# Helping your child sleep

**Many children have sleep issues. But for those with autism, sleeping well may be particularly difficult. Here we look at how families can help their child to sleep well.**

## Sleep disorders

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**How do you define a sleep disorder?**

It's important to consider your own expectations about when and how much a child should sleep.

- There are no guidelines on how long a child should sleep.
- Most babies do not sleep all night every night until they are around a year old.
- Having 'slept through', many babies return to night waking.
- Children can't simply go to bed early and wake up late. They won't remain asleep for more than a certain period of time.
- How much sleep a person needs can vary considerably.

All children are likely to have brief periods of poor sleep after illness, during holidays and festivals like Christmas or during periods of particular stress such as exams or if somebody close to them is ill. After events such as these, a normal sleep pattern should be established again within a few days.

If your child is regularly unable to sleep or has a period of good sleep which is disrupted, they may have a sleep disorder.

We recommend keeping a sleep diary to record when, where and for how long your child sleeps. This can be a first step in addressing any issues. If your child is at nursery or school, speak to staff so that they know about the problem and can offer support. Approach your GP or social worker too, and ask about a referral to an expert in sleep disorders.

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**What causes sleep disorders?**

The answer to this is likely to be different for every person. Unfortunately, it seems that virtually all children with autism are likely to suffer from disturbed sleep patterns at some point or another, but we don't know why.

Sleep problems can be divided into:

- settling problems, where a child has difficulty going to sleep
- waking problems, where a child wakes repeatedly during the night
- 'social cueing' problems, where your child doesn't make the connection between the family going to bed and their own need to sleep
- melatonin issues
- sensory issues
- problems caused by allergy and food sensitivities
- hypersomnia - sleeping too much.

**Settling and waking problems**

Donna Williams, who has written extensively about living with an autism spectrum disorder, describes her fear of falling asleep in her autobiographies:

*Sleep was not a secure place. Sleep was a place where darkness ate you alive. Sleep was a place without colour or light. In the darkness you could not see your reflection. You couldn't get 'lost' in sleep. Sleep just came and stole you beyond your control. Anything that robbed me of total control was no friend of mine.*

***Somebody somewhere*, Donna Williams**

*I was afraid to sleep, always had been. I would sleep with my eyes open and I did this for years. I guess I did not appear to be terribly normal. 'Haunting' or 'haunted' would have been better adjectives. I was afraid of the dark, though I loved the early dawn and dusk.*

***Nobody nowhere*, Donna Williams**

These descriptions are subjective and do not necessarily describe the experience for everyone. They do suggest that Donna had more problems with settling than waking. We don't know which problems children with autism are most likely to suffer from although we are aware of children who have problems with both.

In Donna's case her fear of the unknown prevented her sleeping and this may well be true for some children with autism. For most children with autism this is unlikely to be the only explanation. Many children will have disturbed sleep as a result of a number of root causes.

Waking problems may in some cases be a continuation of settling problems - like the child who wakes up to go to the toilet but then finds it difficult to fall asleep again. In very young children waking problems are an indication that they still haven't developed mature sleep patterns. As babies they woke up to feed every couple of hours and this pattern has persisted. In the older child with autism there may be an indication that they suffer from sleep disturbances. This could mean anxiety making it difficult for them to fall into a deep sleep or acute nightmares waking them up.

Although many experts would suggest approaches to settling and waking problems which require the parent to gradually give less and less attention to the child, we would suggest that attention is unlikely to be the main motivation for a child with autism. Instead, coping with waking problems may require consistent reassurance on your part and a creative approach to your child's needs.

**Social cueing problems**

Children with autism may have difficulty understanding why and when they need to sleep. Problems with 'social cueing' - that is learning why and in what order things should happen - are common in autism and this may mean your child does not make the connection between their family going to bed and their own need to sleep. Some children may find the transition from sleeping in their parent's room to their own room by themselves difficult. This can be related to difficulty with change but also the need for reassurance around bedtime and sleeping.

**Melatonin**

This is a hormone secreted by the pineal gland. It has been shown to regulate sleep patterns in animals and that taking melatonin supplements can help to ward off jet-lag. It is also thought that patterns of melatonin secretion may be irregular in children with autism. It isn't that they don't produce it but that they don't produce it at the right times of day.

**Sensory issues**

Children with autism can have significant problems with hypersensitivity to touch, visual stimuli or sound. This can be both distracting and distressing and make the process of falling asleep very difficult. For more on sensory issues, see www.autism.org.uk/sensory

**Food and drink**

If your child has caffeinated drinks close to bedtime, such as tea, coffee or cola, this might disturb their sleep. Some people with an ASD also have gastrointestinal problems, so they may experience discomfort during or after eating, such as wind or constipation, which might disturb their sleep.

**Hypersomnia - sleeping too much**

If you keep a sleep diary, you may find that your child sleeps for far longer than you would expect. This is a condition known as hypersomnia. Contact your GP for advice or a referral to a paediatrician.

For some children with autism, their bed or bedroom may simply be a place where they feel comfortable and relaxed. You could try cues or incentives for getting up, eg

- Making waking up sessions as gentle and relaxed as possible. One suggestion from the Parent survival manual came from the family who woke their son up by sending their pet cat into his bedroom. This meant he got up in a good mood. You could try doing something similar with your child's favourite toy or glove puppets.
- Playing gentle music at around the time your child is waking up.
- Using breakfast or other reward as an incentive.
- Sticking to the same structured routines each day.

Older children and teenagers are especially likely to have motivational difficulties. They may have very real fears about the day ahead, or be experiencing depression. Excessive sleep in this age group could signify psychological problems and it is important to investigate.

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## What can we do?

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**Keep a sleep diary**

Sleep diaries can be useful for a number of reasons:

- They can help to establish any unusual patterns of sleep.
- If you do decide to try any routines, behavioural modifications or dietary changes to help your child to sleep, then a sleep diary will allow you to see if what you're doing is working consistently, sporadically or not at all.
- You can show a sleep diary to professionals involved in your child's life, such as teachers, GPs or social workers, to give them a clearer idea of the impact your child's sleep patterns are having on your son or daughter, and on you and your family. People may assume you're exaggerating if you tell them you only get an average of two hours sleep a night but if you can show them charts with times specified they may take more notice.

- Certain benefit application forms, for example the one for Disability Living Allowance (DLA), ask you how often you have to get up in the night to help your child. You can send in a copy of the sleep diary to support your application.
- A sleep diary can act as a visual reminder for more able children with autism of their disruptive sleep patterns. They can then be used to establish incentives for staying in bed and trying to sleep, eg a gold star for every night when the child doesn't get out of bed plus a small reward if the child doesn't get out of bed for three nights in a row.

  For an example of a sleep diary, see page 16 of the National Children's Bureau's *Information about sleep*.

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**Establish a routine**

Children with autism respond well to routines because they allow them to feel safe and in control. Create a routine that you can use every day and anywhere. If you make playing on a particular climbing frame part of the routine, this will be a problem if you stay overnight somewhere else. Here's an example:

- 6.00pm: dinner
- 6.30pm: quiet time
- 6.45pm: drink
- 7.15pm: bath
- 7.25pm: clean teeth
- 7.30pm: bedtime/sleep
- 7.30am: waking up/getting up.

A new routine can take time to get used to. It may help to present the routine visually and you could include quite a lot of detail, for example: close the curtains, get into bed, turn the light off, lie down, pull the cover up. It may also be worth setting aside time to prepare for the next day in the routine. This could include getting the school bag ready or making a list/timetable of things that need to be done the next day.

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**Consider changes to food and drink**

Changing bedtime routines can be stressful and if your child is used to having certain drinks or snacks near bedtime, suddenly switching to something different may be counterproductive. However, you could try changing to decaffeinated tea, coffee and cola, or reducing the amount of the food which could be causing wind or constipation.

Alternatively, you could try gently phasing certain foods out over a period of days or weeks so that less and less is consumed overall without anything suddenly being taken away. For example, you could offer one biscuit instead of two, or mix decaffeinated and caffeinated drinks together.

Some people advocate making radical changes to a child's diet like completely eliminating caffeine. We suggest that this is only worth doing if you have already tried a more moderate approach. We also suggest that you visit a dietician before introducing any major changes just to check that you're continuing to offer your child a balanced diet.

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**Use relaxation techniques**

Children with autism may feel particularly anxious around bedtime and not be able to articulate their need to unwind. Relaxation techniques can helpful. Here are some examples.

- A few drops of lavender oil to your child's bath.
- A gentle foot, hand or scalp massage.
- An hour's quiet time before bedtime. Doing a quiet activity could help your child to unwind. It also provides a social cue: if everyone in the house is quiet and relaxed then it is time to get ready to sleep. You could mark the quiet time on a daily timetable so the child knows what to expect and becomes familiar with this routine.
- Music.
- Gentle exercise, such as yoga.
- Gentle lighting in the bedroom.
- Time each evening when your child can talk about their day. It may help to have a "worry book"; so your child can write down or draw any concerns before they go to bed.
- Rough and tumble play. Although this is the opposite of quiet time, it might be more effective for your child.

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**Make sleep more comfortable**

Your child might find being in bed uncomfortable. Some children are very sensitive to light, sounds, smells and touch. Here are some ideas that could help.

- Block out light using dark curtains or black-out blinds.
- Reduce noise using thick carpet, shutting doors fully, turning off appliances, and moving your child's bed away from a wall with activity going on on the other side.
- Block out noises by letting your child use ear plugs or listen to music through headphones.
- Remove labels from bedding and night clothes, or try bedding and nightclothes made from other materials.
- Reduce smells coming into the room by closing the door fully, or by using scented oils that you child finds relaxing.
- Use a weighted blanket - these are made from thick material with bean-filled pockets – which some people believe can calm children with autism by allowing them to better feel their movements and understand where their bodies are in space.
- Remove distractions, such as toys on the bed and pictures on the wall (unless your child finds these relaxing), and consider a different colour on the walls.

For more, see our information about environment and surroundings atwww.autism.org.uk/environment

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**Explain sleep**

Children can have difficulty understanding the need for sleep. A social story™ (developed by Carol Gray) could be used to explain this. Here is an example of a social story™ by Carol Gray, taken from *My social stories book*, Jessica Kingsley Publishers, 2002.

**What does it mean when people say, "Time to go to bed"?**
All people sleep. Most people sleep on Monday, Tuesday, Wednesday, Thursday, Friday, Saturday and Sunday. They wake up each morning. I sleep in a bed. Usually Mom or Dad says, "Time to go to bed." This means it is time to get into bed and go to sleep.

Copyright © Jenison Public Schools and the Gray Center for Social Learning and Understanding 2002
Reproduced by permission of Jessica Kingsley Publishers
For more information, see www.autism.org.uk/socialstories

Visual supports such as flow charts could also be used to explain sleep or children's books that provide the biological explanation for sleep. For more, see www.autism.org.uk/visualsupports

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**Medication**

Medical interventions are typically seen as a last resort in treating sleep disorders in children as they can be habit-forming and they don't always treat the root cause of the problem.

Melatonin supplements are only available on prescription in the UK. For further information you should consult your GP. Some foods are rich in melatonin such as oats, rice, sweetcorn, tomatoes, plums, bananas and brazil nuts, but current research is not clear whether a melatonin-rich diet could be effective in helping children to sleep.

As a general rule it is better to minimise the medication your child is on but at certain times it may be desirable to have a mild sedative to hand, for example, if you are going on holiday and are concerned about the consequences of jet-lag, or if you feel that your child's health is genuinely suffering as a result of their poor sleep. GPs may be prepared to prescribe under these circumstances.

Some parents have found that using medication in tandem with a behavioural approach can help to restore a good sleep pattern. The combination is crucial as without the behavioural intervention when the medical treatment ends the child is likely to return to their old sleep patterns.

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**Natural remedies**

Health food stores offer "natural" remedies which claim to treat insomnia and other sleep disorders. It's important to consider how such products might interact with any other medication you child is taking. If you are thinking of trying a "natural" or "alternative" remedy, you should discuss this with your GP first.

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## Common problems and possible strategies

David Bramble is a consultant psychiatrist who works for Shropshire CAMHS and specialises in the mental health of children with learning disabilities. He has a longstanding interest in children's sleep problems and works with a number of children with autism and their families. He suggests the following strategies to be tried for common sleep problems: (Taken from the 2006 BILD conference: Valuing good practice in autism)

**Children who insist on parent's presence**

Graded withdrawal

1. Lie next to child on bed for three nights.
2. Lie on mattress next to bed for three nights.
3. Move mattress closer to door every three nights.
4. Sit on chair in bedroom at door with door open for three nights.
5. Sit outside door whilst still visible to child for three nights.
6. Sit outside door not visible to child for three nights.
7. Sit outside room with door closed for three nights.

Social stories could also be used to reassure your child that they are safe when sleeping/alone.

**For night waking**

Scheduled awakening

1. From sleep diary see when child wakes up during the night.
2. Set alarm clock for 30 minutes before this.
3. Wake child and allow to fall back to sleep.
4. If child doesn't fall back to sleep try waking 45 minutes before on the next night and experiment until you find the best time.

**To ensure your child is sleepy at bed time**

Restricting sleep:

1. From sleep diary see average hours of sleep per night.
2. Calculate ninety percent of this and make this the new sleeping time (delay bedtime and/or waking time) – never restrict below five hours.
3. If lying awake occupy in another room until sleepy.

4. Avoid naps in day/oversleeping at weekend.
5. After a week move settling/waking time by 15 minutes - continue until desired pattern of sleep occurs.

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## Summary

None of these suggestions can be guaranteed to work in themselves. You may find that a combination of them proves most effective. Close examination of your child's sleep diaries is likely to give you the greatest insight into what is causing your child's problems and which solution is most likely to work. When implementing these strategies, problem might get worse before it gets better. However it's important to remain consistent in your approach. Rewarding and praise following a better night's sleep will help to positively reinforce it.

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## Getting some sleep yourself

Getting proper night's sleep is hugely important. It may have been suggested that you sleep when your child sleeps, but this won't necessarily be convenient and it can be difficult to 'switch off' on demand. By the time you have got your child to sleep, particularly if they needed calming down, you may feel too wound up to sleep yourself.

**Safety-proofing**

Making your child's room safe can be one of the easiest ways to improve your own sleep. If you know that your child cannot do any harm while you are asleep, it can help you to relax.

In the *Parent's Survival Manual* author Eric Schopler cites a number of parents who have found creative ways of achieving this. One parent installed a stable door in their child's bedroom. In the evenings after the child had gone to bed but was still awake the parents left the top half of the door open but the bottom half closed. The child stayed in the room but was able to call his parents should anything happen. This meant the parents had time to relax in the evenings before going to bed, could look in on their child without disturbing or distracting him and were able to respond quickly if the child had any accidents. For more, see our information about environment and surroundings at www.autism.org.uk/environment

**Getting respite**

All parents of children with disabilities are entitled to be assessed to see if they're eligible for respite services. Unfortunately, there's no specified minimum and the amount of provision families receive can vary enormously. If you're not currently receiving any services then you should contact your local social services department and request an assessment of need for your child and a carer's assessment for yourself. For more, see our community care information at www.autism.org.uk/benefits

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## Further information

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**What other help is available?**

The approaches recommended in some parenting books can often be inappropriate for children with autism for a number of reasons. We also recognise that long term lack of sleep can make it very difficult for parents to effectively implement a behaviour modification programme when their primary agenda is getting back to bed. For this reason we would suggest trying to get someone outside the immediate family to support you during this time.

- There are far too few specialists able to help parents of children with autism who have sleep disorders. But there are some and you can contact your GP, social worker or your child's school for help and advice.
- You could talk through the issues with an adviser at our Autism Helpline (0808 800 4104, www.autism.org.uk/enquiry).
- You may also find that other parents have been in the same position and are able to talk it through with you. Use our Autism Services Directory to find National Autistic Society branches and other support groups in your area: www.autism.org.uk/directory
- We also operate a telephone support service called Parent to Parent provided by parent volunteers. Call 0808 800 4106 and leave a message on our 24 hour answer phone. We will call you back as soon as possible at a time that suits you, including evenings and weekends. Alternatively you can use our online enquiry service at www.autism.org.uk/p2p

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**Useful reading**

Betts, D.E and Betts S.W. (2006). *Yoga for children with autistic spectrum disorders*. London: Jessica Kingsley Publishers ISBN: 978 1 84310 817 7

*Dunn Buron, K. (2003). *When my worries get too big: a relaxation book for children with autistic spectrum disorders*. Shawnee Mission, KS: Autism Asperger Publishing Company ISBN: 978 1 93128 292 5

Durand, V.M. (1998). *Sleep Better! A guide to improving sleep for children with special need*s. Baltimore, MD: Paul H. Brookes Publishing ISBN: 1557663157

Gray, C. and White, A.L. (2002). *My social stories book*. London: Jessica Kingsley Publishers ISBN: 978 1 85302 950 9

Harrison, J., Price, S. and Sanderson, H. (1991). *Aromatherapy and massage for people with learning difficulties*. Birmingham: Hands On Publishing

Williams, D. (1992). *Nobody nowhere*. London: Jessica Kingsley Publishers. ISBN: 1853027189

Williams, D. (1994). *Somebody somewhere*. London: Jessica Kingsley Publishers. ISBN: 9781853027192

If an item is marked *, it is available from the NAS. Please contact:

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# Contacts

**Cerebra Sleep Service**

Cerebra is a charity for children with brain-related neurological conditions. They have a team of sleep practitioners covering parts of the UK who can offer help and advice on sleep issues.

Tel: 01267 244210

Email: sleep@cerebra.org.uk

Web: www.cerebra.org.uk

**ISIS: Infant Sleep Information Source**

The ISIS website gives information about normal infant sleep for parents who wish to make informed choices about infant sleep and night-time care and for health professionals who wish to share evidence-based information with parents about infant sleep.

Web: www.isisonline.org.uk

**Rompa**

Sells weighted blankets and other sensory products.

Tel: 0845 230 1177

Email: sales@rompa.com

Web: www.rompa.com

**The Children's Sleep Charity**

The Children's Sleep Charity was set up by a sleep practitioner to support parents and children to improve sleep patterns. The charity runs workshops for parents in autism and sleep issues.

Tel: 07912 667676

Email: info@thechildrenssleepcharity.org.uk

Web: www.thechildrenssleepcharity.org.uk

**TFH UK**

Sells weighted blankets and other sensory products.

Tel: 01299 827820

Email: info@tfhuk.com

Web: www.specialneedstoys.com

Adapted from National Autistic Society – www.autism.org.uk

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