



# Research Review

## Sleep Problems and Autism

### INTRODUCTION

Our research reviews are designed to summarise the research evidence and clinical guidance on specific topics.

This research review examines the evidence on sleep problems in people on the autism spectrum. It examines the research evidence on some of the interventions designed to overcome those problems.

It also summarises clinical guidance from the National Institute for Health and Care Excellence (NICE) and the Autism Treatment Network (ATN) Sleep Committee.

It is not intended to provide advice or recommendations on what you should or should not do about those sleep problems.

### KEY FINDINGS

- Sleep problems are very common in people on the autism spectrum and in other members of their families.
- Those sleep problems include difficulty falling asleep, waking during the night, erratic/irregular sleep patterns, other arousals/disturbances, and daytime sleepiness.
- There are a number of factors associated with sleep problems including a range of underlying medical and mental health problems, as well as the nature of autism itself.
- Sleep problems can cause stress, anxiety and depression in parents and carers of children on the autism spectrum.
- Taken together, all of these problems may make it difficult to function normally, to attend school/college and/or to hold down regular employment.
- There are a number of interventions designed to overcome sleep problems in people. These include behavioural approaches, medications, and dietary supplements.
- There is very little research evidence on the effectiveness of these interventions for people on the autism spectrum.
- NICE and the ATN Sleep Committee have each developed clinical guidelines on how to approach and treat sleep problems in children and adolescents on the autism spectrum.
- These guidelines stress the importance of drawing up an appropriate treatment plan based on identifying the underlying cause or causes of the specific sleep problems.
- Further research is required to replicate and extend research into those interventions which appear to be effective.

## HOW MANY PEOPLE ON THE AUTISM SPECTRUM HAVE SLEEP PROBLEMS?

Research suggests that sleep problems affect between 40% to 80% of people on the autism spectrum.

In a 2004 survey of the membership of the National Autistic Society in the UK, over half of the respondents reported significant sleep problems.

## WHAT SLEEP PROBLEMS DO PEOPLE ON THE AUTISM SPECTRUM HAVE?

Some children on the autism spectrum eventually grow out of their sleep problems, just like other children do. Unfortunately many children with autism do not grow out of their sleep problems and the problems remain into adulthood.

Specific problems include:

- problems falling asleep
- frequent waking during the night
- early morning waking
- short duration sleep
- irregular or erratic sleep patterns
- other arousals/disturbances
- daytime sleepiness

## WHAT FACTORS ARE ASSOCIATED WITH SLEEP PROBLEMS IN PEOPLE ON THE AUTISM SPECTRUM?

There are various factors associated with sleep problems in people on the autism spectrum including:

- abnormal circadian rhythm (body clock)
- learnt behaviours, such as when and how to fall asleep
- mental health problems, such as anxiety and depression
- medical problems, such as reflux and constipation
- neurological conditions, such as epilepsy
- side effects of medications, such as stimulants

## WHAT EFFECT DO SLEEP PROBLEMS HAVE ON PEOPLE ON THE AUTISM SPECTRUM?

Sleep problems affect each individual on the autism spectrum (and their family and carers) in a different way. For example:

- Lack of sleep can cause exhaustion in the individual on the autism spectrum, as well as in their parents, siblings, partners and other carers
- Sleep problems may lead to difficulties with thought processes and emotions. They can worsen the symptoms of autism and produce challenging behaviours.
- Sleep problems and associated issues can make it very difficult to attend school/college or to hold down regular employment
- Sleep problems can cause stress, anxiety and depression in parents and carers of children on the autism spectrum.

## WHAT INTERVENTIONS (TREATMENTS AND THERAPIES) ARE AVAILABLE?

Most of the interventions used to help people on the autism spectrum with sleep problems are the same as those designed to help anyone with sleep problems.

For example, it can be difficult to get to sleep if you don't have a regular bedtime routine, if you are distracted by excessive light or noise, if you have underlying health problems, or if you are constantly worried about something. It is important to identify and, if possible, eliminate these problems before considering other solutions.

## BEHAVIOURAL APPROACHES

There are a number of behavioural approaches used to help people with sleep problems. These approaches include

- **Bedtime fading:** going to bed at progressively earlier times, working back in blocks of 10-15 minutes from the time they actually fall asleep.
- **Scheduled awakening:** waking someone up at predetermined times, usually 30 mins or so, before they normally wake in the night.
- **Sleep restriction:** limiting the time someone spends in bed to 90% of the time they normally spend in bed.
- **Extinctions procedures:** removing parental involvement during bedtime disruptions. This can be done abruptly (e.g. the parent puts the child to bed and doesn't interact with them until morning) or more gradually (e.g. reducing parental involvement over successive nights or only going in at predetermined times).
- **Parent training programmes:** educational programmes which teach parents how to use one or more of the techniques listed above.

## BIOMEDICAL APPROACHES

There are a number of biomedical approaches used to help people on the autism spectrum with sleep problems.

- Medications include sedatives (such as mirtazapine); anti-hypertensives (such as clonidine); and hormones (such as melatonin).
- Dietary supplements include 5-HTP, iron, kava, multivitamins, and valerian.
- Exclusion diets involve restricting or removing certain foodstuffs, such as sugar, caffeine and/or additives.

## OTHER APPROACHES

There are numerous other interventions designed to help people on the autism spectrum with sleep problems. Those interventions include aromatherapy, exercise programmes, homeopathy, light therapy, massage, weighted blankets and yoga.

## PLEASE NOTE

Some medications and supplements should only be used for a limited period and under the direction of a suitably qualified practitioner, such as a GP or a dietician. Some medications and supplements have significant side effects or interactions with other substances. Some medications and supplements may actually make sleep problems worse. (Please see our website for details.)

## EVIDENCE BASE

We carried out a systematic search for research reviews, and clinical guidance, on the topic of sleep problems in people on the autism spectrum.

We searched a range of databases (such as CINAHL, Medline, Psychinfo) and identified 25 scientific reviews on this topic. We also examined the clinical guidance published by NICE and by the Autism Treatment Network Sleep Committee.

## SUMMARY OF EVIDENCE

- There is very little research evidence on the use of interventions to help people on the autism spectrum with sleep problems.
- There is limited/inconclusive evidence on whether any interventions help adults on the autism spectrum with sleep problems.
- There is stronger research evidence to suggest that some behavioural approaches (such as parent training programmes) are beneficial in treating sleep problems in children and young people on the autism spectrum.
- There is stronger research evidence to suggest that melatonin may be effective in decreasing the time it takes some children and young people on the autism spectrum to fall asleep and to stay asleep, especially when used in conjunction with behavioural approaches.
- There is limited/inconclusive evidence on whether other dietary supplements are beneficial in treating sleep problems in children and young people on the autism spectrum.
- There is limited/inconclusive evidence on whether any of the other interventions currently being used (such as aromatherapy, massage therapy or weighted blankets) are effective in the treatment of sleep problems in children and young people on the autism spectrum.
- There is limited evidence that some interventions (such as aripiprazole, methylphenidate and omega-3 fatty acids) may actually increase sleep problems in some people on the autism spectrum.

## FUTURE RESEARCH

There is a need for further research into the sleep problems of people on the autism spectrum and the most effective interventions to overcome those problems. Specifically there is a need for studies which

- replicate and extend existing research into interventions which appear to be effective
- identify which individuals are most likely to benefit from those interventions
- focus on the development and evaluation of standardised parent training programmes
- develop contextually appropriate interventions i.e. Interventions which will work with culturally and linguistically diverse families

You can see details of our search strategy and the reviews we identified at <http://researchautism.net/sleep-review>

## NICE GUIDANCE ON SLEEP IN PEOPLE ON THE AUTISM SPECTRUM

The National Institute for Health and Care Excellence (NICE) is a UK government body which supports healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money.

NICE has not made any recommendations on sleep problems in adults on the autism spectrum.

NICE has made the following recommendations on sleep problems in children and young people on the autism spectrum.

- The first step should be a full assessment of any sleep problem to determine its precise nature and any factors that might be contributing to it, such as the sleep environment, co-morbidities (other conditions) and current medication
- Following the assessment, parents and carers should be supported to develop a sleep plan to encourage the child or young person to develop positive sleep habits, and use a diary to record sleeping patterns and bedtimes
- Medication should not be considered until it is clear behavioural interventions would be ineffective and the child or young person's negative sleep behaviours would persist and have a detrimental impact on them and their family or carers
- Medication should only be used following consultation with a specialist paediatrician or psychiatrist who has expertise in the management of autism or paediatric sleep medicine, and in conjunction with behavioural interventions
- Any medication to aid sleep should be regularly reviewed to ensure that its benefits continue to outweigh the side effects and risks in children and young people with autism.
- Loud snoring, choking or witnessed apnoeas (the cessation of airflow during sleep preventing air from entering the lungs caused by an obstruction) should prompt referral to a sleep expert to exclude diagnosis of obstructive sleep apnoea.

*Source: The management and support of children and young people on the autism spectrum. (2013). London: National Institute for Health and Clinical Excellence. Clinical guidance CG 170 (PDF document).*

## SLEEP COMMITTEE OF THE AUTISM TREATMENT NETWORK

The Sleep Committee of the Autism Treatment Network is a US-based organisation which consists of pediatric sleep medicine specialists as well as developmental pediatricians, neurologists, and psychiatrists.

The ATN Sleep Committee has created a clinical practice pathway which is designed to assist primary care providers and others working directly with families affected by ASD in addressing the challenge of insomnia with regard to identification assessment, and management.

The pathway recommends that

1. all children who have ASD should be screened for insomnia,
2. screening should be done for potential contributing factors, including other medical problems,
3. the need for therapeutic intervention should be determined,
4. therapeutic interventions should begin with parent education in the use of behavioural approaches as a first-line approach,
5. pharmacologic therapy [medication] may be indicated [used] in certain situations, and
6. there should be follow-up after any intervention to evaluate effectiveness and tolerance of the therapy.

*Source: Malow B.A. et al. (2012). A practice pathway for the identification, evaluation, and management of insomnia in children and adolescents with autism spectrum disorders. Pediatrics. 130(Suppl 2), S106-124*

## OTHER READING

- Montgomery P. and Wiggs L. (2010). Encouraging good sleep habits in children with learning disabilities. Oxford
- National Autistic Society [2011?] Sleep and autism: helping your child. London: National Autistic Society.
- NHS Choices( 2009). Insomnia. London: NHS Information Centre for Health and Social Care.
- Royal College of Psychiatry (2011). Sleeping well. London: Royal College of Psychiatrists.

## ORGANISATIONS

- British Sleep Society. UK organisation for medical, scientific and healthcare workers dealing with sleeping disorders. Tel. 01480 364240. Website. [www.sleepsociety.org.uk](http://www.sleepsociety.org.uk)
- Cerebra. UK charity for children with brain related conditions. Provides a sleep support service. Tel. 0800 328 1159. Website. [www.cerebra.org.uk](http://www.cerebra.org.uk)
- National Sleep Foundation. US, non-profit, organisation dedicated to improving the quality of life for Americans who suffer from sleep problems and disorders. Tel. (703) 243-1697. Website. [www.sleepfoundation.org](http://www.sleepfoundation.org)

## FURTHER INFORMATION

You can find more information on this topic (including sources of evidence, glossary of terms used etc.) on Research Autism's website at <http://researchautism.net/sleep-review>

## RESEARCH REVIEWS

'Research Reviews' are designed to summarise the research evidence and clinical guidance on particular topics. They are not designed to provide specific advice or recommendations about what you should or should not do. However they may help you think through the issues on the topics covered.

## RESEARCH AUTISM

We are the only UK charity exclusively dedicated to research into interventions in autism. We commission, carry out and support high quality, independent research into new and existing health, education, social and other interventions. We are currently working on a number of activities relating to sleep problems and autism. For details please see

<http://researchautism.net/sleep-review>

## DISCLAIMER

The information published in this review has been written by non-medically qualified individuals. Any such information should be therefore be treated with care. The fact that we mention an intervention does not necessarily mean that we think it is effective. The fact that we list a publication or organisation does not necessarily mean that we agree with its findings or position on this issue.



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