

Sleep

Background

Sleep difficulties are common in children and adults with cerebral palsy. In a questionnaire survey, 23% of children with cerebral palsy had an abnormal Total Sleep Score (compared to 5% of the normative sample), and 44% had at least one clinically significant sleep disorder.¹

Sleep disturbance has adverse effects on health and development, behaviour, learning, memory, mood and performance. In people with cerebral palsy, the effects of sleep disturbance compound with other impairments to reduce well-being, daily function and quality of life.²

Children's sleep disturbance affects their parents' sleep, with increased parental daytime sleepiness, stress, depression, fatigue, and impairment of health and social functioning.³⁻⁵

Diverse factors affect the sleep of people with cerebral palsy, with concerns related to breathing, pain, cramps and muscle spasm, postural discomfort and need for assistance to change position, epilepsy and medications, circadian difficulties, use of night splints or positioning equipment, toileting needs, bedtime resistance or anxiety, gastro-oesophageal reflux and other swallowing and digestive difficulties, skin conditions such as itchiness or pressure sores, disturbances of vision or hearing, and thermoregulation difficulties such as cold extremities, overheating and hyperhidrosis. Many have combinations of these factors.⁶⁻⁸

Sleep problems affect people with all levels of severity of cerebral palsy. There is a risk of under-identification of sleep problems in people with 'mild' cerebral palsy. For this group, the sleep setting, bedtime routines, daytime activities, communication and behaviour, and sensory regulation may be of particular concern. People with more severe physical impairment are more likely to have concerns related to their lying position, movement control, breathing, reflux, pain, pressure care, body temperature and safety in bed.⁹

It is important **to ask about sleep**. Many people do not report sleep concerns, believing that it is 'just part of having cerebral palsy'. It is important to **ask again**. Parents may say that sleep is 'okay', and only when probed report that they are getting up to their child several times each night. Adults may report that their sleep is 'fine' and only when probed report that they take a long time to get to sleep, or have severe daytime sleepiness.

Where to start?

The **BEARS**¹⁰ provides a useful starting point, to discuss and explore sleep difficulties:

B = bedtime problems

E = excessive daytime behaviours, daytime sleepiness

A = arousals or awakenings during the night

R = regularity and duration of sleep (and routines)

S = sleep disordered breathing (snoring), and safety

For people with cerebral palsy, all of the above may be features of the sleep problem.

The **Chailey Sleep Questionnaire** can be used to gather more in-depth sleep information, with red flags to identify key risks.

Keeping records such as sleep diaries, day-night activity logs, behaviour logs and pain mapping charts are all useful tools to provide to parents and carers, to help to inform discussion about the person's sleep.

Interview/history is most important.

Causes of sleep difficulties

Causes of sleep difficulties may be the same as in any other individual of that age and gender, and include:

1. General medical concerns and health conditions, timing and effects of medications.
2. Pain: see *Module 7* for further information.
3. Respiratory issues such as hay fever, asthma, tonsils/adenoids, rhinitis, sinusitis or lung disease.
4. Social: emotional issues, such as anxiety, stress, communication difficulties, attachment, behavioural difficulties.
5. Environment and lifestyle, including timing and content of meals and drinks, timing of daytime naps, timing of screen use, timing of physical activity, and the household and bedroom environment (noise, light, temperature, general comfort).
6. Sensory modulation difficulties, with poor regulation of levels of arousal.
7. Specific sleep disorders*, including:
 - Sleep onset association disorder
 - Delayed sleep phase disorder
 - Restless legs syndrome
 - Periodic limb movement disorder
 - Rhythmic movement disorder
 - Nightmares
 - Night terrors
 - REM-sleep related behaviours

*See Mindell and Owens *Clinical Guide to Paediatric Sleep*¹¹; this includes access to electronic versions of information handouts.

These resources are designed to support healthcare practitioners in the care of their patients with cerebral palsy in Australia. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. They have been amended for use by healthcare workers globally in partnership with IAACD. The initial project was funded by an Avant Quality Improvement Grant 2017.

MonashHealth

CDDH
Centre for Developmental Disability Health
Better Health Better Lives

murdoch
children's
research
institute

The Royal Children's
Hospital Melbourne

IAACD
International Alliance
of Academies of
Childhood Disability

In addition to the above, people with cerebral palsy are particularly vulnerable to and affected by:

1. Pain: see *Module 7*; consider musculoskeletal and gastro-intestinal effects.
2. Respiratory dysfunction: more specific to cerebral palsy including excessive oral secretions, poorly coordinated swallow, insufficient cough, lung disease, obstructive and central apnoeas.¹²
3. Skin breakdown: pressure and shearing injuries.
4. Temperature dysregulation: cold extremities, proximal overheating, hyperhidrosis.
5. Movement and positioning impairment: inability to change position, uncontrolled movements into painful, damaging or unsafe positions.
6. Hygiene and toileting difficulties.
7. Communication and behaviour difficulties related to co-existing intellectual disability, autism or ADHD.
8. Hunger (or indigestion, gastro-oesophageal reflux), thirst (dehydration) or effects of night feeding protocols.
9. Anxiety and other social-emotional concerns related to the challenges of living with their condition.

What to do?

Depends on the nature of the problem/s, and the family's resources and capacity to manage suggested interventions. Be guided by your clinical judgement as a healthcare practitioner.

Consider options for further investigations, intervention and support, including:

- Specialist paediatrician
- Occupational therapist
- Respiratory physician
- Speech and language therapist
- Gastroenterologist
- Community nurse
- Neurologist
- Clinical psychologist
- Orthopaedic surgeon
- Social worker
- Rehabilitation specialist
- Respite services
- Physiotherapist

Families and individuals with cerebral palsy should have access to services through a local service provider, with a key contact person who can help to coordinate such supports.

Special notes

1. Restless legs syndrome: emerging research suggests that this is an often undiagnosed cause of sleep onset insomnia. People may seem restless, agitated, or resistant to bed. Seen as a behavioural difficulty, when in fact it is Restless Legs Syndrome. Characterised by limb (usually legs) discomfort when tired, urge to move, not relieved by rest. Check iron/serum ferritin, family history and diet.
2. Melatonin: although well known as effective medication for sleep onset insomnia, it is not so well known that people may have 'delayed response' to melatonin. Usual dose at usual time is not effective – in fact pushes sleep phase further back, and causes morning irritability and grogginess. Instead, try smaller dose (0.5–1.0g) several hours before desired bedtime. In all instances, explain to families that melatonin will be most effective if used at the same time each day, and if other healthy sleep practices are in place (e.g. no caffeine after 3pm; no screens an hour before bedtime; have dim light prior to bedtime, and dark room to go to sleep).

Resources

Australian Sleep Association

- Home page: www.sleep.org.au
- Fact sheets: <https://sleep.org.au/Public/Resources/Consumers/Public/Resource-Centre/Consumers.aspx?hkey=43302712-12b2-4aa4-b575-c6301aa864e5>
- <https://sleep.org.au/Public/Resources/Health-Professionals/Public/Resource-Centre/HP-info.aspx?hkey=2c598913-2c1c-49d8-a1b8-348d70038071>

Sleep Health Foundation

- Home page: www.sleephealthfoundation.org.au
- Information: <https://www.sleephealthfoundation.org.au/fact-sheets.html>
- <https://www.sleephealthfoundation.org.au/facts-about-sleep-for-parents-and-school-staff.html>

Chailey Questionnaire: this can be obtained by request via email to sam.weddell@nhs.net

Mindell, J and Owens, J: A Clinical Guide to Pediatric Sleep: Diagnosis and Management of Sleep Problems (available online, local and international booksellers)

Respiratory checklist (Ability Centre): www.abilitycentre.com.au/cp-checklist

SleepLinks: www.sleeplinks.com.au (website in development – for sleep diaries, pain maps and activity logs)

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