



Smith-Magenis Syndrome COVID-19 Survey

This survey is being conducted by the Smith-Magenis Syndrome (SMS) Foundation UK with the purpose of improving our understanding of COVID-19 in people with Smith-Magenis Syndrome across the world. After collating the results and appropriate consultation with our scientific and clinical advisers, we intend to publish a summary of our findings. This is a piece of work being undertaken with the intent to better support individuals within the community and is not a formal piece of academic research.

The survey will take less than 10 minutes to complete and the information provided allows for complete anonymity. For information about the handling of data by the SMS Foundation UK please visit <https://smith-magenis.org/privacy-policy/> (<https://smith-magenis.org/privacy-policy/>).

Please only complete this survey if the person you care for, with SMS, has had COVID-19 or experienced symptoms and COVID-19 has been suspected. Please answer the following questions in respect of the person you care for (or yourself) with SMS. If you care for more than one person with SMS, please complete one survey per person.

If you have any questions or queries about the completion of this survey, please contact:

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Details about the individual with SMS

1. What is the age of the person with SMS?

2. Which country are they a resident of?

3. Where have they been living during lock-down? Eg Family home, care-home, independent living.

4. Have they been shielding (staying at home or isolating) during the COVID-19 pandemic? Please describe below.

5. In terms of risk of becoming seriously ill from COVID-19. Have they been classified as extremely clinically vulnerable, clinically vulnerable, or not vulnerable? Please describe if they have been classified differently.

Extremely clinically vulnerable

Clinically vulnerable

Not vulnerable

Other

6. Do they have any tendency to respiratory problems? Eg a history of recurrent chest infections.

Yes

No

7. Please add additional comments (if any) for question 6.

8. Do they have any swallowing difficulties? Eg obstructions like enlarged tongue, gastronomy, or feeding tube.

Yes

No

9. Please add additional comments (if any) for question 8.

10. Do they have scoliosis, a curved or twisted spine?

- Yes
- No

11. Have they had surgery for their scoliosis?

- Yes
- No

12. Please add additional comments (if any) for question 10 and 11.

Their experience having COVID-19

13. Since the start of COVID-19, have they come into contact with anyone who has displayed COVID-19 symptoms, or has had a positive test, necessitating that person's self-isolation?

Yes

No

14. Please add additional comments (if any) for question 13.

15. Since the start of COVID-19, have they displayed COVID-19 symptoms? Please tick all the COVID-19 symptoms that apply, or tick the relevant no symptoms answer.

- New continuous cough
- High temperature
- Shortness of breath/difficulty breathing
- Chills
- Muscle pain
- Headache
- Sore throat
- New loss of taste or smell
- Abdominal pain
- Gastrointestinal symptoms
- No symptoms but COVID-19 suspected asymptotically
- No symptoms and COVID-19 not suspected
-

Other

16. If they have displayed COVID-19 symptoms but you do not suspect COVID-19 please explain why.

17. How do they normally respond when they become ill? Eg fever, lethargic, sleeping changes, vomiting, cough.

18. Have they been tested for COVID-19? Have you had an ANTIGEN test to see if you CURRENTLY have COVID-19? Have you had an ANTIBODY test to see if you have PREVIOUSLY had COVID-19?

- Yes - positive for ANTIGEN test
- Yes - negative for ANTIGEN test
- Yes - pending result for ANTIGEN test
- Yes - positive for ANTIBODY test
- Yes - negative for ANTIBODY test
- Yes - pending result for ANTIBODY test
- No - not tested

19. Do they usually experience seizures, and if so, has the frequency, intensity, and length of them changed when they displayed COVID-19 symptoms and/or you suspected they had COVID-19?

20. Please describe how their sleep has been impacted, if at all, when they displayed COVID-19 symptoms and/or you suspected they had COVID-19. Eg duration, interruptions, time of day, frequency.

21. Please describe how their behaviour has been impacted, if at all, when they displayed COVID-19 symptoms and/or you suspected they had COVID-19. Eg challenging and self-injurious behaviour, social behaviours and mood, their interactions with you.

22. Please describe any other neurological or non-neurological complications experienced when they displayed COVID-19 symptoms and/or you suspected they had COVID-19. If there were none, you can leave this section blank.

23. Was medical attention required at all whilst they had COVID-19? If so, you will be asked about the type of medical attention required in the next question

Yes

No

24. Which of the following interventions were required? Please tick all that apply.

Monitoring SATS

Fluids

Oxygen

Ventilation

Resuscitation

Other

25. In which setting was medical attention administered? Eg hospital, GP.

26. Is there any continuing medication/intervention? If so, please describe below.

Recovery from COVID-19

27. How long (days) did it take to recover from their symptoms?

28. Has there been any continuing change to their sleep and behaviour? I.e. still experiencing increased/decreased lethargy.

29. Have any symptoms persisted after recovery? Please tick all the COVID-19 symptoms that apply.

- New continuous cough
- High temperature
- Shortness of breath/difficulty breathing
- Chills
- Muscle pain
- Headache
- Sore throat
- New loss of taste or smell
- Abdominal pain
- Gastrointestinal symptoms

Other

COVID-19 Reinfections

30. Since recovery, has the person been confirmed with COVID for a subsequent time?

- Yes - confirmed through testing
- Yes - suspected but not tested
- No

31. How long after the initial case of COVID was this subsequent case confirmed or suspected?

32. How did the subsequent COVID case differ to the initial? Eg symptoms, severity of symptoms, duration.

Other

33. Is there anything else you would like to tell us, or do you have any further comments?

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