

DSUK COVID-19 Survey

This survey is being conducted by Dravet Syndrome UK (DSUK). The purpose of this survey is to improve clinical understanding of COVID-19 in people with Dravet Syndrome in the UK by providing a snap-shot of its presentation. This survey will close at 9am on Monday 13th July 2020.

The results of this survey will be shared with DSUK's Medical Advisory Board and may be made public, subject to consultation with the DSUK Medical Advisory Board. This survey will take less than 5 minutes to complete and is anonymous. For information about the handling of data held by DSUK please visit <https://www.dravet.org.uk/privacy-policy/>.

Please answer the following questions in respect of the person you care for living with Dravet syndrome. If you care for more than one person with Dravet syndrome please complete one survey per person. If you have any questions about the completion of this survey please email info@dravet.org.uk.

* 1. What is the age of the person with Dravet Syndrome?

* 2. Which part of the UK are they ordinarily resident in?

* 3. Where have they been primarily resident during lock-down?

* 4. Have they been given "extremely vulnerable" status during lock-down?

Comments (if any)

* 5. Do they have any tendency to respiratory problems? E.g. a history of recurrent chest infections.

Comments (if any)

* 6. Do they have any swallowing difficulties? E.g. a gastrostomy or feeding tube.

Comments (if any)

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

Comments (if any)

* 8. Since the start of COVID-19 have they come into contact with anyone who has displayed COVID-19 symptoms, necessitating that person's self-isolation?

Comments (if any)

* 9. Since the start of COVID-19 have they displayed COVID-19 symptoms? Please tick all the COVID-19 symptoms that apply (listed below) or tick the relevant no symptoms answer. If they have displayed COVID-19 symptoms but you do not suspect COVID-19 please explain why in the comments box.

- | | |
|---|--|
| <input type="checkbox"/> New continuous cough | <input type="checkbox"/> Headache |
| <input type="checkbox"/> High temperature | <input type="checkbox"/> Sore throat |
| <input type="checkbox"/> Shortness of breath | <input type="checkbox"/> New loss of taste or smell |
| <input type="checkbox"/> Difficulty breathing | <input type="checkbox"/> Abdominal pain |
| <input type="checkbox"/> Chills | <input type="checkbox"/> Gastrointestinal symptoms |
| <input type="checkbox"/> Repeated shaking with chills | <input type="checkbox"/> No symptoms & COVID-19 not suspected |
| <input type="checkbox"/> Muscle pain | <input type="checkbox"/> No symptoms but COVID-19 suspected asymptotically |

Comments (if any)

* 10. Have they been tested for having symptoms of COVID-19 (antigen test) or tested to check if they've already had COVID-19 (antibody test)?

- Yes - positive for antigen test
- Yes - positive for antibody test
- Yes - negative for antigen test
- Yes - negative for antibody test
- Yes - pending result for antigen test
- Yes - pending result for antibody test
- No - not tested
- Comments (if any)



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COVID-19 symptoms displayed and/or suspected COVID-19

* 11. What changes, if any, did you see in seizure frequency when they displayed COVID-19 symptoms and/or you suspected they had COVID-19?

Comments (if any)

* 12. What changes, if any, did you see in seizure length when they displayed COVID-19 symptoms and/or you suspected they had COVID-19?

Comments (if any)

13. Please describe any other neurological or non-neurological complications experienced. If there were none you can leave this section blank.

* 14. Was medical attention required? If so, you will be asked about the type of medical attention required in the next question.



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Medical attention

* 15. In which setting was medical attention administered?

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

Monitoring sats

Ventilation

Fluids

Resuscitation

Oxygen

Other (please specify)



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Final question

17. Is there anything else you would like to tell us?