Management of sleep problems in children with developmental difficulties

Community Paediatrics
Information for parents and carers

Children with developmental disorders such as autism, visual impairment, cerebral palsy, attention deficit disorder (ADHD), or learning difficulties more commonly have persistent sleep disturbance.

This may partly be because the brain’s “sleep-wake” cycle may not be in tune with that of the outside world. This can be difficult for families to cope with and can cause daytime sleepiness.

Initial steps

If you are concerned about your child’s sleep your paediatrician will initially take a history to check that there is no underlying medical reason to account for the sleep problem.

For example this may be due to a breathing difficulty such as snoring, discomfort or lack of mobility or a general health problem. It is helpful if you can keep a “sleep diary” for a week or so indicating your child’s bedtime, times awake in the night and waking time in the morning.

Developing a sleep management plan

The most effective treatment for the majority of children is to develop a consistent night time behavioural plan. Recent studies indicate that this is most likely to lead to long term improvement.

There are two ways your paediatrician may suggest to help:

- a comprehensive advice leaflet “Encouraging Good Sleep Habits in Children with Learning Disabilities”
- one of your child’s health professionals (such as school nurse or member of the health visiting team) may be able to help you develop a sleep management plan or refer for further support.

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Use of Melatonin for sleep difficulties

If the behavioural management plan on its own has not been sufficient to help with your child’s sleep problem your paediatrician may discuss the use of melatonin.

Melatonin occurs naturally in our bodies. It is a hormone produced in the pineal gland in our brain. It is produced at night and helps our sleep patterns. In children with developmental problems this regular pattern may be affected.

Melatonin is most helpful for children who have difficulties getting off to sleep.

It should be given the same time each night, between half an hour and an hour before your child’s agreed bedtime.

Depending on the preparation the effect wears off after a few hours so there is no carry over sleepiness the next day.
Information about Melatonin

Melatonin is generally well tolerated. The most common side effects include headaches, dizziness, nausea and drowsiness. More rarely it can cause an increase in heart rate and may possibly cause an increase in seizures in children with epilepsy. Inform your paediatrician or own doctor if concerned.

Your child’s temperature may fall a little after taking Melatonin. This is a normal reaction.

Which preparation will my child be prescribed?

Normally a preparation called Circadin is used with a starting dose of 2mg. This is because it is a branded preparation which has therefore had rigorous quality control checks.

This is a tablet which has a slightly longer onset and length of action. These should normally be swallowed whole, unless your doctor advises you otherwise. If your child cannot swallow tablets your doctor may advise you to crush them and mix with water, milk, yoghurt or sprinkle on food.

This may have the effect that the tablets act more quickly but is perfectly safe. Occasionally a different type of preparation may be used for example if your child has swallowing difficulties or has a feeding tube.

These include liquid preparation which should be measured with a medicine spoon or syringe. Capsules should be swallowed whole or sprinkled onto soft food such as yogurt or jam and swallowed without chewing.
What follow up will be required?

Normally the paediatrician will arrange a review after a few weeks by telephone to see if the medicine is being effective and adjust the dose if needed.

You will need to contact the child health office to report any problems and request a repeat prescription. Please allow 2 weeks for the prescription to be completed and sent to you.

A follow up appointment will be arranged 6-12 months after starting melatonin.

The aim is to stop the prescription once a good routine is achieved. Some children do need longer term treatment but it is advisable each year to try to withdraw the Melatonin for 1-2 weeks to test the need for this. Your paediatrician will discuss this with you.

Generally repeat prescriptions need to be obtained through the Child Health Office.

Some GPs may be willing to do repeat prescriptions with advice on adjustments in dosage form the paediatrician. Discuss this with your child’s GP.
Further Reading

“Melatonin for sleep disorders - Information for parent and carers.”

This may be given to you by your paediatrician. Alternatively it can be found on the web at www.medicinesforchildren.org.uk and search for Melatonin.

This is a detailed information leaflet for parents and carers which you should look at before giving Melatonin to your child and keep as a reference. This gives details of any possible side effects, storage of the medicine and what to do if your child is ill.

Points to remember:

• a regular good bedtime routine is key to long term success
• follow the guidance in the booklet “Encouraging Good Sleep Habits.”
• continue this routine whilst your child is taking Melatonin, changing old habits may take time.
For further information about this service contact:

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If you require this information in a different format such as in large print or on audio tape, or in a different language please contact the service on the details above.

If you have any concerns about this service or suggestions for improvements, contact our Patient Advice and Liaison Service on Freephone 0800 013 2511 or email: ccs-tr.pals@nhs.net.

For free, confidential health advice and information 24 hours a day, 365 days a year please contact NHS 111.