapist
- One mentioned that Modafinil has helped with fatigue (but not enough to enable the person to return to work)
- One respondent mentioned that steroid inhalers and Ventolin had helped with respiration. They have also been prescribed antihistamines and received acupuncture, which helped with “muscle cramps and nerve pains”.

Managing daily living and ongoing care needs

Further, most respondents, 91.5% (43 out of 47), reported that they received no support to manage daily living or ongoing care needs.

Of the remaining four respondents:

- 2 said they received support from family
- One mentioned that their employer had been flexible about returning to work
- One mentioned Wandsworth Occupational Health
- No respondents have reported any support from long term social or community care organisations.

Friends and family

Friends and family have continually been shown to be one of the biggest support to our respondents. The level of support ranged from emotional and moral support to helping manage daily living, although the prior seemed to be more common.

We asked our respondents specifically if they have someone (e.g., a friend, relative, neighbour, or other type of carer) who helps them with their daily living, not as part of their paid profession. 46 people answered.

- 13 people said they do
- 33 said they do not.

Seven respondents commented further on whether they felt their unpaid carers were sufficiently involved and communicated with regarding their care.

- 4 of those making comments wrote of friends or family helping them and being involved but they did not identify any communication that these supporters had received regarding care. One of the 4 said that the family had supported and been **“Very involved in my care”** but **“there are some difficulties in understanding of what I am going through.”**
- One other respondent answered the question with the comment **“as much as they could be”**.
- Two respondents answered ‘No’, with one adding **“because there has been no official support or treatment offered.”**

Self-help

Other respondents had also sought ways of helping themselves with **exercise, memory games, meditation and yoga** used by one, while another found it necessary to **“not over think or stress and not to do too much”**. Another respondent was using a **special diet** and a **low dose medication**; a fourth felt there had been a **“huge improvement after taking antihistamines and the Covid vaccination.”**

Respect for personal preferences

Only 34 respondents (out of the total of 50) indicated whether they felt their personal preferences, such as lifestyle, culture, and beliefs, were respected or not. It is possible that someone’s preferences were respected at one service but were not at another, or that certain preferences were respected, while others were not, therefore people could mark multiple answer options to this question.

25 people thought their personal preferences were respected, 2 said they were not, while 8 people preferred not to respond. Only one person chose to go into more detail about their experience; they said that the service they accessed were not an official support service, but **“displayed deep concern for the background and any disadvantages of potential users of their app”**.

Current needs and possible improvements

Based on the responses we received from residents of Wandsworth and some neighbouring boroughs, **there seem to be big differences across the healthcare services in the area regarding knowledge of Long Covid and the support they provided.** For example, one person was full of praise for the hospital team who were described as **“fantastic”**, but they also commented **“I don’t think my own surgery believes long Covid exists.”** However, most of our respondents felt that the help they have received with managing their condition was not adequate and that **“more needs to be done.”**

“I feel like there has not been much support, no one understands what this is. It brings me frustration and makes me feel alone”

Lack of awareness and knowledge of Long Covid

A general picture emerged from the responses of a level of frustration that medical practitioners seemed to lack of recognition or understanding of symptoms that seemed obvious to respondents. This was hard for them as so many of the symptoms continued for a long time. And as we have seen earlier in the report, there was a significant impact on their lives including work, leisure activities, day-to-day chores, relationships, emotional wellbeing and, of course, physical health.

“I became ill in October 2020 after a viral infection but am still suffering serious problems 10 months later and have been unable to return to work. My NHS doctors just told me to wait and I will eventually get better but I was not willing to adopt that approach so I’ve seen a number of specialists privately. A cardiovascular specialist sent for an autonomic function test which showed severe Pandyautonomia and he has been treating me ever since”

Some felt that the lack of understanding of the condition caused them to receive inappropriate support.

“The NHS advice of exercise therapy and CBT is completely unhelpful. If I do too much one day, I am completely unable to get out of bed for about 1 to 3 days afterwards.”

“No help as they [the GP practice] aren’t sure how to support it.”

These comments all suggest that there is a great need for everyone - sufferers, family members, work colleagues and the medical profession - to be much better informed about Long Covid symptoms and how they impact on daily life. The below comment shows that simply finding out about Long Covid symptoms could be important:

“I think I will seek help/support as I hadn’t really put this down to Covid but now I have assessed my own symptoms I think it has to be down to when I got Covid late last year.”

Lack of support

‘Support’ from healthcare professionals was not often mentioned in the comments of our respondents. Only one respondent described their GP surgery as “Very supportive”, while another felt lucky to be able to pay for private treatment and tests through medical insurance. Some also felt unsupported by their workplace.

“I don’t think Covid symptoms are recognised and managed by employers and none of my colleagues have had Covid.”

“Had to pay for ALL support - only now have I had any help from any NHS services. I have been left to manage this all on my own pretty much for the last 17 months. Researching my own condition to try and find any way to help myself”

Another issue appeared to be people’s lack of awareness of the support available to them; because of this, a considerable amount of our respondents have not been seeking out help.

“I don’t know what support is available so I don’t know what might be of help.”

“That’s part of the problem. I don’t feel as though there is anything anyone can do about how I feel at the moment.”

“There should be some place where you can get help especially for long covid, rather than people guessing what is wrong with you.”

Recommendations from our respondents

We asked people if there was any other support or information for their Long-Covid like symptoms that they think would help. 24 people responded and we received a number of useful suggestions.

Medical interventions

Suggestions were dominated by access to the GP, especially face to face (mentioned by 5 people). 2 other people wanted general advice about symptoms, and one wanted a referral to specialist medical help and support.

“I would like to be able to talk to a doctor face to face about my symptoms, not have use an app. (I am no good with tech and this sort of thing is completely alien. ... I find them completely unhelpful.)”

Other calls for medical support included:

- Recovery plan (1 person),
- Ongoing monitoring of symptoms (1 person),
- Treatment of specific conditions like tinnitus (1 person), memory loss (1 person), and breathing (1 person), a pain clinic (1 person) and physical rehabilitation (1 person).

The need for more information about Long Covid was also echoed.

“I’ve been experiencing this for 11 months now and it still impacts my everyday life, so I would really appreciate some advice or support from a medical professional to determine if there’s anything that can be done to help (even if it’s just stuff I can do myself), or if not, at least a clearer sense of what to expect and an understanding of my symptoms. I know this is a new disease and everyone is finding their way - but I am a solution-focused person and that would really help me feel less alone in dealing with it! “

“... doctors need to know where to refer patients to with long covid.”

Non-medical support

3 respondents mentioned support groups or emotional support, in order to build a community so others do not feel alone and can all relate to what everyone is going through. One person mentioned financial support, while another felt the need for support for them to be able to support their staff as a manager. Others wish there was more support available at the workplace.

“I think it’s important that Managers are made aware of the effects of Long Covid and how best they can support their staff as a long term. People think that as soon as you return to work everything is solved, they don’t realise that you are still trying to balance everything.”

“The Gov. needs to make employers more supportive and accommodating re long covid...”

Conclusions and Recommendations:

Thank you to everyone who took the time to complete our survey and shared their stories on experiencing Long Covid symptoms, managing life with the condition, getting diagnosed and receiving support, as well as feedback on current unmet needs. Throughout the report we have included detailed information to shed light on the lived experiences people shared. However, below are key points for consideration by health and care organisations as we learn more about Long Covid and Post-Covid Syndrome.

Increasing knowledge and awareness of Long Covid and available support

Our findings suggest that there is a great need for everyone - including those suffering from Long Covid - to be much better informed about Long Covid symptoms and how they impact on daily life.

- Learning more about Long Covid symptoms could be important to patients, to help them recognise the condition, seek appropriate help and advocate for themselves in receiving the support they need.

More information on Long Covid would be particularly useful to the support network of Long-Covid sufferers as well; many of our respondents said that while their friends and family members tried to help them as best as they could, they did not fully understand what was happening. Similarly, people felt that their workplace did not have a good understanding of their condition.

- We recommend various services (NHS, Wandsworth Council) to produce a guidance for friends and family members, as well as employers on what Long Covid is, and how they can best support people experiencing Long Covid or symptoms resembling Long Covid.

None of our respondents said that they accessed voluntary or other community services to help them manage their Long Covid symptoms.

- We would recommend involving communities and providing them with information and awareness of Long Covid to help them support each other.
- Some called for support groups, which would help them connect to others with similar experiences. We believe it would be a great addition to the support already available in the borough.

There seem to be discrepancies across healthcare services in terms of identifying, diagnosing and providing support for Long Covid, including referring patients onto specialist services. Numerous respondents said that their GPs were not able to commit to a diagnosis, misdiagnosed their patients, were not sure how to help them or were even dismissive of people's concerns.

- We would recommend providing GP practices (who are often the first point of contact for people experiencing Long Covid type symptoms) with more information on common symptoms of Long Covid, treatment options and a list of services in the borough/South West London that GPs can refer or signpost their patients to.

Widening the support available and shortening waiting times

Almost all of our respondents had some experience with COVID-19, but half of them said they have never received an official diagnosis. Many of our respondents said that as a result, their currently experienced symptoms could also not be officially diagnosed as Long Covid. While antibody tests can help retrospectively indicate whether someone had had COVID-19 or not, they are only effective when the person was infected in the past few months. Most of our respondents have had Long-Covid-like symptoms for 6 months or longer, therefore confirming their condition with an antibody test is not an option.

- We recommend that in addition to the standardised information mentioned above for healthcare services, to develop a diagnostic procedure/criteria for referrals that do not depend on a Covid-19 diagnosis. Waiting for a test and diagnosis left people without support to manage symptoms, some could be signposted to some aspects of support without having to wait.
- Health and social care services are also encouraged to provide support or offer referrals to those whose Long Covid status cannot be confirmed but are experiencing symptoms characteristic of the condition. There also may be people experiencing symptoms who do not have symptoms whose cause might be identifiable as COVID-19, but they still need support in managing symptoms. Moreover, not having a diagnosis had impacted on people seeking support from professionals and elsewhere, yet they could have benefited from encouragement to seek self-management support or professional support.

None of our respondents said that they accessed support from social care services, with a few mentioning that there was no support available.

- Support available for help with daily living and access to social care should be considered as part of the holistic care.
- As mentioned above, more information and support for family and friends who might support people not eligible for social care would also be helpful, as there may be a number of people who are new to caring roles. It would also be important to check if someone has a friend or relative to support their daily living, as it cannot be presumed to be the case since many people in the borough live alone.

It was evident that maintaining quality of life and managing day by day had been, or still is, a real challenge to the majority of our respondents.

- Given that the impact can be wide reaching, it is important to look into providing holistic support, ranging from healthcare support tackling physical symptoms, through support from employers, to financial support.
- A number of people said it took time to get support. As the impact of managing symptoms had wide reaching effects, holistic support should also consider managing symptoms whilst people wait for support.

Developing mental health issues such as anxiety and depression are commonly experienced symptoms of Long Covid. Nearly three quarters of people responding to our survey said there had been an impact on their emotional wellbeing or mental health. Further, the negative impact that suffering from Long Covid had on daily activities, worries about often scary physical symptoms, as well as the uncertainty about how long symptoms would last and fluctuations in symptoms and the lack of understanding/support, appear to have also affected people's emotional wellbeing and caused them to experience high levels of anxiety.

- Therefore, we recommend service providers pay special attention to the mental wellbeing of their patients and clients and ensure that they are aware of mental health support available to them.
- As Long-Covid symptoms seem to often be persistent and long-lasting, many people would also benefit from the mental health support that has in the past been offered to individuals living with chronic illnesses and other long-term health conditions, to help them make any necessary lifestyle adjustments. This is particularly relevant to those who were in good health and physically active before they became ill.