HOLISTIC APPROACH TO SLEEP IN CHILDREN WITH MOVEMENT DISORDERS:

Therapists’ Approach

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Sleep is thought to be essential in helping maintain mood, memory, and cognitive performance. It also plays a pivotal role in the normal function of the endocrine and immune systems. Chronic or severe sleep disturbances contribute to a range of difficulties for both the child and wider family, leading to family conflict and disruption for siblings (Cowdell 2007). A child’s temperament, lack of established sleep routines or inconsistent parenting can all lead to problems with sleep (McGreavey 2005). Tietze (2012) conducted a review of the literature on sleep and children with multiple disabilities, and found that in children suffering severe global cerebral injuries prevalence of sleep disturbances was >90%. The Family Fund report ‘Tired all the Time’ found that 49% of parents with disabled children had health related issues caused by a lack of sleep (Family Fund 2013).

Over the last 10 years, postural management programmes have been recommended for children with complex movement disorders. Studies have been conducted which discuss that impact of postural management on the development of structural deformity
when used for individuals with movement disorders (Gough, 2009; Lloyd et al, 2011; Hutton and Coxen, 2011; Maher et al, 2011). Postural management over a 24-hour period has also been shown to prevent contractures and hip subluxation in children with cerebral palsy (Pountney 2009).

Sleep systems aim to encourage and provide support to maintain a comfortable symmetrical sleeping position. There appears to be a lack of systematic research about the concurrence between sleep surface and bedding on sleep quality in children with disability (Jan et al 2008).

Goldsmith (2000) suggests that postural care relies on the availability of appropriate equipment and training to ensure that all carers are skilled in its use. She argues that parents should be acknowledged as experts on their own child and need to be empowered by training sessions to have a greater understanding of what postural management is, and their role in its provision.

Humphreys and Pountney (2006) state that service provision for postural management equipment has often been fragmented and depends on local therapists' knowledge and expertise. Pountney et al (2009) reported that equipment usage declined over their 5
year follow-up period in children with movement disorders. Gough (2009) suggested that parents and carers might not comply with postural management programmes if they perceive their child is in pain or discomfort.

The need for training to successfully manage a 24-hour postural management programme is also discussed by Humphreys and Pountney (2006). They suggest that a key part of the feedback from carers and staff was the need for all members of the team to be trained in using postural management.

The success of behavioural approaches in the treatment of sleep problems can quickly become evident, even where the difficulties are long-standing and associated with physical or intellectual problems (Wiggs 2000). The first line of treatment to improve sleep should be the promotion of sleep habits or “hygiene.” Despite the importance of sleep hygiene principles, clinicians frequently lack appropriate knowledge and skills required for the implementation of such a regime. It should be emphasized that other interventions are unlikely to be successful if poor sleep habits are not recognized and addressed (Jan et al 2008).
Sleep hygiene is defined as a set of sleep-related behaviours that expose persons to activities that prepare them for, and promote effective sleep (Meltzer and Mindell 2004). There are four categories:

Environmental: The bedroom environment needs to be made unexciting for the child to reduce environmental stimulation and increase relaxation.

Scheduling: A sleep/wake schedule is of particular importance for children with disabilities as both their sleep and circadian rhythms are more likely to be disrupted. For example, there should not be more than an hour’s difference in bedtimes and wake-up times during the week and weekends. Where a pattern of poor behavior is already established, a strategy of “extinction” should be gradually introduced so that detrimental behavior is not reinforced. Evidence shows this to be an effective treatment strategy in children with disabilities (Thackeray and Richdale 2002).

Sleep practices: Using calming activities including well-structured routine, quiet baths, listening to familiar stories within a quiet environment can aid sleep.
Physiologic: Encouraging physical activity during daylight hours should help children with disabilities to sleep better at night, because bright daylight aids the nocturnal melatonin rise promoting better sleep (Takasu et al 2006).

Key Points

- Sleep hygiene is essential as a first line of treatment for sleeping problems.
- It is crucial that parents are given sufficient training and support, in order to be confident in the use of postural management equipment, such as sleep systems, which encourage good sleeping positions in children with movement disorders.
- Sleep systems are not always successful with everyone even if good sleep hygiene is in place, due to some medical conditions, or issues with temperature control.
- Better quality research is required investigating the benefits of postural management in relation to sleep patterns, quality of life and pain in children with movement difficulties.
References


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