Managing sleep disturbances in children with learning disabilities


The view that children with special needs are more likely to experience sleep disturbances is well recognised. Various physical and psychological factors associated with the child’s condition, as well as the influence that the child’s disability has on parents’ attitude and management, combine to increase the likelihood of the child developing sleep disturbances. However, these factors should not act as a barrier to trying to find successful solutions.

The associations between sleep disturbances and daytime behaviour are well documented (Zuckerman et al, 1987; Quine, 1991). One study that looked at associations between sleep problems and challenging behaviour found sleep problems to be more common in children with severe learning disabilities. It also found more stereotypical behaviours as a result of the sleep problems and that children with severe learning disabilities are more likely to show daytime irritability, lethargy and hyperactivity (Wiggs and Stores, 1996).

Alongside sleep disturbances children will often present difficult behaviours around bedtime and during night waking. Challenging behaviour at night-time can cause greater problems than during the day for the child, her or his family, and sometimes the neighbours.

Many parents are unable to listen to their children crying, even for a short period of time. If children have past or ongoing medical problems, which is often the case in this group of children, parents tend to be anxious that the crying could have a physical cause.

Also, due to medical concerns, some children need parental attention during the night for, for example, epilepsy or breathing disorders. Parents often report feelings of guilt about leaving their ‘disabled’ child to cry and tend to be unsure of the extent to which the sleep disturbance is a part of the child’s condition.

For these reasons extinction techniques, which involve leaving children to cry so that they learn to fall asleep alone in their own beds, are unacceptable to many parents. While developmental disorders are associated directly with sleep disorders there can also be an indirect effect through the impact that the child’s condition has on parents. Unhelpful attitudes and an inability to cope, particularly if associated with parental anxiety or depression, can lead to inconsistent handling (Durand and Mindell, 1990). The problem is likely to increase considerably if there is family disagreement about the cause of the sleep difficulties and responses to it (Stores and Wiggs, 2001).

Assessments process

Detailed assessments of each child’s sleep difficulties were carried out by interviewing the parents. These elicited information about the families’ sociocultural beliefs, parenting styles, family stresses, details about the child’s developmental history, the progress of the sleep disturbance, what strategies have previously been tried, the extent the sleep disturbance impacts on the life of the family and any daytime behavioural difficulties the child may have.

As well as gathering information, this process is important in helping to develop a therapeutic partnership with parents that is based on mutual trust and understanding. It is important that parents feel listened to and that their concerns and constraints are being taken into consideration.

These meetings take place in the family home – families who are caring for children with disabilities are frequently required to attend outpatient clinics, which can be difficult and stressful for parents, the child, and other siblings. Home visits avoid undue stress and reduce unattended or cancelled appointments. Also, this is an opportunity to see the living and sleeping environment. Parents are requested to complete the Albany Sleep Problem Scale (ASPS) (Durand, 1998), a 46-point
questionnaire, which asks for detailed descriptions of:
- Sleep routines and habits;
- Bedtime and night waking behaviours;
- Nightmares and sleep terrors;
- Hypersomnia and narcolepsy;
- Breathing difficulties;
- Sleepwalking and sleep talking;
- Limb and rhythmic movements;
- Bedwetting;
- Tooth grinding;
- Anxiety and depression;
- Daytime behavioural problems;
- Other medical conditions and medication.

The questionnaire is carried out with parents so that problem areas can be explored in more detail and helps avoid one-word answers that may need more clarity.

Sleep diaries are recorded between 2–4 weeks. Parental reporting alone can both under and overestimate the difficulties.

Information provided by sleep diaries includes:
- Time child is put to bed;
- Time child falls asleep;
- Time and length of any night wakings;
- Description of child’s behaviour on waking and who does what;
- Time child wakes in morning;
- Length and times of any daytime naps.

The information collected from the parental interviews, ASPS and sleep diaries goes towards devising appropriate strategies that will address the children’s sleep disturbances, but of equal importance, what will be acceptable to the child’s parent(s). Consideration needs to be given to any identifiable medical factors that are likely to be contributing to or likely to be exacerbated by implementing a sleep plan.

Parents can then be reassured that their child’s sleep difficulties are more likely to be as a result of poor sleep habits and routine. Parents are given information about the nature of sleep, and factors that are likely to be influencing their own child’s sleep disturbances.

**Treatment implemented**

Having chosen a technique that parent(s) feel they can implement (see case studies below), consideration is given to the level of support that is needed by the parents to help them put the plan into practice. This can differ greatly for some parents making the smallest of changes can be very difficult and high levels of support may be required in the early stages. The parents’ motivation and ability to make changes can be affected by their own physical and psychological well-being, and this needs to be taken into account.

Maintaining frequent contact in the early stage is important for all. Parents’ feedback about this has been that it helps them feel they are not alone and encourages them to keep going as well as allowing them to express and discuss concerns as they arise. It also helps in monitoring the effectiveness of the plan. Monitoring is also carried out using sleep diaries that parents are requested to continue recording as this allows for problems to be identified and rectified early on.

The sleep diaries also provide a visual means of monitoring change – this is important particularly when changes happen slowly. The diaries provide a way of seeing those changes that may be so small initially that they are not immediately being experienced. Being able to see the positive benefits of their efforts gives parents the motivation and confidence to keep going.

Although two different techniques are described below, the basic starting point to the development of good sleep habits is establishing a consistent routine before bedtime. This is called ‘the wind-down time’ (Box 1). Parents are encouraged to do what suits them and their child, but to stick to the basic principles – that it needs to happen around the same time every night and in the same order in preparation for sleep.

**Case study one**

B is a seven-year-old boy who lives with both parents and a younger brother. He was born with very complex medical problems and was diagnosed as suffering from cerebral palsy. He required a liver transplant and bowel resection in his first year, developed septicaemia and multi-organ failure, and at the age of two contracted meningococcal septicaemia. B communicates using some single words supported by ‘sign-a-long’ hand gestures.

B’s sleep disturbance started around the age of four, which coincided with severe gastro-oesophageal reflux. He refused to fall asleep in his own bed, avoided sleep by playing and trying to engage his parents in activities and would eventually fall asleep on the sofa or on the lounge floor. His parents would then carry him to bed. He would wake during the night crying and screaming only falling back to sleep if one of his parents remained with him. His parents had made several attempts at leaving him to cry, which had resulted in aggressive resistance, including screaming, crying and hitting out.

This created parental disagreements and inconsistencies in management. His parents were anxious that he was in pain or discomfort and found it difficult to listen to his
Guided reflection

Use the following points to write a reflection for your PREP portfolio:

- Outline where you work and why this article is relevant to your practice;
- What are the key points about sleep disturbances this article has taught you;
- Identify something new this article has taught you about sleep disturbances;
- Consider how you will use what you have learnt in your future practice;
- Explain how you intend to follow up what you have learnt in your practice.

Box 2. Anatomy and sleep disturbances in cerebral palsy (Kotagal, 2001)

CEREBRUM
- Seizures leading to arousal
- Anticonvulsant medication leading to arousal
- Circadian rhythm abnormalities – advanced sleep phase syndrome, delayed sleep phase syndrome, irregular sleep-wake rhythms

UPPER AIRWAY
- Obstructive or mixed sleep apnoea from macro-glossia, glossoptosis, adenotonsillar hypertrophy

GASTROINTESTINAL
- Gastro-oesophageal reflux

PULMONARY
- Recurrent aspiration pneumonia

MUSCULOSKELETAL
- Decreased ability to change body position, thus provoking arousal

Sleep disturbances have been associated with cerebral palsy (Box 2) and this, along with possible effects of B’s medication, needed to be considered.

Medical factors were discussed with B’s multi-disciplinary team and it was established that the reflux that may have contributed previously, had been resolved. While musculoskeletal problems could be contributing to his night waking, there were no settling or night waking disturbances reported during the time that B spent in an overnight respite care home. There were no other obvious medical factors identified.

In addition to the sleep disturbance B presented some difficult daytime behaviours, which included screaming, hair pulling, biting, poor attention and excitability. Information gathered during assessment showed that

B did not have a ‘wind-down time’. He would fall asleep between 8pm and 10pm, and of the 12 nights recorded he woke during the night on six occasions, taking between one and one-and-a-half hours to fall back to sleep. He awoke at around 7am, giving him an average of nine-and-a-half hours sleep per night. The typical amount of sleep needed for a child of B’s age is 10 or 11 hours per night.

The most likely cause of B’s sleep disturbance was a sleep association problem. This is related to partial waking, which happens to everyone several times a night. These periods are often very brief, lasting only a few seconds and are rarely remembered. The most common reason for partial waking leading to full waking is that the environment that we have fallen asleep in has changed causing alarm or anxiety.

A graduated extinction technique was chosen, this involved leaving B to cry, while continuing to check on him, but gradually extending the time between checks (Box 3). B’s bedtime was set at 8.30pm. This time was chosen as it would give him 10.5 hours sleep. He rarely fell asleep before this time. His parents wish was for a 7.30pm bedtime, but it would be unlikely that B would be tired at this time. Trying to enforce a bedtime too early would result in much more resistance than if he was tired.

The plan was explained to B by his parents and schoolteachers as a positive thing that happens when children grow up, providing additional reinforcement. His parents expected to be faced with sleepless nights and lacked confidence of any success so it was agreed that a phone call between 8.30–9pm each night would be made to check on their progress and provide reassurance and guidance as necessary.

From the first night the plan was implemented B was asleep before 8.30pm. Although his bedtime was set at 8.30pm he had wanted to sleep on the sofa. When prevented from doing this he was asked to go to bed, and although he did protest this was very brief. On subsequent nights his parents changed his bedtime to 8pm. The fourth night B was no longer resisting bedtime. B did not have any night waking and his total sleep time increased to 11 hours per night.

Case study two
R is a six-year-old girl who lives with both parents and a younger brother. She has a diagnosis of atypical Rett syndrome. She communicates using Makaton signs and symbols. She had been having night waking problems for eight months and the problem had become progressively worse over time. R presented some difficult daytime behaviours, including slapping others, pulling hair, hyperactivity and excitability.

Sleep disturbance has been associated with Rett syndrome (Roanne and Piazza, 2001). Information collected during assessment showed that R had a regular and consistent ‘wind-down time’. She was put to bed at 7.30pm and was generally asleep
times. R’s parents found that when they missed a night’s suggestions returned. It was also agreed that there would be sleep diaries weekly and would get feedback and information about awakening times (Box 4).

There were two occasions during the night that R would regularly wake but then fall back to sleep again. If R wakes up but then falls back to sleep again, gently touching or shaking her to the point where she wakes up but then falls back to sleep again. If R appears to wake too easily then the following night move the time back by 15 minutes.

The first consideration was R’s bedtime. Her parents were asked to delay her bedtime by 30 minutes to 8pm and to wake her at 7am, giving R 10.5 hours sleep each night. This is within the typical range for her age (10–11 hrs). While R appeared unaffected by the sleep disturbance, showing no signs of daytime sleepiness, both her parents were experiencing the effects of sleep disturbance. They described feeling irritable, impatient and drowsy during the day.

The techniques available to address R’s night wakings were discussed with the parents and they chose to use a scheduled awakening technique. This involved waking R at a time just before she would normally wake, thereby disrupting the sleep/wake cycle and starting a new one (Durand, 1998). The important factor in using this technique is that the person shows patterns of awakening at around the same time each night.

The first consideration was R’s bedtime. Her parents were asked to delay her bedtime by 30 minutes to 8pm and to wake her at 7am, giving R 11 hours sleep. As there were two occasions during the night that R regularly woke, it was agreed to have two scheduled awakening times (Box 4).

The parents felt confident they could follow the plan, and it was agreed that they would e-mail the recorded sleep diaries weekly and would get feedback and suggestions returned. It was also agreed that there would be face-to-face contact monthly.

During the first two weeks of assessment R woke 33 times per night. Both parents reported improvement in their own sleep. They also felt that R’s daytime behaviours had improved and she appeared calmer and more focused. This view was also reported by R’s teachers.

Conclusion

The two cases describe successful outcomes to two different behaviour management techniques used to solve sleep disturbances in children with special needs. While no data was collected about the effects this had on daytime behaviour, the amount of undisturbed sleep that the children were getting increased in both cases.

Techniques to manage sleep disturbances need to be considered and based on careful assessment of the needs of the child and family. The level of support that families need to carry out the sleep plans varies depending on the effect that the sleep disturbances have on their own physical and psychological well-being and on their experience of previously attempted solutions.

Preliminary work that focuses on developing a therapeutic partnership and explores parental concerns and anxieties, as well as education about the nature of sleep, is an essential component to successful outcomes. Many parents believe that the sleep disturbance is an inevitable part of their child’s condition and unless this view is corrected they may never realise that treatment can be effective in resolving the problem.

Not all outcomes are as successful as the cases described. The complexities of the child’s needs and family life can present a challenge, however, these factors should not act as a barrier to trying to find successful solutions to children’s sleep disturbance.

References


Box 3. B’s Graduated Extinction Sleep Plan

- Start wind-down time 30 minutes before bed
- Do not allow B to fall asleep in the lounge prior to bedtime
- Put B to bed calmly and with firm confidence
- If B is crying after eight minutes, tell him ‘It’s time to go to sleep, goodnight,’ then leave the room. Should be done in less than 15 seconds
- Do not pick him up, give food/drink, or engage in conversation
- Wait a further eight minutes, if B is still crying repeat as before, remaining calm and boring
- Continue until he is asleep
- Extend the time by two minutes each night
- If B wakes during the night wait the agreed time before going to him, after checking he is comfortable. Leave the room, continue as before

Box 4. R’s Scheduled Waking Plan

- Start R’s wind-down time 30 minutes before bed
- On the first night wake R at 12am and 3am by gently touching or shaking her to the point where she wakes up but then falls back to sleep again. If R appears to wake too easily then the following night move the time back by 15 minutes
- Repeat this each night until R goes for a full seven nights without waking. When she has managed this level of success, skip one night of scheduled waking. If, however, R has woken, then go back to scheduled awakenings every night