

Helping your child's sleep

Information for parents of disabled children in England,
Northern Ireland, Scotland and Wales



Introduction

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 over-active, 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 wellbeing 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. However, disabled children and those with certain medical conditions are more likely to have problems with sleeping for a number of reasons.

There are some standard approaches that help all children, but these might need to be adapted for some disabled children, such as children with learning disabilities, ADHD and autism.

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This guide was written by Sheila Davies and Karin Beeler

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Why sleep can be a problem

86% of children with additional needs have issues with sleep

So if you are experiencing difficulties you are not alone.

There can be various reasons for this.

- Physical disability may mean children find it harder to get comfortable at night, or experience discomfort caused by muscle spasms, incontinence or breathing difficulties. Any child in discomfort will naturally wake up.
- If your child cannot move independently and needs to be turned in the night, this is likely to disturb their sleep.
- Visual impairment can mean children may miss cues for night and day.
- Hearing impairment can mean children become anxious and feel isolated when they remove hearing aids at night.
- Neurological conditions which affect the brain, such as cerebral palsy and epilepsy can also affect the brain's normal sleep-wake cycle.
- Prescribed medication might also affect a child's sleep pattern – for example medication for epilepsy and ADHD can cause sleeplessness.
- Learning disabilities or difficulty in communicating might make it difficult for children to understand why and when they need to sleep.
- Difficulties breathing while asleep (sleep apnoea) can disturb a child's sleep.

It is important to seek medical advice to make sure there is not a medical cause for your child's problems with sleeping.

There are many different strategies and approaches to helping children sleep. This guide is an overview of some of the strategies and resources available.

Autism

Children with autism frequently seem to be affected with a disturbed sleep pattern. They might have difficulty going to sleep or wake frequently for no obvious reason, or only need a few hours' sleep.

Some research suggests that children with autism do not produce enough melatonin, a chemical that our brain makes that helps us to go to sleep at night time (see page 20). A good bedtime routine (page 10) can help in melatonin production and help to improve sleep patterns.





Make the bedroom a relaxing place

It helps to make your child's bedroom a safe, calm and pleasant place to be in. Make sure they also **think** of the bedroom as a comfortable and relaxing place – so avoid sending them to their room as punishment, (see page 17 'Avoiding bad habits').

There are also certain 'props' you can put in place at the start of the night to help your child sleep, like music or night lights. These need to stay on or in position all night otherwise your child will become confused if things have changed when they wake up.

Sound and vision

- Certain children respond to calming background music or sounds to help them relax (but it needs to be able to stay on throughout the night).
- Reduce noise coming into the room as much as possible by placing your child's bed as far away from sources of noise as possible.
- Avoid TV, iPads, mobile phones, computer screens or play stations for at least one hour before bedtime, as the blue light from these screens can disrupt your child's normal sleep rhythm.

Light and colour

- Where possible, decorate the bedroom in pale shades as these are less stimulating than bright colours.
- If the bedroom is too light try blackout linings on curtains.
- If your child finds the bedroom too dark try a small night light that glows softly (not a blue light or LED light that comes from computer screens and phones).
- Simple 'sleep training' clocks with different colours for night and day can help children know when it is night and day.
- Aromatherapy night lamps have 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, but there's also evidence of it not being good for boys of a certain age and children with epilepsy, so talk to your GP.
- Toy shops often sell lullaby lamps that provide a soft light and shapes with music, but sleep practitioners don't recommend these, because they don't stay on all night.

Temperature

- Check the temperature of the room – are there any draughts coming in? Is it too hot or cold for your child?
- If your child can't regulate their body temperature well, for example in the case of night sweats, cooling gel supports, sheets and pillows made of special material may help. The suppliers on page 9 should be able to help.

“ A child can stop sleeping or alter their pattern at any age for lots of reasons. Often disabled children are sensitive to environmental changes, changes in medication, hormonal changes. You might need to go back to basic sleep techniques again and again. Don't get disillusioned, it will be worth it. ”

Furniture and equipment

- Avoid too much furniture and lots of stimulating toys and games, but do include a few favourite pictures, posters and cuddly toys.
- Some children feel more comfortable with a blanket whilst others prefer a duvet.
- An occupational therapist (OT) may help you with equipment to help your child sleep, like different styles of beds and moulded mattresses that can support your child to sleep in the right position. You can also get cushioned supports for hips, body, legs, knees and ankles that relieve pressure and help stop your child rolling into an uncomfortable position they will wake up from. These can also help them sleep as symmetrically as possible.
- A weighted blanket helps some children feel less anxious and stressed, helping them to have a peaceful night's sleep, especially children with autism. Only use them on the advice of an OT.
- If your child has seizures when they sleep you may be able to get devices like a safety pillow or seizure monitors for them. You can also get devices to monitor breathing.
- If your child wakes and moves around the house, you might find an alarm system helpful. Care assistant alarms (used with older people or people with dementia so they can stay in their own homes) can be either on a doorway or under the bed and wake you immediately.
- If your child is anxious going to sleep there are a number of things you could try. For example you could make a 'monster spray' to spray under the bed and around the bedroom to banish monsters – or use 'worry dolls' or 'dream catchers'.
- If your child has behavioural problems, prepare the bedroom and remove anything they may hurt themselves on. Using a stair gate may not be enough to stop them from getting into other areas of the house - they may try and climb over and injure themselves. Having a 'stable' door has worked well for some families.
- Some parents whose children have very challenging behaviour have had to resort to screwing furniture down. You can also get 'tough furniture' and safe 'soft spaces' for the bedroom – see the suppliers listed on page 9.

Work out what suits your child best.



Equipment that may be helpful is available from these organisations

> Disabled Living Foundation

Impartial information and advice on equipment to assist your child at home. Including baby monitors, beds, sleep systems and night time postural support, cots and accessories.

 Helpline 0300 999 0004

 www.livingmadeeasy.org.uk

> Independent Living

Information about equipment to help living with a disability – such as ‘tough’ furniture and sleep solutions.

 www.independentliving.co.uk

> Fledglings

Charity that runs a helpline that helps parents search for products for individual children, including sleep wear, day and night-time wetting, equipment for bedtime like stay-on duvets.

 Helpline 0845 458 1124 /
01799 541 807

 www.fledglings.org.uk

> ERIC

Charity that supports children with continence problems, their parents and professionals. Their helpline can help with potty training, bed wetting, daytime wetting, constipation and soiling. They also have a range of products to use at night to minimise the effort of changing bedding.

 Helpline 0845 370 8008

 www.eric.org.uk

> Sensory Direct

Set up by parents, Sensory Direct sells weighted blankets for children and teenagers, and other weighted and sensory products that help children with sensory processing issues.

 Helpline 0800 0837 212

 www.sensorydirect.com

Bedtime routine

- Put your child to bed at the same time each night and wake them at the same time each morning.
- Make day time naps age-appropriate and schedule them in (see page 11).
- Make sure your child is not hungry or thirsty at bedtime but avoid drinks or food with high sugar content.
- Make sure your child has gone to the toilet before bed.
- Make sure all family members or child carers who put them for bed follow the same routine
- Avoid TV, computers, iPads and so on for one hour before bed – their light disrupts sleep patterns.

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

- **relaxation time** – when your child has as much undivided attention as possible, for example colouring, jigsaws, finger rhymes. Avoid stimulating activity such as rough play or frightening fairy tales
- **warm milk drink** – certain foods help sleep, such as milk and wholegrain toast. Avoid sugary foods such as biscuits or cereals
- **bath time** – you can also add lavender oil to the bath, or try calming bath soaks
- **story time** – or a song or music
- **settle in bed** – tucked in with their special toy if they have one. A special toy isn't necessary if your child doesn't already have one
- **goodnight kiss or phrase** – for example "Goodnight, sleep tight, see you in the morning". Your child will understand from this it is time to settle down and go to sleep.

It is very common for children to recognise when it is time for bed and object to or try and avoid it. Keeping calm and continuing with the routine will help your child to settle more easily in the future.

Helping your child understand a bedroom routine

Different things help different children and it helps to work out what is best for your child, for example:

- your child may communicate using objects, pictures, signs or symbols – for example Makaton and Picture Exchange Communication System (PECS) – you can use to help them understand bedtime and the bedtime routine

			
Age		Daytime sleep	Nighttime sleep
	3 months	5 hours	10 hours
	12 months	2.5 hours	11.5 hours
	3 years	1 hour	11 hours
	6 years	None	10.5 hours
	9 years	None	10 hours

How much sleep does my child need?

Every child is different, so use this table as a guide.

The amount of sleep a child needs reduces by around 15 minutes for each year after age 9.

- certain objects, for example a doll's 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 your child become familiar with it
- social stories may help children with learning difficulties or autism understand the routine. You can find information at www.autism.org.uk (search 'social stories').

If other members of the family or child carers prepare them for bed try to make sure everyone follows the same routine.

Daytime naps

Many children will benefit from a daytime nap until they are two and sometimes three years of age (see table above).

Some older children with disabilities who are using a lot of energy during the day may also occasionally need a daytime nap. However, it is important that you monitor this situation as having a daytime nap will sometimes mean your child is not tired at night.

You may want to experiment by reducing the length of time your child is asleep during the day to see if this helps them sleep better at night. Each child is different and the number of hours sleep they need changes as they grow older.

Keeping a sleep diary

A sleep diary can be useful to help you find out what triggers poor sleep behaviour and what seems to help.

As many children will show variable patterns to their sleep it is helpful to keep one over a two week period to understand more fully what is happening.

The diary can also be useful:

- to help show strategies you have tried and your consistency with these and other aspects of your child's behaviour. It can also be helpful to record the most appropriate interventions and advice to show to professionals to help them understand the nature of the sleep problem
- to share with other people who are involved in their bed time routine
- to provide evidence when applying for benefits, for example Disability Living Allowance.

Reward good behaviour

If good behaviour is rewarded it is more likely to happen again. A reward can be anything a child finds pleasant, such as praise, 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.

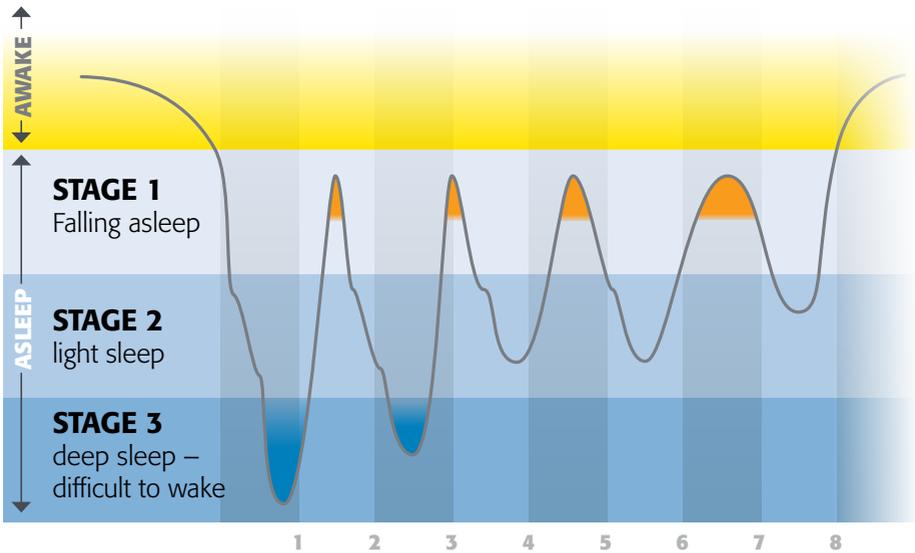
At first start with simple goals, (for example, going to the bedroom when asked) and gradually set more demanding ones (for example, staying in bed once you have left the room, staying in bedroom all night). Once your child has a set number of stars reward them with an activity they enjoy, for example a trip to the cinema or park.

Younger children and those with learning disabilities often need rewards quite quickly to have an impact. These do not have to be big events or cost money. The next day they might choose a programme to watch on TV or an activity they enjoy as a reward. Show them this on their star chart.

	Start date: / /						
	MON	TUE	WED	THUR	FRI	SAT	SUN
Naps – time and length of?							
Time of and type of food before bed							
How was bedtime routine (what worked/any changes?)							
Time to bed							
Affects of any medication?							
Time to sleep							
Times they woke up							
What did they do when they awoke							
What did you do when they awoke							
Time of morning waking							
Tiredness/Irritability next day (1-5)							
Other comments							

The sleep cycle

This diagram shows the different stages of sleep. It shows an average adult eight-hour sleep. Children go through the same cycle, but it varies depending on age, lasting an hour in infants, and 90 minutes in young people.



Falling asleep

It takes around 15 minutes to move from stage one to deeper sleep. Your child can wake easily during this time. If you stay with them while they fall asleep and then leave the room before they enter deep sleep you may wake them up. We experience this series of sleep stages several times each night.

Partial waking

- Happens when we move between stages of sleep.
- Normally we simply turn over and go back to sleep.
- Children who have not learnt to settle themselves may wake fully at this point.
- Waking in a different environment may cause your child to become fully awake – for example, if your child falls asleep on the sofa and you carry them up to bed.

REM sleep

- Happens approximately 70–90 minutes after we fall asleep.
- Eyes move underneath our eyelids (Rapid Eye Movement)
- Vivid dreaming
- Brain is very active
- Body deeply relaxed and cannot move.

We complete a sleep cycle when we pass through the three stages of non-REM sleep (which repairs our body and immune system) and REM sleep (which consolidates memory, repairs the brain and processes information learned during the day). If we are not getting enough sleep, our body will try to make up deep sleep at the expense of REM sleep. This is why mood and behaviour can be affected if a child isn't getting enough sleep.

Night terrors, sleep talking / walking

- Happen when moving from deep sleep to lighter sleep.
- Child may scream and appear to be in a panic and not recognise you. They are not harmful – avoid waking your child during a night terror. See NHS Choices www.nhs.uk (search for night terrors).

Common causes of sleep disturbance

- The inability to self-settle. If your child can't soothe themselves to sleep they will wake after every sleep cycle. They will also wake if they only ever go to sleep with a bottle.
- Being over tired.
- Sensory processing issues, like touch, sound, vision, smell. For example a child who is noise sensitive during the day may also find noises interrupt their sleep patterns.
- Discomfort.
- Illness and physical pain.
- Change in sleep environment, for example a light turned off when parents go to bed.
- A prop being missing, like a dummy, a teddy or a parent!
- Too much sugary food in the day or a diet high in additives
- Becoming too hot or cold – a cooler bedroom often improves sleep.
- Being hungry or thirsty. But if you give milk or food during the night your child will wake wanting a drink or food. After 9 to 12 months night feeds are not needed unless you have been told there is a medical reason for them.
- Nappy needing changing.
- Bad dreams or night terrors.



Avoiding bad bedtime habits

It is normal for all children to sometimes wake in the night and seek your attention.

Have a bedtime routine and stick to it. If your child awakes during the night, go into their room to soothe them, but only for a short while with as little touching as possible, before repeating your 'goodnight phrase' and leaving them in their bed.

It can be tempting to let your child into bed with you, rather than get up and take them back to their room. However, you may find yourself with a long-term habit that's difficult to break and becomes a problem as they grow older and are approaching puberty. If your child has been sleeping in your bed for many years, it is much harder to persuade them to sleep on their own.

Do not send your child to their bedroom during the day as a punishment – they will associate being sent to their bedroom with being punished. Try to find other ways to encourage good behaviour.

 *Our guide **Understanding your child's behaviour** has ideas to help with behaviour. Call our freephone helpline for a free copy **0808 808 3555** or download it from our website.*

Changing bad habits

Pick a good time if you want to change your child's bedtime habits. You need to choose a time when you feel you can carry out a change of routine for at least two weeks. For example, do not begin this just before going on holiday when your child will be sleeping in unfamiliar surroundings. Consider having additional support at this time if possible, like a friend or family, especially if you have other children.

“ Some children just take their time to get there. My daughter has finally just started sleeping through the night all night in her own bed. Not every night yet, she still comes to us some nights and asks us to take her back to bed, so only needing a small amount of attention ”

Crying at bedtime

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

There are two 'techniques' commonly used to tackle problem crying at bedtime. Which works best will depend on the needs of your child and the rest of the family.

Leaving the child to cry ('extinction')

Health visitors and doctors often recommend this approach. But there are many reasons why this technique might not be appropriate for a disabled child:

- A child with limited communication skills may use a cry to indicate they are too hot/cold, thirsty/hungry, uncomfortable, unwell – all things that will prevent them sleeping if not responded to.
- A child with sensory impairment or learning disability might be anxious about being alone, or simply not understand that it is

night time and they are expected to go to sleep.

- Some children might respond to being left with self-injurious behaviour, so it is not safe to leave them.
- Another child's sleep would be severely disrupted because they share a bedroom with the disabled child.

This approach should only be tried after discussion with a health visitor or other health professional, especially if the child has a medical condition or other significant additional need.

How it works

Parents are asked to 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. To begin with, the crying may go on for hours, and parents can find this approach very stressful and need to be sure they can carry it through. If you ignore the crying for say 30 minutes, but then find it impossible to bear any longer you effectively teach your child that persistent crying pays.

Because a disabled child is likely to be crying because something is preventing them from sleeping, the next method may be a better choice for your family.



Gradual retreat

If your child starts to cry, go in after 2-5 minutes (less if the crying upsets you) 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. You may have to go in many times to begin with but this will lessen each time until your child eventually falls asleep on their own.

If your 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 your 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 three days gradually increase the distance between you and your child (for example, sit by the bed, sit a bit further away, stand in the door, stand outside the door) until your child no longer needs you to be there for them to fall asleep

! Be patient and firm

Whichever of these techniques you use, it is common for a child to start to improve and then for their sleep behaviour to get worse, before getting better again. It is important to be firm and stick to the routine, otherwise your child will continue to have bad habits, which may result in constant attention-seeking and postponement of bed times. Changing bedtime habits might take a while, but if you persevere it can have great benefits for everyone.

Melatonin

What is it?

Melatonin is a chemical that occurs naturally in our bodies and helps us get to sleep. It starts being produced in the evening when the light is getting dim, which is why it is a good idea to put your child to sleep in a darkened room.

Avoid screen time before bedtime

The light that comes from computer screens, mobile phones and pads can make you produce less melatonin. This is why it's best to not have these items in the bedroom, and to make sure your child doesn't use them for at least an hour before bedtime.

Who can it help?

Research has shown prescribing melatonin can help some children with learning disabilities or on the autism spectrum get to sleep at night. However, it does not work for all children and does not mean the child will sleep all night once they get to sleep. Some children, especially those on the autism spectrum or with rare genetic syndromes seem to need much less sleep than what is expected in other children.

How is it prescribed?

Melatonin is widely available in America but in the United Kingdom it is classified as an unlicensed medication for children (although it is licensed for elderly individuals who have difficulties settling to sleep). This means it can only be prescribed by a specialist (usually a consultant paediatrician or child and adolescent psychiatrist) rather than a General Practitioner. In some areas there is a 'shared care' agreement so that GPs can give repeat prescriptions for Melatonin. However it is always the consultant who is responsible for monitoring the child whilst on Melatonin.

Keep to your bedtime routine

Even if your child is prescribed melatonin you should still keep up a good bedtime routine (see page 10). Melatonin will only help if all other conditions for sleep are correct, for example, your child is tired, comfortable, in a quiet dark room, not hungry and feeling relaxed.

Don't buy Melatonin over the internet.

It should always be prescribed and supervised by a specialist.

Getting support

NHS

Specialist health visitors and community nurses can often provide advice on encouraging children to sleep. Your GP or paediatrician might be able to refer you to a sleep specialist – look around for what is available in your area. Or call our freephone helpline who can look for you on 0808 808 3555.

Sleep Workshops

Training workshops are provided in some areas. They can give you more strategies to help your child develop good sleep habits, and manage problems such as difficulty settling and night time waking. In some areas you may be able to get help with a one to one sleep counselling service.

Support groups

National support groups often have information on sleeping for families of children with certain conditions. 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 and national parent support groups.

Getting help for yourself

If your sleep is being continually disturbed and you're exhausted, it will effect your health and your ability to function during the day. If this is

happening to you, 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 night's sleep.

 *Our guide **Getting help with social care services - England**, gives more details of how to go about this. Call our freephone helpline on **0808 808 3555** for a free copy.*

There are similar rights for families in Northern Ireland, Scotland and Wales. Call our helpline for advice on how to get help in your area.

Money to help with sleep issues

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.

 *Our guide **Claiming Disability Living Allowance for children** has further information. It's available free from our freephone helpline, who can also give you other information, or to download from our website.*

Other useful contacts

> Children's Sleep Charity

Offer sleep clinics for parents to meet on a one-to-one basis with one of our sleep practitioners in some part of the country. Sleep clinics are generally bought in by other organisations to support their families, funded by grants or commissioned by local authorities.

 www.thechildrenssleepcharity.org.uk

 07912 667676

> Sleep Scotland

Helps families of children with special needs or with severe sleep problems.

 0845 603 1212

 enquiries@sleepscotland.org

 www.sleepscotland.org

> The National Autistic Society

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

Offers an interpreting service in over 200 different languages to callers using landline telephones in the UK.

 0845 070 4004

 www.nas.org.uk

> Scope: Sleep solutions

Information and advice for people affected by cerebral palsy. Their information fact sheet 'Sleep problems in children' can be downloaded from their website.

 0808 800 33 33

 response@scope.org.uk

 www.scope.org.uk

> Sense

Information for parents of children on sleep who are deaf blind.

 www.sense.org.uk

> The Early Support Sleep guide

Contains more detailed information.

 www.councilfordisabledchildren.org.uk

> Cerebra

A team of sleep practitioners covering parts of the UK who can offer help and advice on sleep issues.

 www.cerebra.org.uk

> Parenting NI

Support, education, counselling, and training for parents who are stressed and or dealing with behavioural issues.

 0808 8010 722

 www.parentingni.org

How Contact a family can help

Contact a Family is a UK charity that provides support and information to families with disabled children, whatever the condition or disability.



Our helpline

Our freephone helpline can give advice about any aspect of raising a disabled child, including help with finances, education, emotional and practical support.

 **0808 808 3555**  **helpline@cafamily.org.uk**



Guides for parents

We have guides that are free for parents on a range of topics, including:

- *Concerned about your child* (the role of the different health professionals)
- *Developmental delay* (explanation and developmental milestones)

A full list of our guides is at the link below. All our guides are free to parents who call our helpline, and are free to download.

 **www.cafamily.org.uk/publicationslist**  **0808 808 3555**

Further reading

You can buy these or you may be able to borrow them from your local library:

Sleep and Your Special Needs Child

Antonia Chitty and Victoria Dawson (Robert Hale Ltd) 2014

Teach Your Child to Sleep: Solving Sleep Problems from Newborn Through Childhood

Millpond Sleep Clinic (Hamlyn Health) 2005

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

V. Mark Durand Paul H PhD. (Brookes Publishing Co) 2013

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

Lyn Quine (Beckett Karson) 1997

contact a family
for families with disabled children

Get in contact with us

209–211 City Road, London EC1V 1JN

 020 7608 8700

 info@cafamily.org.uk

 www.cafamily.org.uk

 www.facebook.com/contactafamily

 www.twitter.com/contactafamily

 www.youtube.com/cafamily

Free helpline for parents and families:

 **0808 808 3555** (Mon–Fri, 9.30am–5pm)

 helpline@cafamily.org.uk (Access to over 200 languages)

Our free family linking service

 www.makingcontact.org



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