



Supporting families of Autistic children experiencing sleep difficulties

For general practitioners and allied health professionals

Introduction

Sleep difficulties are a very common co-occurring condition experienced by Autistic children. It is estimated that 50–80% of Autistic children experience a sleep disorder.^{1,2}

Sleep difficulties experienced by Autistic children can result in challenges and stress that impact various aspects of life for the children themselves as well as their family members.² When parents/carers and families seek your professional advice and support, it is important to consider the health effects not just for the children directly impacted, but also for the family as a whole.

The following two case studies provide examples of the kinds of impacts children and families can experience, and common supports that contribute to effective management of sleep difficulties for Autistic children.

1. Reynolds AM, Malow BA. *Pediatr Clin North Am* 2011;58(3):685–698.

2. Williams Buckley A, et al. *Neurology* 2020;94(9):392–404.

Case study 1

Family profile

Basic profile of Autistic child: Simon, 12-year-old male.

Autism-related characteristics: Language delay.

Co-occurring health conditions:

- Borderline intellectual disability based on formal cognitive assessment.
- Not formally diagnosed with dyslexia but has been informally assessed as meeting the criteria.

Age at the time of autism diagnosis/

identification: 5 years.

Family member information: Nicole (mother);

Lewis (father); Miranda (Autistic older sister)

Sleep history of Autistic child

Age at which sleep difficulties began: Since birth

Age at which sleep difficulties improved/were

effectively managed: 7 years

Types of sleep difficulties experienced:

- Awakenings through the night
- Early morning awakenings
- Slept during the day
- Dependence on parental presence

Typical sleep pattern of Autistic child (before intervention)

- Put to bed at 7 pm, fell asleep with ease.
- Night awakenings: 1-2 per night; 30 minutes each and needed parental presence to fall back asleep.
- First awakening: 4 - 5 am. Would not return to sleep.
- Frequent naps during the day, particularly once morning had passed.

Autism-related characteristics/co-occurring conditions that may have compounded sleep difficulties

Simon experienced challenges with language comprehension as a young child, which may have affected his ability to understand some of the directions his parents gave him regarding his sleep routine when he was younger.

Impacts of sleep difficulties - on the child

- Sleepiness and falling asleep during the day.
- Missed out on social opportunities.
- Missed out on family time, e.g. dinners and social outings.
- More emotionally sensitive.
- Therapies had to be scheduled for the mornings, which impacted schooling.

Impacts of sleep difficulties - on the family

- Both parents experienced exhaustion and significant stress.
- Relationship between parents impacted due to reduced quality time spent together.
- Lifestyle limitations, e.g. fewer opportunities for travel, and social outings.
- Strain on relationship with sibling.

✘ Ineffective interventions/supports

- Presence of sibling in a shared bedroom.
- Parental presence in the child's own, separate bedroom.
- White noise.
- Weighted blankets.
- Different toys.
- Tweaks to bedtime schedule.
- Reward chart.
- Varying bedtimes (later/earlier)

✓ Effective interventions/supports

- Use of a sleep trainer clock. Wake time was very gradually adjusted to later in the morning until Simon formed the habit of waking up at 7am.
- Redirection back to bed. Supported Simon to understand that his bedroom is a quiet space for him to relax.
- Rewarded with access to iPad on weekends.
- Greater choice and control over own sleep routine as Simon grew older.

Changes following the introduction of effective interventions/supports

Changes experienced by the child:

- No waking through the night.
- Slept through to 7am.
- Alert during the day.
- Simon himself started to recognise that he felt better as a result of getting quality sleep through the night.
- Simon himself started to recognise the social opportunities and family time he missed out on if he didn't get quality sleep through the night.
- No need for parental presence to fall asleep.
- Could attend appointments after school hours. Impact on schooling reduced.

Changes experienced by the family:

- Exhaustion and stress experienced by parents significantly reduced.
- Parents able to have more quality time together as a couple.
- Improved quality family time.
- Improved quality of relationship with sibling.

Case study 2

Family profile

Basic profile of Autistic child: Tom, 14-year-old male

Autism-related characteristics: Level 3 diagnosis. Limited but emerging functional verbal communication.

Co-occurring health conditions:

- Intellectual disability, anxiety, ADHD
- Avoidant restrictive food intake disorder (ARFID)
- Separation anxiety

Age at the time of autism diagnosis/identification: 3 years

Family member information: Louise (mother); John (father); Sam (non-Autistic younger brother)

Sleep history of Autistic child

Age at which sleep difficulties began: Since birth

Age at which sleep difficulties improved/were effectively managed: 10 years (approximately)

Types of sleep difficulties experienced:

- Late sleep onset
- Awakenings through the night
- Dependence on parental presence

Typical sleep pattern of Autistic child (before intervention)

- Put to bed between 7.30 and 8.30 pm. Fell asleep between 9 pm and 12 pm. Typical sleep latency: between 2–3.5 hours. Tom experienced challenges calming and regulating at bedtime.
- Night awakenings: up until approximately 5 or 6 years of age, 1 per night. Needed parental presence to fall back asleep.
- First awakening: 6–8 am.

Autism-related characteristics/co-occurring conditions that may have compounded sleep difficulties

Tom experienced separation anxiety, which contributed to his distress at bedtime when Louise left his side, and his reliance on parental presence to fall asleep.

Impacts of sleep difficulties – on the child

- Limited sleep during early years may have impacted behaviour and learning.
- Tom remained very active at night. Engaged in behaviours of concern, including mouthing unsafe objects, climbing and, for a limited period, urinating and defecating in his room.

Impacts of sleep difficulties – on the family

- Both parents experienced exhaustion and significant stress.
- Relationship between parents impacted due to reduced quality time spent together and on their own.
- Reduced opportunities for Louise to go to social engagements and attend to other tasks due to Tom's need for her presence at bedtime.

Impacts of sleep difficulties – on the family (cont.)

- Strain on relationship between Tom and Louise.
- Strain on relationship between Sam (younger brother) and Louise due to Tom's need for her presence at bedtime.
- Strain on relationship between Tom and Sam.

✘ Ineffective interventions/supports

- Weighted blankets.
- Various sensory toys.
- Tweaks to bedtime schedule.
- Different activities to support emotional regulation before bedtime, e.g. baths, reading books.
- Essential oils.
- Sleep trainer clock.

✓ Effective interventions/supports

- Use of a visual schedule. Reassured Tom that mummy would return. Tom was able to stay calm and go to sleep before Louise returned home after going out.
- Redirection back to bed. Supported Tom to understand that his bedroom is a quiet space for him to relax.
- Melatonin: Supported Tom to fall asleep and remain asleep through the night.
- Use of the iPad before bedtime: supported Tom to relax and remain in his room. Tom has enjoyed having greater responsibility and autonomy over access to the iPad as he has gotten older.
- Chewing sugar-free gum.
- Use of a multi-coloured nightlight.
- Greater choice and control over his sleep routine as Tom grew older.

Changes following the introduction of effective interventions/supports

Changes experienced by the child:

- No waking through the night.
- Slept through to 7 am.
- Alert during the day.
- Tom himself started to recognise that he felt better as a result of getting quality sleep through the night.
- Tom himself started to recognise the social opportunities and family time he missed out on if he didn't get quality sleep through the night.
- No need for parental presence to fall asleep.
- Could attend appointments after school hours. Impact on schooling reduced.

Changes experienced by the family:

- Exhaustion and stress experienced by parents significantly reduced.
- Parents able to have more quality time together as a couple.
- Improved quality family time.
- Improved quality of relationship with sibling.

Conclusion

Addressing sleep difficulties experienced by Autistic children is often an iterative process of trial and error. There are several key principles GPs and allied health professionals can draw on when supporting Autistic children experiencing sleep difficulties alongside their families. These key principles are:

- **Family-centred:** A family-centred approach involves recognising the family as a system in which the health and well-being of individual family members can affect the health and well-being of the family as a whole. A family-centred approach entails working in partnership with the family to determine what will work best in the specific context of their family.
- **Strengths-based:** Remain open to introducing supports that draw on a child's unique interests and capacities, and provide opportunities to promote their learning, development and growth.
- **Autism-specific:** Supports that are appropriate and work for a non-Autistic child may not for an Autistic child. Autistic children may require support and advice tailored to meet their autism-specific needs.
- **Individualised:** Supports that are effective for one Autistic child, may not be for another Autistic child. Ensure recommended supports are based on the specific needs, preferences, and strengths of the child in front of you.

Referral options

For information on non-medical services that can provide general support and advice to Autistic children and their families, see the list below:

- **Autism Connect:** Amaze operates a free, national autism helpline, providing independent and expert information for Autistic people and their supporters.

Phone: 1300 308 699

Email: info@autismconnect.org.au

Website and webchat:

www.amaze.org.au/autismconnect/

- **Carer Gateway:** an Australian government program providing free services and support for carers.

Phone: 1800 422 737

Website:

<https://www.carergateway.gov.au/>

- **Disability Gateway:** An Australian government program providing information and services to help people with disability, their families, friends and carers, to find the support they need in Australia.

Phone: 1800 645 787

Email: disabilitygateway@benevolent.org.au

Website:

<https://www.disabilitygateway.gov.au/>



This article was independently written by AMAZE with funding provided by Aspen Australia. Aspen Australia includes Aspen Pharmacare Australia Pty Ltd (ABN 51 096 236 985) and Aspen Pharma Pty Ltd (ABN 88 004 118 594). FD24793 AU-MEL-092024-AF08893