

Sleeping difficulties in children and young people with learning disabilities

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West London Mental Health



NHS Trust

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Contents

Introduction	3
Assessment	8
Causes of sleeping difficulties	10
Strategies	14
Good sleep habits checklist	18
Example resources	19

Introduction

What is normal sleep?

In most people the 'sleep-wake cycle' runs its course over a period of 24 hours and our biological clock informs our brain to help us sleep at night and wake in the morning.

Each night we go through several stages of sleep. We begin our sleep in 'light sleep'. This is when you feel awake but are in the process of falling to sleep and you may feel your thoughts drift. You may notice your child jerking or twitching at this time. We then move to 'deeper sleep', then 'deepest sleep'.

When in the deepest stage of sleep, it would be difficult to wake your child. We then move to the 'Rapid Eye Movement' phase of sleep (REM). Here the body is very relaxed, but the brain is active and it is at this time that dreaming takes place. You may notice your child's eyes moving under their eyelids at this time. REM sleep would usually begin after your child has been asleep for about 90 minutes.

We cycle through these stages a number of times each night, e.g. after light sleep, deeper sleep, deepest sleep and REM sleep we move back to light sleep. However, between each cycle we experience a 'partial waking' which may only last a few seconds and which you will not remember the next day.

How much sleep does your child need

Every child is different – some children need far more sleep than others. Some children may only need five hours sleep and will feel rested the next day, whilst others may sleep for 10 hours and still feel sleepy the next morning.

The amount that your child needs to sleep may differ from night to night, but in general, people's sleeping needs are pretty constant. So, if you compare your child's sleep from week to week or month to month, they will tend to sleep, on average about the same amount each day.

The amount that your child needs to sleep may depend on their age, with the amount needed decreasing as they get older. Below is a rough guide of how much sleep children need.

Age	Hours of sleep needed at night (and day)
12 month	11 ½ (2 ½)
2 years	11 ¾ (1 ¼)
3 years	11 (1)
4 years	11 ½ (0)
5 years	11 (0)
6 years	10 ¾ (0)
7 years	10 ½ (0)
8 years	10 ¼ (0)
9 years	10 (0)

Age	Hours of sleep needed at night (and day)
10 years	9 $\frac{3}{4}$ (0)
11 years	9 $\frac{1}{2}$ (0)
12 years	9 $\frac{1}{4}$ (0)
13 years	9 $\frac{1}{4}$ (0)
14 years	9 (0)
15 years	8 $\frac{3}{4}$ (0)
16 years	8 $\frac{1}{2}$ (0)

As mentioned, some people require far less sleep than others, e.g. your child may only need 4 hours of sleep each night and feel rested. Experts believe that sleep only becomes a problem if your child is concerned by the amount that they sleep and it affects their daily activities because they are tired.

A wide range of difficulties would be considered a sleeping problem and are often due to physical, emotional and/or behavioural problems

Some common problems include:

- **Sleep deprivation** - insomnia. This is usually seen in one of the following forms:
 - » difficulty falling asleep (15-30 mins to fall asleep is typical)
 - » difficulty maintaining sleep - waking frequently during the night or waking early
 - » non-restorative sleep - not feeling rested after a reasonable amount of sleep

- **Sleep schedule problems** – where your child sleeps fine, but at the wrong times.
- **Nightmares** – when your child experiences frightening dreams and awakens feeling distressed. When recurrent, it can lead to disrupted sleep because it may result in your child fearing bed time.
- **Sleep terrors** – occur in the stage of sleep when your is not dreaming. Your child may scream although they are asleep and may appear extremely upset and frightened. It is difficult to wake them and they cannot be comforted easily. Often, they do not remember the incident the next day.
- **Bed-wetting**
- **Tooth grinding** – this is not very well understood, but may be linked to dental problems and/or stress.

Children with special needs often present two challenges – the sleep problem itself and the difficult behaviours that go along with it. Behavioural problems associated with the sleep problems include:

- Tantrums and emotional outbursts when asked to go to bed
- Repeatedly getting out of bed at bedtime
- Refusing to sleep without parent close-by
- Elaborate routines to prolong waking time and put off bed time
- Going into parents' room throughout the night
- Being destructive in their bedroom or other parts of the house
- Insisting on sleeping in someone else's bedroom.

Impact of sleep problems

Sleep problems have a huge impact on both the children who experience them and their family. These include:

Effects on the family

- Increase in family stress
- Negative impact on the parent-child relationship
- Negative impact on the parents own relationship and relationship with their other children

Effects on the child

- Emotional well being - e.g. causing low mood, irritability
- Non compliance and difficult behaviours during the day such as aggression
- Hyperactivity
- Daytime sleepiness
- Decline in motivation and concentration leading to mistakes and decreased capacity to learn

How common are sleep problems?

Sleep problems are extremely common, with as many as one in four healthy adults experiencing them. Unfortunately, there is a lot of evidence that shows that sleeping problems occur more often in people with learning disabilities (LD).

One survey has shown over 80% of parents report sleep difficulties in their children who have LD, with one quarter saying the sleep problems are severe.

Assessment

A number of factors may be contributing to your child's difficulties. It is therefore useful to monitor your child's sleep to help see the type of problems you face, the extent of the problem and the patterns of sleep (amount slept, difficulty falling asleep or maintaining sleep). This helps to get the intervention right sooner.

Keep a sleep diary (like the one below) for a week.

Sleep diary

	MON	TUE	WED	THUR	FRI	SAT	SUN
Time put to bed							
Time fell asleep							
Nighttime waking (time/ how long)							
Describe night waking							
Time awoke in morning							
Describe any naps							

Behaviour log

If bedtimes and night waking are a particular problem it is helpful to also complete a behaviour log. This tells us the nature of problems, the number of times you experience difficulties each night and how you deal with it.

	Time	Behaviour at bedtime	What did you do to handle the problem?	Behaviour during awakenings	What did you do to handle the problem?
Sun	8pm – 11pm	Kept coming down into the lounge	Ended up laying with him until he fell asleep		
Mon	2-3am			Came into my room crying and screaming, tried to return him to bed and ignore the crying but he wouldn't go back to bed.	Eventually let him sleep in my bed.

Causes of sleep difficulties

There are many reasons why a child may not go to sleep straight away, or may wake up repeatedly during the night. Many factors influence sleep and affect different people in different ways. There are a number of suggestions below as to the causes of sleep problems and what you can do to help your child.

The bedtime routine

Does your child have a regular bedtime routine that is the same each night as well as a regular time when they go to bed and wake? This is the first step.

Children like structure and, although they may resist this at first, if you are consistent they will soon learn to accept the structure you impose.

- Make the last 30 minutes before sleep a regular routine that happens each night and ensure that you direct the routine.
- Most children need a wind down period of relaxing activities to help them transition to sleep – include activities such as a bath, getting dressed into nightwear and stories (avoid television/ computers during this time).
- Keep the order and timing the same each night
- Avoid extending the routine (e.g. for 'one more story').
- You may wish to make a visual schedule of the routine (see example routine at the back of this booklet).
- It is helpful for you to try structure the bed time/waking time to occur at regular times each day. Try to stick to this as much as possible avoiding too big a change at weekends. Look at the sleep diary and table above and determine roughly how much sleep your child should need (e.g. 10 hours).

Determine the time that your child needs to be up in the morning (e.g. 7am) and work backwards to determine the bed time (e.g. 7am, minus 10 hours is 9pm)

Sleep hygiene and sleep habits

- Does my child consume caffeine before bedtime?
- Is my child's diet full of fat?
- Does my child engage in vigorous activity before bedtime?
- Is the room environment right? (e.g. too noisy, too light or too warm?)

All of the above factors can have a negative impact on your child's ability to sleep. Caffeine acts as a stimulant and stays in our system for up to six hours. Avoid food and drink containing caffeine (cola, coffee, tea, chocolate, pain relief medication and cold remedies) for this amount of time before bedtime.

High fat foods and food that causes heartburn and stomach upsets (e.g. beans/ cucumber) may also disturb sleep and may need to be limited. Night time feeding in young children, beyond the age when it is necessary may activate digestion and make the child more alert. It may be helpful to reduce eating late at night.

Additionally, exercising too close to bedtime may impact on sleep - our temperature usually dips before bedtime to signal for us to become drowsy, but exercise may act to keep the temperature high making your child more alert. Allow a few hours between exercise and sleep (preferable 4-6 hours).

Light and noise may impact on the ability of your child to fall asleep. Lay in your child's room for 20 minutes and see if there is anything that may affect their sleep that you might

not have noticed before, e.g. noises from other rooms/hallway and street lights.

Finally, the child's bed should be associated with sleeping. If it is a place for play or eating or punishment, then the child may have a number of other associations with the bed and may then find it difficult to recognise it as a place to sleep. Try to restrict the activities in bed so it is only used for sleeping.

Bedtime and night time battles

- Does my child resist going to bed although they may be tired?
- Does my child wake in the night and show problematic behaviour?
- Does my child have behaviour difficulties at times during the day?

Bedtime resistance and tantrums can be extremely upsetting. As described above, calm bedtime routine is helpful to stimulate sleep and therefore tantrums in themselves may have a negative impact on the sleep. A child may or may not feel sleepy, but may not have the temperament to try to sleep.

Nightwaking

Early sleep patterns set the stage for later sleep problems. For example, a child may fall asleep in their parent's arms in a well lit and safe environment. The child then awakens during the partial waking stage of sleep (which happens to us all several times each night when we move from REM to non REM sleep) but is now alone in dark and unfamiliar surroundings.

Instead of falling back to sleep, the child becomes frightened and cries and fully awakens. The parents enter and comfort the child who falls back to sleep with their help. The child may never learn to fall asleep independently.



Bedtime strategy 1 - Graduated extinction

If your child refuses to go to bed at night, you might want to try the following plan – but pick a good night to begin (e.g. a Friday where there is no school the next day) as you should assume that no one will have a good nights sleep that night, including you!

- Introduce a bedtime routine, being firm about bedtime.
- Determine how long you are able to wait before checking up on your child (this can be any time between 30 seconds and 10 mins).
- Put your child to bed, leave the room and wait the agreed time (e.g. 3 mins). If after 3 minutes your child is still crying, go into the room. **DO NOT** pick up, hug or kiss your child. Calmly tell them to go back to bed, then leave. Repeat this until your child is asleep.

On each subsequent night, extend the time between visits by (e.g. by 2 or 3 minutes).

Bedtime strategy 2 - Bedtime fading

For parents who cannot tolerate any crying from their child, or who worry that they may disturb neighbours, or if the tantrums are dangerous, there is an alternative approach that may be used – keeping your child up later than usual.

- Look at the sleep diary and see if there were any occasions when your child stayed up late and managed to fall asleep without resistance. To be safe, add 30 minutes to this time. Otherwise, pick a night to stay up late. Keep activities boring and see when your child begins to nod off, then add 30 minutes to that time.

- Use a bedtime routine for 30 minutes before this new later bedtime – making sure they stay awake during the routine. Do not be tempted to allow your child to sleep earlier either on the sofa or during the routine. You want your child to fall asleep in bed. If once in bed your child seems fully awake after 15 mins, get them up and extend the bedtime for an hour.
- If your child falls asleep within 15 minutes for two nights in a row, move back the bedtime by 15 minutes.
- Keep moving the bedtime back until you reach a bedtime that you want or until your child no longer falls asleep in 15 minutes.

Nightwaking strategy 1 - Graduated extinction

If your child wakes and is disruptive at night – you may use the graded extinction technique as described above – waiting progressively longer periods before checking on your child.

If your child shows dangerous behaviour at night you may want to put a bell on their bedroom door so you know when they are up and then you can implement the graded extinction technique.

Nightwaking strategy 2 – Sleep restriction

Alternatively, you may wish to try a strategy to help your child sleep through the night while avoiding disruptive behaviour.

- Using the sleep diary estimate the average hours that your child sleeps each night (not including time when they are in bed, but awake).

- Multiply this by 0.9 (to get 90%) of the time your child should be sleeping. E.g. if your child sleeps 8 hours total; 8×0.9 is 7.2 hours.
- Adjust your child's bedtime or waking time so that s/he has that amount (e.g 7 hours) in bed.
- If night waking is eliminated for 1 week, readjust the bedtime or waking time by 15 minutes.
- This may be adjusted by 15 mins each week until you reach the desired bed and/or waking time.

Nightwaking strategy 3 – Scheduled waking

This involves waking your child in the period before they usually awaken. This is a simple, but often effective method used to tackle night waking.

- Use the sleep diary to determine the times your child typically awakens during the night.
- On the night you begin the programme, wake your child 30 mins prior to the typical awakening time (e.g. at 11.30pm, for a child who usually wakes at midnight). If they wake easily, move the time back by 15 minutes (e.g. 11.15)
- If there is a broad range in the times when your child wakes up, (e.g. from 11.30pm to 1.00 am) wake them about 30 mins prior to the earliest time (e.g. in this case at 11pm).
- Do not fully awaken your child. Gently touch or talk to them until they open their eyes, then let them fall back to sleep.
- Repeat this plan each night until your child goes for seven

nights without waking. Then you may skip a night in the week. (If your child has awakenings increase go back to every night for another week).

- Slowly reduce the number of nights in the week with scheduled wakings until your child is no longer waking in the night.



Good sleep habits checklist

- Establish a bedtime routine
- Develop a regular bedtime and a regular time to wake up
- Eliminate all food and drinks that contain caffeine six hours before bedtime
- Eat a balanced diet limiting fat
- Do not exercise or participate in rigorous activities in the hours before bedtime.
- Do include a weekly programme of exercise during the day
- Restrict activities in bed to those that help induce sleep
- Reduce noise in the bedroom
- Reduce light in the bedroom
- Avoid extreme temperature in the bedroom (i.e. too hot or too cold)

Example bedtime routine



Bath



Get into pyjamas



Brush teeth



Toilet



Story



Lights out



Sleep

Example sleep diary

	Time put to bed	Time fell asleep	Night w (time/h long)
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

waking now	Describe night waking	Time awoke in morning	Describe any naps

Example behaviour log

	Time	Behaviour at bedtime	What do to probl
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

How did you handle the problem?	Behaviour during wakenings	What did you do to handle the problem?

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