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Autism and sleep disturbance

Autism and sleep disturbance have long been linked but all too often the impact of poor sleep on family life can be overlooked. Sleep Scotland addresses sleep issues with behavioural and cognitive interventions tailored to each child.

Every child we work with is different, however throughout our work at Sleep Scotland we have seen particular challenges being presented to us by families with autistic children. These difficulties fall largely into three categories and their prevalence has been highlighted in previous research (Williams et al., 2004).

Restless sleep

Autistic children have been found to be overactive and energetic when their sleep is disturbed (Richdale, 1999). Whilst this is counter-intuitive, it is often reported by carers and can only add to their distress as a sleepless night is followed by a busy day. Keeping consistency in the sleeping environment is key to tackling this issue and carers should be wary of using techniques to get their child off to sleep which they are not willing to do several times throughout the night.

Settling

The act of falling asleep is something we often take for granted, and we can all think of the frustration that comes when our minds are too active to hit the standby button. Autistic children may experience this every night, and without the resilience to keep their head on the pillow they often seek stimulation in the form of mum and dad.

Sensory difficulties add a further consideration when trying to help autistic children to settle. The sound of a distant car alarm, the smooth fabric of a duvet or even just a garishly wallpapered room have all been identified as overly stimulating inputs in previous Sleep Scotland cases. Our Sleep Counsellors must remain vigilant for such stimuli and never underestimate their effect on autistic children. Combining these factors it is clear why settling is the one of the main causes of sleep disturbance for those with autism.

Sleep Scotland tackles sleep disturbance from a biopsychosocial perspective (Engel, 1977), viewing a child's diagnosis as only one part of their sleep problem. Support is given to families at all stages and our service continues to evolve as new studies into paediatric sleep disturbance are carried out. Recent research pointing to correlations between blue light emitting devices such as iPads and the cessation of melatonin production have added an additional dimension to our work and our trained staff work hard to overcome these new challenges.

Case study

LD was referred to Sleep Scotland by her mother. She was thirteen at the time of the intervention, and has a diagnosis of autism spectrum condition with learning difficulties. Her mother identified her anxieties surrounding transitional periods as being a factor in her difficulty settling to sleep, and told Sleep Scotland that LD was no longer going to school due to these fears. Using the information parents provide us in the first instance allows the team at Sleep Scotland to match each child to a suitable Sleep Counsellor.

One of Sleep Scotland's Sleep Counsellors undertook an initial assessment with the family at their home. Completion of a Sleep Disturbance Index (SDI) (Quine, 1991) with the family was illuminating and highlighted how difficult LD found it to settle to sleep. Assessing the ability of a child to settle, the frequency with which the child gets out of bed and the impact of this behaviour on the parents makes the Sleep Disturbance Index a valuable tool for our Sleep Counsellors. The SDI gave a result of five points out of a possible eight where zero is good sleep and eight is poor sleep. A further qualitative assessment allowed the counsellor to identify LD's fear of her bedroom as being central to her anxieties.

The family were given sleep diaries which were to be kept over the next two weeks. The diary is an easy way to get quantifiable information on the child's sleep in a very simple format. We ask one family member to record the details of the child's bedtime, wake time and how long it took them to settle amongst other things. Analysis of the diary's pointed to one major issue in LD's sleep routine; consistency.

Whilst LD's mother put her into bed at 8pm every night she was inconsistent in how she dealt with her several hours later when she came out of her room. LD's mother would often relent to LD's demands to be allowed to sleep in her parent's bed and although this secured one good night's sleep for the family it was fostering LD's anxieties about her own bedroom. Not only did this cause confusion but this pattern was interspersed with periods where LD's mother would try and return LD to her own bed leading to further distress for both parties.

Our Sleep Counsellor noted this as an issue that needed to be tackled. He suggested that LD's mother should return LD to her bed with minimal communication or interaction to avoid instigating what LD may see as a game. The Sleep Counsellor also came up with a routine which he developed into a social story which LD could be part of. The story incorporated photographs from around the family home of LD's bedroom and her pyjamas amongst other things. This allowed LD to follow what was happening and to feel some level of control, further extinguishing her anxieties about transitioning from day into night.

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Date of publication: 15 February 2016

The family were supported over the next couple of weeks via regular telephone calls with the Sleep Counsellor. This allowed the Sleep Counsellor to tweak and adjust the programme as was needed. The family reported the sleep problems were resolved around four weeks after our counsellor had first visited. A Sleep Disturbance Index was used to measure the results with LD's score dropping from five down to zero.

Example of a sleep routine

6pm Evening Meal

6:30pm Playtime

7:30pm Quiet play e.g. Jigsaw Puzzles and Snack

8pm Relaxing Bath

8:30pm Pyjamas, teeth cleaned and into bed

8:35pm Bedtime Story

8:45pm Cuddle from parent/carer

8:50pm Left to settle

The above is an example of a sleep routine which would be used by a Sleep Scotland counsellor in the above case. We can see how from half past seven the child is entering a relaxed state with the aim of lowering cortisol levels to allow melatonin levels to rise sufficiently before the child is put to bed. The bath is used to mimic the natural physiological changes that happen before we got to sleep i.e. body temperature drop. The principles of conditioning are at play in the bedtime routines we use, and associations play a strong role in letting the child know that it is time to go to sleep.

Training to professionals

Sleep Scotland also trains professionals across the United Kingdom from a range of disciplines including health visitors and educational psychologists. Poor sleep can have devastating effect on those with additional support needs and those without. Those in the helping professions are coming round to a more holistic approach to their practice and now see that sleep and behaviour are in fact bedfellows. Sleep Scotland will continue to work with autistic children with a view to improving their lives and the lives of those around them.

References

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