# FASD Hub Australia

Information on Fetal Alcohol Spectrum Disorder (FASD) for all Australians FACT SHEET FOR HEALTH PROFESSIONALS

## Sleep problems among children with FASD

### The FASD perspective

Sleep problems are common among children with FASD and other neurodevelopmental disorders<sup>1</sup>, being reported in as many as 75% to 80% of children<sup>2-4</sup>. In comparison, approximately 25% of typically developing children experience sleeping problems. Sleep problems among children with FASD may be evident from birth, tend to be chronic and continue into adolescence and even adulthood<sup>5</sup>. Sleep problems among people with FASD include difficulty initiating or maintaining sleep and early morning awakening<sup>6,a</sup>. People with FASD are also more likely than typically developing people to experience sleep anxiety and parasomnia<sup>1,8</sup>, e.g. nightmares, sleep walking and abnormal movement.

The cause of the sleep problems experienced by people with neurodevelopmental disorders are multifactorial and can often result from underlying disease-related factors, e.g. brain abnormalities and sensory issues. External factors such as the environment (e.g. sleeping space) and issues related to the caregivers/family (e.g. family dynamics, parental stress, parental sleep patterns) can also influence a child's sleep<sup>4,9</sup>. Sleep difficulties among people with FASD are associated with emotional, behavioural, cognitive and academic daytime functioning, including hyperactivity, disorganised or aggressive behaviour, and heightened sensitivity to sensory stimuli<sup>5,9</sup>. Addressing sleep problems may improve daytime behaviours exacerbated by fatigue.

<sup>a</sup> These characteristics belong to the diagnostic category of circadian rhythm sleep disorders<sup>7</sup>

#### Assessment

A thorough assessment of the person's sleep problems needs to be undertaken to identify the most appropriate combination of strategies. Reviewing the sleep habits of the person, such as their bedtime routine and sleep environment can reveal environmental factors that may contribute to their sleep problem. In addition to discussing the sleep problems with the caregivers, questioning the child, when appropriate, may uncover sleep difficulties that the caregivers had not identified<sup>4</sup>. Frequently used sleep assessment tools include:

- The Children's Sleep Habit Questionnaire<sup>10</sup>: completed by the caregiver, who rates how often their child displays various sleep behaviours over the previous week.
- a sleep diary (recorded by the caregiver): the caregiver records the child's sleep behaviour for 2 4 weeks (e.g. bedtimes, night awakenings, morning rousing, daily situations that may impact sleep e.g. daytime naps, health status).
- Actigraphy: a movement monitor (similar to a watch) worn by the child to capture their sleep/wake behaviour. It is used in unison with a sleep diary to collect other details that may impact sleep (e.g. behavioural, emotional and daily events).

 Polysomnography: a sleep study at a specialist clinic. A polysomnography should be considered for serious and persistent sleep problems. A polysomnography usually includes an electroencephalography to measure brain waves, an electrocardiography to measure heart rate, electrooculography to measure eye movement, electromyography to measure muscle and skeletal activation, pressure transducers to measure respiration rate and a pulse oximetry to measure blood oxygen level.

#### **Management Strategies**

A multidisciplinary approach, including positive sleep hygiene practices, sensory and sleep environmental considerations, behavioural stabilisation and family support, regulating circadian rhythm, and (where necessary) the administration of medication, will optimise sleep management for these children<sup>5</sup>. In providing treatment, it is important for professionals to consider the needs of both the child and caregivers/family and ensure that caregivers understand the processes and anticipated outcomes of the interventions and strategies. For example, some caregivers may require education about sleep hygiene<sup>11</sup>. Information regarding sleep hygiene, sensory considerations, regulating circadian rhythm and medication are provided below.

**Sleep Hygiene:** The first step to address sleep problems is the promotion of improved sleep habits, also known as sleep hygiene<sup>4</sup>. This includes the establishment of regular sleep scheduling, such as a regular bedtime routine and arousal time. A visual sleep schedule tailored for the child can help them learn their bedtime routine and will reduce sleep anxiety in some children<sup>4</sup>. Sleep hygiene encourages sleep by reducing environmental stimulation and increasing relaxation<sup>4</sup>. The schedule should be designed specifically for the individual in collaboration with caregivers. More stimulating activities (e.g. showering, dressing, brushing teeth done earlier and the relaxing and enjoyable activities (e.g. reading a book) closer to bedtime. Daytime naps should be limited, and screen time should be stopped at least two hours before bedtime. Children should not be exposed to the blue light of phones, computers and iPads/tablets within 2 hours before bedtime as it can disrupt circadian rhythm. Caregivers of children with sleeping problems are also likely to be sleep deprived. Sleep hygiene strategies that address the needs of both the child and the caregiver are more likely to be effective<sup>4</sup>. Positive sleep hygiene alone may be insufficient to treat sleep problems among children with FASD, however other strategies are unlikely to be successful if poor sleep hygiene is not addressed<sup>4</sup>.

<u>Evidence</u>: There are currently no randomised controlled trials addressing sleep hygiene in FASD. However, there is evidence that even brief sleep education interventions can have positive impacts on sleep for children with neurodevelopmental disorders<sup>11</sup>. For further information, we recommend the comprehensive review of sleep hygiene for children with neurodevelopmental disorders<sup>4</sup>, and an article on the clinical considerations of sleep health issues for children with FASD<sup>6</sup>. These articles are based on clinical experience and provide recommendations for sleep-promotion practices and tips for caregivers.

**Sensory Considerations and the Sleep Environment:** Sensory processing is essential in the initiation and maintenance of sleep<sup>8</sup>. Children with FASD may have problems with sensory processing e.g. abnormal responses to noise, light, texture and should have an occupational therapy evaluation to determine their sensory needs. The occupation therapist can administer sensory questionnaires to gather information about the sensory processing of the child (e.g. Infant/Toddler Sensory Profile; Sensory Profile Caregiver Questionnaire). Observing the child in their home and/or school environment is important so the occupational therapist can understand the child's sensory processing and design an individualised intervention program<sup>12</sup>. The type of intervention implemented will depend on the child's sensory registration, seeking/avoiding behaviours and level of sensitivity to various stimuli<sup>8</sup>. In addition to sleep hygiene, interventions may include cognitive strategies (e.g. social stories) and/or sensory-based strategies (e.g. sensory integration therapy – an intervention usually conducted by an OT to help children learn how to receive, modulate and integrate

sensory information<sup>8</sup>). Sensory-based strategies should be trialled for several weeks before determining their level of effectiveness. Caregivers can keep a sleep journal to help assist with analysing the strategies effectiveness<sup>12</sup>. Creating a supportive environment for the child such as changes to their bedroom, reducing stimuli, manipulating the sensory input and self-regulation strategies, e.g. the Alert Program<sup>13</sup>, is also necessary to support children with FASD who have sleep problems<sup>12</sup>.

*Evidence:* Children with FASD have higher rates of sleep disturbances and more sensory processing abnormalities than typically developing children<sup>8</sup>, sensory processing abnormalities are linked to sleep problems. A pilot study measuring the sleep and sensory processing of infants/toddlers with confirmed alcohol exposure found that children who slept less during the day were sensation seeking; while those who were awake more in the night were sensation avoiding (the researchers suggest these children may have been woken by noises, lighting and/or pyjama or blanket fabrics)<sup>12</sup>.

**Regulating Circadian Rhythm:** There are various forms of circadian rhythm sleep disorders<sup>7</sup>, which include delayed sleep onset, frequent night-time arousals and persistent early morning awakenings. Children with circadian rhythm sleep disorders generally have impaired pineal melatonin production. Melatonin replacement therapy is widely used and can usually (but not always) improve their sleep. Melatonin replacement therapy is highly effective, is available in short and slow-release forms, acts quickly, has no significant adverse effects, does not develop a tolerance and is not addictive<sup>7</sup>. Although used frequently in other neurodevelopmental disorders, there are no guidelines on how to prescribe in this group. Exposure to light in the morning advances sleep onset at night, while exposure in the late afternoon delays it. While light therapy works, it is less commonly applied than melatonin, primarily because it requires exposure for one to two hours in the morning and many children, especially those with a neurodevelopmental disorder such as FASD, are unable to co-operate. If the child is able to co-operate, the combination of light therapy and melatonin is recommended<sup>7</sup>. Circadian rhythm is influenced by a number of neurotransmitters as well as other anatomical, neuromodulator, biochemical and endocrine functions – beyond the scope of this fact sheet.

*Evidence:* In a sleep study of children with FASD (aged 6-18 years old), 19 of the 24 children had abnormal melatonin secretion, suggesting an underlying disturbance to the regulation of melatonin and potentially abnormal circadian rhythm function<sup>14.</sup> Thirteen randomised-controlled trials were included in a review of melatonin therapy use for the management of sleep problems in children with neurodevelopmental disorders<sup>15.</sup> In 9 studies melatonin significantly improved total sleep time compared to a placebo and 11 studies found sleep onset latency improved with melatonin therapy. No differences were noted regarding the frequency of nocturnal awakenings.



**Medication:** The medication will depend on the type of sleep behaviour and underlying cause. Medication should be used in conjunction with behavioural strategies, if behavioural strategies alone are not successful. Melatonin or other medications should only be prescribed by an experienced clinician. The recommendations below are provided by a developmental paediatrician and diagnostic researcher for CanFASD<sup>5</sup>.

- 1. Difficulty falling asleep
  - Melatonin
  - Circadin (prolonged release melatonin)
  - Overactivity: Stimulant, alpha agonist
  - Anxiety: selective serotonin reuptake inhibitor, alpha agonist

- 2. Difficulty staying asleep
  - Anxiety/mood stabilisation: selective serotonin reuptake inhibitors, anticonvulsant
  - Self-regulation: stimulant
  - Behavioural Stabilisation:
    atypical antipsychotic
  - Restless leg syndrome: Iron
  - Melatonin

- 3. Early morning wakening
  - Anxiety: selective serotonin reuptake inhibitor
  - Melatonin
  - Circadin (prolonged release melatonin)
  - Decreased sleep need: no pharmacology needed
  - Melatonin

<u>Evidence</u>: There are currently no randomised controlled trials for medications relating to sleep and FASD. The information provided above is Dr. Hanlon-Dearman's approach to medication<sup>5</sup>. Dr. Hanlon-Dearman is a developmental paediatrician and diagnostic researcher for CanFASD.

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