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Get Involved - Research Projects

Understanding Caregiver Experiences of Sleep Management Difficulties in Individuals with Smith-Magenis Syndrome



Researchers at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham are inviting parents and caregivers of children/adults with Smith-Magenis syndrome to take part in a research study exploring sleep management difficulties associated with SMS. This research is funded by Cerebra and the SMS Foundation UK.

Who can take part?

This study consists of three stages. All parents/caregivers (national and international families) are invited to take part in the first stage of this study (an online survey). Stages two (face-to-face interviews) and three (focus group discussion) are only open to parents/caregivers within the UK given the practicalities of travel.

Why is this research being conducted?

Sleep difficulties are well-characterised in SMS but caregiver experiences of managing difficult night-time behaviours are not well-documented in the literature. Maintaining a safe environment for the child/adult with SMS, as well as ensuring the safety of the family during the night, is of significant concern to parents and caregivers. Therefore, the aim of this research is to understand more about caregiver experiences of sleep difficulties in SMS, with a particular emphasis on consequences to the family, safe-sleeping interventions and access to services and support. Based on accounts provided by both caregivers and professionals, 'best practice' sleep management guidelines will be developed that will be of benefit to caregivers and professionals within the SMS community.

What will participation involve?

As part of the first stage of the research, we are inviting all parents/caregivers caring for a child or adult with SMS to take part in an online survey. This survey will provide us with information about your experiences of sleep management strategies, access to services and overall impact of sleep difficulties on the family. UK families who provide consent to be contacted by the research team will also be invited to take part in stages two and three of the research; a face-to-face interview (either at your home or during a research visit to the University of Birmingham) and participation in a focus group with other caregivers at the University of Birmingham. These stages of the research will allow us to explore sleep management difficulties and your experiences with services in more detail. Parents/caregivers are under no obligation to take part in all stages of the research and are under no obligation to be contacted by the research team after completing the online survey. You may also wish to discuss the research with your child/person you care for with SMS before a decision is made about taking part.

How long will the online survey and interview take?

The online survey will take approximately 45 minutes to complete (with the option to discuss your answers in more detail as part of a 15-minute follow-up Skype/telephone call). Face-to-face interviews will last approximately one hour, but duration may vary depending on the level of description you provide. The focus group at the University of Birmingham will be scheduled to take place between 10am-2pm (date to be confirmed for March 2019). Lunch will be provided and travel costs will be reimbursed.

How do I take part?

This project is no longer recruiting. Results are currently being analysed and will be written up

Who do I contact for more information?

If you have any questions about the study or require further information, please contact the researcher Stacey Bissell via telephone (0121 414 9775) or email (S.L.Bissell@bham.ac.uk).



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