

Long COVID Feedback

Data from – 1st January - 1st March 2022



- 37 people have taken part in our feedback survey.
- 30 people have tested positive for Covid-19
- 5 people did not test for Covid-19 but believe they did have it.
- 2 people tested negative for Covid-19 but thought they still may have had it.
- The majority of people who had taken the survey felt their mental and physical health had been impacted.
- More than two thirds of people have experienced extreme tiredness since Long Covid.
- Just under half the people who taken part in the survey have been diagnosed with Long COVID.
- Only 3 people were referred to the Long COVID support group but this could be that they weren't established when they were diagnosed.

Which symptoms have you had from Long COVID?

Αι	nswer Choices	Response Percent	Response Total
1	extreme tiredness (fatigue)	86.49%	32
2	shortness of breath	56.76%	21
3	chest pain or tightness	37.84%	14
4	problems with memory and concentration ("brain fog")	75.68%	28
5	difficulty sleeping (insomnia)	56.76%	21
6	heart palpitations	40.54%	15
7	dizziness	45.95%	17

A high number of people 86.49% who have taken the survey claimed they had extreme tiredness.



Which symptoms have you had from Long COVID?

8	pins and needles	27.03%	10
9	joint pain	45.95%	17
10	depression and anxiety	45.95%	17
11	tinnitus, earaches	21.62%	8
12	feeling sick, diarrhoea, stomach aches, loss of appetite	27.03%	10
13	a high temperature, cough, headaches, sore throat, changes to sense of smell or taste	40.54%	15
14	rashes	29.73%	11

Tinnitus and earaches were the least common symptom but still over 20% of survey takers had this symptom.

What has been the impact of Long COVID?

Aı	nswer Choices	Response Percent	Response Total
1	My ability to keep up with home chores / admin	64.86%	24
2	My ability to take care of myself	24.32%	9
3	My ability to work or the number of hours I can work	37.84%	14
4	My ability to attend or take part in education	2.70%	1
5	My personal relationships	35.14%	13
6	My mental health and wellbeing	72.97%	27
7	My ability to make plans	45.95%	17

It is clear that the Mental Health and wellbeing of survey respondents was affected with 73% reporting that having long covid has had an impact.



What has been the impact of Long COVID?

My ability to do things that I enjoy	72.97%	27
My physical health	72.97%	27
My caring/parenting responsibilities	27.03%	10
My household or personal finances	24.32%	9
Long COVID has not impacted my life	0.00%	0
Other (please specify):	5.41%	2

As well as the reduced ability to undertake everyday tasks, people's Physical health and their ability to do things that they enjoyed were also impacted due to Long COVID.

Lack of focus, making mistakes at work, irritability due to tinnitus

Long COVID and Job security

- 14 people responded to this open-ended question.
- With only 1 person saying that this has affected their job security.
- 6 people reported that they have been off work for over 6 months.

I have had to give up my job as it was physical, they have finished me.

I have been put under pressure to go back to work before I feel ready to return.

I work in the NHS so not really affected me so far but felt guilty being off work knowing we were short staffed due to covid etc

Long COVID and physical and mental wellbeing

- 32 people responded to this open-ended question.
- With 10 people saying that they used to go walking more and now it is a struggle.
- 10 people have also said that the mental health/anxiety has detartrated since having Long COVID.

Anxiety has impacted on daily activities and shortness of breath and low oxygen levels has been a struggle. Brain fog and being wiped out doing anything is still impacting

I am unable to climb stairs without getting breathless. This has impacted my ability to enjoy outside exercise like I used to and limited my day to day activities which is consequently impacting my mental health.

Findings Comments on Long COVID affecting physical and mental wellbeing

I have had to start on anti depressants as I have become very anxious. I was previously fit, walked 14, 000 steps most days, now I am in bed most of the time, and going in the back garden seems like a massive physical feat

I have no energy and I'm so tired all the time. I was a very active person before I had covid, my memory is shocking, and it is stopping me do my voluntary gardening at a local school, just no energy, it's awful it makes me feel so down because I have to ask for help from my family to do normal household chores

> Lack of motivation to do tasks, in the workplace. Feeling low or 'can't be bothered' in general.

How long have you been living with Long COVID

1-2 months	24.32%	9
3-5 months	18.92%	7
6-8 months	13.51%	5
9-11 months	10.81%	4
12+ months	32.43%	12
I have recovered	0.00%	0

Everyone who took part in the Long COVID survey, no one has yet fully recovered from their symptoms.

GP/ Other health care provider about Long COVID

Have you been to see your GP/ other health care provider about your Long COVID symptoms?

- 24 people said yes
- 13 people said that they haven't

If they had not been to see their GP they were asked why

I didn't know that I was experiencing Long Covid	38.46%	5
I am embarrassed	7.69%	1
I didn't think my needs were a priority	23.08%	3
I didn't think my GP could help	30.77%	4
I tried but I couldn't get through to my GP	7.69%	1

Findings Getting Diagnosed for Long COVID

Out of 24 responses

13 people have been diagnosed with Long COVID while 11 respondents were not diagnosed.

Of the 13 people that were diagnosed with Long COVID

- Just under half were diagnosed in the last 2 and 3 months.

Some people that were not diagnosed with Long COVID were diagnosed with a chest infection and high blood pressure, respectively.

Findings Long COVID Support Groups

Only 3 people were referred to a Long COVID support group following diagnosis of Long COVID by their GP.

Feedback from the Long COVID support group

- Really good to know that there are others going through similar experiences. It is important to know what we can do to help with easing symptoms and how it has affected others.
- Went once to the support group but not again [they didn't say why]
- My wife got some details, but I was too anxious to attend

Findings from the



Findings from the Long COVID support Group

Date of meeting: 26th January 2022

We attended the Stockport Long Covid Support Group to speak to members of the group, this is what they told us:

- The Long COVID group has helped them with advice, and it helped them to understand that they are not alone.
- The local M.E Group has helped people understand chronic fatigue and they have since provided advice also.
- GPs have also helped in some cases offering advice.
- One of the members was referred to a doctor specializing in Long COVID.

Findings from the Long COVID support Group

Effects of Covid on members of the group

- Brain fog (This is a word we have seen used all throughout the survey)
- Loss of hair and fatigue.
- Mental health decline
- Dry eyes and rashes appeared
- Lost in taste and smell (common in a lot of Covid cases)
- Some of the exercise groups recommended were too intensive for members

Summary Points

- Regardless of having a diagnosis of Long Covid, those experiencing symptoms have reported that their daily living has been affected
- The impact has been felt on the following:
 - The ability to carry out daily chores/tasks,
 - Maintain previous working levels, with some respondents being off for significant periods,
 - Maintain personal relationships and being able to make future plans,
 - Physical health has been affected including taking part in activities previously enjoyed,
 - Most of all mental health has been impacted

Summary Points

- Whilst some respondents did not feel comfortable with attending a support group, many found them valuable in knowing they were not alone in experiencing their symptoms and the effects these were having on their life.
- They found the information shared was useful and helpful.

Points for consideration

- Promotion and use of the <u>Your Covid Recovery website</u>
- Consistent approaches used by primary care to support patients
- Evaluating support groups with the potential to promote and establish others to meet needs
- Utilise the expertise of other existing groups such as ME support
- Alternatives for those not comfortable with or who are anxious about attending a support group
- Information and guidance in the workplace for employers supporting employees with long covid symptoms
- Targeted mental health support for those with long covid symptoms
- Coordinated referrals to low impact exercise groups such as tai chi

Demographics

Age (16 - 25 to 49 years old) (11 - 50 to 64 years old) (4 - 65 to 79 years old)

Gender (**27** - *woman*) and (**7** - *man*)

Employment Status

(14 – Full time employed) (10 Part time employed) (4 – Retired) (4 – on sick leave) (1 – Unemployed)

Postcode

(2 - SK1)(2 - SK2)(5 - SK3)(3 - SK4)(2 - SK5)(2 - SK6)(3 - SK7)(2 - SK8)

For more information

Healthwatch Stockport Land O' Cakes 48 Middle Hillgate Stockport Greater Manchester SK1 3DL

www.healthwatchstockport.co.uk

t: 0161 974 0753

e: info@healthwatch.co.uk

@HWStockport

f Facebook.com/Healthwatchstockport

