The management of sleep problems in children with neurodevelopmental problems including the role of melatonin

Sleep problems in children are very common and often have an impact on the whole family. While there is an increasing amount of information about sleep available, there is still some uncertainty and confusion about what can and should be offered to improve sleep problems in children with additional needs and disabilities. This paper provides a personal view about sleep management and is written for parents and practitioners working with families. It does not attempt to provide an exhaustive account but rather the main aims of this paper are to:

• highlight some important information about sleep
• explain why sleep problems are more likely in children with neurodevelopmental difficulties
• suggest what to consider when a child presents with sleep problems
• document effective behavioural management strategies
• clarify the role melatonin has in managing sleep problems
• signpost to reliable sources of information

SLEEP

Sleep is important¹.² It is very relevant to health and overall well being and therefore should be routinely asked about in medical appointments. If sleep has not been asked about is very appropriate to ask to talk about it. This includes checking what would be the expected amount of sleep for a child of a certain age and good habits to get into even if there is not a current concern. Some information about expected amounts of sleep for young children can be found on page 13 of the Early Support Information for parents on sleep booklet [www.ncb.org.uk/media/875230/earlysupportsleepfinal2.pdf](http://www.ncb.org.uk/media/875230/earlysupportsleepfinal2.pdf)

There are many different things that affect how much we sleep. These include our age (with babies needing the most sleep), how physically active we are and what our individual biological needs are. Sometimes parents’ need for sleep does not match up to their child’s. Whilst most adults need around 7 - 8 hours, some need more and some need less. Children’s sleep requirements also vary. Some parents worry their child sleeps too much but that is not the focus of this paper.

While there are some things we cannot alter about sleep there are many things we can. Sleep is a habit and therefore with practice we can get better at it¹. There are also some things that make it much easier to sleep and others that make it harder to sleep. Addressing these issues that promote or disturb sleep is sometimes referred to as sleep hygiene.

Ways of promoting sleep:
• put your child to bed and get them up at the same time each day
• do not let them have long lie ins at the weekend
The management of sleep problems in children with neurodevelopmental problems including the role of melatonin  
BACD Personal Practice Paper September 2013

- follow the same bed time routine each night
- make sure the temperature in the bedroom is not too hot or cold ($18^\circ$ degrees is often recommended)
- avoid caffeine containing food and drink for at least 6 hours before bedtime e.g. chocolate, cola, coffee (some suggest up to 12 hours)
- do not give your child a big meal before bed but sometimes a light snack or milky drink is helpful
- do not give your child drinks or food overnight unless there is a medical reason
- avoid TV, computer games and high levels of excitement for at least an hour before bedtime

WHY SLEEP PROBLEMS ARE MORE COMMON
Sleep problems are common in childhood. However we know that they are even more common in children with developmental problems and disabilities and they can be more persistent and difficult to treat. There are a number of reasons for this. These include:

- parents being more concerned or protective about their child with additional needs and therefore not following the same strategies they used with their other children or being less strict with them
- people thinking that the usual behaviour strategies will not work with this child
- children with neurodevelopmental problems not picking up on the usual cues that indicate that it is coming up to bedtime and so not being ready to settle off to bed
- an increased incidence of issues that will interfere with sleep including pain, gastro-oesophageal reflux, constipation, epilepsy, night time use of equipment (such as feeding pumps), muscle spasms, obstructive sleep apnoea, problems with temperature regulation
- parents worrying that there might be a reason for their child’s sleep problems and therefore being reluctant to try or persist with behavioural management

It is very important to have a clear understanding of the nature of the sleep problem in order to introduce the right strategies to successfully address it. Quite often there are several different things going on which each need attention. To help clarify the issues a sleep diary is very helpful and should be kept for at least 2 weeks to get a good idea of the child’s sleep pattern and what approaches parents are using. Sometimes parents feel they know what is going on each night but it is still very important to record this.

The sleep diary records the normal bedtime routine, what time the child goes to bed, what time they go to sleep and any problems with this and what the parents did to overcome them. It also records any night wakenings and again how the parent responded. The time the child is up in the morning and any daytime naps completes the information. Not only is this record important to help ensure the right advice and interventions are given it is also a valuable resource to evaluate any response to strategies tried. Parents can just write this information down or use a pre-designed sleep diary provided for them.
WHAT THINGS TO CONSIDER WHEN A CHILD HAS SLEEP DIFFICULTIES

Parents will often find it very useful to talk through their concerns about their child’s sleep. Sometimes just discussing the issues and highlighting good sleep hygiene principles enables parents to identify what needs to be changed and to be confident to achieve these changes. For other parents, focusing on their child’s sleep and keeping a sleep diary again facilitates their own identification of solutions. However, sometimes through discussing the issues it becomes clear that there are other things going on that advice and behavioural strategies are unlikely to resolve. These include child issues and issues unrelated to the child.

Child issues include problems highlighted above as being more common in children with neurodevelopmental problems such as gastro-oesophageal reflux and obstructive sleep apnoea. It is therefore important for doctors to take a careful history and examine the child to identify if there is likely to be a health problem that is contributing to the sleep problems. These then need to be appropriately treated. However, it is not unusual that when the health need has been addressed there are still some behavioural issues contributing to the sleep problems. Therefore, it is often an ongoing process to optimise a child’s sleep and it is important to support the family through this.

Some conditions are known to be more common in certain groups of children such as sleep apnoea in children with craniofacial abnormalities or Down Syndrome, or gastro-oesophageal reflux in children with cerebral palsy. There are usually typical clues in the history pointing to these diagnoses. However, sometimes it can be difficult to work out if there is a health issue or not and then one has to carefully consider all the possibilities, be clear about the nature of the sleep problem and keep re-evaluating if required. Occasionally, formal evaluation of a child’s sleep by a specialist sleep centre may be required.

Difficulties settling and short sleep duration are more common in certain conditions such as autism, Angelman syndrome, Smith Magenis Syndrome and Fragile X. However, knowing a child has one of these diagnoses should never be used as a reason for not providing support for the sleep difficulties as these children can respond well to good bedtime routine and specific strategies.

Issues unrelated to the child but important to sleep are often due to environment, circumstances and attitudes. If all the family are living in a single room, or the child does not have their own bed, many of the sleep issues are going to be difficult to address. Instead the focus should be on improving the home situation. Then it may be appropriate to focus on sleeping issues if they are still a problem. Equally if the child is just about to have an operation, or parents have a very demanding period at work or an older sibling is just about to sit exams, this may not be the best time to tackle the sleep problems as very often sleep problems will temporarily get worse before they get better. It is very important that once the sleep strategy is started it is followed consistently as if not, the situation may become worse and harder to address in the future. Therefore, it is essential that parents understand what is being expected of them, are united in their commitment to seeing the intervention through and are supported to succeed by wider family members and health professionals. Sometimes sleep counsellors are also available to provide advice and support.
It is helpful to set clear goals with regards to improving sleep. Sometimes our goal is that the child goes to bed at seven and sleeps all the way through the night till seven the next morning. However, this is sometimes too big a change from the current situation and parents become disheartened when it is not immediately achieved. Instead by focusing on what the main problem is and addressing that, success can usually be achieved and gradually other issues tackled over time. For instance, the biggest problem may be that the parents do not have anytime by themselves in the evening as the child takes hours to settle to bed. Alternatively the main problem may be the child waking lots of times overnight. Sometimes while the amount of time a child sleeps does not majorly increase, the amount they disturb their parents does. Again being clear and realistic what the goal is helps to ensure that it is achieved.

**EFFECTIVE BEHAVIOURAL STRATEGIES**

There are clear behavioural strategies that are helpful in addressing sleep problems. A booklet called “Encouraging Good Sleep Habits in Children with Learning Disabilities” describes many of these and can be found at [http://researchautism.net/publicfiles/good_sleep_habits.pdf](http://researchautism.net/publicfiles/good_sleep_habits.pdf)

A summary of the general tips from that booklet is shown below

**GENERAL TIPS**

- Teach your child to fall asleep on his own
- Reward good night time behaviour
- Decide on a bedtime and stick to it
- Establish a bedtime routine and use it every night
- Put your child to bed while he is still awake
- Try not to give night time drinks
- Try to avoid taking your child into your bed for sleep
- Try to be as ‘boring’ as possible when dealing with your child in the night

**REMEMBER**

- If you change an old habit, your child may get a little worse at first while he tests out the new rules.
- Changing old habits may take time.
- However, if you set the limits and are firm and consistent, problems will start to get better.

Early Support have also produced quite a detailed booklet on sleep that is downloadable from [http://www.ncb.org.uk/media/875230/earlysupportsleepfinal2.pdf](http://www.ncb.org.uk/media/875230/earlysupportsleepfinal2.pdf)

Contact a Family have produced a brief sleep leaflet that can be requested or downloaded from [http://www.cafamily.org.uk/media/389272/papt_english_sleeping.pdf](http://www.cafamily.org.uk/media/389272/papt_english_sleeping.pdf)

This is also available translated in Arabic, Bengali, Cantonese, Gujarati, Punjabi and Urdu.

These publications also signpost to further sources of information and support.
Sometimes it is easier to make changes to behavioural habits if there is specific support available. Several charities and organisations provide sleep counsellors or help lines or workshops. These include SCOPE, Cerebra, Contact a Family, Sleep Scotland, Handsel Trust, The Children’s Sleep Charity and The National Autistic Society. Family Health Visitors and local parenting programmes for children with special needs should also provide support. Some child development centres will have specialist health visitors who can offer tailored support for sleep problems. It is important that there is a range of support available as different families will require different types of support and while workshops can be helpful in some situations other families will require longer more individualised support from an experienced health care professional.

A project undertaken by the Social Policy Research Unit in York looked at what literature was available about the effectiveness of behavioural interventions for sleep problems in children with disabilities and then evaluated some behavioural intervention programmes. The literature review, which can be found at [http://www.york.ac.uk/inst/spru/research/pdf/interventionsReviews.pdf](http://www.york.ac.uk/inst/spru/research/pdf/interventionsReviews.pdf) found that programmes that used a range of strategies tailored to a particular child’s sleep problems and individual situation tended to be the most effective. A range of different programmes from individual to group interventions were then prospectively evaluated.³

One of the programmes evaluated was the service we provide in Blackpool through the Child Development Centre. Sleep problems are actively enquired about during routine clinic appointments with community paediatricians. Medical issues contributing to sleep problems are specifically looked for and if identified, treated. Parents are asked to keep sleep diaries for at least a two week period. If the sleep diaries suggest there are issues that are likely to respond to behavioural strategies a home visit is conducted by a specialist health visitor to look at and discuss environmental issues and to produce an individualised sleep strategy. This includes clear goals agreed with parents. Parents are supported in the implementation of that strategy by either home visits or telephone support. Six weeks is the typical duration of strategy implementation. Evaluation of this programme showed positive outcomes for parents and children.

However, not all sleep problems respond to behavioural strategies alone. In particular children who have difficulty falling asleep may benefit from melatonin treatment.

### The Role of Melatonin

Melatonin is a hormone that is important in regulating our sleep/wake cycles, also referred to as circadian rhythms. Light is a very important influence on how much and when we produce melatonin. Changes in the times when we go to bed and when we get up can also affect when melatonin is produced.

The amount of melatonin we naturally produce varies at different stages of our lives. Babies do not produce melatonin until around 4-6 months of age. Melatonin levels are then relatively high in childhood compared to adults as a similar amount is produced but children’s body weight and size are less.⁴ However, children metabolise melatonin more quickly than adults. This means that unlike other medications, the dose of melatonin is not dependant on the body weight or the age of the child. Rather there is a standard dose range
that is used, usually between 2mg to 10mg throughout the whole of childhood and adolescence. It is recommended to start at the lower dose and then to increase only if required. Doses above 10mg are unlikely to provide any additional benefit but increase the likelihood of side effects. Information about melatonin can be found in the Children’s British National Formulary (BNF) http://www.bnf.org/bnf/index.htm

Melatonin is not currently licensed for use in children in the UK though is in other parts of the world. However, quite a lot of the medicines regularly given to children are not specifically licensed for children as there need to have been trials done in children in order to get a licence. This is gradually changing as pharmaceutical companies are being required to address this issue. However, there have been some trials done in children with melatonin including a study in the UK called the MENDS trial. The MENDS trial and other trials have shown that melatonin is a safe medication, with few side-effects, certainly in the short-term. Longer term usage also appears to be safe but there is less data about this.

The MENDS trial and other trials have also consistently shown that melatonin is often helpful in reducing the time it takes for a child to fall asleep. However, there is less evidence to suggest that it increases total sleep time significantly or reduces night time wakenings. The melatonin most commonly used in these studies has been immediate release (fast release) melatonin.

There is currently a slow release melatonin preparation that is licensed for use in adults in the UK over the age of 55 years. It is called Circadin and comes as a 2mg tablet. In order to maintain its slow release properties it needs to be swallowed whole. It can be crushed and then put in strawberry yoghurt, strawberry jam, semi skimmed milk or orange juice. It will then act as immediate release melatonin.

As melatonin is currently unlicensed it should be started by a specialist i.e. an experienced paediatrician and not a GP. If there is a shared care agreement in place then the GP can continue providing repeat prescriptions. The British National Formulary for Children (BNFC) - see http://www.bnf.org/bnf/index.htm says that ‘treatment with Melatonin should be initiated and supervised by a specialist, but may be continued by general practitioners under a shared care arrangement’. This arrangement is often more convenient for families and is more efficient. Many shared care agreements specify that if possible Circadin should be prescribed as it is licensed. However, in certain situations a liquid preparation may be required. This is more expensive and therefore it is important to consider whether it is definitely the only suitable preparation for that child.

Melatonin should be considered for children who take a long time to fall asleep (more than an hour), several nights a week after other issues have been addressed, and behavioural strategies including sleep hygiene have been used. In most children, it will be of benefit but if it is not being of benefit it should be discontinued. It is given about 40 minutes before desired sleep time as part of a consistent bedtime routine. Slow release melatonin needs to be given 1 – 2 hours before desired sleep time.

Melatonin works in a number of different ways to promote sleep. Firstly, it helps regulate the sleep/wake cycle so that the child feels ready to go to sleep at a more normal time. Secondly, it has a direct soporific
effect i.e. it helps make the child fall asleep. That is why it is also used to help children having certain procedures such as sleep EEG’s fall asleep. Thirdly it acts as an anxiolytic. From my experience this can be very helpful for children on the autism spectrum and even for those children who do not go off to sleep, parents report a benefit from their child being calmer and more amenable to engage in the bedtime routine.

It is important to establish what the most appropriate dose is for each child and therefore there should be regular monitoring for the first couple of months in order to make changes to the dose as required. This can often be done over the telephone. Melatonin can be stopped immediately without having to wean down doses and does not need to be given every night if the child does not require this. Once the correct dose is achieved this should be reviewed at least 6 monthly. This includes a period off the melatonin to assess if it is still required. Behavioural strategies should continue to be used throughout. While some children may be able to discontinue melatonin use, many require it long-term.

No specific blood tests are required to be checked while a child is on melatonin. However, as with all medications if a child develops new symptoms while on the melatonin these should be carefully evaluated and any possible connection to the melatonin treatment considered.

Tolerance is not supposed to be an issue with melatonin. However some children do appear to no longer benefit from its use after they have been taking it for a while. One reason for this has been suggested that these children are slow metabolisers of melatonin. Consequently melatonin accumulates throughout the daytime, limiting its effectiveness. Therefore rather than increasing the dose a break from treatment may be required.

SUMMARY

- Sleep is important and advice on good sleep habits should be given from an early age and early intervention provided when sleep problems arise.

- Medical causes should be considered and actively addressed.

- Sleep diaries should be kept.

- Sleep hygiene should be optimised.

- Environmental and family issues should be considered and support provided if needed.

- Parents should be encouraged to set specific goals with regards to their child’s sleep.

- Behavioural strategies require commitment and consistency on the part of parents. It needs to be the right time to address the problem and support should be provided during the process. This support must be appropriate to the needs of the child and the family.

- Melatonin may be very useful in conjunction with behavioural strategies and can often enable parents to continue to implement the behavioural strategies.
• Melatonin needs to be started by a specialist and in some areas can be continued by a GP and in other areas needs to be continued by the specialist.

• The need to continue melatonin should be reviewed at least 6 monthly and at least a week off medication should occur every 6 months to help evaluate its need.

• Melatonin may be needed long-term.

REFERENCES


