

# Sleep and autism: helping your child

I freely admit this is 'nicked' from the National Autism Society's website and can be found at: [www.autism.org.uk/10225](http://www.autism.org.uk/10225)

So all credit goes to them for this useful article!

**Learning to sleep through the night is something all children have to do. But for children with autism, it can often be a difficult and seemingly impossible process. This, in turn, can have an enormous impact on their families. This guide explains why your child may have a sleep disorder, and what you can do to give them, and you, a more peaceful night.**

Helping your child to overcome their sleep disorder will not be easy. Most experts would recommend you ask for advice and support from somebody outside your immediate family. An ideal person would be an expert in sleep disorders; this might be a child psychiatrist or a paediatrician. However, getting a referral to a suitable professional can be very difficult. You could approach your FAMILY DOCTOR or social worker first and you might also be able to get support from your local family or child development centre.

It is also worth liaising with your child's teachers to ensure that they are aware of the problems and also that they can support your child adequately. They may be able to contribute to keeping a sleep diary and you can also ask them to let you know how alert your child is during the day.

## How do you define a sleep disorder?

By the age of one year, most children should be sleeping through the night. If after that time your child is regularly unable to sleep or if they have a period of good sleep which is disrupted then this constitutes a sleep disorder. It is important to be aware that 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.

It is also important to be aware of your expectations: children cannot go to bed early and wake up late. They will not remain asleep for more than a certain period of time. There are no guidelines on how long a child should sleep; how much sleep a person needs can vary considerably. On average the amount of sleep a child needs per night decreases by a quarter of an hour per year until the age of sixteen. So a five-year-old needs an average of eleven hours sleep a night and a 16-year-old needs an average of eight-and-a-half hours a night. But these are not hard and fast figures and you may have a 16-year-old who needs ten hours sleep a night or a five-year-old who only needs seven.

If you think your child may have a sleep disorder and you want to get an idea of the extent of the problem, it is a good idea to keep a sleep diary as the initial step to solving the problem.

## Why keep a sleep diary?

Sleep diaries can be useful for a number of reasons.

- They can help to establish any unusual patterns of sleep. For example, Jo actually sleeps for seven hours a day but takes a nap after returning from school, which then disturbs his sleep at night. If over a period of time this became a consistent pattern his parents could think about ways of keeping him stimulated after coming home from school. In time he might begin to sleep more at night and less during the day. It is also clear that his most disturbed night follows the time away which he spends with his Gran. This suggests that consistency and routine are very important to Jo.
- If you do decide to try any routines or behavioural modifications to help your child to sleep then the sleep diary will allow you to see if what you are 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, Family Doctors or social workers, to give them a clearer idea of the impact your child's sleep patterns are having on the child, you and your family. People may assume you are 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.
- For more able children with autism a sleep diary can act as a visual reminder 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.

## What causes sleep disorders?

### Settling and waking problems

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. Sleep problems can be divided into two main groups: settling problems, where the child has difficulty going to sleep at the appropriate time, and waking problems, where the child wakes repeatedly during the night. Both of these will be dealt with on this page.

We don't know why children with autism are so vulnerable to disturbed sleep, but Donna Williams, who has written extensively about living with an autistic spectrum disorder, describes her fear of falling asleep in her autobiography:

“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.”

“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* by 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 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 hasn't yet been eradicated. 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.

Although many experts would suggest approaches to waking problems such as bed-time fading - where you look in on your child when he/she wakes but for shorter periods each time so that they learn not to rely on this behaviour for attention - we would suggest that attention is unlikely to be the main motivation of children with autism. Instead, coping with waking problems may require consistent reassurance on your part and a creative approach to your child's needs.

### **Social sense**

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 parents rooms to their own room by themselves. 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 which has been shown to regulate sleep patterns in animals. There have been studies conducted which have shown that taking melatonin supplements can help to ward off jet-lag after long journeys. It is also thought that in children with autism, their patterns of melatonin secretion may be irregular so it is not that they don't produce, it but that they don't produce it at the right times of day.

Melatonin supplements must be prescribed in the UK. For further information you should consult with your Family Doctor. 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.

### **Too much information**

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.

### **Allergy and food sensitivities**

Children with autism are perhaps more likely than their peers to be sensitive to foodstuffs like sugar, caffeine and additives which can keep people awake. If your child frequently has sweet or caffeine-rich drinks and foodstuffs near bed time then it is worth checking whether this could be disturbing their sleep.

## **What can we do?**

### **Natural remedies**

Many of the natural remedies available from health food stores are supposed to treat insomnia and other sleep disorders. These may have similar effects to conventional medicines but carry less risk of side-effects than conventional sedatives. You could also try contacting a homoeopath.

### **Removing stimulants from the diet**

If you are already keeping a sleep diary then monitoring this should not be a problem. If you are not then it is advisable that you at least start keeping note of when your child sleeps so that you can monitor any improvements.

Changing your child's bedtime routine can be stressful and if they are used to having certain drinks or snacks near bedtime, suddenly switching to something different may be counter-productive. However, you could change to decaffeinated drinks, replace ordinary chocolate with sugar-free chocolate bought in health food stores, use carob powder to replace cocoa and chocolate, switch to sugar-free drinks or replace sugar in drinks with sweetener or fruit sugar, which may help some children.

Alternatively, you could try gently phasing certain foods out over a period of days or weeks so that your child is consuming less and less sugar and caffeine overall without having anything suddenly taken away from them; for example, you could offer them one biscuit instead of two, put just half a spoonful of sugar in their tea and mix decaffeinated and caffeinated drinks together. This also has the advantage of reducing your child's taste for sweet foods, which can help improve oral hygiene.

Some people advocate making radical changes to the child's diet like completely eliminating sugar and caffeine. We would suggest that this is only worth doing if you have already tried a more

moderate approach. We would also suggest that you should visit a dietician before introducing any major changes in order to ensure that you continue to offer your child a balanced diet.

### **Using relaxation techniques**

We all have difficulty sleeping if we are feeling wound up when we go to bed. Settling down when a lot has been happening or when we are feeling emotional can be very difficult. Children with autism may not be able to articulate their need to unwind and relax. Additionally, they may feel more anxious and confused around bedtime.

Relaxation techniques can be introduced in low-key, non-intrusive ways in many areas of family life. Some possible techniques follow.

- Adding a few drops of lavender oil to your child's bath; this has been shown to have a soothing effect.
- Giving your child a massage. Direct skin contact can be uncomfortable for some children with autism but some types of massage, such as shiatsu, can be conducted through clothing. A gentle foot, hand or scalp massage in the right environment might help your child to calm down before going to bed. Please see the 'Useful reading' section for details of books on this subject.
- Introducing an hour's quiet time before the child's bedtime could serve two purposes. Doing a quiet activity, perhaps with help from you or a sibling, could help them unwind and it also provides a valuable social cue. If everyone in the house is quiet and relaxed then the message the child receives is consistent, not mixed as it is if the house is still lively and noisy even though the child is expected to sleep. Clearly, introducing a quiet period in the day may be easier said than done but you could start with small things, such as suggesting the TV/computer is turned off for an hour. It may take a while to get into this pattern but it could have a huge impact when you do. It is even worth marking this quiet time on a daily timetable so the child knows what to expect and becomes familiar with this routine.
- Many experts have said that teaching formal relaxation techniques to people with autism can be counter-productive as they may find them more distressing than relaxing. Some people advocate using exercise as a way of winding down and this does have some merits. Physically exhausting your children is a good way of ensuring that they sleep! Many children with autism enjoy rough and tumble play and although this may seem to be the opposite of the points made above regarding quiet time at the end of the day, it might be more effective for some children. You will know best whether your child falls into this group.
- Some parents have found formal relaxation aids such as music and exercises (for example yoga) very useful. These aids are widely available and you can judge for yourselves what your child is most likely to respond to. Some parents have reported having lighting, such as a lava lamp, in the bedroom can be helpful.
- It may be worth providing the child with a set time to talk about their day or their worries as part of the evening routine. It may even help to have a 'worry book' or diary next to the bed so the child

can write down or draw any concerns. They are then dealt with before bedtime. Alternatively, the child could have a worry box, so that worries can be written down and shut away in it.

### **Establishing a routine**

Children with autism respond well to routine and structure because it allows them to feel safe and in control. Although sticking to routines can be frustrating during the day, setting up a routine that fits in with your family's needs and helps your child feel calm by the time they go to bed could be very helpful. To do this effectively you will need to look carefully at the routine your family follows at the moment. Things to consider include:

- Is it possible for you to eat dinner at the same time each night?
- Do you do this already?
- Is this quite late in the evening or quite early?
- Is it possible for your child with autism to have a bath at the same time each night?
- Is there anything about your child's routine that can only be done in your home? This could be something like playing on a particular climbing frame or having their own space for time out in the evenings.

Essentially, an evening routine needs to be fairly simple, with scope for flexibility. This means that if you go away, or your child goes away, the basic routine can be preserved. You could try something like:

- 6.30pm: dinner
- 7.00pm: quiet time
- 7.15pm: drink and a piece of fruit
- 7.45pm: bath
- 8.25pm: clean teeth
- 8.30pm: bedtime/sleep
- 7.30am: waking up/getting up.

Essentially, whatever routine you try to impose needs to be something you feel comfortable implementing and that your family can agree on. It may take several weeks for it to alter your child's sleep patterns. It can help to present this routine visually, using a timetable for instance, so your child knows exactly what to expect, including getting up in the morning. If the routine needs to be altered, it can then be explained visually. It may be that your child's timetable needs to be more detailed so that they are told exactly what to do when going to bed, for instance, draw the curtains, get in to bed, turn light off, lie down, pull 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.

### **Making sleep more comfortable**

Sleep, as Donna Williams describes it, sounds pretty uncomfortable. If that is what your child is experiencing then it is not surprising if they get a bit agitated near bedtime. But there are ways of working with your child's fears to help them.

Some children are exceptionally sensitive to light so sleeping when there is even a very dim light on could be very difficult for them. Putting up thick curtains which will block out as much light as possible in your child's room.

Similarly, some parents have found that their children can be woken by very slight sounds at night. Aside from general advice about having a thick carpet in the room and making sure the door shuts properly, other parents have tried a more specific approach. One family found that after their child with autism had gone to bed, she could be woken by the noise of their changing in the bedroom next door. To solve this they moved her bed to the other side of the room and built shelves and cupboards along the wall the two rooms shared to act as sound-proofing. Sometimes even a computer left on standby can be enough to disrupt sleep. Ear plugs, or music playing on headphones, could also be used to block out noise for those children who are comfortable with wearing these.

Touch sensitivity is extremely common in autism: some children experience certain types of touch as physical pain. Temple Grandin (a woman with autism) describes being unable to sleep if one of her legs touches the other so she always has to wear pyjama trousers, even in the hottest weather. Labels on bed clothes and different materials can also be uncomfortable. Some children respond well to a weighted blanket, which is made from thick blanket material like a quilt with the pockets filled with beans instead of hollowfibre. The pressure of the blanket can be re-assuring and it works on much the same principle as the 'squeeze machine' which Temple Grandin invented to help her learn to cope with touch.

It is also worth considering if smells in the room, or coming from other parts of the house, may affect people with heightened senses.

The layout of the room may also need to be adjusted. Although it may be comforting for some children to have lots of their belongings around them, it may serve to be quite distracting for others. Even the colours of the room or pictures on the wall may be disturbing. See the information sheet 'Environment and surroundings: making them autism-friendly' for more advice.

### **Explaining sleep**

As mentioned before, children can often have difficulty understanding the need for sleep. A social story (developed by Carol Gray) could be used to explain this. Visual supports, such as flow charts, could also be used to explain sleep; as can children's books that provide the biological explanation for sleep.

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 in to bed and go to sleep.”

### **Medication**

Medical interventions are typically seen as a last resort in treating sleep disorders in children as they can be habit-forming and they do not treat the root cause of the problem. 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. Most Family Doctors will be prepared to prescribe under these circumstances.

Some parents have also 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.

## **Common problems and possible strategies**

David Bramble is a consultant psychiatrist who 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 an ASD 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 parents' 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 or in bed alone. Please see the 'Useful fact sheets' section for further details.

### **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 90% 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.

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 it may be that the problem gets worse before it gets better. However, it is important to remain consistent in your approach. Rewarding and praise following a better night's sleep will help to positively reinforce it.

## **Getting some sleep yourself**

It is not unusual for professionals to suggest that you sleep when your child sleeps. Anyone who has actually been in the position of caring for a child with a sleep disorder knows how difficult this is. We cannot just switch our bodies on and off like a light bulb. By the time you have eventually calmed your child down enough for them to sleep you may be far too wound up to sleep yourself. Your child may not choose to sleep at times which are convenient to you and if there are other children in the family they may need your attention when your child with autism is asleep.

It is important to be assertive about your need to sleep. Sleep deprivation can be extremely dangerous (for example, falling asleep at the wheel causes 20% of all fatal road traffic accidents) and can have a very negative impact on your overall health and mental well-being. So getting a proper night's sleep is hugely important, but this may be easier said than done.

### **Safety-proofing**

Making your child's room safe can be one of the easiest ways to improve your own sleep. If you can fall asleep knowing that even if your child wakes up they cannot do any harm, you are already improving your chances of not being disturbed.

In the *Parents' survival manual*, Eric Schopler quotes 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.

### **Getting respite**

All parents of children with disabilities are entitled to be assessed to see if they are eligible for respite services (UK). Unfortunately there is no specified minimum and the amount of provision families receive can vary enormously. If you are not currently receiving any respite support, you should contact your local social services department and request an assessment of need for your child and a carer's assessment for yourself.

## **My child sleeps too much**

If you start keeping a sleep diary, you may find that what you perceive as your child sleeping too much is more that your child sleeping at the wrong times; for example, sleeping in the mornings or not wanting to get out of bed at weekends. However, you may also find that your child really does sleep for far longer than you would expect, a condition known as hypersomnia.

There has been very little research conducted into the causes of hypersomnia or how much it affects children with special needs. Medical treatments available for the condition are restricted to stimulant drugs such as Ritalin which are not always effective. We would advise contacting your Family Doctor and asking for their advice or a referral to a paediatrician with experience of working with children on the autistic spectrum.

Children with autism may, however, have other reasons for appearing to sleep too much. For example, you may find that getting your child out of bed is difficult but this may have nothing to do with their need to sleep. Their bed or bedroom may be somewhere they feel relaxed and may have pleasant associations. We all feel reluctant to get up and get going occasionally. Children

with autism, however, may also lack some of the incentives that motivate others. Many of the potential approaches you can use here are the same as for the child who sleeps too little.

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

For older children and teenagers this may not seem appropriate and these are the young people most likely to have motivational difficulties in the morning. It may be, especially for young people with higher functioning autism, that they have very real fears about the day ahead. Alternatively, they may be suffering from depression, which effects their motivation. Excessive sleep in this age group could signify very real psychological problems and it is important to investigate these rather than dismissing excessive sleep as laziness. Again, monitoring sleep may help to establish patterns which could indicate where the problems lie.

### **What else is out there?**

We recognise that often the approaches recommended in books can 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 program 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 out there able to help parents of children with autism who have sleep disorders. But there are some and you can contact your Family Doctor, social worker or your child's school for help and advice.

You may also find that other parents have been in the same position and are able to offer their advice and expertise as well.