



LONG COVID SURVEY - SUMMARY OF NOTABLE FINDINGS

Independent research, not peer reviewed

NO LIABILITY

The content of this document consists of respondents' answers to survey questions, and comments directly from the respondents, based on their own opinions, observations and experiences. They do not constitute advice, medical or otherwise, or recommendations in any way.

Background

This survey was created on an independent basis as a broad scoping tool for the purpose of researching detailed background medical, environmental and lifestyle factors, and their possible effects (or otherwise) on the incidence and experience of Long Covid.

The survey was open to participants from 11th November 2020 to 1st January 2021. In total 527 people responded to the survey, with 378 people completing it fully. All results are given as actual numbers, or percentages of respondents to that question, rather than percentages of total participants. Survey participants became aware of the survey primarily via Long Covid/Covid-19 Facebook groups, Instagram, and by word of mouth, meaning possible sample bias. It was completed anonymously.

Some notable findings are reported below, rounded to nearest whole percentage points. Full results are available in the 'Full Results' PDF document on www.longcovidsurvey.com/survey-results.

Notable findings

First Infection and Testing

- 68% of respondents reported that they believe they were first infected with Covid-19 in March or April 2020 (52% in March, 16% in April).
- 26% of respondents reported having a positive Covid-19 test when they were first infected. [Noting that general testing was not widely available in March 2020 in the UK].
- 49% of respondents reported that at the time of responding, they had not been tested for Covid-19 antibodies.

Respondents and health history

- 84% of respondents to the question identify as female
- 77% of respondents to the question state their age as between 35 and 59
- 69% reported that prior to Covid-19 infection they did not have any long-standing illness, disability or infirmity
- 76% reported that prior to Covid-19 their general health was Good or Very Good. Just 3% reported it as being Poor or Very Poor
- 76% reported that they had not previously been diagnosed with any respiratory illnesses or conditions (in contrast 67% reported experiencing breathlessness at the time of responding).
- 74% reported that they had not previously experienced notable fatigue prior to Covid-19 (in contrast, 90% reported experiencing fatigue at the time of responding)
- 94% reported that they had not previously been diagnosed with any cardio-vascular conditions prior to Covid-19 (in contrast, 52% reported experiencing heart palpitations at the time of responding)

Copyright 2021 – not to be reproduced, published or distributed (in part or whole) without permission. The content of this document consists of respondents' answers to survey questions, and comments directly from the respondents based on their own opinions, observations and experiences. They do not constitute advice, medical or otherwise, or recommendations in any way.

- 97% reported that they had never been diagnosed with cancer
- 92% reported that they had not ever been diagnosed with diabetes
- 80% rated their typical energy levels prior to Covid-19 as having been Good or Very Good. 4% rated their typical energy levels prior to Covid-19 as having been Poor or Very Poor. The remainder rated their prior energy levels as OK.
- 79% reported that they had not ever had an abnormal thyroid function test result

Covid-19 and Long Covid symptoms experienced

- The 5 most commonly reported symptoms to have been experienced during the **original** Covid-19 infection are:
 - Fatigue - 74%
 - Headache - 62%
 - Shortness of breath - 61%
 - Aching - 57%
 - General feeling of malaise - 56%
- 66% categorise their health at the time of responding as Poor or Very Poor (noting the previously reported 76% categorising it as having been Good or Very Good prior to Covid-19)
- 76% categorise their energy levels at the time of responding as Poor or Very Poor (noting the previously reported 80% stating it as having been Good or Very Good prior to Covid-19)
- Amongst a large number of symptoms experienced, the 5 most commonly reported **Long Covid** symptoms to be experienced at the time of responding to the survey are shown below. Notably, brain fog and forgetfulness are within the top 5 for **Long Covid** but not the original **Covid-19** infection:
 - Fatigue - 90%
 - Brain fog - 73%
 - Breathlessness - 67%
 - Aching/general pain - 63%
 - Forgetfulness - 63%
- 58% reported that they had **not** experienced the same symptoms before Covid-19
- 47% reported that they are not currently receiving ongoing medical help

Impact on lifestyle

- 66% of respondents reported that they had exercised 3 times or more per week **prior** to Covid-19, whereas 77% of respondents reported they can **now** exercise only very little due to symptoms, or are not able to exercise at all.
- Changes to sleep patterns were widely reported (respondents could pick any descriptions which apply. The largest differences between reported sleep prior to Covid-19 and since Covid-19 are highlighted in ***Bold Italics*** on the next page):

Sleep Patterns

Description	% of respondents who reported this applying PRE Covid-19	% of respondents who reported this applying SINCE Covid-19
6 – 8 hours per night	65%	29%
Variable – sometimes good, sometimes poor	25%	30%
Good quality	23%	3%
Broken sleep	18%	57%
More than 8 hours per night	15%	23%
Less than 6 hours per night	12%	25%
Poor quality	8%	43%

Impact on income/family

- 41% of respondents reported that their income has reduced since Covid-19
- 44% of respondents reported that they were either on sick leave or working in some reduced capacity due to their health/symptoms at the time of responding.
- Individual comments include reference to home-makers who struggle with their tasks now, people with multiple sources of income receiving sick pay for some roles and not others, contracts not being renewed, being made redundant (not necessarily linked to symptoms), zero hours contracts and students.
- 69% of respondents reported that where they believed other members of the household to have had Covid-19, the other household members have not experienced symptoms for more than 12 weeks (Long Covid).

Help with symptoms

- The survey respondents have provided a considerable amount of information regarding the medical tests/treatments they have received or are awaiting, and their feelings regarding their treatment. Details are available in the Full Results document (pages 52 – 63)
- Respondents are trying many different dietary changes, supplements, alternative treatments and other methods to help ease their symptoms. Details are available in the Full Results document (pages 115 – 118, 138 – 154)
- The table over the page summarises the most common 10 themes reported in the **106 responses** to the question “If you have found any other non-medical ways in which to relieve your current symptoms please give details here”. Details are available in the Full Results document (pages 151 – 154)

Copyright 2021 – not to be reproduced, published or distributed (in part or whole) without permission. The content of this document consists of respondents’ answers to survey questions, and comments directly from the respondents based on their own opinions, observations and experiences. They do not constitute advice, medical or otherwise, or recommendations in any way.

Comment	Number of mentions
Rest	24
Meditation/mindfulness	11
Sleep	10
Pacing	10
Breathing exercises/deep breathing/breath work/Wim Hof	7
Yoga/stretching	7
Exercise/gentle exercise	7
Drinking - more water/more healthily/mint & lemon, electrolytes	7
Baths/baths with magnesium/salts	6
Heat - pads, showers, hot water bottles, sauna blanket	6