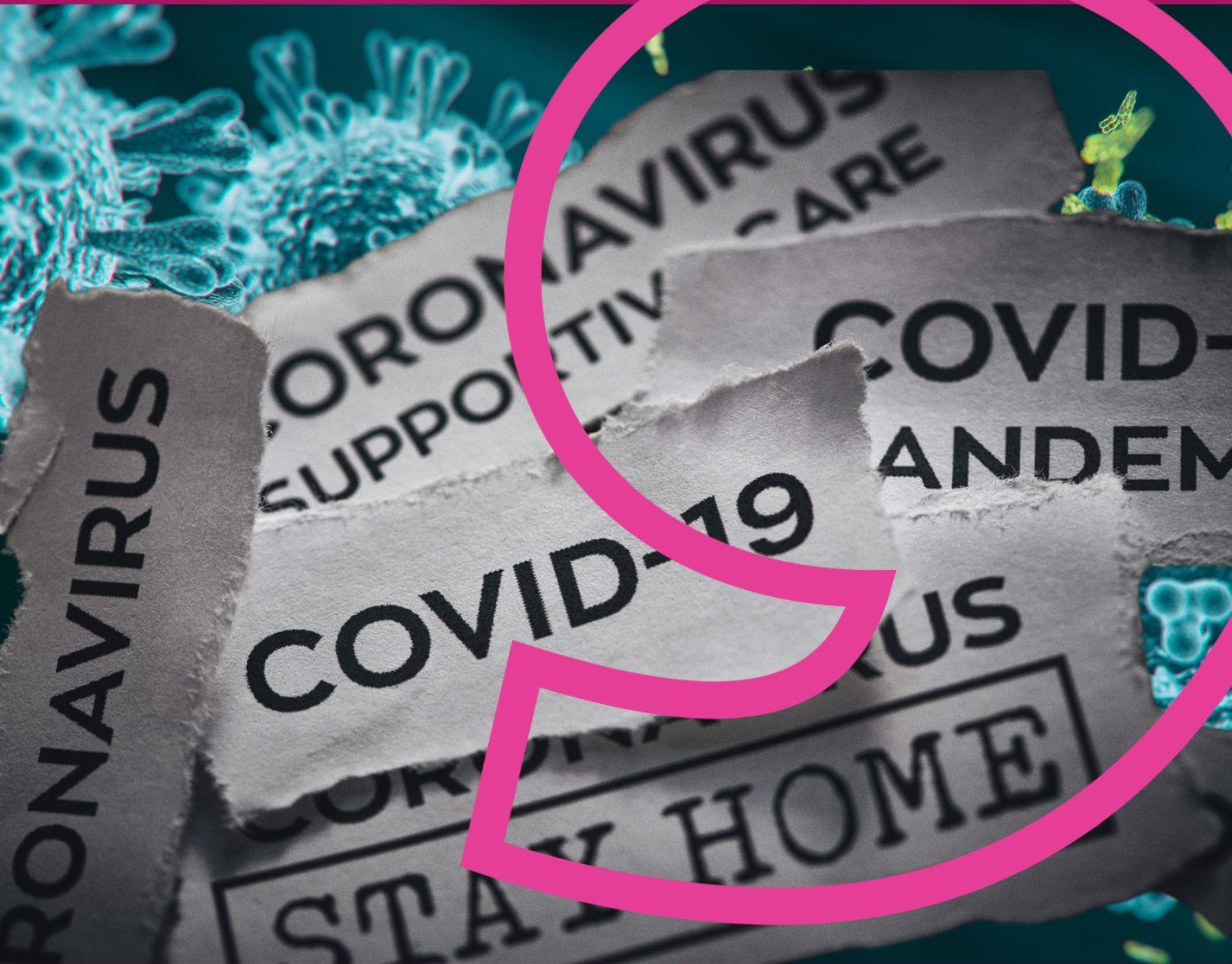


Long COVID support in Walsall report



February 2024

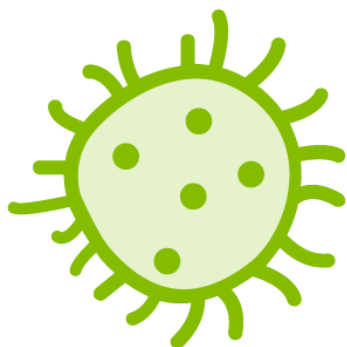


Engaging
Communities
Solutions

healthwatch
Walsall

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Introduction

Healthwatch Walsall is the local, independent voice of the public in health and social care services. We gather feedback from people accessing and using health and social care services about their experiences and work with service providers and commissioners to improve services. On this occasion we have carried out a project about the experiences of people living with Long Covid in Walsall.

An estimated 1.9 million people living in private households in the UK (2.9% of the population) were experiencing self-reported Long Covid (symptoms continuing for more than four weeks after the first confirmed or suspected coronavirus (Covid-19) infection that were not explained by something else) as of 5 March 2023. Long Covid symptoms adversely affected the day-to-day activities of 1.5 million people (79% of those with self-reported Long Covid), with 381,000 (20%) reporting that their ability to undertake their day-to-day activities had been “limited a lot”. Long Covid is an emerging phenomenon that is not yet fully understood¹.

Healthwatch Walsall wanted to look at the local vs national situation with regard to the level of support given to people with Long Covid in the Borough. We wanted to explore if there was sufficient support in primary care, secondary care, social care and employment. From a local perspective, the Long Covid Support Team have had circa 1360 referrals into their service since January 2021.

¹ Office for National Statistics

What is long Covid?²

“Long Covid” means your symptoms carry on even after your Covid infection has resolved.

It can also mean you are having new health problems after your Covid infection.

Most Covid infections get better within the first 4 weeks.

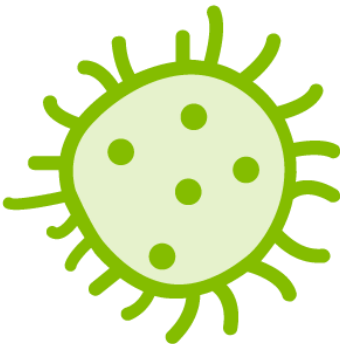
Medical professionals say there are two types of long Covid:

- Ongoing symptomatic Covid: When Covid symptoms carry on for 4 to 12 weeks
- Post-Covid Syndrome: When Covid symptoms carry on for over 12 weeks.

If you have long Covid, there are lots of different problems which can change over time.

These are the most common problems:

- Breathing and chest problems
- Brain problems
- Stomach problems
- Muscle and bone problems
- Mental health and mood problems
- Ear, nose and throat problems
- Skin problems



What we did

We produced and published a survey that encouraged Long Covid sufferers to take part and share their experiences and views around how Long Covid had affected them and what support they had or did not have.

The survey was available online, promoted on our social media platforms and paper copy promoted during our community engagement events.

We also asked for the survey to be distributed by various partner organisations such as: The Specialist Therapist team based in Walsall who deliver Long Covid support, Black Country Integrated Care Board (on their website and to promote to Walsall GP surgeries/practices), Walsall Local Authority, Local Councillors etc.

The project ran from July 2023 – Mid December 2023. The numbers are small, but it is not known how many people in Walsall have been registered as Long Covid sufferers and some Walsall residents who had Covid-19 may not know that they may fit into the category of a ‘Long Covid’ sufferer.

² NHS England Website

Who took part (Note: Not all participants answered all questions)



AGE

- 1 person was 25 - 34 years
- 6 people were 35 - 44 years
- 7 people were 45 - 54 years
- 3 people were 55 - 64 years
- 6 people were 65 - 74 years
- 3 people were 75 years or over



- 4 people were from the WS1 area
- 2 people were from the WS2 area
- 4 people were from the WS3 area
- 4 people were from the WS4 area
- 1 person was from the WS5 area
- 2 people were from the WS6 area
- 1 person was from the WS8 area
- 1 person was from the WS9 area
- 1 person was from the WS10 area
- 1 person was from the WS11 area
- 1 person was from the WV12 area
- 1 person was from the WV13 area



- 17 participants were women
- 9 participants were men



- 11 people said that they cared for either adults or children.
- 3 people were cared for
- 6 people self-cared
- 4 people preferred not to say



- 14 people were employed
- 6 people were unemployed
- 6 people were retired



- 11 people reported that they have a disability
- 14 people reported that they did not have a disability
- 1 person preferred not to say

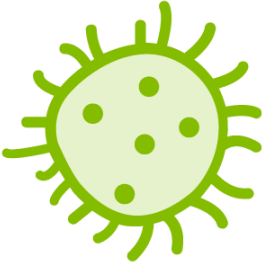
- 11 people reported that they have a long-term condition
- 13 people reported that they did not have a long-term condition
- 1 person preferred not to say

- 17 people were White British
- 1 person was Gypsy/Irish Traveller
- 1 person was White other



- 3 People were Asian Indian
- 3 People were Asian Pakistani
- 1 person was Black Caribbean

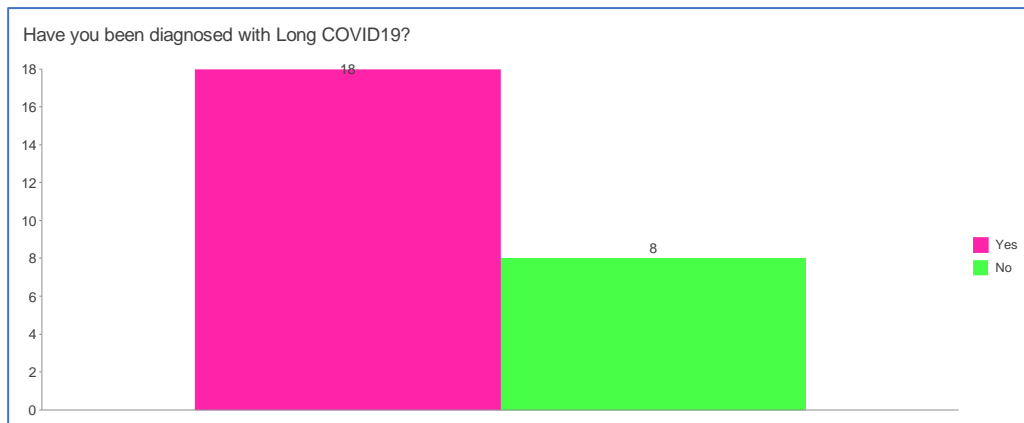
Findings



There were total of **27** responses to the survey. **However, it should be noted that not all of the people who took part in the survey answered all of the questions, therefore there will be discrepancies in the figures presented.** Due to the relatively low response rate the findings have been presented as participant counts rather than as percentages.

People were asked if they had been diagnosed with Long Covid.

- 18 people said that they had received a diagnosis of Long Covid
- 8 people said that they had not had a diagnosis of Long Covid.



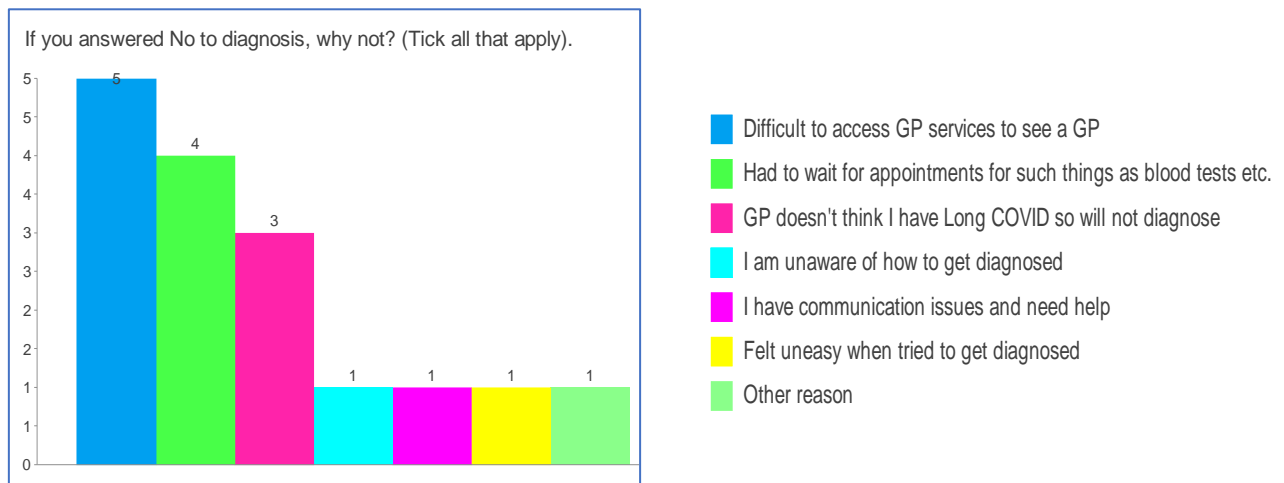
People who had not had a diagnosis of Long Covid were asked why they had not had a diagnosis. They were asked to indicate all of the reasons that applied to them.

- 5 people said that it they had not had a diagnosis because it was difficult to access primary care services to see a GP.
- 4 people said that they had had to wait for appointments for things such as blood tests.
- 3 people said that their GP does not think that they have long covid and will not diagnose them.

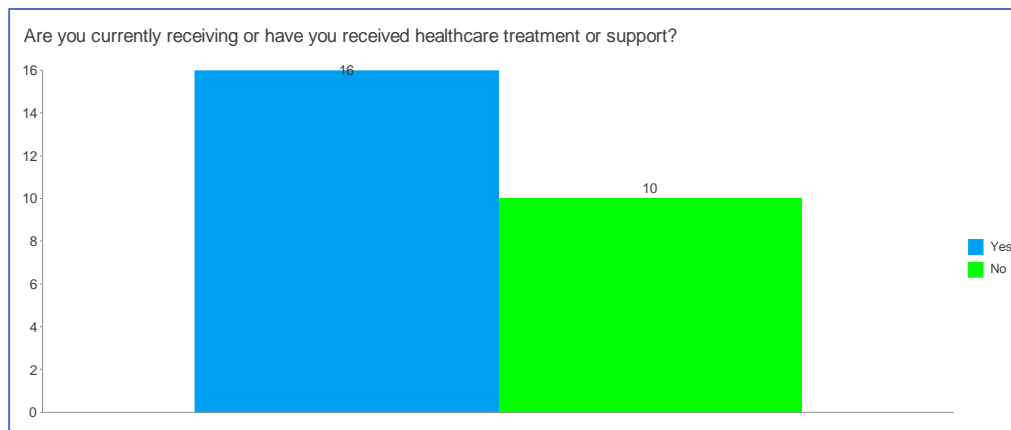
Being unsure how to get a diagnosis, having communication issues meaning they need help and feeling uneasy when they tried to get a diagnosis all got one response each.

- 1 other person said that there was another reason why they have not had a diagnosis.

They said that 'I have made doctors aware and from my symptoms they agreed I have Long Covid. There was no formal diagnosis and I had severe Covid and symptoms [in] November '19 and doctors did not diagnose me with COVID-19 as they said it was not in the country.'



- 16 people were currently receiving or had received healthcare support for their Long Covid.
- 10 people had not received healthcare support.

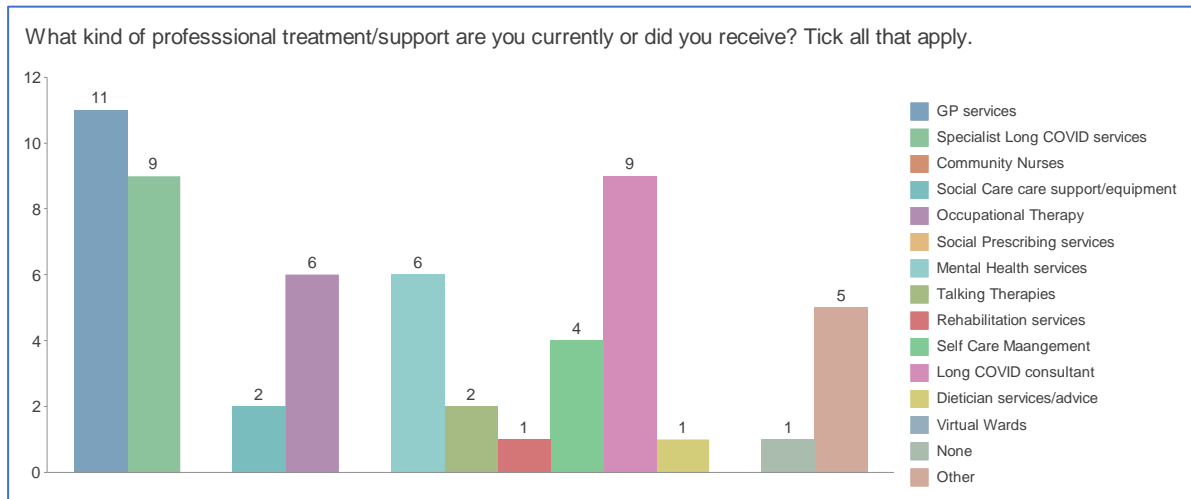


Those who said that they were receiving or had received healthcare support were asked what kind of professional treatment or support they had received. They were asked to indicate all of the types of support that they had received.

- 11 people had been supported by GP services.
- 9 people had been supported by specialist Long Covid services.
- 9 people had been supported by a Long Covid consultant.
- 6 people had received occupational therapy.
- 6 people had used mental health services.
- 4 people had used self-care management.
- 2 people said had received social care support or equipment
- 2 people had accessed talking therapies.
- 1 person had used rehabilitation services.
- 1 person had used a dietician.
- 1 person had accessed none of the services.
- 5 people gave **'other'** as an answer.

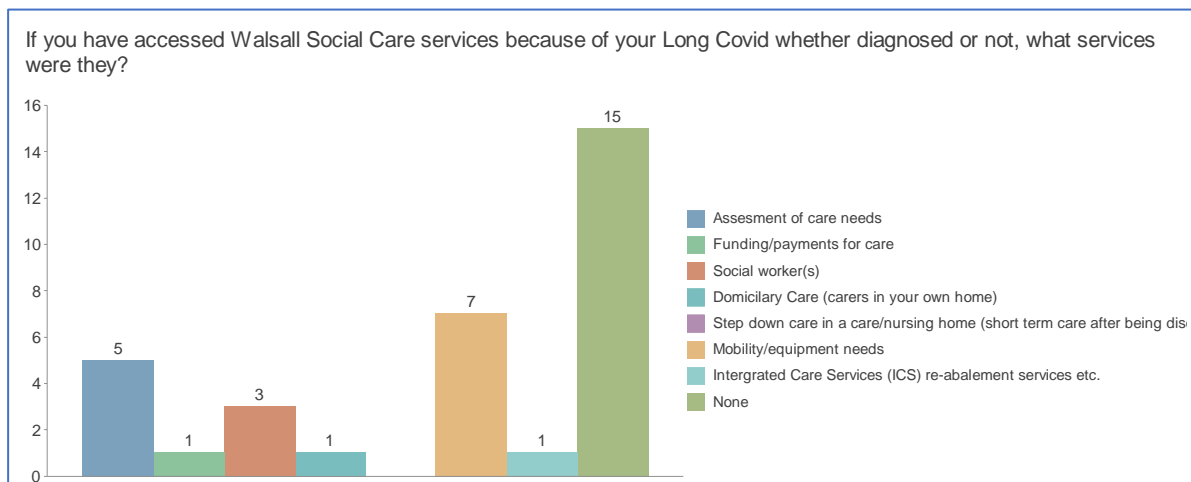
People who answered other were asked what services they had accessed.

- 3 had accessed psychological services.
- 1 person had accessed physiotherapy and a long covid course.
- 1 person had accessed homeopathy.



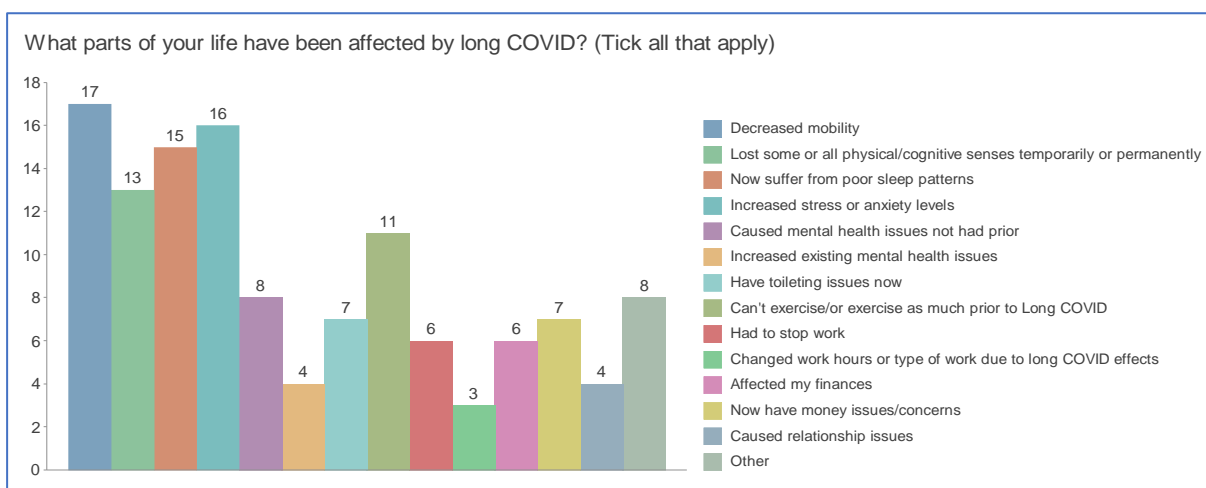
People were asked if they had accessed Walsall Social Care Services and what they had accessed.

- 15 people had not accessed social care services.
- 7 people had accessed mobility aids or equipment.
- 5 people had an assessment of their care needs.
- 3 people had social workers.
- 1 person was receiving funding for care as was domiciliary care and ICS reablement services.
-



When asked what aspects of their lives had been affected by Long Covid people were able to indicate all of the options that applied to them.

- 17 people had decreased mobility.
- 15 people now suffer from poor sleep patterns.
- 13 people cannot exercise or cannot exercise as much as before they had covid.
- 7 people had toileting issues now.
- 16 people had increased stress or anxiety levels.
- 8 people had mental health issues they had not had before.
- 4 people had seen an increase in existing mental health issues.
- 7 people now have money issues and concerns.
- 6 people had to stop work and 6 said that it has affected their finances.
- 3 people had to change their work hours or the type of work they did.
- 4 people said that their Long Covid had caused relationship issues.



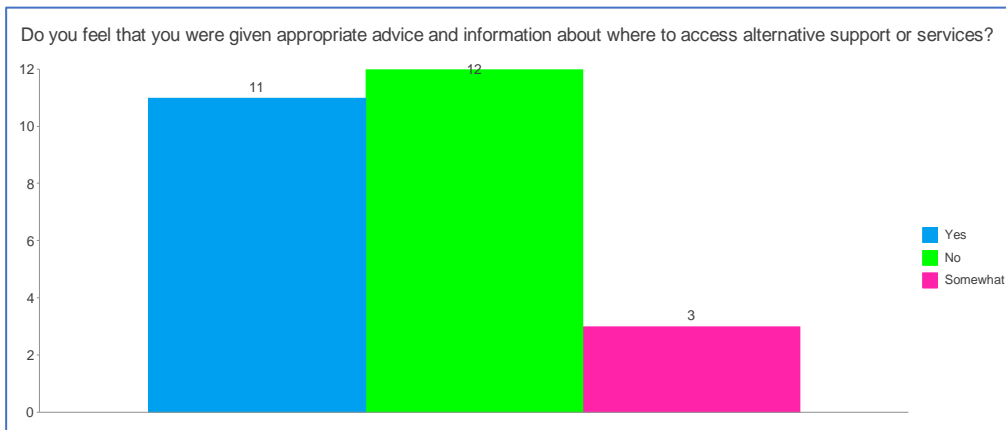
People who answered other were asked to explain more about their answer. People gave answers that included **'brain fog'** with one person saying that they **'have to second guess myself due to brain fog.'** Another said that their **'memory was affected for a while, lost a lot of weight because I lacked an appetite, and I lost a lot of hair.'**

Another person said that it has **'totally destroyed my health and life! Totally fit and healthy along with my two sons pre-covid. Now always ill from dysregulated immune system, CFS, PEM, chronic idiopathic urticaria.'**

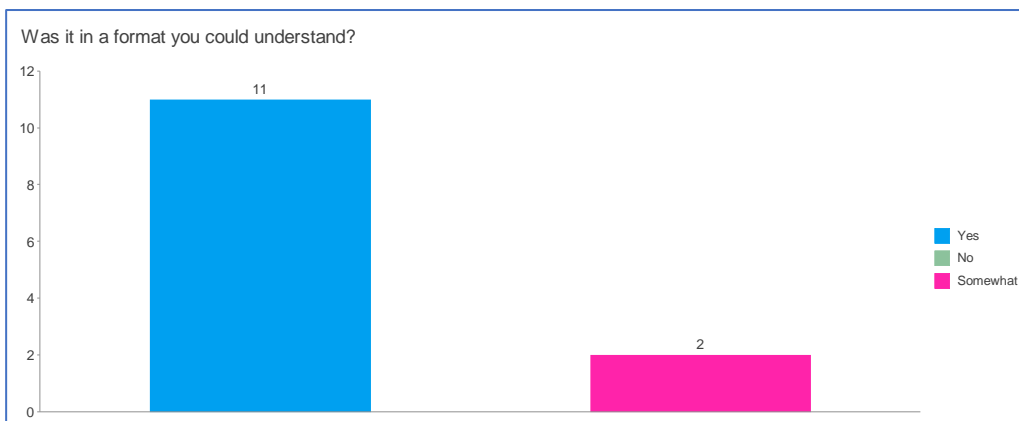
Another told how they now needed **'a family member as a carer to cook, clean and take care of me... Unable to drive due to symptoms.'**

Another person said that their **'condition had been dismissed by professionals/health providers.'**

- 11 people had been given appropriate advice and information on where to access alternative support or services.
- 12 people did not.
- 3 people felt somewhat that they had received appropriate advice and information.

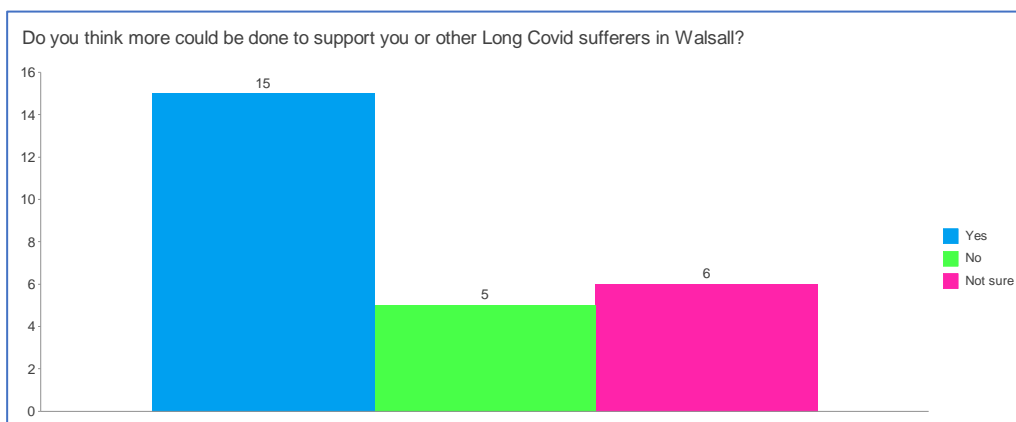


- 11 people received information and advice in a format that they could understand.
- 2 people received information in a format that they could somewhat understand.



When asked if they thought that more could be done to support them and other Long Covid sufferers in Walsall

- 15 people said that more could be done
- 5 people said that they did not think more could be done.
- 6 people were unsure.



People who said that they thought there was more that could be done to support Long Covid sufferers in Walsall were asked what they thought that support could be.

Primary care

There were a number of comments about how primary care support could be improved.

One person suggested that there should be a ***'GP qualified in Covid-19'***.

Another said that there should be ***'more support from GP and doctors rather than just saying rest with paracetamol.'***

Others said that there should be ***'better access to appointments'*** and that ***'COVID patients need to be given priority with GP appointments.'***

One person said that they ***'could not fault the help that I got, but I do know that other people had none of the help I had, all of my support was down to my GP and district nurses.'***

People in Employment

One person suggested that there was a need to ***'support those in work.'***

Accessible information

It was suggested by one person that information should be made ***'more accurate'*** and ***'more accessible to the older generation.'***

Peer support

One person suggested that peer support would be helpful saying ***'A better support network between people with Long COVID so that we can speak to each other.'***

Flexible and ongoing support

The need for access to support as it was needed was raised by people. One person said that ***'Due to the longevity of the illness it would be good to have support services available to support with daily challenges that arise and symptoms that come and go.'***

Another person made the point that ***'LC is a chronic condition that is not going away.'*** They felt that ***'follow up is important'*** and that care and support ***'need to continue.'***

Another person said that ***'all support listed [earlier in the survey] should be offered routinely. I was given to understand that there was not much support available whenever I asked questions.'***

Children's services

It was suggested by one person that there was a need for a children's service in Walsall.

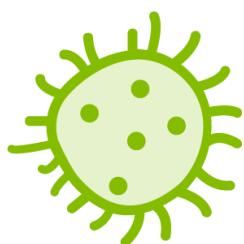
They said that ***'BCH has one but only get one appointment and no follow up with them.'***

They went on to say that ***'LC care is better for adults in Walsall.'***

Improved testing and diagnosis

The route to diagnosis was raised by one person who said that *'I was not initially believed. I had tests done but never appropriate feedback. I have never been formally diagnosed and I now have asthma but I haven't been diagnosed or seen a specialist regarding my breathing issues.'*

Another person spoke about the need for better testing. They said *'Better testing should be offered initially to rule out any damage e.g. organ damage and anything sinister/life threatening re symptoms [such as] cardiology, respiratory, immunology, etc. It took months and months for me to get any testing.'*



Conclusions

Although most of the people who took part in the survey said that they had had a diagnosis of Long Covid there were a number who had not had a diagnosis for a range of reasons.

However, the key reasons were largely concerned with access to primary care appointments, long waiting times for appointments, or their GP who is the gateway to further treatment and support not being in agreement with a perceived self-diagnosis.

People who had accessed health care and support used various services with the highest number using primary care services. There were some that had accessed specialist Long Covid treatment and support. Other services accessed including mental health and wellbeing services.

Most people had not accessed Social Care Services as a result of their Long Covid. However, of those that had, the highest number had accessed mobility aids or other equipment through social care services.

When asked how their Long Covid had impacted on their lives people gave a range of impacts that can be divided into impacts on their independence and physical health such as mobility issues; mental health impacts; impacts on their financial wellbeing and employment; and impacts on their relationships.

Access to appropriate information and advice about where to access support for Long Covid was given mixed feedback with more people saying that they had not received appropriate information and advice than those who had. There were a small number who gave a neutral answer.

Those who had received advice and information generally said that it was in a format that they could understand. Although there was some feedback that there was a need to make information more accessible to older people.

When asked if there were more that could be done to support people with Long Covid in Walsall there were more people who thought there was than those who did not. People made a range of suggestions of what could be done relating to access to and support from primary care; supporting people who are in work; improving accessibility of information; peer support; greater provision and flexibility of ongoing support; as well as services for children; and better testing and diagnosis of Long Covid.

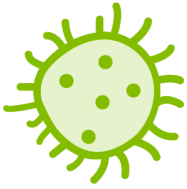
Recommendations

1. A greater awareness of Long Covid is needed by both the general public and medical professionals as people may not be aware that they are/may be suffering from Long Covid. Information around Long Covid and support should be made available in accessible formats as required by a patient.
2. The Black Country Integrated Care Board (BCICB) could consider a campaign directed at the Walsall public and medical professionals about Long Covid and available support in Walsall. This could run alongside any local Covid vaccination campaigns.
3. Access to GPs (Primary Care) is important as they are the referral route to any support. Consideration for appointments should be considered as important so that the referral process to support and information is timely.
4. Confirm that there is 'wrap around' support for Long Covid sufferers to address issues or concerns, such as: mobility improvement/equipment, social care support (own home or nursing care), finance advice, mental health treatment support, dietary advice, etc. So that patient led support/elements can be chosen to make an individual and focused treatment/support package.

If you have any suggestions that you feel may help then please contact us and we can share them with the services commissioners and services providers.

Tel; 0800 470 1660

Or Email: info@healthwatchwalsall.co.uk



Current support in Walsall

There are clinical staff who deliver a wide range of support/ services available to Walsall Long Covid sufferers who have been referred successfully to the services.

Such support includes: access and support to a Long Covid Consultant, dietary advice, self-care management, respiratory support, physiotherapy, Tai Chi, peer support groups, Long Covid Multi-disciplinary Team access, aids and equipment support and mental health support services.

We asked a few questions to the frontline delivery staff to get a better awareness of the current support/services and delivery.

Q. How do service users access the service/support?

Referral from a health care professional, often their GP.

Q. Do service users visit you or do you do home visits?

Mixture, depending on where they want to be seen. Can see at home, in clinic, in community setting or virtually. Or albeit of all of these options

Q. How long do service users stay supported?

As long as needed. Hugely varies, have some patient on for 1.5 years., sometimes only seen once and then referred onto other community-based services.

Q. How long has the service being going?

Initially set up in Jan 2021 (Dr Hartland's Clinic, psychology support etc), OT and PT added to service full time in December 2021

Q. How many service users have you supported?

Therapy approx. 750 patients since December 2021. Total patients to service: 2,769.

Q. What barriers are there for service users to access the service?

- Speed of referral(s) from GP.
- GP or patient may not understand that Long covid could be the cause of their problem(s).
- Lack of awareness of services from patient point of view that may be available to them in their local community.

Information and support

NHS England website: <https://www.england.nhs.uk/coronavirus/post-covid-syndrome-long-covid/>

Long Covid information link: <http://tinyurl.com/mss8wxwc>

Support information link: <http://tinyurl.com/mt6t7d63>

Your Covid recovery link: <https://www.yourcovidrecovery.nhs.uk/>

Black Country Integrated Care Board (BCICB) Long Covid information web page link: <http://tinyurl.com/5n7k2n6c>

Have you or are you suffering from
LONG COVID?

Or
Are you a friend, carer, or family
to a sufferer?
Would you like to join a support group?

Then come and join us
The First Tuesday Of Every Month
1.30pm to 2.30pm

BENTLEY COMMUNITY CENTRE
Wilkes Avenue, Bentley,
Walsall. WS20JN

With Guest Speakers,
Refreshments and a Chat
You can Share Experiences
and Help find the Support
or Care You Need.

Information for family, friends and carers
Supporting your family member, relative or friend following their COVID illness can be challenging. You may be providing emotional and physical help in addition to all your other responsibilities. This can be a very stressful time for you both and we hope the information within the website will give you reassurance and support during their recovery.

Supported by Old Hall Peoples Partnership – Resilient Communities Locality Lead – West

There is a newly formed peer support group for Long Covid sufferers that meets at Bentley Community Centre, Wilkenson Avenue, Bentley, WS2 0JN. Telephone the centre for more information: **01922 721097**

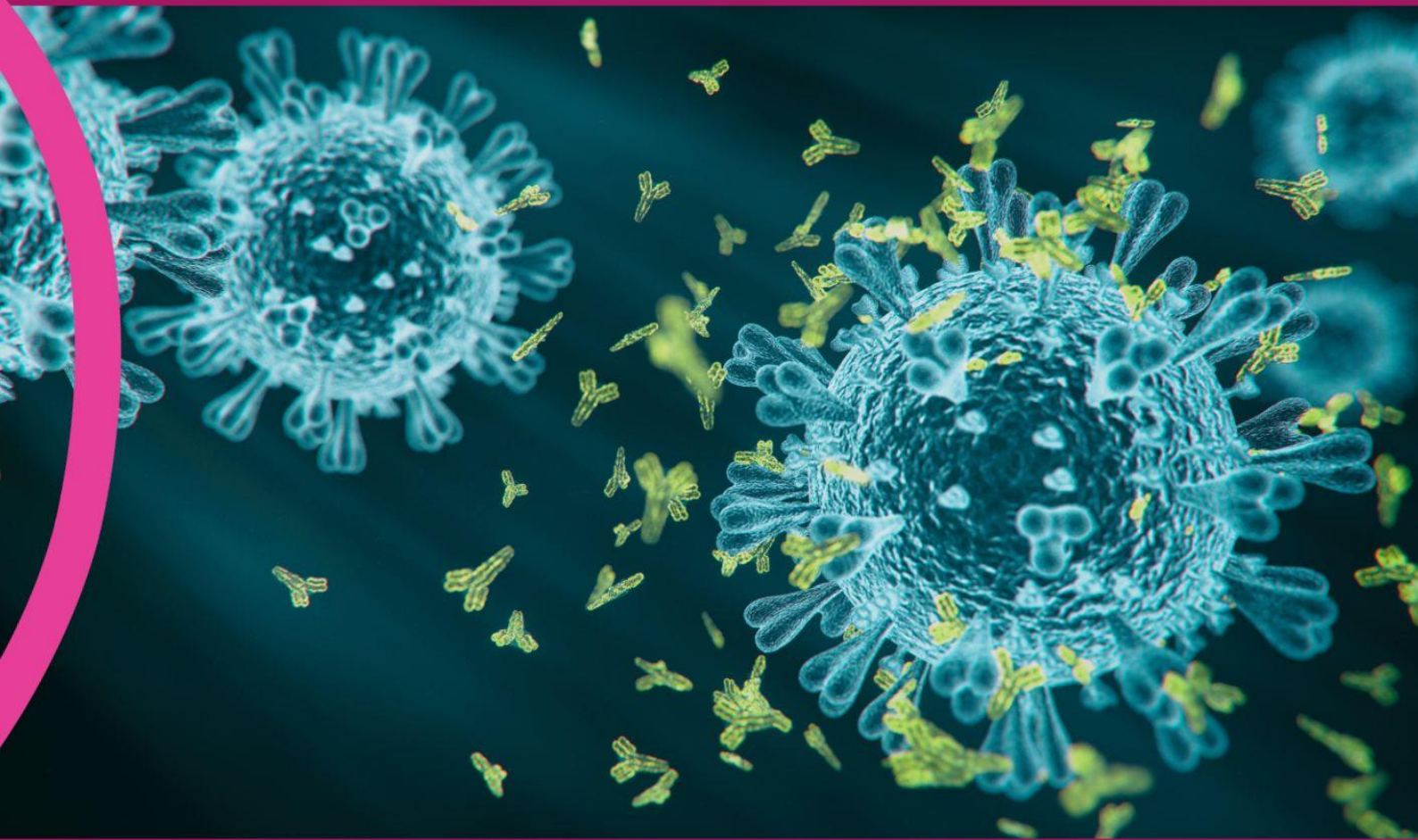
Acknowledgements

Healthwatch Walsall would like to thank all participants who took the time to complete the survey and to the Long Covid Support Team for their assistance in disseminating surveys to their service users. We would also like to thank our partners for sharing the survey through their network of contacts.

healthwatch

Walsall

Share your health or social care services experiences
by visiting our 'Have Your Say' section of our website
<https://www.healthwatchwalsall.co.uk/share-your-views>



Contact us

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