



Getting in contact with us

Telephone Contact a Family:
0808 808 3555

Open Monday – Friday 10am – 4pm
and Monday 5.30pm – 7.30pm

This call is free

We are happy to give information to family, friends or anyone who knows the family well.

Online:

www.cafamily.org.uk
www.makingcontact.org

This leaflet is available from Contact a Family, translated in various languages.

Telephone interpreter service

You can telephone Contact a Family and access qualified interpreters in over 100 languages who can assist in providing information.

To use this service:

- telephone Contact a Family on **0808 808 3555**
- give them your telephone number
- tell them which language you need
- if you can, let them know in English what type of help you are looking for
- within a few minutes someone will ring you back with an interpreter to assist your call.



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Helping your child's sleep

Information for parents of disabled children

Order code: C2

Parents & Paediatricians together

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Introduction

Sleep problems affect the whole family

A child who does not sleep well can affect the whole family. Parents can be left exhausted, unable to think clearly and struggling to cope with their daily activities. The child can be left feeling either tired or overactive, both signs of lack of sleep. Brothers and sisters are also affected, feeling tired at school and sometimes resentful towards the sibling disturbing their sleep. If this continues over a long period of time it can have an adverse effect on the health and well being of all members of the family.

Many children are sleeping through the night by the age of one, though it is quite normal for sleep to be occasionally disturbed because of illness or other changes in routine. Disabled children and those with certain medical conditions are more likely to have persistent problems with sleeping.

There are some standard approaches which help all children, including disabled children, but these might take longer to work depending on the nature of the child's medical condition or disability.

Why disabled children can have sleep problems

If a child is having trouble sleeping it is important to seek medical advice, to make sure there is not a medical cause. Disabled children are more likely to have sleep disorders such as sleep apnoea, which disturbs their nights sleep. If a sleep disorder is suspected, the child might need to spend a night in hospital so tests can be carried out while they sleep.

A child with a **physical disability** might find it difficult to get comfortable at night, or experience discomfort caused by muscle spasm, incontinence or breathing difficulties. Where a child cannot move independently and needs to be turned in the night it is much harder for the child to learn that night-time is for sleeping. Professionals may be able to help; for example, a physiotherapist might be able to give advice about a good position for the child to sleep in or a doctor might be able to prescribe medication to relieve any discomfort. A child's prescribed medicine can sometimes affect their sleep pattern e.g. medication for epilepsy can cause sleeplessness.



Neurological conditions which affect the brain, such as cerebral palsy, can also cause sleep problems if the brain's normal sleep-wake cycle is disturbed. If this is the case a doctor might be able to prescribe medication to assist but having regular bedtime routines will also help. It is advisable not to use medicines purchased over the counter without first talking to a doctor.

Children with **learning disabilities** or difficulty in communicating might find it difficult to understand why and when they need to sleep. Many children with autism seem to be affected with a disturbed sleep pattern. They might have difficulty in going to sleep or wake frequently for no obvious reason or because they want reassurance.

What can cause a child to wake

Some common causes of sleep disturbance include:

- Too much sugary food during the day or a diet which is high in additives.
- Becoming too hot or cold, a cooler bedroom often improves people's sleep.
- Being hungry or thirsty.
- Having a nappy that needs changing.
- Experiencing bad dreams.
- Attention seeking behaviour.

What might help

Make the bedroom a relaxing place

It helps to make the child's bedroom a safe, calm and pleasant place for the child to be in. If you can, decorate in pale shades as these are less stimulating than bright colours. Avoid too much furniture and lots of stimulating toys and games but do include a few favourite pictures, posters and cuddly toys. Reduce noise coming into the room as much as possible by placing the child's bed as far away from sources of noise as possible.

If the bedroom is too light try using black out linings on curtains to make the room darker. If the child finds the bedroom too dark try using a small night light. Some children feel more comfortable with a blanket whilst others prefer a duvet. Certain children respond to calming background music to help them relax. Toy shops often sell lullaby lamps that provide a soft light shapes with music. Electric aromatherapy night lamps have also been found helpful in setting a relaxing environment for some children. There is scientific evidence that lavender and bergamot essential oils can help with sleep problems. Work out which of all of these suits your child best.

Make sure the child thinks of the bedroom as a comfortable and relaxing place. Try not to send a child to the bedroom during the day as a punishment. Try to find other ways to encourage good behaviour. Contact a Family Health Nurse for a fact sheet in English called 'Understanding Your Child's Behaviour' which might provide ideas.

Keeping a sleep diary

A sleep diary can be useful to help parents find out what triggers poor sleep behaviour and what seems to help. A sleep diary might contain:

- The time the child went to sleep and period of times awake during the night.
- The number and length of naps during the day to see if cutting down naps and keeping child awake for longer periods during the day helps.
- The process of preparing the child for bed to identify whether changes to bedtime routine work well.
- Medication and time given as giving medication at different times of the day might help.



The diary can also be useful:

- To show to professionals to help them understand the severity of their child's sleep behaviour.
- To provide evidence when applying for benefits e.g. Disability Living Allowance.
- As a visual incentive so the child can be rewarded if they stay in bed and try to sleep.

Having a regular bedtime routine

It always helps to have regular routines around going to bed so the child becomes familiar with the routine and can predict what happens next. Pick a good time to start a new bedtime routine. e.g. not just before going on holiday when the child will be sleeping in unfamiliar surroundings. If other members of the family occasionally prepare the child for bed try to make sure everyone follows the same routine. It helps to:

- Keep a regular bedtime for the child and wake them at the same time each morning.
- Limit day time naps.
- Make sure the child is not hungry at bedtime.
- Avoid drinks with high sugar content and foods full of additives during the day.
- Avoid TV, computer screens or play stations for at least one hour before bedtime, as the light from the screen can disrupt the child's normal sleep rhythm.

The routine needs to fit in with everyday family life and be one the child finds pleasurable. Typically the routine might consist of four or five calming activities such as:

- Relaxation time when the child receives as much undivided attention as possible. Avoid stimulating activity such as rough play or frightening fairy tales.
- Biscuit / milky drink.
- Bath time.
- Story, song or music tape.
- Settle in bed – tucked in with special toy – goodnight kiss or phrase e.g. “Goodnight, sleep tight, see you in the morning”. The child understands from this it is time to settle down and go to sleep.

Different things help different children and it helps to work out what is best for each child. If the child has difficulty communicating and/or understanding then pictures, photos, symbols or certain objects e.g. a dolls pillow may be used to help them understand what comes next. Favourite toys can also be used to act out the bedtime routine to help the child become familiar with it.

Once in bed...

It is normal for all children to wake a few times in the night. It is best not to stay with the child in the bedroom until they are sleep. This way the child gets used to falling asleep on their own, does not expect to see you should they awake and instead learns to settle themselves.

If your child comes into your bedroom during the night allowing them into your bed might help in the short term but sets a long term habit that is difficult to break.



Breaking bad habits

Crying to avoid bedtime

Sometimes children cry to get their parent's attention, because they don't want to go to sleep. It can be difficult for parents to know whether the crying is because the child is distressed or simply wanting attention, especially if the child cannot talk. Some parents find it very difficult to leave their child to cry, but if they go to them the moment the crying starts, the child soon learns that this is a way of avoiding bedtime and it becomes a regular occurrence.

Sleep experts advocate two methods of tackling this type of behaviour, both of which are known to work and are described below.

Technique 1 – Leaving the child to cry

This technique should only be tried after discussion with a health visitor or other health professional, especially where the child has a medical condition or other significant additional need. Parents often find leaving their child to cry stressful and might prefer the next technique, though it can take longer to work.

Parents leave the child to cry until the child eventually learns crying does not work. The first few nights this is tried the child is likely to cry for some considerable length of time. This is the fastest way of resolving this type of behaviour but before trying this approach, parents need to give it some careful thought and planning.

1. To begin with the crying may go on for hours, but this will ease as days go by. Parents may want to start this approach at a time when disturbing other family members is not too much of a concern, for example during school holidays. Parents may also need to take practical steps such as warning neighbours.
2. Parents can find this approach very stressful and need to be sure they can carry it through. If parents ignore the crying for say 30 minutes, but then find it impossible to bear any longer, they effectively teach the child that persistent crying pays.
3. If the child has behavioural problems, parents need to know the child will be safe. They might need to prepare the bedroom and remove anything the child may hurt themselves on and use a stairgate to prevent the child from getting into other areas of the house. Some parents whose children have very challenging behaviour have had to resort to screwing furniture down.

Technique 2 – Controlled Crying

If the child starts to cry, go in after 2-5 minutes (less if the crying upsets them) and gently but firmly resettle them with as little touching as possible and repeat your 'goodnight phrase'. Leave again. If the crying persists, go back at regular intervals of 2-5 minutes and go through the same resettling routine. Parents may have to go in many times to begin with but this will lessen each time until the child eventually falls asleep on their own.

If the child comes out of the bedroom take them immediately back to bed without giving eye contact or talking and gently but firmly resettle them. Repeat their 'goodnight phrase' and leave again. If they come out again, just repeat this.

If the child wants you in the room

If your child is used to having you in the bedroom when they go to sleep, and is very distressed when you leave them, it helps to gradually get them accustomed to you not being in the room. To begin with sit alongside them and avoid getting into bed with them or cuddling them to sleep. Try to avoid eye contact and any conversation. If you find this hard then reading a book or magazine to yourself might help.



Every few days gradually increase the distance between you and your child (e.g. sit by the bed, sit a bit further away, stand in the door, stand outside the door etc.) until the child no longer needs you to be there for them to fall asleep.

Remember to be patient and firm

Whichever of these techniques you use, it is common for a child to start to improve and then for their behaviour to get worse. It is important to be firm and stick to the routine and their behaviour will start to improve again. Otherwise the child continues to have bad habits which results in constant attention-seeking and postponement of bed times.

Changing bedtime habits might take a while, and the child's behaviour might get worse before it gets better, but if you persevere, it can have great benefits for everyone.

Reward your child's good behaviour

If a particular behaviour is 'rewarded' in some way it is more likely to happen again. A reward can be anything that a child finds pleasant, such as praise, a drink, a hug or attention. Star charts are one way of rewarding good behaviour which children often like. Make a chart showing all the days of the week, place it in the home where everyone can see it and show it to people who visit. Each day your child is given a goal and if they achieve it they are given a star. At first start with simple goals, (eg. going to the bedroom when asked) and gradually set more demanding ones (eg. staying in bed once parents have left the room, staying in bedroom all night etc). Once the child has got a set number of stars they are rewarded with an activity they enjoy e.g. a trip to the cinema or park.

This factsheet is available from Contact a Family, translated in various languages

Getting help

This information sheet has listed a few ideas that might help, but there are other sources of help and support available.

- Health visitors and community nurses can often provide advice on encouraging children to sleep.
- Your GP or paediatrician might also be able to help, or refer you to a psychologist, psychiatrist or sleep specialist.
- If you live in Scotland the charity Sleep Scotland provides both information and a sleep counselling service for families of children with additional needs who have severe sleep problems – see contact details below.
- National support groups often provide information on sleeping for families of children with certain conditions. A few are listed below and Contact a Family can provide details of others.
- Many families find it helps to talk to others who have had, or are facing similar problems. Contact a Family can provide details of local parent support groups.
- If your sleep is being continuously disturbed you can ask for a Carer's Assessment from Social Services. They may be able to provide short breaks or respite, where someone else looks after your child for a few nights so you can get an uninterrupted nights sleep Contact a Family have a factsheet called 'A Guide to Assessments and Services' which gives more details of this.
- If your child needs care and attention during the night because of sleep problems, you might qualify for Disability Living Allowance (DLA) or a higher rate if you're getting this already. Contact our Helpline for further information.

Useful contacts

Contact a Family

Freephone helpline 0808 808 3555
open Monday – Friday 10am-4pm,
Monday evening 5.30pm to 7.30 pm
Offers an interpreting service in over
120 different languages
Email: helpline@cafamily.org.uk
Web: <http://www.camily.org.uk>
Address: 209-211 City Road,
London, EC1V 1JN

Sleep Scotland provides a service
in Scotland to help families of children
with special needs or with severe
sleep problems.

Tel: 0845 603 1212
Mon-Fri 9:30am – 5.30pm
Email: enquiries@sleepscotland.org
Web: <http://www.sleepscotland.org>
Address: 8 Hope Park Square,
Edinburgh, EH8 9NW, Scotland

The National Autistic Society provide
information, advice and support for
people affected by Autistic Spectrum
Disorders (ASD). Their information fact
sheet 'Helping your child with autism
to sleep better' can be downloaded
from their website.

Tel: 0845 070 4004
Monday-Friday 10.00am – 4.00pm
Offers an interpreting service in over
120 different languages to callers using
landline telephones in the UK
Web: <http://www.nas.org.uk>
393 City Road, London, EC1V 1NG

Scope provide information and advice
to people affected by cerebral palsy.
Their information fact sheet 'Sleep
problems in children' can be
downloaded from their website.
Freephone: 0808 800 33 33
9am – 7pm weekdays and 10am – 2pm
on Saturday
Email: response@scope.org.uk
Web: <http://www.scope.org.uk>
Address: Scope Response,
PO Box 833, Milton Keynes, MK12 5NY
(Please include SAE for a reply)

Further reading

'The Good Sleep Guide for you and your baby'

Angela Henderson
Published by ABC Health Guides 1997
Muir of Logie Farmhouse, Forres, Moray,
IV36 2QG Tel: 07020 922 750

'Sleep Better! – A Guide to Improving Sleep for Children with Special Needs'

V. Mark Durand
Paul H. Brookes Publishing Co. 1998

'Solving Children's Sleep Problems: A Step by Step Guide for Parents'

Lyn Quine
Beckett Karlson (Huntingdon) 1997

'Solve Your Child's Problems; The Complete Practical Guide for Parents'

Dr Richard Ferber
Dorling Kindersley, London 1986