

## LONG COVID



*"I haven't been back to the GP. I'd rather just sit it out myself. It takes time."*

*"The fatigue is my overwhelming symptom. I have got other symptoms as well but managing the fatigue is definitely the biggest thing. Breaking things down into little chunks helps."*

**May 2023**

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## Acknowledgements

Healthwatch Oxfordshire would like to thank everyone who took the time to share their experiences and stories with us.

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# 1. Executive Summary

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Healthwatch Oxfordshire wanted to hear about people's experiences of Long COVID and the support they received from health and care services for this condition.

Long COVID is a new and evolving condition that can greatly impact health and quality of life. The precise causes of Long COVID are unclear and recovery time varies for each patient. More research is required to develop a standardised pathway from diagnosis to treatment and management of the condition. Most people are diagnosed by their GP, and if so, can then access tailored Long COVID services which provide multi-disciplinary support.

The Long COVID service in Oxfordshire is run jointly by Oxford University Hospitals (OUH) NHS Foundation Trust and Oxford Health NHS Foundation Trust.

We aimed to gather experiences of people across the treatment pathway, from those seeking support in primary care from their GP, in the community, and those requiring support from a Long COVID clinic. **50 people** responded to a short survey promoted between February and March 2023. This survey gave people an opportunity to comment on experiences of accessing and using services to support those facing Long COVID. Seven people kindly came forward to share their stories in depth. These stories are included at the end of this report and on our website at [www.healthwatchoxfordshire.co.uk/have-your-say/your-stories](http://www.healthwatchoxfordshire.co.uk/have-your-say/your-stories)

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## 2. Key themes

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People told us that:

- Long COVID symptoms varied widely, and most respondents reported experiencing more than one symptom. Fatigue/extreme tiredness was the most common impact of Long COVID, making it difficult to do daily activities, and impacting on quality of life, relationships, jobs, finance and caring responsibilities. Long COVID's impact on mental health was a strong theme.
- People seeking diagnosis and support for Long COVID felt that some GPs were initially limited in their knowledge and understanding of the condition.

Whilst some patients felt that they were offered limited help, undiagnosed symptoms and little information received, others felt more supported. Being listened to and 'believed' was important.

*"My GP was very candid in stating that no one really knew anything about long-COVID at that point."*

*"I approached my GP, he's just been really good. When I can get an appointment with him, I know it'll be a satisfactory appointment. He referred me to the Long COVID clinic straightaway which was really positive."*

- Long COVID clinics have provided a valuable source of support, with multi-disciplinary and peer support and shared experience, and common ground having a positive impact on mental health for patients.

*"Excellent service, understanding and sympathetic, offered lots of workshops and resources."*

- People found peer support from other sources including family, friends, online or in-person communities and holistic approaches. They found this was a useful way to get support and an understanding of ways to self manage their condition and symptoms.

*"Meeting with other sufferers that know what you are going through is very helpful."*

- Some took multiple pathways to various services, and considerable time before finding support or accessing a Long COVID clinic. Symptoms of Long COVID made it difficult to be proactive to seek help and a pathway to support.
- 92% of respondents indicated that Long COVID had an impact on their health and fitness. People found that access to physical activities could have a positive effect on their mental health and ability to manage symptoms.
- More needs to be done to hear about the experiences and support needs for Long COVID by those from Black and minority ethnic communities, those living in the most deprived areas and people living with who are unable to seek support due to pressures of work, caring or financial pressures.

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## 3. Next steps

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This report gives insight into people living with Long COVID and their experiences of seeking support. It will be shared with commissioners and providers of services – including Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board, Oxford Health NHS Foundation Trust, and Oxford University Hospitals NHS Foundation Trust Long COVID clinic.

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## 4. Background

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Long COVID is a new and evolving condition that can greatly impact health and quality of life. The precise causes of Long COVID are unclear and recovery time varies for each patient. More research is required to develop a standardised pathway from diagnosis to treatment and management of the condition.

There is currently no formally agreed clinical definition of Long COVID. The National Institute for Health and Care Excellence (NICE) recommendation is that ‘Ongoing symptomatic COVID-19’ be used when symptoms continue after 4 weeks of contracting COVID-19 and are not explained by an alternative diagnosis. ‘Post-COVID-19 syndrome’ is used when symptoms continue beyond 12 weeks or newer symptoms develop. Both are commonly called Long COVID by laypeople.

Long COVID presents itself through a wide range of clustered symptoms of which over 200 have been documented, the most common being fatigue, breathlessness, fast heart rate, palpitations, chest pain, brain-fog, lack of concentration, as well as muscle aches and pains. [The Office for National Statistics \(ONS\)](#) reports that 2.1 million people in the UK have self-reported Long COVID symptoms – just over 3% of the population – as of October 1st 2022.

To tackle the debilitating impact of the condition, the [Long COVID NHS Plan](#) invested £100 million in 2022 to support patients. There are now approximately 90 Post-COVID Specialist Clinics across England. These specialist clinics provide physical, cognitive and psychological treatments. The plan outlines additional establishment of paediatric hubs to support children and young people suffering from Long COVID.

## Long COVID support in Oxfordshire

People in Oxfordshire who are experiencing long-term symptoms after getting COVID-19 are benefitting from an integrated service combining the expertise of Oxford's two NHS trusts.

The Long COVID service is run jointly by Oxford University Hospitals (OUH) NHS Foundation Trust and Oxford Health NHS Foundation Trust ([www.ouh.nhs.uk/services/departments/specialist-medicine/respiratory-medicine/long-COVID/](http://www.ouh.nhs.uk/services/departments/specialist-medicine/respiratory-medicine/long-COVID/)) Specialists from the two trusts triage patients referred to them by GPs to the most appropriate service, whether hospital or community-based support.

The clinic, based at the Churchill Hospital, began in January 2021 with funding from NHS England, building on previous partnership work. The team includes doctors, nurses, psychologists, physiotherapists and occupational therapists offering both physical and psychological assessments of patients, and triage to the appropriate treatment and rehabilitation services.

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## 5. What we did

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Healthwatch Oxfordshire wanted to hear from people about their experience of Long COVID to support development of services to help local people to manage their symptoms.

An anonymous online survey was launched in February 2023, followed up with additional in-depth interviews. The survey was distributed via social media, through local community networks and news. Surveys in paper form and other formats were provided on request.

The survey focused on understanding the impact of Long COVID on people's lives, their physical and mental health, access to NHS treatment, and experience with care and of healthcare professionals. We also asked people to tell us about what worked for them and suggestions for improvement.

We aimed to gather experiences of people across treatment pathway, from those seeking support in primary care from their GP, in the community, and those requiring support from a Long COVID clinic. We wanted to hear from those who had never reached out for help and were managing symptoms on their own.

Whilst not representative of all experiences, 50 people completed the survey, giving a snapshot some of the challenges people face with this condition. Seven people shared stories in more depth.

## 6. Who did we hear from?

Of **50 respondents** from Oxfordshire:

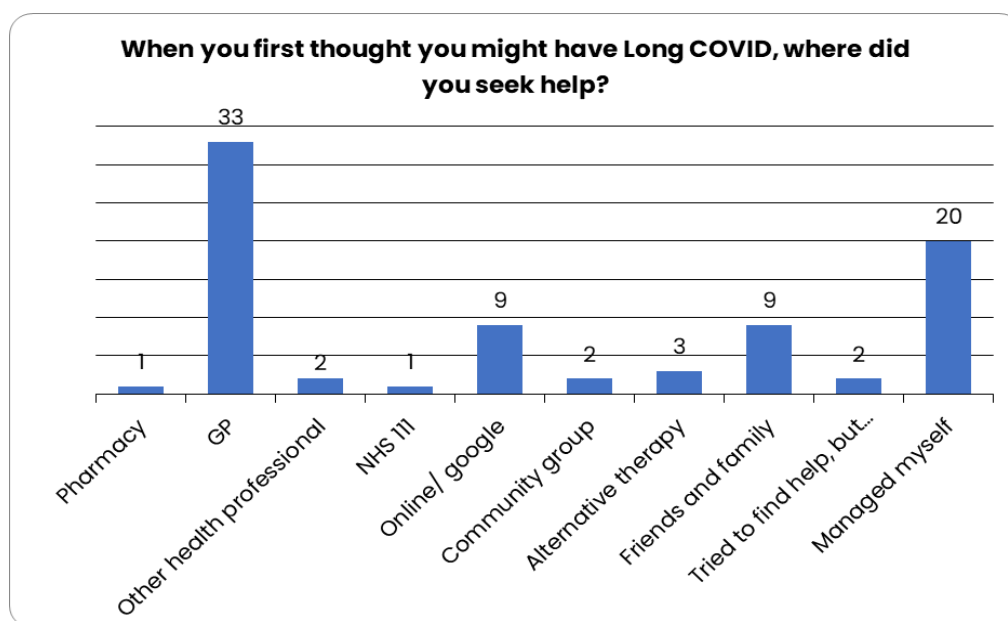
- 44% were from Oxford city, 15% from Cherwell, 10% from South Oxon, 10% from West Oxon, 15% from the Vale of White Horse.
- 70% respondents were aged over 50 years.
- 74% identified as woman, and 18% man, and 8% other.
- 74% identified as White: British / English / Northern Irish / Scottish / Welsh
- 59% respondents told us they had had COVID over a year ago, 28% between six and twelve months ago, and the remainder within the last six months of the survey (February 2023).

Seven people kindly shared their stories in more depth via phone interviews.

## 7. Results – what we heard

### Seeking help

We asked people to tell us where they sought help once they suspected they had Long COVID.



(Number of responses)

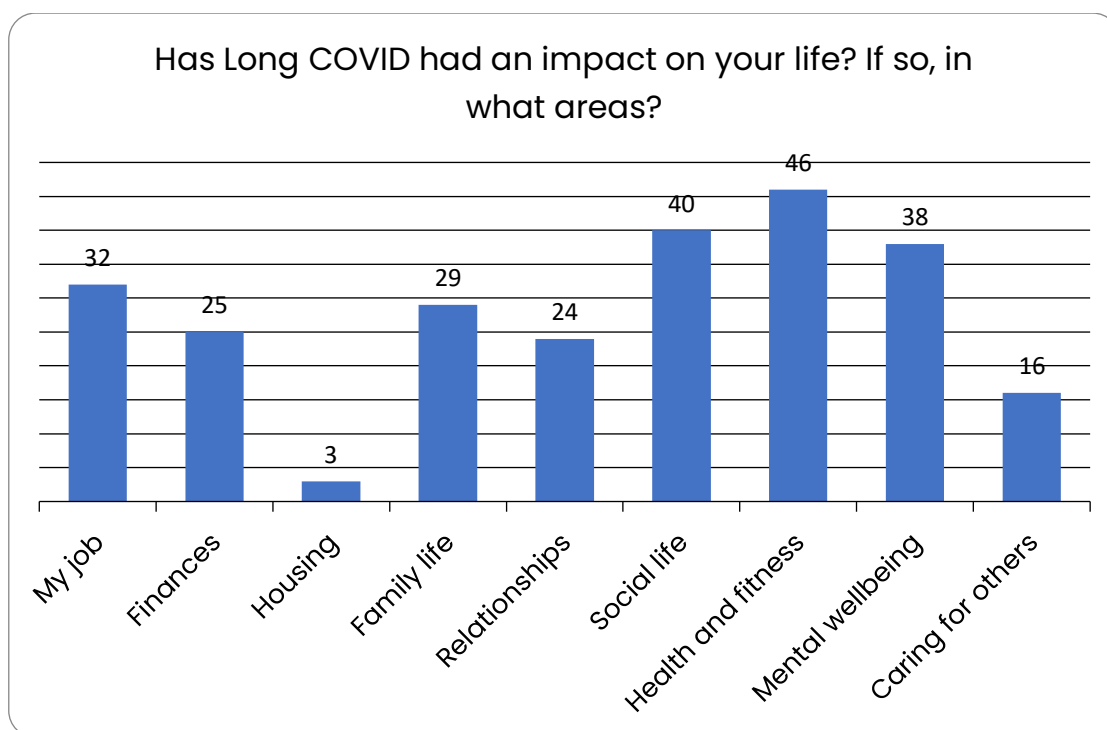
Of 50 respondents, people indicated they tried a mix of places in seeking help. 33 told us they approached their GP when they first had symptoms. 20 told us they 'managed it themselves'. Notably few tried other sources of help, including pharmacy (1), and NHS 111 (1).

*"I was given a completely wrong diagnosis by my GP who sent me to hospital outpatients supposedly with a heart condition. There was nothing wrong with my heart (confirmed by Consultant). It was all temporary stuff due to the virus messing up my system. The symptoms of Long COVID were completely missed by the GP and the hospita.,"*

*"I didn't think it was COVID because my symptoms weren't the ones being advertised by the government. After two weeks my GP said they thought it was COVID."*

*"My body, and brain aren't recognisable to me, and it's been a very long journey understanding a) what is happening to me b) my recovery isn't linear c) understanding that most medical professionals have no idea how to help me."*

### Impact of Long COVID on daily living



(Number of responses)

We asked people to tell us about the impact Long COVID had had on their lives. Comments highlighted the impact of symptoms of extreme tiredness and fatigue, and aches and pains on all aspects of life. Impacts included on health and fitness (46 responses), impact on jobs and finances (32 and 25 responses) on mental



wellbeing (38 responses), and 69 responses focused on impact on family life, relationships, and ability to care for self or others.

*"It has significantly impacted every aspect of my life, to the point where I was unable to work, socialise, or take care of myself or my home."*

*"I'm currently in my third month of being off work which has given me a feeling of uselessness and adding more stress to the NHS service I work for. I am already taking medication for depression and having Long COVID has been difficult mentally."*

*"It has been over two years of a living nightmare."*

Some described the need to rely on support from others to manage.

*"Neighbours and friends had to do my shopping for me. My mobility impairment and fatigue prevented me from doing my own errands. Also I couldn't manage to clean my home. I needed help with that."*

A key impact was on health and fitness, particularly hard for those who had previously been active.

*"I went from doing several classes a week at the gym and swimming nearly 100 lengths a week to not being able to do anything."*

*"I felt extremely isolated being ill with long COVID for 5.5 months. My friends and family were sympathetic but didn't really understand - none of them had been very sick at all when they got COVID. I live alone. I was a very active athlete and it completely destroyed my mental wellbeing to lose the mental and physical benefits of exercise for so long while I was ill. I withdrew socially from in-person contact because I was so afraid of getting COVID yet again."*

32 responses indicated impact on employment and 25 noted financial pressure.

*"I live on my own so it's been pretty lonely. I'm nearly at the end of statutory sick pay and don't know if I will retain my job. In no fit state to find a new one if I do. Driving has been a real issue so very narrow world. Have had to rely on other people. People don't understand what you are going through."*

Family life, relationships and ability to care for others was also impacted. People described becoming more isolated as a result, and often felt misunderstood.

*"I care for my mum who lives in the next road, I had to drive rather than walk. I couldn't play with my grandchildren."*

*"I have struggled to work, become isolated and have put strain on my partner. I became depressed and suicidal."*

*“For the best part of a year, I have felt a shell of the person I was before COVID.”*

Some struggled to feel that family members understood the symptoms.

*“Trying to justify to my work, friendships, family and partner that this recovery isn't like any type of flu or cold recovery - getting them to understand that getting fresh air and exercise, eating healthily and doing all the things you'd usually do after a period of illness - doesn't work.”*

Other aspects of life that people told us had been impacted were education, nutrition, and sense of smell and taste (See story 7).

*“Loss of two of my five senses - smell and therefore taste/flavour, has a wide ranging and very negative effect many aspects of life, including complete loss of appetite.”*

## Insights into the impact of Long COVID

*“Everything is harder and I have to ruthlessly prioritise. All aspects of life have been negatively affected. Long periods off work sick then work very supportive in creating a new half-time lower level role for me. My income will halve.”*

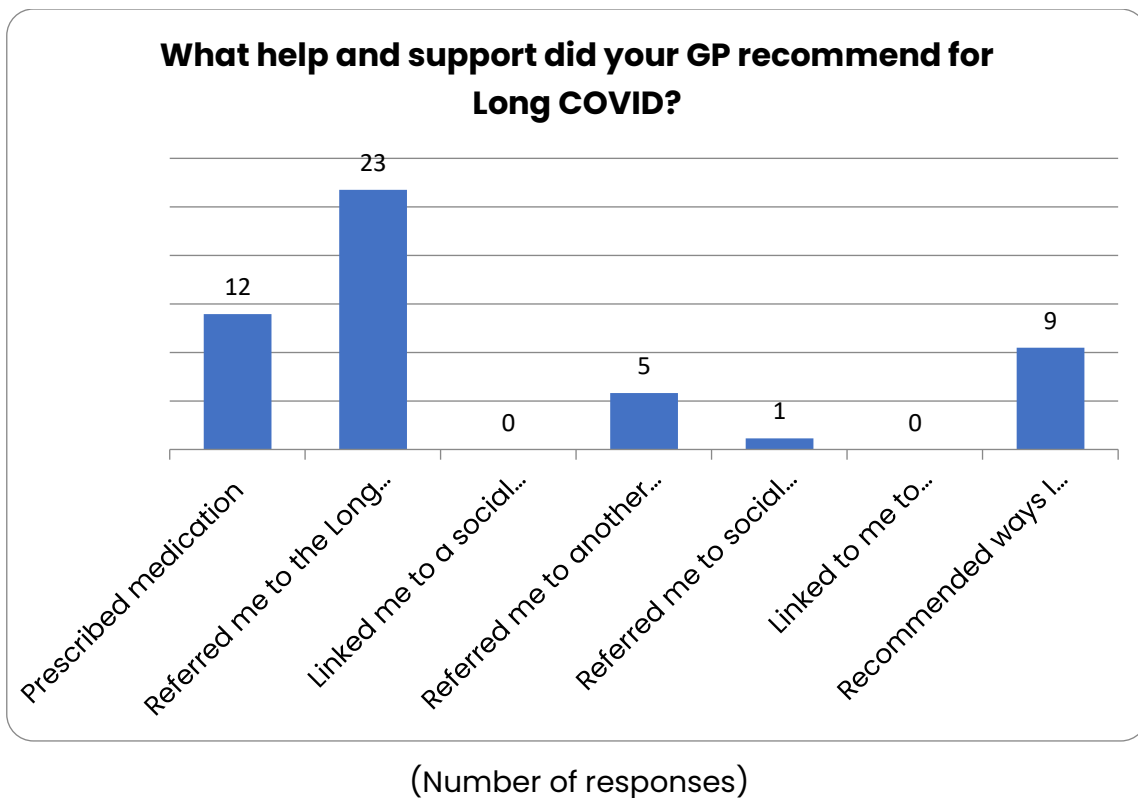
*“Have been unable to work as a personal trainer as could not walk at one point. Self-employed - so bringing no money in. Unable to exercise. Couldn't look after my kids initially as I was too poorly to do so for several months. My husband took the strain, financially and with the kids. My mental health has taken a severe hit, having never suffered any mental health issues prior to this. The bizarre nature of this illness makes it extremely difficult to deal with mentally.”*

*“I have not been able to hold down a job as I am constantly getting sick with bugs that make my Long COVID symptoms worse. I am unable to recover quickly from them like the members of my family are able to do which leaves me mentally and physically exhausted. Because I'm always sick I miss out on a lot of social activities.”*

*“I have bouts of brain fog. Deafness. Ringing in the ears. Headaches. Chronic muscle pain and discomfort. Daily fatigue. Depression.”*

## Getting support

Once people had seen a GP, we asked them about the help and support they received or was recommended.



23 responses indicated they had been referred to a Long COVID Clinic. 17 responses noted they had been referred to other health professionals, or prescribed medication. 14 had been given information on ways to manage symptoms through self-help.

No links were made by GPs to community-based support such as social prescribers or community settings. Of 14 people who gave 'other' comments, more than half felt had received 'no help'. Others noted 'being signed off work', 'vitamins' and 'options to address anxiety' had helped them.

People made positive comments about the Long COVID clinics once they had been referred and seen. Support from health professionals, and new skills to self manage were important.

*"The respiratory physios have been fantastic. Very positive and reassuring, and helping with learning to breath properly. I've attended breathing and fatigue workshops and am waiting to hear from speech therapy."*

*"Brilliant service from one-to-ones, to workshops, to quick referral to Talking Space. I was given a lot of support and it has definitely helped. I still struggle with fatigue but I now have the tools to deal more effectively with it."*

*"Excellent service, understanding and sympathetic, offered lots of workshops and resources".*

*“Positive experience with the whole multi-disciplinary team including consultant, physiotherapist and OT. All very knowledgeable and supportive both with physical symptoms and return to work support.”*

*“The Long COVID team were nothing short of amazing. They understood what I was going to, were sympathetic and understanding, and took the time to listen to me. We only ended the appointment because they could see I was visibly tiring. They referred me on to a number of different services, including a SALT therapist and several online workshops. They also signed me up for “Living With” app.”*

*“I did get a lot of support from the clinic: oxygen at home, respiratory physio for breathing pattern dysfunction, and counselling. But no treatment that is holistic or looked at root causes.”*

Some people described what they saw as confusion about symptoms or misdiagnosis by a GP with existing or new conditions. This was perceived as impacting on the time taken to get help. It might also indicate need for clearer communication from GPs around the diagnosis process, time scales and pathways to help

*“My diagnosis was given by the Long COVID clinic at the JR, I also received a diagnosis of fibromyalgia.”*

*“I had many trips to see my GP. I went in telling them ‘I think I have Long COVID’ as I had all the main symptoms. They didn’t take me seriously and after many blood tests and antibiotics I didn’t need I was finally diagnosed with Long COVID. I then waited over a year to be referred to the Long COVID clinic.”*

*“I had to have a blood test, chest x-ray, CT scan and an ECG before I was referred to the post-COVID clinic.”*

*“I have no help. No treatment. No formal diagnosis. Just told its highly likely I have Long COVID and I must manage it myself.”*

Some commented on long waiting times to access the clinic, with some waiting up to a year.

*“It took over a year. GP did refer me, but the clinic was overwhelmed and they lost my referral. By the time they got in touch, I was already recovering slowly.”*

### **What has been most helpful to you with your ongoing recovery?**

Some commented on other sources of help and support, including peer support, online groups, and holistic approaches.

## 'Support group has been invaluable'

*"I enjoyed the online workshops for a number of reasons. It provided me with a focus during a period when I was unable to work or do very much at all. It also made me feel less lonely and isolated as I was with a group of people going through a similar experience."*

*"English National Opera Breathe programme and an excellent local physio."*

*"Rest. Doing less than I think I can. Avoiding sugar."*

*"I have taken an hour's exercise every day with very few exceptions. And I don't always feel like I want to do it, but I do it."*

*"Long COVID Facebook support group have been invaluable. Made me feel normal by having same symptoms."*

Some however, remained feeling that they had not been able to find support that had helped.

## 'Not really getting the support'

*"I have no help. No treatment. No formal diagnosis. Just told its highly likely I have Long COVID and I must manage it myself."*

*"I've not really had any support. Just a tentative diagnosis and advice. Basically left to get on with life."*

*"Not really getting the support. Don't feel they understand."*

*"I did many workshops with the Long COVID team, from fatigue management to getting back to work. They repeated themselves a lot and the only advice they gave was to "pace myself" and "not do too much". This did not help me at all."*

*"I wish there were treatments rather than just helping manage day to day and waiting for things to get better."*

## What might improve support?

Some people felt that they have valuable lived experience and insights to offer. For example, comments noted the value of peer support and learning from others as 'experts by experience' about what helps:

*“Long COVID Facebook support group have been invaluable. Made me feel normal by having same symptoms. We often joke that we know more about Long COVID than GPs and so-called specialists. Nobody is talking to us though. Even LC clinic think they know best!!!”*

*“We need help, acknowledgement from medics and government, proper research, financial help. People are losing their homes as they can't pay their mortgage. The experts should speak to us directly. Whoever the experts may be...”*

*“When I told them I had lost my job as I thought they would be recording how many patients had lost job – they said not recording that!! Beggars belief.”*

One comment noted that practical support in daily living could be given.

*“Nothing has worked well. My life is now following a different course. If I were prime minister, as soon as someone got a long term illness I would assign them a support worker to do their admin for e.g. blue badge, benefits, organise medical appointments, fill in forms etc. When you're ill in England you have a ton of extra admin at exactly the time you don't have the energy / brain clarity do it. I feel abandoned. If my mum hadn't worked part-time and then stopped work, my life would have collapsed”.*

Many people wanted clearer, more tangible information about treatments and support available.

*“I have got all my information from the internet. The NHS website is not particularly helpful.”*

*“I wish there were treatments available rather than just helping to manage day to day and waiting for things to get better.”*

Some reflected that they have sought alternative treatment, such as acupuncture, which had helped some.

*“At the time I finally got help I was also told about a health supplement, within a couple of weeks of taking this I felt as if a switch had been flicked and I was back.”*

*“When the doctor at the post COVID clinic suggested new inhalers, it took up to four weeks to actually receive them, as it had to go via my GP*

*surgery. Maybe a prescription issued on the day would speed up treatment."*

*"I would have benefited from something that was a little more structured. I felt it was a little 'ad-hoc'."*

Many people valued being listened to and their experience being validated.

*"Clinicians understanding and actually BELIEVING that Long COVID actually exists would be helpful."*

*"To be listened to and not dismissed. It is the strangest, most bizarre illness. One day you feel fine. The next you can't walk and it goes in cycles like this for months on end. Symptoms come and go and you think you've got rid of them and then they come back. It is extremely lonely, scary and debilitating."*

Others reflected wider themes such as frustrations with access to primary care.

*"Follow-up call and referral back to the hospital would have helped. I'm still not back to normal and trying to see a doctor is impossible - all they want to do is speak over the phone it feels quite dismissive. Guidance and support managing anxiety issues I wasn't aware I had initially would be welcome along with a referral for managing exercise would be helpful along with the opportunity to discuss impact on my health right now."*

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## 8. Patient stories

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### **Story 1 - "Still nowhere near recovered"**

*"The starting point was when I tested positive for the best part of four weeks. I was clearly having some difficulties getting rid of it, despite having all my vaccinations, it was annoying that it lasted so long. I was left with muscle and joint pain which has continued ever since. I'm still nowhere near recovered. We're talking from February 2022 to now and it can get a bit better, it can get worse. And at the moment, it's a lot worse. I went on a trip into London, which would be a two or three hour journey by car but I didn't feel up to driving. So I had to use public transport and that was exhausting. And similarly, we were doing some*

*gardening and we had four bags of potting compost, so that's a case of moving those 40kg bags about 10 yards. Well, I was still feeling that a week later.*

*I contacted the GP, I said, "Look, I've still got it, you know", And he said to come back in in three months. So I did and then he says it's Long COVID. The only thing was they didn't have anything else to give me but they sent me to the Long COVID clinic for a one off appointment where they took the same information and referred me to occupational health I'm still waiting for an appointment. I mean, it's been, you know, it took, you know, six months to get any sort of discussion going.*

*The real problem is that people put themselves in a much worse situation because they don't feel great and therefore, they don't do anything. I have taken an hour's exercise every day with very few exceptions. And I don't always feel like I want to do it, but I do it. And I think that is that is the right thing to do. But at the same time, I have to manage it, I do have to balance it out. I still drive but I don't really want to drive for more than about an hour.*

*But it still leaves me waiting for an appointment with occupational health."*

## **Story 2 – A long journey with multiple symptoms**

*"I was having symptoms this time last year, breathless, coughing, muscle pain and weakness, difficulty walking and fatigue. Finally, I thought I'd better go and see the doctor. I managed to get an appointment with a nurse practitioner and after a bit of messing about, he diagnosed tonsillitis. He said, 'bodies are funny things' and these symptoms will 'just clear by themselves'. No mention was made of the possibility that it could be COVID related.*

*Finally, I managed to get an appointment with a GP, who listened to my chest and wanted to send me for emergency tests on my heart. My friend had to take me to the hospital early the next morning. I was there for nine hours, underwent many tests. They couldn't find anything wrong with me apart from a strange sound coming from my heart.*

*I didn't want to go back to the surgery because of the GP's misdiagnosis. So I coughed and I had muscle aches and pains and weakness, it was very difficult to walk and the brain fog was terrible! Friends had to go shopping for me. At one point I was getting horrible palpitations and I really, really thought it was going to die. So much so that I wrote letters of goodbye to significant people.*

*Eventually I started to get a bit better and my legs supported me a bit more. I'm still coughing and my voice has gone quite gruff. I haven't been back to the GP, I'd rather just sit it out myself. It takes time.*



*I am now feeling much better and can get about again. The heart 'problem' turned out to be nothing at all. This was confirmed by the Head Heart Consultant at the John Radcliffe Hospital.*

*The Long COVID clinic at the Churchill involves taking a bus, which used to go into the hospital grounds but now you have to walk about three quarters of a mile from the main road. I know some people who take taxis, but not everyone can afford that.*

*I was never offered a Long COVID clinic at all. In fact, neither the Practice Nurse, the GP nor the John Radcliffe Hospital diagnosed Long COVID. I worked that out for myself from the NHS list of about fifteen symptoms. I counted twelve!"*

### **Story 3 - Help from English National Opera 'Breathe'**

*"I was very unlucky and caught COVID very early on, February 2020. That meant I didn't get a diagnosis of COVID initially, because that was when the government wasn't testing. At that point the GP surgery was very unhelpful. When I was really ill, I phoned them and asked if they could give me some extra paracetamol because I constantly had a fever. And I got this horrible GP who said, 'Well, why can't you go to the shop and get some?' And I thought that I would have to go in a taxi, and that would put a taxi driver at risk and all his other customers. He made me argue for 20 minutes, just to get extra paracetamol added to my prescriptions. I was really ill at the time.*

*I literally lost about four or five months with the initial illness, and if I hadn't been a doctor, I would have been in hospital. I was offered hospital three times. And each time having read the science about viral loads, I just thought, no, stick it out here. I eventually agreed to go to A&E because my breathing was so bad. And that's when I got a diagnosis of Long COVID.*

*At that point, there was still no help out there, there weren't any Long COVID clinics. And I couldn't have had this conversation with you then because I was so breathless. I could barely speak.*

*As soon as I heard there was an online Long COVID clinic in Oxford, I asked to be referred. But there was a psychiatrist in the interview who wrote in his report that he had decided I should have a medication review and wrote that I obviously suffered from health anxiety because I refuse to go to my hospital appointment, even though COVID was everywhere at that point. It really made me so angry.*

*As a result of having COVID five times, not only have I lost my mobility, I'm now in the wheelchair for good. My 'word finding' comes and goes. We just don't know what this virus is doing to our bodies. I've never had a virus that made my hair fall out, it was coming out in huge clumps.*

*I asked my GP if I could get the antibody treatment and the booster vaccine for the vulnerable group. They refused and I read the guidelines and made a complaint to the practice, I contacted my local MP. They backed down and offered me to antivirus and I changed GP.*

*I got support from most amazing programme: English National Opera Breathe Programme. It's a breathing control and muscle control and relaxation to get your breathing back together again.*

*I think probably the biggest thing with the GP was that they were hiding behind not knowing and sending patients away. They worked on the premise, 'if the person doesn't get better, they'll come back'. But what if patients don't come back?*

*I was on a Facebook group for a long time for a Long COVID support in the UK. And there were people there being diagnosed with dementia, who just had the COVID brain fog. Now that must be frightening for them, that's really scary."*

#### **Story 4 – "Anxiety went through the roof"**

*"I was actually the fittest that I think I've ever been prior to getting COVID, I was going to the gym, doing Aqua aerobics three times a week. I was swimming 30/40 lengths. I was doing a body pump class, Pilates and Zumba. And then I had COVID. And I was thinking, Oh, it's only a couple of days, I'd be back at the gym. I then developed a really bad cough and trouble breathing. They took blood tests because they knew there was something not right.*

*I was just tired it and it's not tired, it's fatigue. There's a difference between the two, it's hard to explain. I pulled all my muscles around my ribs from coughing, I was in a lot of pain, they put me on strong painkillers. I then went and had another x-ray after that. Everything came back clear again. I was still very tired and out of breath. After Christmas I had my third jab. Two days later, I just didn't feel right. And I felt that I couldn't breathe, I was scaring myself. But the more you think about it, the more you scare yourself, the more you can't breathe. In the end, I phoned 111 and the doctor there told me to go to A&E. And I said to them, I think I'm scaring myself, but none of them ever made me feel like I was being stupid. So I had an ECG, bloods X ray, the whole lot, everything came back clear.*

*So it seemed like nothing is wrong with me, but the doctor said 'it sounds like you've got Long COVID'. After that, she referred me to the Long COVID clinic at the hospital who just listened to my story because I was getting a bit upset because I couldn't grasp that I couldn't do anything from being such an active person. They were going to refer me to Talking Spaces, but that that never happened somehow and I didn't hear from them again or anybody really. So I just kept*

going but at a very, very slow pace. And resting. I mean, it was just completely different life to what I was used to. I did get quite low about it.

And the other thing was the brain fog, I've never experienced anything like it. I couldn't cope with having too much to do in a day. You know if I had more than if I had an appointment in a week that was enough. The anxiety that went through the roof, it was just ridiculous.

After a while, I went back to swimming and I couldn't even swim a length. I also did a rehabilitation for COVID course at the gym, which was good, because you were talking to other people that knew what you were going through. It got me back into very slow exercise, it was frustrating, the pace of recovery.

I had a letter from the Long COVID clinic, saying, 'Did I want any more help?' There was a breathing workshop and a fatigue workshop. I also had CBT therapy through Talking Spaces as well.

And then I bumped into somebody in my village who asked me how I was, I was saying 'not good'. She'd been researching and had found some supplements made from fermented beans so I took those. Within two weeks, it was as if somebody had flicked me back on again. I don't know whether it's them or whether it's coincidence, but that was just over a year I've been suffering with it. I've not had the anxiety, I've not had that feeling of somebody leaning on my chest. All the symptoms have gone apart from I've got a bit of tinnitus, but I can live with that. Today I've done 30 lengths in the swimming pool and Aqua class."

## **Story 5 – “GP and Long COVID clinic really helped”**

"After being hospitalised with COVID, I was making good progress day on day, doing 10 paces more on walks and adding on. And then suddenly, I hit a wall, I just wasn't making progress and had a chest infection. So I ended up being treated for a chest infection. But after that just never fully got back to normal. I had a follow up appointment with the ITU consultant who said, 'Oh, you just need to push yourself'. So I went for a walk. I think I was up to walking about 20 minutes maximum. So I pushed myself and walked faster for half an hour. And that just wiped me out for days. So I thought this really isn't in my head.

I approached my GP, he's just been really good. When I can get an appointment with him, I know it'll be a satisfactory appointment. He referred me to the Long COVID clinic straightaway which was really positive. I ended up on a couple of research projects from that. I also had ongoing physio appointments where they came to the house, because I was unable to go out. I was seeing an Occupational Therapist and they were really helpful from a fatigue management point of view. I was off work for the whole of 2021, then started to do little tiny bits of work early 2022 and I was actually dismissed on the grounds of ill health last

week. My job was physical and it came to a point where I was living to work not working to live.

The fatigue is my overwhelming symptom. I have got other symptoms as well but managing the fatigue is definitely the biggest thing. Breaking things down into little chunks helps.

The Long COVID clinic has really helped from a support point of view, I think any hidden disability can make you feel very much that it could be in your head. So having the support of somebody saying, 'No, it's not in your head' really helps. My family have been really supportive as well. So it's just having a good network of people around you.

I also found Talking Space very helpful, because I was having flashbacks to ITU which they helped with, and then they carried on trying to help me adjust to Long COVID and people's expectations of me.

I told my physiotherapist that I was still having ongoing chest problems and they referred me back to the respiratory consultant. It seems like, as long as you're in the clinic, you've still got access to the whole clinic. I felt very supported. And I suspect even after I'm discharged from the clinic, if my GP referred me back, I'd get a similarly positive response.

## **Story 6 - "Postcode lottery"**

"When I spoke to my doctor, they just said it was a really, really busy period. I've gained probably about three stone and my breathing is really bad. Apparently, I snore quite loudly, which I didn't before. Obviously, I can't walk as far as I used to because I do get out of breath. I didn't realise the amount of anxiety I had until everything opened up and we were able to go back to work. I didn't go into work straightaway; I've worked from home. My employer agreed flexible working and were brilliant.

I have a friend who had gained weight, they've referred her to the gym. I spoke to the Long COVID clinic once and that was over teams, I went for the X ray, had the lung function test and that's it.

I pushed myself when I first went back to work full time, I was wiped out. That's where I struggle most with steps, I struggle with the breathing. I have to have a bottle of water with me and I've got an inhaler.

They did recommend I go on a walk with an organised group, but, well, one of the issues I have is struggling with my breathing. So going on a walk won't help. I don't want a support group. I don't need a support group. I think it's a postcode lottery where you live on the service that you get."

## **Story 7 – “Lost my sense of smell”**

*“Loss of two of my five senses – smell and therefore taste/flavour, has a wide ranging and very negative effect many aspects of life, including:*

*- complete loss of appetite, I have no appetite, and no sense of when I am hungry, many foods are unpleasantly tasteless. Affects nutrition, enjoyment of eating/social life around food/ability to cook and prepare food for others, due to lack of ability to know if it tastes good. The blandness is all depressing and detracts from social enjoyment. I have to eat as fuel, not as enjoyment.*

*- safety - I cannot smell gas, burning food, traffic fumes, much of smoke, poo (e.g. on shoe or nappies). I cannot smell or taste if food has gone off (e.g. milk gone sour). This has many safety implications.*

*- hygiene - I cannot smell any "bathroom" smells - my own hygiene smells, or other people - if the house is dirty or something is gone off in the fridge. This has huge social and emotional consequences, and provokes anxiety around hygiene and washing.*

*- emotional - no smells of flowers, nature, perfumes, summer smells, family, your home, anything - it is very depressing being cut off from this aspect of life. Like walking around in a sterile environment.*

*You might think that loss of smell and taste is not so serious, but it has taken many months to get used to this devastating change in my senses. I think smell is very closely tied in with emotions, memories and enjoyment of every aspect of our lives. Think of never again smelling a baking cake, a curry, your family, flowers, it affects everything.”*



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