

sleep

tips and techniques
for families who have a
child with a brain condition

CEREBRA
Working wonders for children
with brain conditions

We're the charity dedicated to helping families who have a child with a brain condition discover a better life together.

Children with brain conditions often have trouble sleeping. This might include:

- Refusing to go to bed
- Difficulty going to sleep
- Not wanting to sleep alone
- Waking up during the night
- Waking up early
- And lots more...

In this leaflet we explain several different techniques that may help your child's sleep and give lots of hints and tips for putting them into practice.



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Our Sleep Service:

How we can help you get a better night's sleep:

★ **One-to-one support:** We can give advice over the phone on your child's specific sleep problem.

★ **Sleep Workshops:** If you run a parent group, one of our workshops might be just the thing you're looking for. We also run CPD accredited workshops for professionals. Contact us to find out more.

★ **Sleep information resources:** Our sleep guide, cards and other resources are packed full of information and advice that could help you get a good night's sleep.

If you'd like further advice you can download our Parent Guide on Sleep free of charge from our website, complete our on-line enquiry form or call us on 01267 244 210.

Our Sleep Service is strengthened by research at the Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham. Our sleep research is trying to understand why sleep problems occur and help families find solutions to them. This booklet is based on our research.

01267 244210
0800 3281159
Sleep@cerebra.org.uk
www.cerebra.org.uk



1. Bedtime routine



A bedtime routine is a set of activities that occur every night at the same time in the same order.

An example of a bedtime routine is:

1. Turn off the T.V. and other electronic devices and have a 'calm down' time e.g. colouring, drawing, play-dough, playing with toys
2. Have a snack and drink (avoid caffeine)
3. Up to the bathroom for bath/wash, teeth and toilet
4. Bedroom for story/massage/music

This is just an example of a bedtime routine – plan your routine to include things your child finds calming.

The length of the routine will vary depending on your child. Ideally it would take 30 minutes but in some cases can take up to an hour.

Consider:

Using visual schedules for your child to follow. Keep your voice calm, avoid confrontation and any bright lighting.



2. Calming time before sleep



Sometimes children with brain conditions can be **easily overstimulated**. To avoid this, bedtime activities should be **planned** and chosen based on what your child finds **relaxing**.

- Keep lights dim leading up to bedtime. Blue light is in your everyday white light bulbs, TVs, tablets and phones and this light suppresses melatonin (the sleep hormone) levels. We suggest you use red based lights where possible and make sure the curtains/blinds block out any outside light. You can use a filter on electronic equipment.
- Use a fixed bedroom routine and once your child is in bed use additional relaxation techniques, such as stroking, massage, and relaxing music (depending on your child). This will help your child to relax rather than soothe them to sleep. Additional relaxation techniques should be at the beginning of the routine. You don't want your child to fall asleep at this stage.

Things your child may find relaxing:

- Quiet baths
- Stories
- Lullabies
- The presence of small toys
- Familiar blanket
- A comfortable bed
- Rhythmic, repetitive movements
- Soft music

3. A good sleep environment



A good sleep environment can help your child to **fall to sleep quicker** and **stay asleep** during the night:

Consider the following:

- ★ **Keep the bedtime environment dark**, or use a red based light/night light if your child is afraid of the dark. Black-out blinds can reduce light coming in from outside.
- ★ **Stimulus control** (where the bed, bedroom and bedtime routine all signal sleep). Make sure the environment is one your child associates with bedtime. For example, keep toys to a minimum, or put them away at night time. Avoid electronic equipment such as T.V.s, tablets, phones and computers in the bedroom.
- ★ **Bedding** – your child should be comfortable and each child will have their own preferences (consider their sensory needs). Some children may like heavy blankets or sleeping bags, some may not like the feel of the bedding. It's important to make sure that your child is at a temperature that is comfortable for them.
- ★ **Noise levels** – this can vary based on the individual. Some children may like music or white noise for sleep, and this can also help block out background noise.

★
Consider:
Using neutral colours. Avoid too many distractions in the room, such as posters on the wall.

4. Positive sleep associations



Creating positive associations involves developing a **set bedtime routine** characterised by quiet activities that your child enjoys and also **associates with sleep**.

Many children with brain conditions fall asleep with specific sleep associations, such as being rocked or fed. These may not be available during the night when they wake.

Children experience brief awakenings at the end of each natural sleep cycle, usually every 60-90 minutes (see our Sleep Guide for more information on this). If they cannot get back to sleep they will search for the positive associations they have made at bedtime.

We recommend that these positive sleep associations do not involve you. Where possible, train your child to be independent with their sleep associations.

For example:
If your child listens to music to go to sleep, perhaps they could turn the music on by themselves. Or have the music on all night at a low level so that you don't need to go in.

5. Using a comforting object



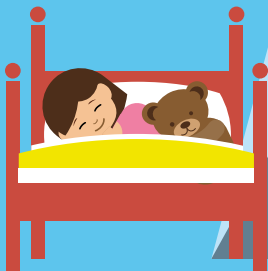
Using an object that your child finds comforting can be a substitute for a parent or carer when your child is settling at night. This can also **help your child settle** back to sleep if they wake during the night.

1. Decide what object to use – it may be better to allow your child to pick. You will need to get your child used to the object first.
2. This can be done by slowly introducing the object during the day in one-to-one time, calm time or play time. This interaction needs to be with you and repeated on a daily basis. It may take a month to establish.
3. Once your child is attached to the object and is using it to comfort themselves in the day, it can be introduced to the bedroom. The easiest way to find out if they are attached to it, is to leave the object in a different room and see if they go and get it or communicate that they want it.
4. You can then introduce it at bedtime to help them settle without you. If night waking is the issue, you leave the object with them when they settle as a reminder of you.

Consider:
A blanket, teddy, or item of parents' clothing can be used as a comforting object to substitute a parent.



6. Gradual withdrawal from the bedroom



If your **child settles** with you in the room, they will often need you there to settle again when they wake during the night. Gradual withdrawal means gradually **increasing the distance** between you and your child at night.

1. The first night sit on a chair by the bed, and remain there until your child falls asleep.
2. Once your child is used to this stage (this could be a few days, weeks or months, at a pace that suits you both), move the chair a bit further away, and sit there until your child falls asleep.
3. Continue to do this until the chair is by the door, and then you are out of the room/out of sight, and then back in your own room/downstairs.

Variations: If your child is used to having someone in the bed, the first step might be to lie/sit on the bed and gradually withdraw contact. You could use a mattress to sleep on, and gradually move away, so you can sleep there while doing this technique. The gradual approach can be used for items as well, such as a bottle (gradually reducing or diluting the amount of milk).

Consider: Using an item of comfort as a substitute for the parent/object during the withdrawal process.



7. Moving bedtime backwards

(Phase advancement)



If your child is having difficulty falling asleep at a desired time, but is settling before 1am then 'phase advancement' or moving their bedtime backwards may help.

This technique helps to move sleep patterns to the desired time, can increase the average sleep time at night and decrease sleep disturbances.

First decide on an appropriate bedtime and waking time based on your child's sleep needs (these are individual for your child and you may need to speak to a Sleep Practitioner to help with this).

1. If you need to make changes to get to these times, do so by 15 minutes each day (or at a slower pace if needed).
2. Using bright light in the morning can help advance the body clock.

Example: If your child is put to bed at 8pm, and doesn't sleep until 11pm, you would start by putting them to bed at 11pm (with a calm down routine before). Gradually make this time earlier by 15 minutes each day, until you get to a more reasonable time.



Consider:
If your child is taking longer than 15/20 minutes to settle, you may want to keep the time consistent for a few days before moving the time again.

8. Moving bedtime forwards

(Chronotherapy)



If your child is **staying awake** until after 1am, then this technique may help to **move their sleep** time forward. Chronotherapy has been shown to increase a child's average sleep time at night and decrease sleep disturbances.

1. Chronotherapy involves carefully and consistently delaying your child's bedtime and wake up time each day whilst maintaining a regular schedule during waking hours.
2. This method works best with a structured bedtime routine and calm down time.
3. Move the bedtimes and wake times forward by three hours each time (please note, this means sleeping in the day during the process so school holidays are usually the best time to try).
4. Using bright light in the evening will help delay the body clock.

For advice about using this technique, please get in touch with us.

For example:

- Day 1: Sleep 4am - 12 midday
- Day 2: Sleep 7am - 3pm
- Day 3: Sleep 10am - 6pm
- Day 4: Sleep 1pm - 9pm
- Day 5: Sleep 4pm - 12 midnight
- Day 6: Sleep 7pm - 3am
- Day 7-13: Sleep 10pm - 6am
- Day 14+: Sleep 11pm - 7am

9. Creating a rewards system



A reward system can be used to **encourage good sleep practice** with your child:

- ★ Rewards, also known as positive reinforcement, can be used to encourage desired behaviours e.g. staying in their bed all night and not going into your bed.
- ★ It is very important that you choose a reward that you know will motivate your child. If possible, ask your child what reward they would like to have or work towards having.
- ★ Rewards can take many forms e.g. praise, sticker charts, pocket money, an outing, time on an electronic device, time with a favourite toy/object, time with a particular person.
- ★ Once a reward has been achieved for positive behaviours, they shouldn't be taken away, even if your child displays unwanted behaviour afterwards. It is important your child knows that the reward was achieved and earned.
- ★ Some children may need to earn their reward immediately, in which case you would need a reward that can be given *first thing* in the morning. If your child can wait, then you may be able to delay the reward until the weekend.

Consider:
Some children may get bored of the reward system so this might need to be changed to keep them motivated.

10. Reducing daytime naps



If your child naps in the day and has **trouble falling asleep** at bedtime and/or wakes frequently at night, it might be that they are getting **too much sleep** during the day:

- ★ If your child is having a regular nap each day, don't cut this out straight away.
- ★ Reduce the nap time by 5 minutes each time (e.g. each week) until the nap is cut out altogether.
- ★ To reduce nap time you can either delay the start time or wake them a bit earlier (to suit meal time/nursery/school runs etc). Try to keep the nap times fairly consistent (e.g. don't let them nap in the morning one day, and then in afternoon the next).
- ★ If your child is in school make the school aware that you are using this process to reduce naps and ask them to follow it.

Tip: Keep bedtimes and wake times the same so that consistency in overnight sleep times supports this process.

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For further advice
you can call us on:
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