PROMOTING EFFECTIVE INTERVENTIONS FOR SLEEP PROBLEMS

Julie Sutton discusses how to be active in tackling sleep disorders and suggests ways in which this can be extended to support children with disabilities and their families.

Abstract

Health visitors and children’s nurses can do much to help families prevent the development of sleep problems in children with and without disabilities, and to treat existing disorder. Sleep difficulties among children with learning disabilities are common and receive inadequate attention in most practitioners’ training. This needs to be urgently addressed because untreated issues may persist into adulthood. A sound knowledge of sleep theory, the increasing literature on sleep, and the high quality sleep practitioner training that is available can all support health professionals in this role. Working in partnership with the family and carers is fundamental to success. Specialist services such as children’s learning disability nursing teams, child and adolescent mental health services and sleep centres can assist with complex cases.

Keywords

Children’s nursing, family-centred care, health visiting, learning disability practice, sleep disorders

SLEEP IS ESSENTIAL because it restores and refreshes us. In children it is especially important for development and sleep problems can affect many aspects of their day-to-day life. Stores (2001) found sleep loss in children to have a negative affect on their cognitive development and social and emotional wellbeing.

Meijer et al (2000) showed that sleep deprivation in school children is linked to daytime drowsiness and reduced performance at school. Following an inadequate night’s sleep, a child is often irritable and more inclined to have arguments and accidents (Ferber 2006). The condition’s negative effects on parents and carers is well documented. However, if a child also has a disability there is evidence to suggest a sleep problem left untreated will continue into adulthood (Durand 1998).

The Handsel Trust is a small independent voluntary organisation that promotes effective support for children with disabilities and their families. It studied sleep deprivation among members of this client group and observed that exhaustion, stress, relationship breakdown and employment difficulties were widespread (Handsel Trust 2007). Sleep problems can have long-lasting effects for children and their families, the consequences of which cannot be underestimated.

Sleep problems are common among children under five years, but tend to resolve as the child grows older and starts full-time school. Children’s nurses and health visitors supporting families with babies and young children are well placed to help prevent sleep problems from developing and devise strategies to overcome them, using a range of sleep assessment formats and intervention techniques (Durand 1998, Gurney and Marshall 2005, Ferber 2006). Practitioners using these resources are advised to underpin their work with...
a sound knowledge of sleep theory and, preferably, specialist sleep training. Furthermore, even the best-planned interventions can fail if they are not delivered in partnership with families. A trusting and valued relationship built with the family (Davis and Melzer 2007) in the early stages of intervention is fundamental to success. Parents and carers will value effective advice which will enable them to claw back precious hours of uninterrupted sleep.

Difficulties among children with learning disabilities are common. In 2007, the Handsel Trust questioned 375 affected families and identified 82 per cent who acknowledged that their child had a sleep problem. Worryingly, 65 per cent also reported that they had not received any professional help. Richdale and Wiggs (2005) observed that sleep disorders receive inadequate attention in most practitioners' training; they argued that this needs to be addressed.

Specialist services
Children’s health professionals need to improve their knowledge about sleep disorders and update their skills if they are to extend this support to families with disabled children. Specialist services, such as children's learning disability nursing teams, and child and adolescent mental health services, are on hand to support staff and to deal with more complex cases, but families can often experience lengthy delays due to over-stretched services (Morgan 2003). Improving the skills of more health professionals to support families with disabled children experiencing sleep problems can only be a positive step.

Prevention
Preventive sleep advice should routinely be delivered to all families, but especially to families of children with learning disabilities. Going through a sleep habits checklist (Box 1) is a good starting point. Gurney and Marshall (2005) recommend advising families on setting up positive sleep routines from birth, and they detail a similar checklist to make sure that golden rules for a full night’s sleep are followed. Durand (1998) had extended a similar checklist to cater for the needs of children with disabilities, among whom negative sleep routines can easily develop and become entrenched. When a family learns that their child has a developmental delay, some of the first health professionals they will come into contact with are health visitors and community children’s nurses. These are ideally placed to deliver prophylactic sleep work and can advise families on how to move sleep practices on as the child develops. Sleep issues are not an inevitable consequence of learning disability and much can be done to prevent them (Stores and Wiggs 2001a).

Assessment
There are three fundamental types of child sleep problems that health professionals may come across (Richdale and Wiggs 2005):

- Difficulty getting to sleep or staying asleep.
- Sleeping too much.
- Disturbed episodes that interfere with sleep.

These can be attributed to sleep disorders, more than 80 of which are listed in the International Classification of Sleep Disorders (ICSD) (American Academy of Sleep Medicine 2005).

Common disorders include nightmares, sleep apnoea, sleep terrors and narcolepsy, and

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**Box 1 Good sleep habits checklist**

<table>
<thead>
<tr>
<th>Actions to take</th>
<th>Actions to avoid</th>
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<tbody>
<tr>
<td>Put your baby to bed drowsy but not asleep.</td>
<td>Create a bedtime routine that requires your presence or props, which could become inappropriate sleep associations.*</td>
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<tr>
<td>Establish a regular bedtime routine.</td>
<td>Confuse your child by bringing your child back into the living area once the bedtime routine is completed.</td>
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<tr>
<td>Set behavioural limits at bedtime and during night wakings.</td>
<td>Soothe your baby to sleep with a feed after the age of six months.</td>
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<tr>
<td>Encourage your child to drink milk before bedtime.</td>
<td>Send your child to bed as a punishment; their bedroom needs to be a calm and happy place.</td>
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<tr>
<td>Keep the bedroom temperature around 18°C (64°F).</td>
<td>Allow your child to nap after 3.30pm, after the age of nine months.</td>
</tr>
<tr>
<td>Keep ambient noise to a minimum at bedtimes.</td>
<td>Give your child food or drink containing caffeine in the evening.</td>
</tr>
<tr>
<td>Reduce light in the bedroom.</td>
<td>Encourage any stimulating activity or exercise in the hour before bedtime.</td>
</tr>
<tr>
<td>Offer a balanced diet, limit fat and sugar intake and avoid additives.</td>
<td></td>
</tr>
<tr>
<td>Ensure your child has plenty of exercise in the day.</td>
<td></td>
</tr>
<tr>
<td>Try to phase out daytime naps as your child reaches the third birthday.</td>
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</tbody>
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*For some children who have sensory issues, certain props or soothers may be necessary at bedtime.*

(Adapted from the Handsel Trust 2009)
Community nursing complex forms may require referral to other agencies such as sleep centres and respiratory specialists. Certain types of sleep disorder are more common in disability conditions such as autistic spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), Down's syndrome and Smith-Magenis syndrome (Durand 1998, Turk 2010). It is necessary to know how sleep is affected in these conditions and when to seek additional support from specialist services.

Sleep history
Before appropriate advice can be offered, a thorough assessment of the child's problem is required and starts with an in-depth sleep history; interview schedules are provided by Durand (1998), Mindell and Owens (2003) and the Handsel Trust (2009). Information gleaned from these questionnaires includes when the problem began, how it is managed and what interventions have been tried in the past. Health professionals then need to know how to interpret these data, to establish possible causes.

The next step is a baseline recording of the sleep difficulty, supporting families to complete a sleep diary for a minimum of two weeks (Figure 1). This helps to confirm the type of advice that the health professional should be giving.

Health issues
Additional complex health issues are often associated with disability and can affect sleep. Richdale and Wiggs (2005) noted that sensory impairments can cause difficulties if the child receives reduced social and environmental cues that it is time to sleep or wake. A child's epilepsy and anticonvulsant regimen, for example, can cause abnormalities in sleep patterns and structure (Stores et al 1998).

Providing an inclusive sleep service will require understanding about how children with communication difficulties receive information and express themselves. The family and carers should be asked about systems the child uses to support communication, such as Picture Exchange Communication System (PECS) or Makaton signing. The Sleep Wise programme, devised by O'Connell and Vannan (2008), shows how communication strategies can successfully be incorporated into individualised sleep interventions. For example, sleep stories, gestures and visual tools can help the disabled child to learn the new sleep routine.

Treatment
Once the health professional is confident about the causes and nature of the child's sleep problem, a well-informed treatment plan can be designed in partnership with the family. Many sleep issues can be resolved by ensuring, first, that a defined and consistent bedtime routine is in place (case study, page 18). The name of the child in the case study has been changed to protect confidentiality. The child is referred to as Jacob. Jacob's story describes a relatively simple sleep intervention.

Sleep interventions will range from individual steps of advice, such as increasing physical activity in the day, limiting television viewing in the child's bedroom at bedtime or cutting out fizzy drinks at bedtime, to more complex evidence-based behavioural interventions (Gurney and Marshall 2005, Richdale and Wiggs 2005). Behavioural strategies effective in common sleep problems include bedtime fading, graduated extinction, sleep restriction and scheduled awakening. Use of these techniques requires further training.

Although initial treatment of sleep problems is preferably behavioural (Douglas 2005), hypnotic and sedative medications are a common first line of treatment, particularly for children with learning disabilities (Owens et al 2003). Stores and Wiggs

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Community nursing

Case study: Jacob’s story

Four-year-old Jacob was having problems falling asleep at night. He was a lively and energetic young boy who had Down’s syndrome. His parents were becoming worn out with his protestations at bedtime and settling him to sleep was a constant struggle.

His health visitor began by taking a detailed sleep history from Jacob’s parents and supporting them to complete a sleep diary for two weeks. The nature and causes of his night settling problem then became apparent.

In the hour before bedtime, Jacob would bounce on his trampoline for up to 40 minutes. His parents believed this would help tire him out, ready for bed. However, as this physical activity took place too close to bedtime, Jacob was raising his internal body temperature at a time when it should have been naturally falling. Such late exercise resulted in Jacob being too hot to fall asleep and too stimulated to relax in time for bed.

Jacob’s health visitor was then able to advise on making his bedtime routine calmer and more consistent, giving Jacob strong communicative cues that it was now the end of the day and time to rest. His parents followed this advice and moved his trampoline session to an earlier time.

In two weeks Jacob was drifting off to sleep within 15 minutes of going to bed.

(2001b) commented on over-reliance on sleep medication despite evidence on the efficacy of behavioural interventions. This again shows how vital it is that more health professionals are knowledgeable and confident in sleep intervention work.

Currently, melatonin is widely used as a short-term treatment for sleep problems (Turk 2010) but evidence on long-term use is not yet established (Sajith and Clarke 2007). Stores and Wiggs (2001b) concluded that the underlying cause of a child’s sleep problem should be identified first, prescribing medication only as a last resort and only on a short-term basis.

Conclusion

Health visitors and children’s nurses are well placed to help families prevent the development of sleep problems in children with and without disabilities, and to treat existing conditions. The importance and need for this type of health promotion work should not be underestimated, particularly among families with disabled children. A sound knowledge of sleep theory, the increasing amount of literature, and the high-quality sleep practitioner training that is available can all support health professionals in this role. With increased confidence and competence in sleep intervention, practitioners can help improve the lives of families affected by sleep problems.

References


