



Where Autism
Professionals Connect

Exclusively sponsored by:



Autistic adults and sleep problems

“Awake middle of the night, my mind going over all conversations from the day... Maybe when (if) I can become self-employed in the future, I’ll try to sleep my natural pattern rather than an imposed pattern.”

(Autistic adult, anonymous)

Sleep is vital for everyone. Optimal length of sleep and its quality serve as protective factors for our mental health and daily functioning. Sleep problems may lead to a number of adverse effects on our health, mood, memory, academic performance and daytime functioning.

Sleep problems are the most common co-occurring conditions experienced by autistic individuals (Baker & Richdale, 2015). Yet despite the vital importance of sleep there have been very few studies focusing on sleep in autistic adults in order to characterise their sleep patterns and the effects of sleep disturbances on their quality of life (Tani et al., 2005).

These sleep difficulties may reduce an autistic person’s opportunities for learning and community participation. For instance, a recent study found that unemployment appears to be associated with the presence of sleep disorders in autistic adults (Baker et al., 2018).

The [Lifespan Learning and Sleep Laboratory \(LiLAS Lab\)](#) is part of the Department of Psychology and Human Development at the Institute of Education at UCL, and we conduct multidisciplinary research across a number of neurodevelopmental disorders from childhood through to adulthood. We wanted to gather baseline evidence about sleep problems experienced by autistic adults and to ask them what future sleep research priorities should be.

The study

A group of autistic adults were involved in the consultation process for this project, and they chose the name of the study – Sleep Focus Autistic. This name arose from a thread on social media that sparked a number of conversations amongst autistic adults on the topic of sleep, all of whom recognised it as a critical issue to explore and understand.

This study involved 1-1 interviews, a focus group and a survey co-designed with 2 autistic advisors.

Focus group feedback

Participants discussed their sleep experiences, perspectives and needs by engaging in dialogue with the researcher and with each other. When asked to define their sleep problems, participants' responses mainly included difficulties to fall asleep and/or to stay asleep during the night.

They also associated their sleep problems with:

- anxieties
- sensory issues
- depression
- gut problems
- post-traumatic stress disorder
- and other issues.

Some adults stated that their sleep patterns simply did not match modern society's sleep clock.

For most participants, sleep issues have been a lifelong issue.

"I have mostly been a night owl in my life...recently it's been quite bad again as I've been feeling a compulsion not to switch off...As a child I was off the chart anxious and would lay awake worrying about everything. I became a big reader very young (I was an advanced reader for my age) to the point where sometimes I would read until the early hours, occasionally all night. Back to the present, I now watch episodes like I used to consume chapters to avoid being alone with my thoughts/anxiety.

Neighbours/any noise drives me mad, (I do mean out of my mind) and if I'm woken up when I'm asleep there's little chance of me going back to sleep."

(Anonymous, autistic participant)

All participants reported consequences of their poor sleep in their quality of life.

"For me, poor sleep has a day to day impact on my quality of life. A particularly bad night leads to a 'bad autism day'. These are days when my balance is poor, where sensory issues have a more extreme affect than usual and where I can only tolerate other people for a limited time, before my stress levels rocket and I'm desperate to go home."

(Anonymous, autistic participant)

Although participants reported that they tried to consider and remedy their sleep problems, they rarely discussed these with healthcare professionals. The participants stated that GPs rarely

Author: Georgia Pavlopoulou, Dagmara Dimitriou
Organisation: Lifespan Learning and Sleep Laboratory (LiLAS)
Date of publication: 7 August 2018

prescribe melatonin, and if they do, the dosage is often questionable and not monitored. At times, doctors might offer the opportunity for autistic adults with sleep problems to visit a sleep clinic. However, all participants agreed this is difficult for them.

“The same doctor was actually quite keen to send me to a sleep clinic. And I thought this is completely pointless because they... I’ve got a friend who went to one and you get wired up to... And how am I going to sleep? I’m not going to sleep if I’m getting wired up to something. So that was the end.”

(Anonymous, autistic participant)

Survey results

In collaboration with two autistic advocates and [Autistica](#), a short survey was developed to gather information about sleep issues as well as to collect questions on the main sleep research priorities. A total of 731 adults responded to the online survey.

This is what we learnt:

- almost 9 in 10 respondents reported poor quality of sleep with frequent and prolonged night-time awakenings
- over 70% of autistic adults said they experienced difficulty falling asleep or staying asleep, associating this with sensory issues and high anxiety
- around half were unable to stay asleep for long, whilst 4 in 10 experienced nightmares.

Based on our survey question: “Please outline one question you would like researched, about sleep or a sleep problem” we established the main research priorities of autistic adults around sleep which include:

- develop sleep interventions
- multidisciplinary partnerships with sleep professionals
- gather data on sleep medication and use of different sleep related strategies.

The LiLAS team is currently refining the co-established sleep research priorities and is actively looking for further funding options to develop the study further, continuing to work with autistic adults to find out their research priorities, needs and experiences.

Acknowledgments: Cos Michael and Jon Adams for their collaboration throughout all stages of this study. Autistica for funding this collaborative effort.

References

[Baker, E.K., Richdale, A.L., \(2015\) Sleep patterns in adults with a diagnosis of high-functioning autism spectrum disorder, *Sleep*, 38\(11\), pp. 1765–1774](#)

Copyright: When reproducing this document, you must fully acknowledge the author of the document as shown at the top of the page. Please see Network Autism Terms and Conditions for details.

Author: Georgia Pavlopoulou, Dagmara Dimitriou
Organisation: Lifespan Learning and Sleep Laboratory (LiLAS)
Date of publication: 7 August 2018

Baker, E.K., Richdale, A.L., Hazi, A., (2018) Employment status is related to sleep problems in adults with autism spectrum disorder and no comorbid intellectual impairment. *Autism*, [Epub ahead of print]

[Tani, P., et al. \(2005\). Actigraphic assessment of sleep in young adults with Asperger syndrome. *Psychiatry and Clinical Neurosciences*, 59: 206-208.](#)