

# Managing sleep problems in children with **DOWN'S SYNDROME**

DOWN'S SYNDROME ASSOCIATION MEDICAL SERIES



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Notes for parents & carers



# Sleep problems

*Many parents will tell you that their child's sleep is a big problem. Helpful advice on how to deal with these problems can be hard to find and many parents tolerate disruptions night after night in the hope that their child will eventually just grow out of it.*

*In addition to the disruptive effect such problems have on the sleep of parents and other family members, they can seriously affect the ability of both the child and parent to function properly the next day and, in the case of children, their learning may be affected and behaviour problems may also develop.*

*These sorts of effects are perhaps even more important to recognise in children with a learning disability as they may add to the child's developmental problems, or they may be misinterpreted as part of the condition or thought of as the child "just being difficult".*

*This booklet provides some basic information about children's sleep. It also outlines the most common childhood sleep problems experienced by children with Down's syndrome and describes the most effective ways of dealing with them as well as where to go for further help. In places, reference is made to one gender and not the other, purely for the sake of brevity.*

**Dr Rebecca Stores, University of Portsmouth School  
of Health Sciences and Social Work**



# Typical sleep requirements in childhood



There is much variation between different children but, generally, as children get older, they require less and less sleep.

In the first few weeks of life, they may sleep for around 16 hours and this gradually reduces to around 13 hours when they are 2 and reduces further as they get older.

In the first few weeks of life, around

half children's total time asleep will occur during the night and half during the day. Later, the proportion of daytime sleep decreases until eventually, at around 3, all their sleep is occurring during the night.

By about 18 years of age, people usually sleep on average 7-8 hours a night and stay at about this level for the rest of their life.

## Sleep states

Once it was thought that sleep was a single state distinguished only from waking. However, we now know that sleep is divided into two very different states: REM (or Rapid Eye Movement) sleep and Non-REM sleep. These states can be identified by monitoring brain waves, eye movements and muscle tone.

- REM sleep is a relatively active state. Your eyes make quick movements during this sleep state (hence its name) and breathing and heart rate are irregular. Brain waves become busy and resemble those recorded in someone awake and alert. Blood flow to the brain is increased. Your muscles are effectively paralysed

as nerve impulses are blocked. It is during this sleep state that most dreaming occurs. Much of sleep is taken up with REM sleep in very early development, suggesting that this type of sleep is important in early learning and memory.

- One view is that most of the restorative function of sleep occurs during Non-REM sleep. During this state, you lie quietly with a regular heart rate and breathing. Non-REM sleep consists of four stages which represent progressive levels of sleep from drowsiness to very deep sleep from which it is difficult to be woken.

## How sleep develops in children

Sleep patterns begin to develop in babies before birth. Beginnings of primitive REM (or 'active') sleep can be seen at about 6 or 7 months gestation, and Non-REM (or 'quiet') sleep between 7 and 8 months.

In newborn babies, as in adults, the two states can be identified. During active sleep, the baby twitches, breathes irregularly and their eyes can be seen to dart about under the eyelids. Smiling

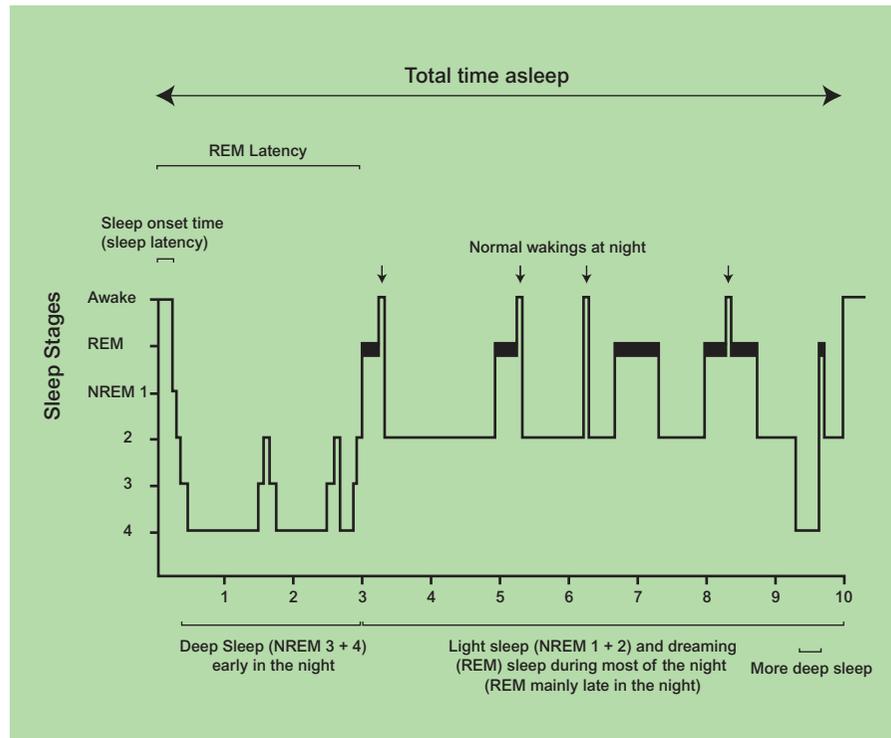
also occurs. Quiet sleep has not yet divided into four stages. Some sleep is a mixture of active and quiet sleep. This is called 'indeterminate' or 'intermediate' sleep.

At around 2-3 months, a sequence of sleep stages can be identified and by 4-6 months, all sleep stages occur and a clear 24 hour sleep wake rhythm has normally started to develop.

## A typical night's sleep

By around 4-6 months of age, a child's night time sleep cycle will be pretty

well developed and will resemble that of an adult.



Most of the first half of the night is spent in the deeper stages of Non-REM sleep and most of the REM sleep occurs towards the end of the night.

experiences these at any age. However, we usually wake and return to sleep so quickly that we are not aware that we woke in the first place.

An important feature of the child's sleep cycle is that a number of brief wakings occur during the night. These are quite normal and everyone

Problems arise when a child will not go back to sleep on his or her own after these wakings. More will be said about these wakings later.

## How common are sleep problems?

A wide range of sleep problems exist as described shortly. However, among the most common problems are difficulties settling children to sleep and repeated waking during the night with children demanding their parents' attention. Frequent settling problems have been reported to occur in at least 20 percent of 1 to 2 year olds in the general population and frequent night

waking in about 25 percent.

Figures are higher for children with learning disabilities. For those with learning disabilities other than Down's syndrome, around 80 percent of children are reported to show some type of sleep problem. Children with Down's syndrome fall somewhere in the middle with problems reported in around half.

## Why should we be concerned about sleep problems?

Research has shown that persistent sleep disturbance can cause a number of problems.

misconstrued as part of the child's condition or them just being "difficult".

- Children with very disturbed sleep are more likely to have behaviour problems than children who sleep well. Sometimes the sleep problems are part of a child's more general behaviour disturbance. As with any of us, if a child is not getting enough sleep at night, this is likely to affect them during the day causing such difficulties as irritability, overactivity, aggression, learning problems and impaired attention and concentration. As already stated, these effects are even more important if present in a child with a learning disability as they may add significantly to the level of delay already experienced and also may be

- In addition to the detrimental effects on the child, having a child with a sleep problem is likely to have a disruptive effect on the sleep of parents and other family members. Mothers of children with a sleep problem report higher stress levels, increased irritability, poorer marital relationships and more negative attitudes towards their spouses, their child and themselves. Having a learning disabled child is often stressful enough; the addition of sleep disturbance is likely to add significantly to parents' difficulties. It is essential, therefore, that help with sleep problems is provided as soon as possible. Ideally they would be prevented from happening at all.

# Types of sleep problems

Virtually all sleep problems which occur in children in general are seen in children with Down's syndrome and children with other learning disabilities.

There are no sleep problems which are specific to such children. However, as will be described later, children with Down's syndrome may be particularly prone to developing certain types of sleep disturbance.

Some sleep problems have a physical cause, others have a behavioural basis. Some are more likely to occur at certain ages, whereas others may appear during childhood and then persist throughout

## Behavioural sleep problems

Behavioural sleep problems are among the most common sleep problems in children, including those with Down's syndrome. Some of these were mentioned earlier. They include difficulty in settling the child to sleep, repeated night time waking with demands for parents' attention, early morning waking and insisting on sleeping with parents. There are many ways in which these

most of the individual's life if treatment is not provided.

It is very important to identify the sleep disorder causing a sleep problem rather than trying to treat the problem in its own right. For example, just as there are many possible reasons why someone is breathless, there are many possible causes of sleeplessness. Treatment depends on the underlying cause.

The most common sleep problems experienced by children with Down's syndrome are described below. Approaches to management are described later.

problems can develop, varying somewhat from child to child. In some cases, a child may have challenging behaviour and the night time problems are just another aspect of this. In other children, the presence of a physical or medical disorder (such as an ear infection or other painful condition) may disturb their sleep. More commonly, the settling and night waking problems develop

as a result of children never having learnt to fall asleep without their parents being present. Therefore, when they wake up in the night, they are unable to re-settle themselves and demand their parents' attention.

It is important to say that what may

be a problem in one family may not be in another.

However, what may not be a problem when children are young, may become a problem when they are older and the longer a behaviour has been going on, the harder it is to do something about it.

## Obstructive sleep apnoea (OSA)

Studies have consistently shown that children with Down's syndrome are more prone to OSA than children in the general population. This is due to various physical characteristics associated with the condition including floppy muscles in the throat, enlarged tonsils and adenoids and a smaller upper airway.

OSA occurs as a result of the upper airway at the back of the throat becoming blocked repeatedly during sleep. Each time this occurs, breathing stops for a time and the child is then woken up by the struggle to breathe. These interruptions in breathing ('apnoeas') may occur hundreds of times during the night causing sleep disruption and poor quality sleep. It is the frequency of these events which determines the severity and whether treatment is necessary.

Night time features include combinations of loud snoring or coughing or choking noises, restless sleep, sleeping with

the head tipped back (to try to open up the airway), other unusual sleeping positions, repeatedly interrupted breathing, excessive sweating and possibly bedwetting. However, these behaviours can occur in the absence of OSA and so careful assessment is needed. An overnight sleep study by a respiratory specialist is usually required to diagnose the problem and establish its severity. Daytime consequences of OSA include excessive sleepiness, behaviour changes and impaired concentration and poor memory.

There is evidence to suggest that OSA is under-recognised in the general population and probably more so in individuals with Down's syndrome. About 2 percent of children in general have some degree of OSA (usually because of the relatively simple matter of enlarged tonsils and adenoids). In contrast, the figure is more like between 50 and 80 percent in children with Down's syndrome.



## Combinations of behavioural and physical sleep problems

Some children may have both a physical and a behavioural sleep problem and it is possible that one may perpetuate the other. Careful assessments need to be carried out to establish the nature of the problems present and

treatment tailored accordingly. A multi disciplinary approach is almost certainly needed in such cases. The physical problem should possibly be treated first and the behavioural problem tackled afterwards.

## Other sleep disorders

Many other types of sleep disturbance are now known to exist in both children and adults. Here is not the place to list them all; those already mentioned have been selected because of their special relevance to children with Down's syndrome. That said, however, because many of these other sleep disorders are common, they might well occur in conjunction or instead of those described

above. Examples include sleepwalking or sleep terrors, headbanging, night time fears, nightmares, bedwetting and night time epileptic attacks. Some of these conditions eventually stop of their own accord; others need special treatment which can often be effective. Further details are provided in the recommended reading at the end of this booklet.



# Management of sleep problems

Before being able to manage a sleep problem, it is useful to carefully describe the symptoms by using a sleep diary kept over a week or two preferably. If help is needed from health professionals, they will find this information very useful.

The type of treatment needed for a sleep problem depends on the specific

nature of the problem. A sleep problem with a physical cause, for example OSA, will require a very different approach to, say, a settling or waking problem.

Methods for treating behavioural sleep problems will be described first and methods for treating OSA will be outlined towards the end of the section. First, a word or two about medication.

## Medication

Medications for sleep problems are among the most commonly prescribed drugs by doctors. This is somewhat surprising as research has shown they are of limited value.

Sedative drugs (mainly antihistamines), either prescribed or bought over-the-counter, have been shown to have limited short-term effects and provide no lasting benefit. Also they can cause an irritable and "grizzly" state especially the next day and do not provide a child with the opportunity to learn to go to sleep at bedtime unaided and to return to sleep after waking during the night. The best current advice is that they

are best reserved for very short-term use where really necessary, for example where parents themselves need a good night's sleep, and as a preparation for starting behavioural treatment.

Melatonin has been recommended by some people in recent years as a treatment for sleepless children but its real value is uncertain. Some children seem to benefit but many do not. Even those who apparently respond might do so because of the changed way their parents behave towards them at bedtime when they started to use the melatonin. Melatonin is usually given in doses that produce much higher levels

in the body than occurs naturally. For this reason there have been some concerns about possible long-term

## Behavioural approaches

More specific and individually designed behavioural approaches may be needed for some sleep disorders and these techniques have been shown to be particularly effective. As stated earlier, many of these problems are a result of parents' unwillingness to set limits and/or children never having learned to fall asleep on their own. Behavioural techniques aim to change the way

## Settling to sleep

A consistent routine throughout the whole day is very helpful for children in general. Starting a bedtime routine as early on in a child's life as possible is definitely a good idea. This should be carried out at the same time every night and consist of relaxing, pleasurable things like having a bath, perhaps a warm drink, a nice story and then being tucked up in bed with a kiss before the light is turned out. It should be a winding down period, without anything exciting happening like boisterous games. If the same routine is used every night, children learn to associate it with sleep and know that sleep is

side effects. Overall, behavioural treatments are preferred to any form of drug treatment.

parents react and deal with the problem.

A brief overview of the techniques used for the individual problems of settling, night waking, early waking and sleeping with parents is given below.

More information is provided in the recommended reading mentioned at the end of this booklet.

coming soon and will start to unwind, relax and become ready for sleep.

It is most important to teach children to fall asleep on their own from a young age. Not doing this often leads to sleep problems later on. It is vitally important that a parent being present does not become a cue for falling asleep otherwise every time your child wakes up he will need you for him to fall asleep again. It is important that your child falls asleep in bed and not downstairs e.g. in front of the TV. As was mentioned earlier, all children wake up during the night, and if things are different from when they

went to sleep, they may be less likely to fall asleep again.

If your child has got into the habit of not falling asleep without you being present,

## Checking method

If, when you put your child down, he settles happily you can leave the room. If he starts to cry, go in after 5 minutes (less if the crying distresses you) and gently but firmly resettle him with as little touching as possible. Leave again. If the crying persists, go back at gradually increasing intervals and use the same resettling routine. You may have to go

## Gradual withdrawal approach

Alternatively, you can gradually increase the distance between you and your child over successive nights (e.g. stand beside cot or bed, stand a bit away, stand in the door, stand outside the door etc.) until your presence is no longer required for him to fall asleep. This approach may take a bit longer than the checking method but it can be more acceptable to some parents as it involves less crying!

Rewards and incentives speed up the learning process! But two vital rules are:

- At no time should a reward be taken away once it has been earned.
- There should be no bargaining about the required behaviour and no giving in.

there are two methods for teaching him to fall asleep on his own. These are the checking method and the gradual withdrawal approach. A description of these methods is given below.

in many times to begin with but this will get fewer each time until he eventually falls asleep rapidly on his own. By doing this, your child will learn to fall asleep on his own and will no longer require you there. Things will probably get worse before they get better, but within a few nights, your child should be falling to sleep on his own fairly quickly.

There are some other points worth bearing in mind:

- Nightlights and comforters can be a useful cue for sleep and, for example, if a child appears to be afraid of the dark.
- Late afternoon naps should be avoided to ensure the child is actually sleepy when put to bed.
- To set an earlier bedtime, you can gradually bring the bedtime routine earlier and earlier, by say 15 minutes, over successive nights until the desired bedtime is reached.

**Firmness and consistency are vital for these approaches!**

## Night waking

The following should be helpful if your child wakes repeatedly at night and demands your attention.

- The first thing is to check he is okay and see if there is a reason for having woken up, for example, being cold or having a wet nappy. Obviously it is very important to know if your child has a medical condition that can disturb him at night such as an asthma attack or an epileptic seizure.
- If you are satisfied that things are alright, then settle him in exactly the same way as bedtime i.e. using the checking method or gradual withdrawal approach, so that he learns to go back to sleep in the same way.
- If your child is old enough to get out of bed, take him back every time! It only needs one time for them not to be taken back to make the situation worse and for him to learn he needs to cry for just a little longer for you to give in.
- Generally speaking, leaving a child completely alone, to cry himself to sleep, is not a good idea. Although in theory this might work after a few nights, it seems too harsh for most parents who, with support, feel happier with the other behavioural

methods just described.

- For older children who come into your bedroom, hanging something noisy on your door can be useful so that you know each time they come in and you do not wake up in the morning and find them in your bed!
- Try to avoid night time drinks or giving much attention in other ways, as this can make night waking a habit.

**Again, firmness and consistency are vital.**



## Early waking

If your child's early waking and demanding attention or making lots of noise is a problem:

- wherever possible(!), try to encourage him to go back to sleep and avoid any encouragement to stay awake i.e. avoid noisy activities.
- reduce light and noise and other external stimuli to reduce the chance of waking early.
- praise should be used to encourage children to stay in their own bed and entertain themselves until a reasonable hour.
- a lamp on a timer can be an additional necessary cue for when

## Sleeping in parents' bed

Some parents are happy to have their child in bed with them and others are not. Neither is right or wrong. However, as said earlier, it is worth remembering that what may not be a problem to you now, may become a problem in the future and the longer a behaviour has been going on, the harder it is to do something about it later on.

If you have decided that you do not

it is acceptable to disturb mum or dad.

- sometimes, children just need less sleep than you might expect. In these cases, try gradually putting bedtime later so that they wake later.
- as the last phase of sleep can become displaced to a daytime nap, it is best to avoid morning naps when a child is waking too early.



want your child in your own bed, leave the child in her own bed or, if she gets up and comes to your bed, take her back every time and resettle as at bedtime. Again, something noisy hanging from your door may be necessary to alert you.

You may have to do this several times on the first few nights but eventually your child will learn to go back to sleep on their own. Be persistent.

## Summary of behavioural approaches

The most important points about behavioural techniques for settling problems, night waking, early waking and sleeping with parents are:

- establishing a consistent evening and bedtime routine ending with your child relaxed and ready for bed.
- from an early age, teaching your child to fall asleep on their own without you being present, avoiding the reinforcement of settling and waking problems by giving in to demands for drinks, food, more stories etc.
- rewarding good night time behaviour.
- trying to avoid taking your child into your bed for sleep.
- avoiding prolonged naps in the late afternoon.
- being kind but firm and consistent!

These principles can be difficult to stick to in the middle of the night but they do work if you are persistent.

Firmness and consistency are the keys to success. If you need to give in, do so straight away but do not give up. Perhaps another technique will be

more appropriate, or try again when you are feeling stronger.

There are an increasing number of sleep clinics being set up around the UK which deal with behavioural sleep problems. They are usually run by health visitors who help plan a programme based on these techniques and offer support whilst you are carrying it out. This can be very helpful and can make it easier than tackling the problem on your own.



# Management of sleep related breathing problems

Unlike the problems just described, OSA requires a medical approach to treatment as the cause is physical.

Paediatricians would usually be the first port of call and in most cases they will arrange an assessment for your child. They will refer onto an Ear, Nose and Throat (ENT) surgeon or respiratory physician for specific treatment if necessary.

As mentioned earlier, where children in the general population are concerned, the most usual cause of obstructive sleep apnoea is enlarged tonsils and adenoids and, therefore, the most effective treatment is their removal.

In children with Down's syndrome, the situation is more complicated and each case needs to be investigated on an individual basis. The cause of the airway obstruction can vary from one child to another.

In some children, removal of the tonsils and adenoids may improve matters sufficiently but in others it may not.

Where it proves ineffective, there are

other surgical interventions which may be appropriate.

For adults in the general population, the most common and effective form of treatment for obstructive sleep apnoea syndrome is a procedure known as Continuous Positive Airway Pressure (or CPAP for short).

This involves wearing a mask which is placed over the nose and mouth during sleep through which air is pumped continuously to keep the airway open therefore preventing obstruction.

Individuals find that the beneficial daytime effects outweigh the inconvenience of wearing the mask. It has been used successfully in a preliminary way with children including some with Down's syndrome. However, as one might imagine, there are often problems with compliance, especially if the procedure cannot be properly explained to the child.

More research is needed into effective forms of management in children with Down's syndrome.

# Recommendations

If you are concerned about your child's sleep you should contact your Health Visitor, School Nurse, GP or Paediatrician.

Health professionals should be aware of which issues to look out for, in particular:

- Sleep problems should be routinely enquired about by health professionals, not only because of the immediate distress that a sleep problem can cause to the child and other family members, but also because treatment of the sleep problem might have a beneficial effect on the child's learning and behaviour.
- In the case of children with Down's syndrome, healthcare professionals should enquire about both sleep disorders of a behavioural origin and those caused by physical factors especially OSA. Combinations of the two types of sleep problems may well occur.
- The possible effects of persistent sleep problems on other members of the family should be considered

carefully. Distress, depression, marital problems and even worse consequences can result from long-standing sleep problems for which no effective help has been sought or provided.

- Community and hospital services ought to be alert to the possibility of severe sleep disorders in children with Down's syndrome. Appropriate psychological, physiological and other clinical investigations need to be available. Treatments appropriate to the individual case should be provided as early in the child's development as possible. Effective treatment is very likely to benefit the child and family as a whole.

# Further information

For further advice on managing children's sleep problems in general, the following books written for parents should be useful:

**Teach Your Child to Sleep: Solving Sleep Problems from Newborn through Childhood** by L Quine, published by Hamlyn Health (2005).

**Solve Your Child's Sleep Problems: New, Revised and Expanded Edition** by R Ferber, published by Fireside Publications (2006).

**Childhood Sleep Disorders: The Facts** by G Stores, published by Oxford University Press (2008).

More detailed information (including references to published studies) can be found in:

**A Clinical Guide to Sleep Disorders in Children and Adolescents** by G Stores, published by Cambridge University Press (2001).

**Sleep Disturbance in Children and Adolescents with Disorders of Development: its Significance and Management** by G Stores and L Wiggs, published by Mac Keith Press (2001).

**Evaluation of brief group administered instruction for parents to prevent or minimize sleep problems in young children with Down's syndrome** by R Stores and G Stores, *Journal of Applied Research in Intellectual Disabilities* (2004) 17 61-70.

**Behavioural approaches to the treatment of sleep problems in children with developmental disorders. What is the state of the art?** by A Richdale and L Wiggs, *International Journal of Behavioural and Consultation Therapy* (2005) 1 165-189.

**Dr Rebecca Stores,**  
University of Portsmouth, School of Health Sciences and Social Work.

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