

## Supplementary B to Submission 309: Findings from our mini-survey

### Background

We ran a short survey among members of the Long COVID Australia Facebook Group to collect additional data on treatments and health status to help answer a few questions that we had.

This mini survey was open for only 6 days in early February. A total of 449 respondents completed this survey. We cannot link data from this mini-survey with our original survey as we did not collect any identifying information for linkage.

Most of the participants were female (84%). Similar to our first survey, the majority of respondents were between 40 to 59 years.

As with our other results, we have not independently QA'd these results due to a lack of resources and time.

### Results

#### Treatments

We asked about 33 specific treatments in our supplementary survey. The full list is presented in Table 2 at the end of this document.

The five most common treatments trialled by Long COVID patients were:

1. Pacing
2. Anti-inflammatories
3. Vitamin B
4. H1 antihistamines
5. Probiotics

All top 5 treatments that have been trialled are treatments that patients are able to research and obtain themselves. This highlights how we are totally relying on our own research and often with no health professionals helping us.

Treatments with the most benefits as reported by Long COVID patients are below. These proportions are valid proportions (among those who have tried a treatment).

1. Pacing (83.4 % improved)
2. H1 antihistamines (62.3 % improved)
3. LDN (61.7 % improved)
4. H2 antihistamines (58.2 % improved)
5. Corticosteroids (57.9 % improved)

Candidate treatments highlighted in a recent review<sup>1</sup> are summarised in Table 1. The findings suggest many potential treatments (those requiring prescription, healthcare professional involvement) are not readily available to Long COVID patients in Australia. There is also a need to increase awareness of simple, cost-effective treatments among health professionals so that they

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<sup>1</sup> Davis, H.E., McCorkell, L., Vogel, J.M. *et al.* Long COVID: major findings, mechanisms and recommendations. *Nat Rev Microbiol* (2023). <https://doi.org/10.1038/s41579022-00846-2>

could recommend them to their patients. We should also be running more clinical trials on these candidate treatments.

*Table 1. Candidate treatments (as per Davis et al. 2023)*

<b>Treatments</b>	<b>% tried among survey respondents</b>	<b>% improved among those who tried treatment</b>
Pacing	81.6%	83.4%
IV immunoglobulins	0.05%	10.5%
Low dose naltrexone (LDN)	20.8%	61.7%
Coenzyme Q10	39.8%	45.5%
Apheresis	0.04%	6.3%
Paxlovid	0.10%	40.0%
Valacyclovir, famciclovir, valganciclovir and other antivirals	0.09%	26.5%
Sulodexide	0.05%	0.0%
Probiotics	57.5%	43.5%
H1 antihistamines	61.6%	62.3%
H2 antihistamines	37.0%	58.2%
Pycnogenol	0.04%	0.0%
Vagus Nerve Stimulation	0.30%	55.5%

### Top 3 treatments

Pacing was nominated by 52% of respondents as their top 3 treatments that helped them. As shown earlier, pacing was also the most common treatment tried by survey respondents. H1 antihistamines were nominated as their top 3 by 22% of respondents and 16% nominated anti-inflammatories as their top 3. Treatments that were nominated as their top 3 about 10% of respondents were Vitamin B, LDN, antidepressants (mainly used for pain) and beta blockers.

Sadly, 13% of respondents indicated 'none' when asked to nominate top 3 treatments that helped them.

### How treatments helped

About two thirds of respondents indicated that the treatments they have tried helped with their ability to perform day to day activities. Half said the treatment helped in reducing the number of symptoms they have experienced. For about a third, treatments helped in reducing the number of relapses or exacerbations they experienced.

### Recovery status

We asked respondents about how they were since they first developed their Long COVID symptoms. We have not analysed this yet by duration of Long COVID.

One in five reported that their symptoms have gone up and down and there was no consistent trend. A similar proportion said they were 1% to 30% better than they were.

Only 1.6% said they were completely recovered. And 18% said they were 61% to 99% better.

One in ten reported that they were feeling worse now than when they first developed Long COVID.

### Duration of Long COVID symptoms

The majority (55%) respondents have had Long COVID symptoms for 7 to 12 months, highlighting the start of the Omicron infections and removal of many of the public health protections in Australia. One in five have had symptoms for a year to 18 months and one in eight have had symptoms for 3 to 6 months. About 6% reported having symptoms for more than 2 years but less than 3 years.

### Health status pre-Long COVID

Over 40% of respondents reported their health status was very good before they developed Long COVID. A further third reported that their health was excellent before Long COVID. Less than 1% said their health was poor before Long COVID. This shows that the vast majority (92%) of people who developed Long COVID were healthy people (good, very good and excellent health status).

Before Long COVID, 40% reported that they had pre-existing condition(s). However, among people with pre-existing conditions, the majority (87%) still rated themselves as healthy before Long COVID. For those with no-pre-existing conditions, all reported that they were healthy pre Long COVID.

### Health status now with Long COVID

In contrast to findings on health pre-long COVID, 63% of respondents reported that their health was poor (<1% before Long COVID). The proportion of healthy people now is less than one in ten (9%).

The overwhelming majority (77%) of people with pre-existing conditions said Long COVID had made their pre-existing conditions worse. One in five reported Long COVID had no impact on pre-existing conditions.

*Table 2. All 33 treatments we asked about in our mini-survey*

<b>Treatment</b>	<b>n tried</b>	<b>% tried</b>	<b>% valid improved</b>	<b>% valid worsened</b>	<b>% valid no difference</b>
LDN	81	20.8	61.7	13.6	24.7
Vitamin B	256	62.7	39.5	6.3	54.3
Nattokinase	54	14.2	44.4	14.8	40.7
Serrapeptase	37	9.7	32.4	21.6	45.9
CoQ10	156	39.8	45.5	6.4	48.1
Antidepressants (could be for pain)	145	36.3	42.1	9.7	48.3
CBD Oil	71	18.3	53.5	11.3	35.2
H1 antihistamines	247	61.6	62.3	3.6	34.0
H2 antihistamines	146	37.1	58.2	6.2	35.6
Prebiotics	141	35.4	37.6	7.8	54.6
Probiotics	230	57.5	43.5	6.5	50.0
Pacing	337	81.6	83.4	1.5	15.1
Hyperbaric Oxygen Therapy	27	7.1	25.9	29.6	44.4
Corticosteroids	121	31.0	57.9	9.9	32.2
Montelukast	36	9.6	19.4	30.6	50.0
Aspirin	138	35.8	35.5	3.6	60.9
Anti-inflammatories	262	63.4	51.1	3.1	45.8
Vagus Nerve Stimulation	119	30.4	55.5	7.6	37.0
Beta blockers	89	23.1	56.2	16.9	27.0
IV Vitamins	55	14.4	40.0	21.8	38.2
Nutraceuticals	64	16.8	39.1	14.1	46.9
Melatonin	187	46.5	47.1	9.1	43.9
Colchicine	50	13.1	40.0	24.0	36.0
Warfarin	25	6.7	16.0	32.0	52.0
Paxlovid	40	10.4	40.0	15.0	45.0
Apheresis	16	4.2	6.3	56.3	37.5
Pycnogenol	16	4.3	0.0	43.8	56.3
IV immunoglobulins	19	5.0	10.5	47.4	42.1
Sulodexide	19	5.1	0.0	47.4	52.6
Valacyclovir, famciclovir, valganciclovir and other antivirals	34	8.9	26.5	29.4	44.1
Stellate ganglion block	19	5.0	15.8	42.1	42.1
Statins	30	11.9	16.7	33.3	50.0