



Report on the impact of Covid-19 on ME

Preliminary findings from a survey on ME and Covid-19

Summary

This summary report provides the preliminary findings from responses to the survey we are carrying out, in partnership with Action for ME, to identify the impact that Covid-19 has on people with ME. The report is based on the analysis of the 220 responses received in the three weeks after the survey went live in late March.

These initial responses show clearly that Covid-19 had a significant impact on respondents, with more than three quarters (76%) of respondents saying that Covid-19 made their ME symptoms worse. This impact appears to be long lasting, with over two thirds of respondents reporting that the worsening in symptoms has lasted more than 6 months and have still not resolved.

The wider impact of Covid-19 is illustrated by the negative impacts on the health of respondents, including 72% reporting new symptoms. The analysis also shows that respondents' ability to attend education or work had decreased and their use of health services had increased significantly, highlighting the potential economic impact of Covid-19.

Survey Background

#MEAction UK and #MEAction Scotland are collaborating with Action for ME to conduct a survey gathering evidence of the impact of Covid-19 on people with ME. The aim of the survey is to provide data that can be used, along with personal stories, to help our campaign to make the government aware of the impact that Covid-19 is having on people with ME and the need to provide effective support to those affected.

The survey was made available online in late March and disseminated via social media by Action for ME, #MEAction UK and #MEAction Scotland. To be eligible, respondents need to have a diagnosis of ME or CFS, suffer from post exertional malaise (PEM) and have had Covid-19 confirmed by either a clinical diagnosis, a positive test or having had symptoms as detailed by the Department for Health.

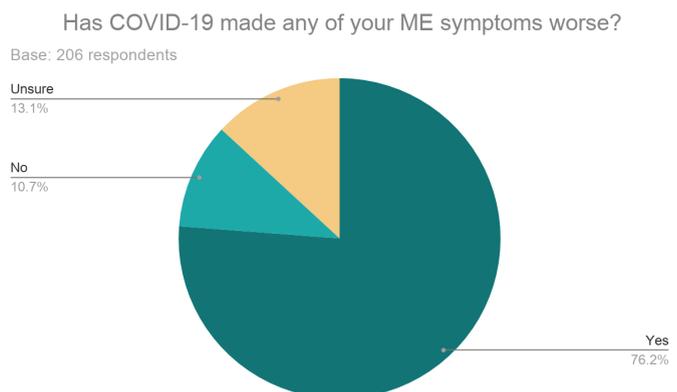
The survey was launched on 22 March 2021 and will remain open for responses over the next few months. This report is based on 220 responses received between 22nd March and 12th April. Overall, the demographics of people with ME responding to the survey are broadly representative of the general population of people with ME. Approximately 80% of respondents were women. 16.6% reported they had severe ME and 2.0% reported very severe ME. The accepted distribution of people being housebound or bed bound is 25% (IOM, 2015; Pendergrast, 2016).

Impact of Covid-19 on ME Symptoms

76% of respondents reported that Covid-19 had made their ME symptoms worse.

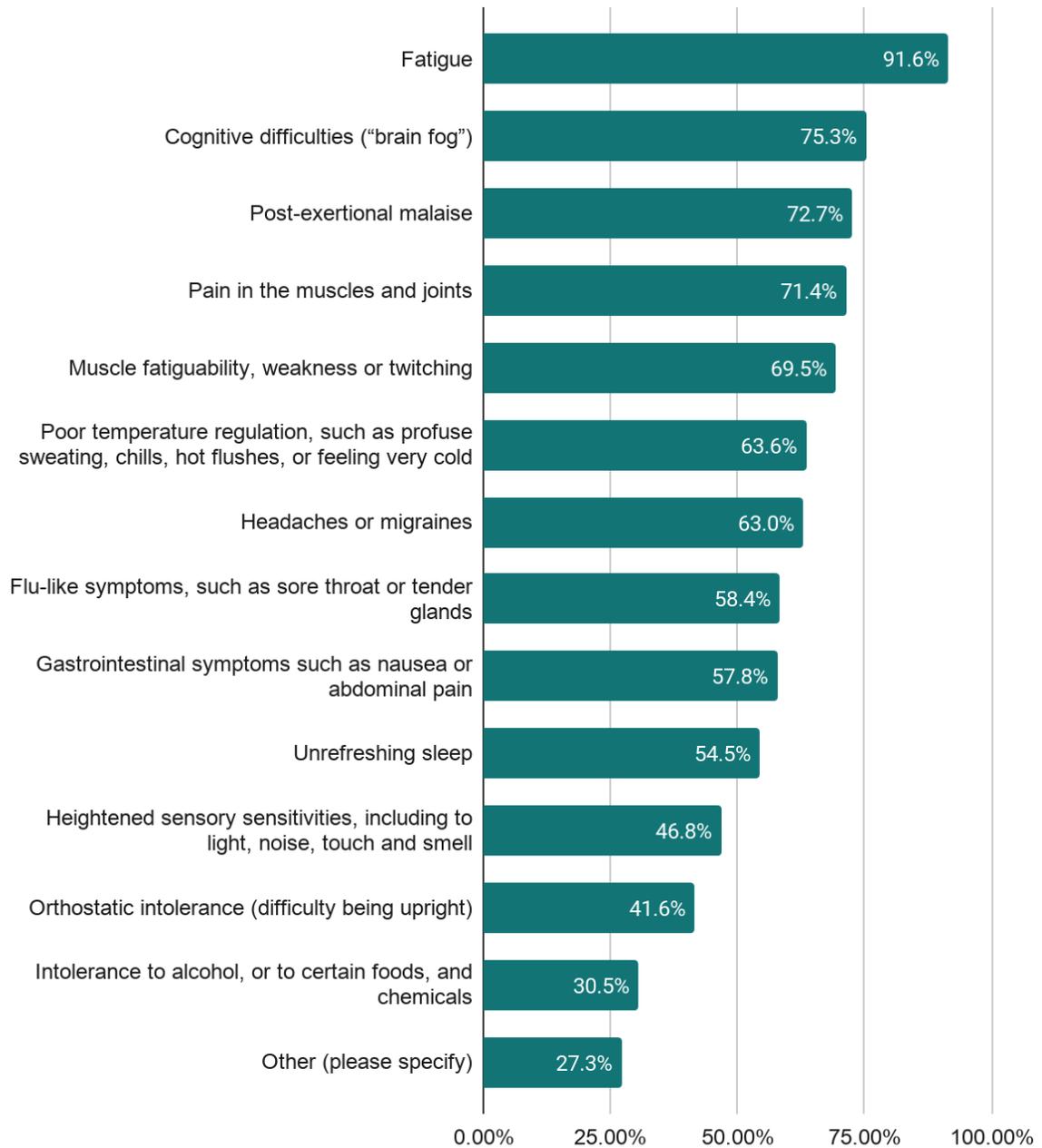
The symptoms that were most likely to have been made worse were with fatigue, cognitive difficulties, post-exertional malaise and pain and muscle fatiguability, each mentioned by 70% or more of respondents. It was clear from the findings that Covid-19 has resulted in worsening of multiple ME symptoms and we will explore this further in the final analysis and report.

In over 66% of cases these worsening symptoms lasted over 6 months and were still not resolved at the time of the survey.



ME symptoms worsened by Covid-19

Base: 154 respondents

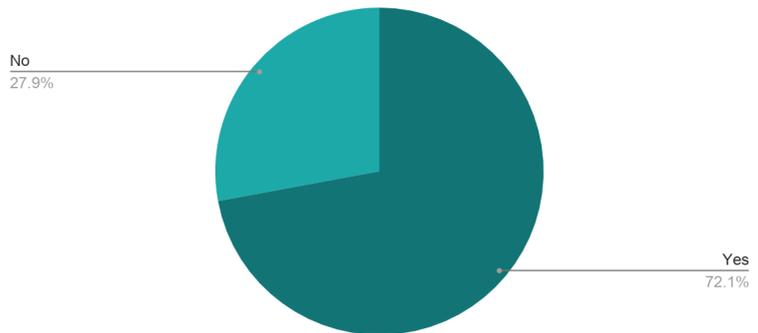


Impact of Covid-19 on People with ME

Covid-19 significantly impacted respondents' health, ability to attend education or work and the use of health services, highlighting the potential economic impact of Covid-19.

Have you experienced any new ongoing symptoms since getting COVID-19?

Base: 197 respondents



The negative impacts of Covid-19 on the **health** of respondents were:

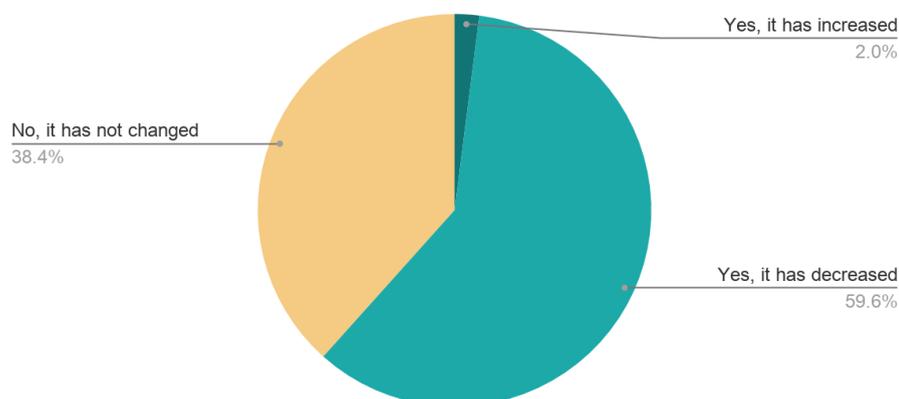
- 77% of respondents reported their cognitive and physical functioning had deteriorated
- 72% had new ongoing symptoms, with the most common new symptoms being shortness of breath, chest pain and dizziness.
- The new symptoms had lasted for longer than 6 months and were still ongoing for 70% of respondents

In addition, the impact on respondents' ability to engage in **education, work or voluntary activities** was likely to have decreased, with 59% of respondents reporting they were less likely to be able to do these activities.

Over half (55%) the respondents said that their **use of health care services** had increased since getting Covid-19.

Has your ability to engage in education, work or voluntary activities changed since you got COVID-19?

Base: 198 respondents



Conclusion

These preliminary findings highlight the terrible impact that Covid-19 has had on many people with ME. We will continue to monitor the results and, with Action for M.E., prepare a full report with detailed analysis to provide evidence which we will use to campaign to get the support that people with ME need.

There is a strong need for research into this area, to ensure people with ME receive appropriate care and support as the pandemic continues.

This survey and report are a collaboration between #MEAction UK, #MEAction Scotland and Action for M.E.

The survey remains open at the time of publication and can be found [here](#).

