

Autism Spectrum Disorder & Sleep: A Guide for Young People & Parents



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Introduction

In this package we will be discussing sleep and a number of sleep issues that families with young people with autism may be experiencing. We will also be exploring some of the reasons sleep difficulties are present and potential strategies to improve them.



Autistic people can often have trouble sleeping. There is a range of reasons for this including difficulties with relaxing or winding down and irregular melatonin levels.

Problems with sleep can be an issue for both adults and young people. It can also be disruptive for parents of autistic young people as their own sleep is affected.

Sleep problems are common in young people with ASD, with prevalence rates of approximately 50% - 80% compared with 9% - 50% in young people with typical development. Young people with ASDs are also reported to have sleep problems more frequently than young people with other developmental disabilities.

Parents of young people with ASD who experience sleep difficulties also have troubles with sleep and anxiety.

What is Sleep?

Sleep is an essential part of our lives and sleeping well is necessary for the rejuvenation of our bodies and our minds.

Lack of sleep can contribute to increased behaviour difficulties, reduced concentration, and irritability.

But it can also have a significant impact on the rest of the family's health and relationships, stress levels and general ability to cope with day to day life.

Sleep is a basic need for everyone. It plays such an important role in helping our brains and bodies recover from everything we did that day.

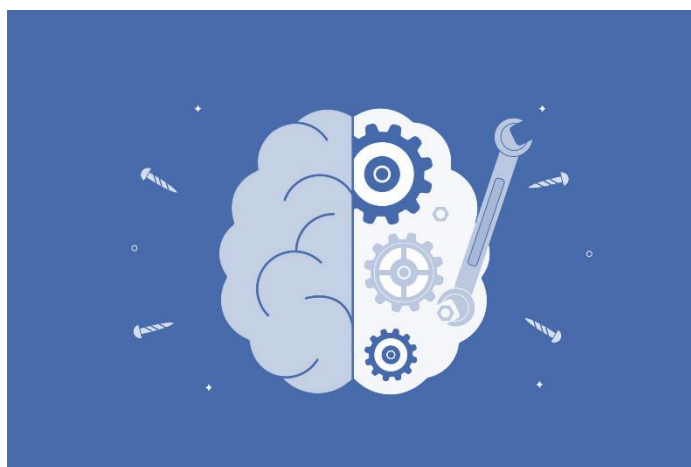
Why is sleep important for teenagers?

Sleep is especially important for teenagers because it helps with mental, physical, social and emotional development.

Sleep helps our brains to remember, memorise and analyse important information. These skills improve performance at school. Teenagers who do not get enough sleep may feel drowsy and find it difficult to focus in the day time.

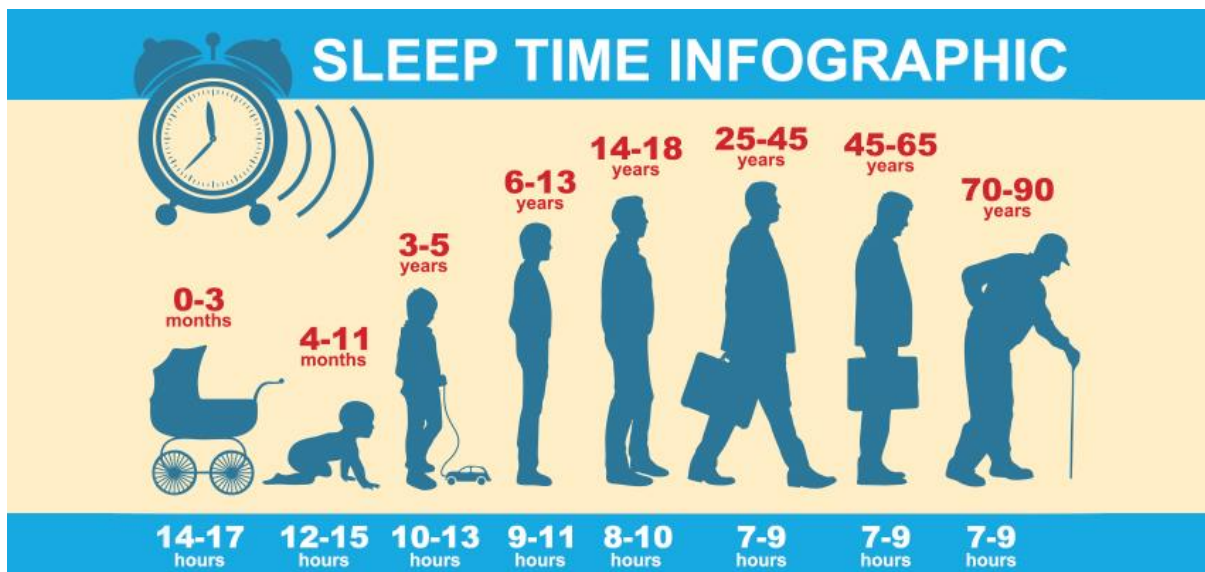
Sleep can also affect our mood. If we don't sleep enough we can get grumpier and react to things more than we normally would. Over a long period of time, not sleeping enough can cause mental health problems like anxiety and low mood.

Even our immune systems can be affected if we don't have enough sleep. Our immune systems help us fight off illnesses.



Typical Sleep Requirements

There is no 'magic number' for the amount of hours we should sleep each night or throughout our lives, as the amount of sleep we require changes. Many people tend to follow the typical sleep requirements but some people may need more or less sleep than the average.



Causes of Disrupted Sleep

- Other conditions such as: ADHD, or Mental Health Problems, such as anxiety and depression, or Neurological conditions such as epilepsy.
- Hunger – could you be hungry? What time are you having your dinner? You could have it later as it can be difficult to fall asleep if you are hungry.



- Getting up to early – do you wake up during the night and awaken like it is the start of the day? You should consider what a reasonable time to begin the day is, and return back to bed if you wake before that time. This will help strengthen your body clock.
- Pain – are you in pain? If you think you might be in pain, you should seek advice from medical professionals. Discomfort which could be due to physically not being about to move around in the night.

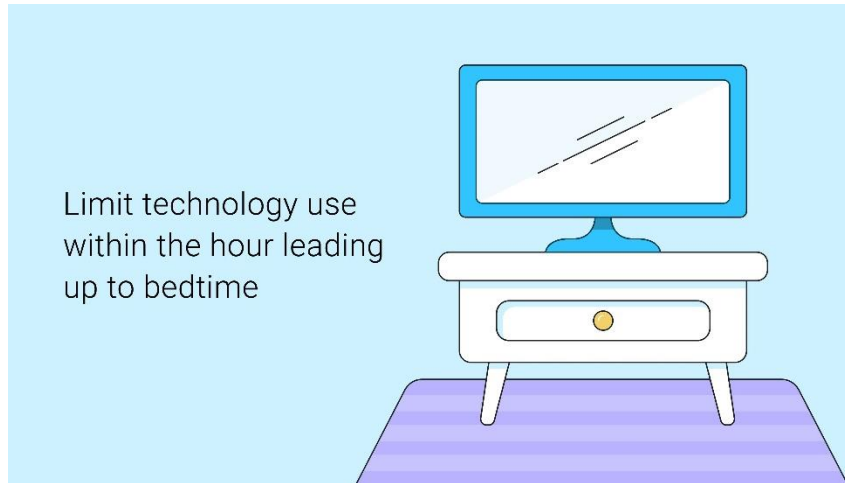


- Medication – are you on medication that could be impacting your sleep? This can be discussed with your GP if you feel this might be disturbing your sleep.
- Allergies or Food Sensitivities – young people with autism can be more sensitive to foods like sugar, caffeine and additives which keep people awake. If you frequently have sweets or caffeine-rich drinks close to your bedtime, consider whether this may be impacting your sleep.

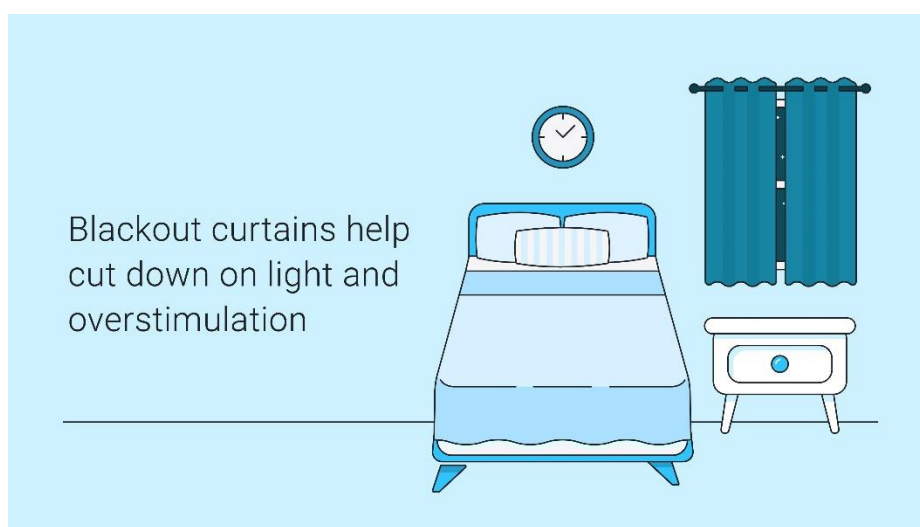


- Melatonin – this is a hormone secreted by the pineal gland which has been shown to regulate sleep patterns. It is thought that in young people with autism their patterns of melatonin secretion may be irregular – so they may not produce it at the right times of the day. Melatonin supplements can be prescribed within the UK but for further information you should consult your GP. Foods that are rich in melatonin include: plums, bananas and brazil nuts, but these alone may not be effective in helping sleep.
- Lack of routine – do you have a good bedtime routine? Has your routine become unsettled lately because of an event?
- Too much information – young people 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.

- An overstimulating room – do you get out of bed to play computer games or watch TV? If so, the room may be an over-stimulated environment. Consider creating a more restful bedroom environment.



- Noise – is there any noise inside or outside the home that may be disturbing your sleep? Young people with sensory issues can be particularly sensitive to noise – what may seem quiet for others can seem very loud to them.
- Light – is the room dark enough? Melatonin is produced when the room is dark. You may want to consider buying black-out curtains to make the room darker.



- Bedding – are you kicking the bedding off during the night and waking because you are cold? If so, consider using a double duvet tucked under the mattress of a single bed. You may also want to consider a comfortable sleep suit.
- Incontinence which can lead to wet and uncomfortable clothing and bedding, or waking up in the night to use the toilet and having difficulty getting back to sleep.
- Comfort – is your bed comfortable? Try lying on it during the day and see how it feels.
- Room Temperature – are you too hot or too cold? Ideally the room temperature in the bedroom should be between 16 C and 20 C.

























When you are too cold:



When you are too warm:



- Lack of understanding about day and night – do you understand the difference between day and night? Sometimes young people with additional needs require help to learn when it is day time and when it is time to sleep. Strategies, like visual timetables, should be considered to reinforce this.

Home Learning Schedule			
			
8:00	breakfast	2:00	learning time
			
9:00	exercise	3:00	life skills
			
10:00	shower / hygiene	4:00	tech time
			
11:00	learning time	5:00	dinner
			
12:00	lunch	6:00	quiet activity
			
1:00	free time	7:00	bedtime

Breezy Special Ed

You can find printable visual timetables at <http://www.do2learn.com/picturecards/printcards/>.

- Social Sense – young people with autism may have difficulty understanding why and when they need to sleep. Problems with ‘social cueing’ (learning why and in what order things should happen) are common in individuals with autism and may mean that they are unable to make the connection between family going to bed and their own need to sleep.
- Hypersomnia – sleeping too much. Increased exhaustion could be caused by the additional stress autistic people experience in social situations.

- Increased anxiety or an inability to relax causing insomnia.
- Sharing a bed/bedroom with others.
- Habit of not falling asleep until early hours of the morning and struggling to change that.
- Needing reassurance from others and struggling to sleep without this.
- Experience of nightmares, sleep walking or sleep talking.
- Fears and anxieties – does your child have fears or anxieties linked to falling asleep or going to bed? Young people with autism may benefit from exploring this matter and identifying the fears experienced around sleeping with a grown-up or a parent.

Sleep Hygiene

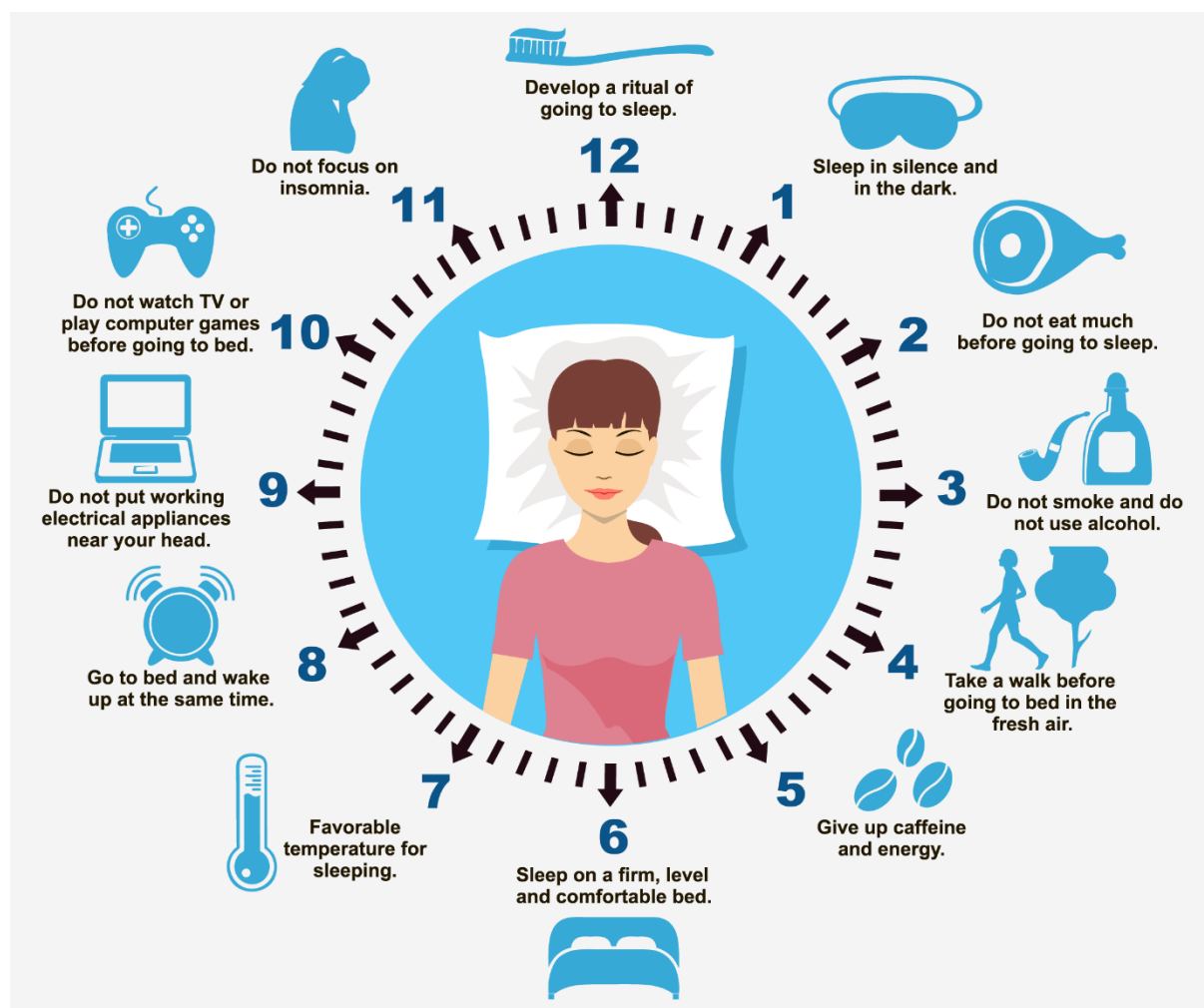
Sleep hygiene is a name used to describe a set of behaviours that can improve the quality of our sleep.

Good quality sleep is sleep that:

- Lasts between 8 – 10 hours
- Helps you wake up feeling refreshed
- You sleep without waking up during the night

Sleep hygiene helps us have better quality sleep by supporting our circadian rhythm. A circadian rhythm is the body's 'inner clock', which helps us feel awake during the day, and sleepy in the evening.

To get our sleep hygiene right, we need to think about the physical, emotional and environmental factors as well as our behaviour during the day that affects our sleep.



Sleep Strategies

Understand sleep – young people may have difficulty understanding the need for sleep. A social story could be used to explain this. They can also be used to reassure young people that they are safe when sleeping.

Keep a sleep diary – this will highlight any unusual patterns of sleep and identify factors which may be influencing your ability to sleep. If you are using other strategies to aid sleep, you will be able to track how effective they are.

Sleep diaries are also useful because you can show them to professionals such as GPs/Social Workers, to give them a clear idea of the impact your sleep issues are having on your life.



SLEEP DIARY

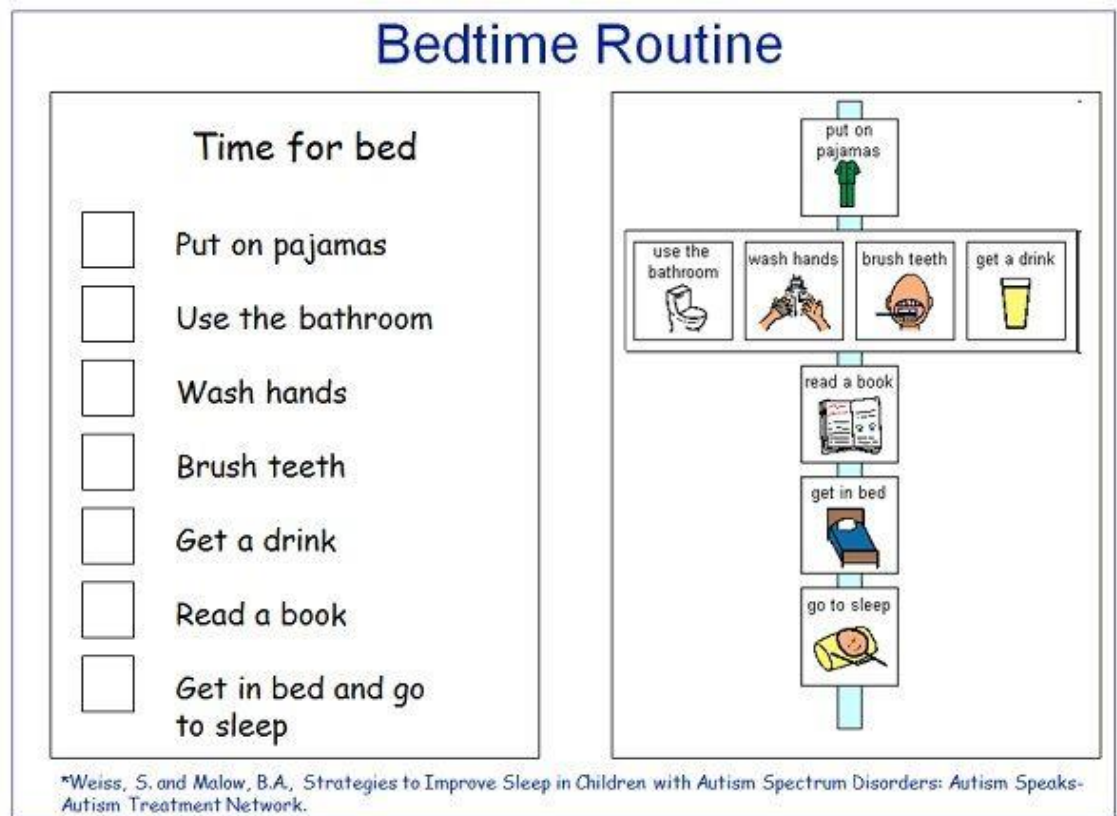
Day Time naps: What time?	What did your child do in the hour before bed?	Time taken to bed, any problems here?	What time did your child fall to sleep?	Waking during the night; What time? What did you do?	Time your child woke in the morning, did you have to wake them?

You can find a bigger version of this diary on page 23 for you to copy and use. You can also create your own diary or find a ready-made one online.

Establish a bedtime routine – young people 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 the family’s need and helps the young person feel calm by the time they go to bed could be very helpful.

Try to create a routine that you can follow in different settings, for example if you are on holiday or staying with family/friends.

There is some research to suggest exposure to bright lights from screens (TVs, computer, tablet, smart phones etc.) can inhibit the production of the sleep hormone Melatonin. You might, therefore want to reduce your screen time before bed.



You can make your own version and even use photos of the items, clothes and rooms the young person will need to use during their bedtime routine.

Make your bedroom more comfortable – you might find certain sensory aspects of your bedroom distracting, making it harder to relax and go to sleep, as well as stay asleep. Your environment and surroundings can also play a role. It may help to:

- Block out light using dark curtains or black-out blinds
- Reduce noise using thick carpet, shutting doors fully, turning off appliances
- Block out noises by using ear plugs or listening to music through headphones
- Remove labels from bedding and night clothes, or try bedding and night clothes made from other materials
- Reduce smells coming into the room by closing the door fully, or by using scented oils that you find relaxing
- Remove distractions, such as electronic devices near the bed and pictures that you do not find relaxing.



Diet – What we eat and drink during the day can affect how well we sleep at night. You may want to consider the following to make sure your diet is not impacting on sleep:

- Review meal times – are you going to bed on a full stomach, which could make it difficult to sleep? Or are you hungry? You might want to consider adjusting the times that you eat to see if this has any impact on your sleep.
- Limit the amount of caffeine – remember that caffeine is found in things like tea, coffee, and chocolate. Caffeine should be avoided at least 6 hours before sleeping.
- Drinking water – can help you feel hydrated. Mild dehydration can cause sleep difficulties.
- Limit sugary snacks – especially before bedtime as this can give you a boost of energy. For example, try cutting out biscuits before bed and replacing them with something like carrot sticks or toast.
- Avoid foods high in fat – this has recently been found to cause poor quality sleep.



Naps – Avoid taking naps that last longer than one hour during the day and resist taking naps in the evening as this can stop you from falling asleep at night.

Go Outside – Try to go outside when it is light as this can improve your sleep quality and help your body clock adjust to day time and night time.

Relaxation Techniques – These can be introduced in low-key, non-intrusive ways in many areas of your life.

- Adding a few drops of lavender oil into your bath is known to show soothing effects.
- Introducing one hour of quiet time before bed time can help you unwind and relax.
- Breathing techniques may help you relax before going to sleep.

Ten Steps to a Quiet Night (FOR PARENTS)

1. Make bedroom **SAFE, SECURE** and **UNSTIMULATING**.
2. Set a regular bedtime and waking time and **STICK TO IT**.
3. **AVOID** stimulating activities in the hour before bedtime.
4. Have a pre-bedtime **SETTLING** routine. You can use symbols and timetables for this.
5. Rapid settling (**LESS THAN 4 MINS**). Tuck in, leave bedroom, lights off, door closed.
6. **IGNORE** thereafter, unless physically unwell. Put your child back without fuss if they get up during the night.

Points to consider:

- Plan any changes carefully and make sure everyone it may affect is in agreement.
- Seek support if needed. For example, have a friend or relative you can turn to for advice or to just share your problem with.
- Make sure you get the timing right. This means making sure you are in good health and that there are no major events coming up that could disrupt your routine.

Sleep for Parents

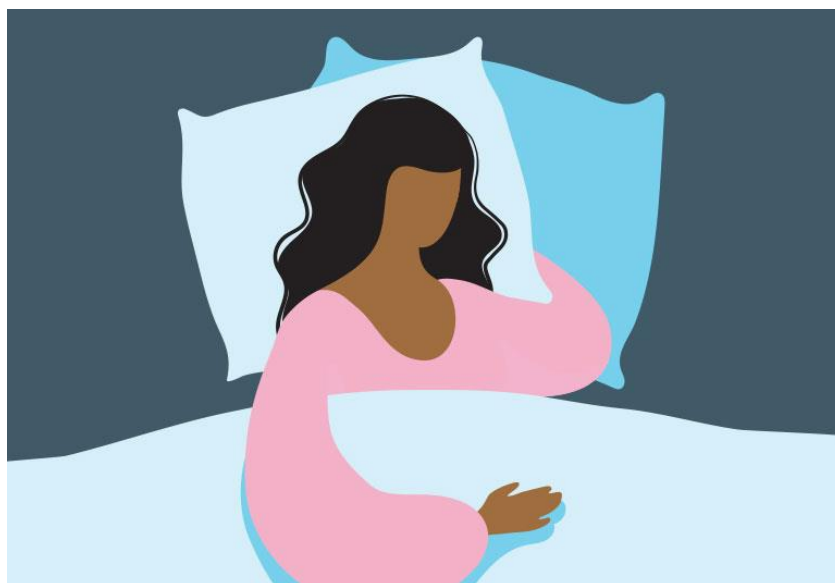
Getting a proper night's sleep is hugely important for you as a parent too!

It may have been suggested that you sleep when your child sleeps, but this won't be necessary or convenient, especially if you have other people to care for and it can also be difficult to 'switch off' on demand. By the time you have got your child to sleep, particularly if they need calming down, you may feel too wound up to sleep yourself.

- Safety proof your child's room so you can relax knowing that they cannot harm themselves while you sleep.

Consider your own routines and habits before going to sleep:

- Limit the use of electronics 15-20 minutes before falling asleep, the light emitted from devices can negatively affect the quality of your sleep.
- Set your own personal routine with clear steps to follow:
For example, have a warm shower, then a cup of herbal tea while comfortable in bed, perhaps read few pages from a book or listen to relaxing music/nature sounds. Make this routine personal to your likes/dislikes but ensure you find it relaxing.



Educate yourself around the topic of sleep. Understanding and knowing more around both your and your child's sleep will provide you with tools and approaches in order to deal with sleep difficulties.

If you're struggling with long-term lack of sleep, implementing strategies such as those above can be impractical. Seek support outside the family such as your GP, social worker or child's school, for help and advice.

FAQs (for parents)

My son wakes up during the night and I don't hear him get into my bed. How can I stop him?

- The parental bed is the greatest reward of all, keep him out at all times, even on a Sunday morning! Make sure he realises that it is your bed and he is not allowed there.
- It is important that you wake up before he manages to get into your bed. Find something that will make a noise as he approaches to wake you up, such as, a wind chime on the door handle or above the door, a musical mat outside his bedroom door.
- As soon as you wake up, return him to his bed with minimal fuss and no conversation.
- Be prepared to carry this out many times during the night, for a number of nights.

If a child wakes up at the same time every night, there is a technique called 'scheduled awakening' which can be tried. You need to know what time your child wakes up and disturb their sleep about 15 minutes before they are due to wake up. You do not need to wake them, just make a slight noise, enough to disturb them so that they fall back to sleep again.

My daughter will only fall asleep when I lay next to her, and it can take a long time for her to sleep, I usually fall asleep before she does.

- It sounds as if your daughter has got into the habit of having you beside her and finds this comforting. This cycle needs to be broken. There is a technique known as 'Graduated Extinction' which can help.
- You will have to learn to ignore cries and protests from your daughter when you start to make the change.
- It is important that you do not get too comfortable and fall asleep. Sit on a chair or on the floor beside the bed so your daughter knows that you are still there but don't be tempted to get on the bed beside her.
- Over the next few nights, start to move further away from the bed but remain in the room.
- Eventually you should not need to remain in the room with her when she falls asleep.
- This will generally take time to achieve and may be difficult initially.

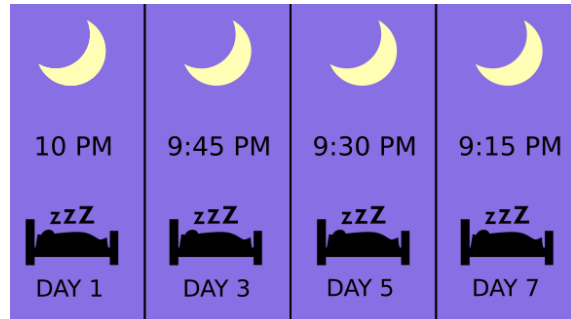
My son will not go to bed or sleep until about midnight each night.

- Keep a sleep diary to monitor what time he is going to bed and falling asleep.

- Make sure you have a good consistent routine in place.
- Over the course of the next couple of weeks, put him to bed 15 minutes earlier every other night until he is going at a more reasonable time. This may also help him wake up earlier the following morning which will help with night-time sleep later on.

Use the bedtime fading technique (by Adams and Rickert, for a simple guide to the technique see:

<https://www.parentingscience.com/bedtime-fading.html>)



My son wakes up about 5am. How do I get him to sleep longer?

- Keep a sleep diary to record what time he is going to sleep and waking.
- Consider if he is getting enough sleep and if he needs to go to sleep later in the evening.
- If he is getting enough sleep, he may need to learn to remain in his room in the morning rather than to get back to sleep.
- Using an alarm or timers on lamps may help him learn what time he is allowed to leave his bedroom.
- *Give the young person a bedtime pass*, this is a ticket the young person can turn in if they feel they must get out of bed. It may be used for bathroom trips, drinks of water, parent visits etc. This gives the young person some measure of control at bedtime. Set up the bedtime pass so that it can only be used one time per night. The bedtime pass needs to be a tangible item that the young person can turn in. *Create rewards for not using the bedtime pass*: total freedom is not a good idea when you're encouraging the young person to sleep. Allow the use of the bedtime pass, but give the person an incentive if they choose not to use it (e.g. special breakfast, extra play time).



Why is my child always tired even though he sleeps for several hours?

This may be related to sleep quality you could employ strategies mentioned in this package to try to improve this. Such strategies are physical exercise, removing distractions from the sleep environment (e.g. limit screen time, lights, control temperature, heavier duvet instead of a light one etc.).

However this issue may not always be related to sleep difficulties.

Changes in your routines or day-to-day life can increase anxiety and can be additional causes for autistic fatigue and burnout. Due to increased sensitivity and stress levels during autistic fatigue, your child may be less able to recover quickly from meltdowns.

Some other causes are:

- sensory overload
- dealing with social situations
- masking or camouflaging their autistic traits
- suppressing stimming
- a sense of not meeting other people's/society's expectations of them

Some suggestions:

Use energy accounting: Energy accounting is a system used to set manageable limits on your energy levels so you do not deplete yourself to the point of burnout.

Help your child or the person you care for to set a limit on how much energy they have in a day or week and estimate how much certain activities drain them. Also work out how much certain activities energise them.

You can then try to plan and balance their activities and energy over a day or week to try and manage stress limits. Make sure you build in time for relaxation and recovery.

Time off and rest/relaxation: Whether you use energy accounting or not, time off from work or school and other high-stress activities is key to managing stress levels. Ensuring time for activities/interests that re-energise and promote relaxation is key. This could be connecting with family and friends or enjoying hobbies or interests.

Time without having to mask: Autistic people often feel the need to hide or mask their autistic traits in public, for example by suppressing the urge to stim. It can be important to factor times into your child's day for things like stimming, somewhere they feel comfortable and able to do so.

Resources

Sleep Apps



Headspace is a science-backed app in mindfulness and meditation, providing unique tools and resources to help reduce stress, build resilience, and aid better sleep.

You can try Headspace for yourself and learn the essentials of meditation and mindfulness with their free basics course. If you enjoy it, you can subscribe. Headspace is available on iOS and Android.

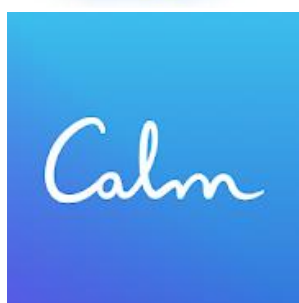


Pzizz is an NHS recommended app that helps you quickly calm your mind, fall asleep fast, stay asleep, and wake up refreshed.

It uses "dreamscapes" – a mix of music, voiceovers and sound effects designed using the latest clinical research – to help you sleep better at night or take power naps during the day. Pzizz is available on iOS and Android.



Free Calm Sleep: Improve your Sleep for Free, is a free app available for Androids. It uses relaxing sleep sounds and ambiances that can be used to help improve your sleep. This app is available on Android.



Calm is an app for meditation and sleep. It uses sleep stories, breathing programs, masterclasses, and relaxing music. Calm is a mindfulness app for beginners, but also includes hundreds of programs for intermediate and advanced users.

Guided meditation sessions are available in lengths of 3-25 minutes so you can choose the length to fit with your schedule.

Calm is available on iOS and Android.



Sleep Sounds - Sleep melodies & Calming sounds, free sleep app. It uses sleeping sounds, nature sounds, rain sounds, meditation sounds and white noise and much more.

This app is available on Android.

Find the Sleep Diary at <https://www.scope.org.uk/advice-and-support/keeping-sleep-diary/>



Day Time naps: What time?	What did your child do in the hour before bed?	Time taken to bed, any problems here?	What time did your child fall to sleep?	Waking during the night; What time? What did you do?	Time your child woke in the morning, did you have to wake them?

AUTISM & SLEEP



People with Autism often have trouble sleeping. There can be a range of reasons for this. Below are some strategies that may improve your sleep difficulties:

1 KEEP A SLEEP DIARY

A sleep diary can help you identify unusual patterns or factors that might be impacting your sleep. If you use other strategies to help you sleep, you can also use a sleep diary to track how effective they are.



2 ESTABLISH A BEDTIME ROUTINE

Establishing a routine can help you feel safe and in control. It can also, help give your body structure. Try creating a routine that you can follow in different settings.



3 MAKE YOUR BEDROOM MORE COMFORTABLE

Certain sensory aspects of your bedroom may be distracting and making it harder for you to relax and go to sleep.



4 CHECK WHAT YOU'RE EATING

What you eat and drink during the day can affect how well you sleep at night. Consider reviewing your meal times, limiting the amount of caffeine you drink and limit sugary snacks.



5 EXERCISE

Exercising during the day can improve your sleep quality at night and decrease the amount of time it takes for you to fall asleep.



6 GO OUTSIDE

Try going outside when it is light as this can improve your sleep quality and help your body clock adjust to day time and night time.



7 TRY RELAXATION TECHNIQUES

Introducing relaxation techniques before bed can help you unwind and relax. There are some great apps for this.



8 AVOID NAPS

Avoid taking naps that last longer than one hour as this can impact you falling asleep at night.



Further information

Name	Website	Email	Telephone No
Autism Bedfordshire	www.autismbedfordshire.net	enquiries@autismbeds.org	01234350704
National Autism Society	www.autism.org.uk	Autismhelpline@nas.org.uk	08450704004
Sleep Foundation	www.sleepfoundation.org	contact@sleepfoundation.org	01312581258
Sleep Scotland	www.sleepscotland.org	sleepsupport@sleepscotland.org	01316511392
The Sleep Council	www.sleepcouncil.org.uk	info@sleepcouncil.org.uk	
Young Minds	www.youngminds.org.uk		08088025544
Living Autism	www.livingautism.co.uk	info@livingautism.co.uk	08007562420

Professional practice and advice – video <https://www.autism.org.uk/advice-and-guidance/professional-practice/sleep-difficulties>

Chris Hoyle is Sleep Tight Trafford Coordinator at the Together Trust and has worked with autistic young people and young people for over 30 years. Ms Hoyle was interviewed by the Network Autism when she attended the National Autistic Society Professional Conference in 2019. In this video, Ms Hoyle outlines the sleep difficulties some autistic young people and young people experience, and the impact on them and their family. She also discusses how the Together Trust supports families with sleep issues.

Useful Reading & References

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