HELPING YOUR CHILD SLEEP



INFORMATION FOR PARENTS OF DISABLED CHILDREN

contact

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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 can help all children, but these might need to be adapted for some disabled children, such as children with learning disabilities, ADHD and autism.

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 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 strategies and approaches to help 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 29). A good bedtime routine (page 14) can help in melatonin production and help to improve sleep patterns.



MAKING 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 23, 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 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 you can.
- 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

- **Decorate the bedroom in pale shades** if possible, as these are less stimulating than bright colours.
- Try blackout linings on curtains if the bedroom is too light.
- 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 12 should be able to help.

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. This is a door in two halves, with a top part that can be left open when the bottom part is shut.
- 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 12.

"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."

Sleep practitioner

EQUIPMENT THAT MAY BE HELPFUL IS AVAILABLE FROM THESE ORGANISATIONS

Fledglings

Fledglings is Contact's not-for-profit shop helps parents search for products for individual children, including sleep wear, day and night-time wetting, equipment for bedtime like stay-on duvets. 0203 319 9772 fledglings.org.uk

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

livingmadeeasy.org.uk

Independent Living

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

independentliving.co.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 0808 169 9949 <u>eric.org.uk</u>

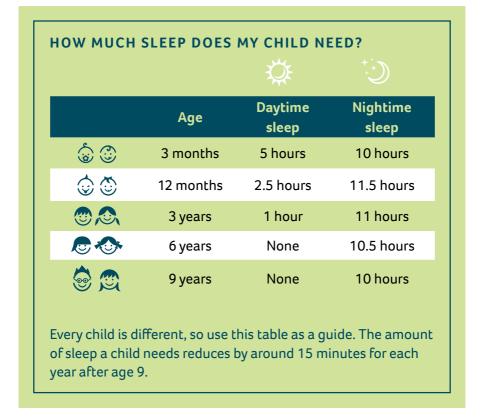


BEDTIME ROUTINE

- **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 15).
- 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 whoever puts your child to bed follows the same routine - this includes other family members or child carers
- 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 milky 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) – which you can use to help them understand bedtime and the bedtime routine
- certain objects, for example a 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 on page 15).
- 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. There is an example on page 18.

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 show which strategies you have tried and your consistency with these and other aspects of your child's behaviour
- 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 others involved in their bed time routine
- to provide evidence when applying for benefits, for example Disability Living Allowance.

	Start date:	1 1					
	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 woke up							
What did you do when they woke up							
Time of morning waking							
Tiredness/Irritability next day (on a scale of 1-5)							
Other comments							

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: tell your child what it is that you like about their behaviour, for example, "I like the way that you put your pyjamas on so quickly", and use phrases such as "well done".
- Hugs children and young people enjoy receiving hugs as rewards
- Signs such as a 'thumbs up', when you are pleased with them.
- Pictures A picture of a happy face can help your child to understand that you are pleased with their efforts.

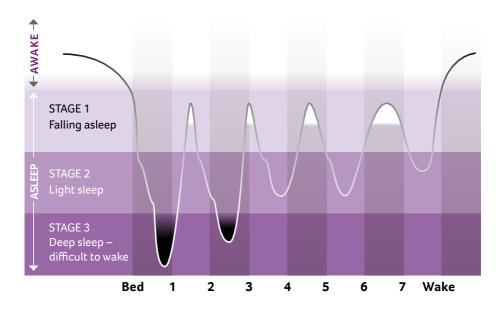
Star charts are one way of rewarding good behaviour which children often like. Make a chart showing all the days of the week, place it in the home where everyone can see it and show it to people who visit. Give your child a goal each day, and give them a star if they achieve it. At first start with simple 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 the 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 park or cinema.

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. You should:

- give your child praise at bedtime for what they are doing well.
- give consistent rewards until the behaviour is firmly established
- choose rewards that are motivating for your child
- ignore where possible negative behaviour and focus on positive behaviour.

THE SLEEP CYCLE

This diagram shows the stages of sleep. It shows an average adult eighthour 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

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

REM SLEEP

- This happens between 70 and 90 minutes after we fall asleep.
- Our eyes move underneath our eyelids (Rapid Eye Movement).
- We experience vivid dreaming.
- Our brain is very active.
- Our body is 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 don't get enough sleep, our bodies will try to make up for it by going into deep sleep, and miss out on REM sleep. This is why mood and behaviour can be affected if a child isn't getting enough sleep.

NIGHT TERRORS, SLEEP TALKING / WALKING

- These happen when moving from deep sleep to lighter sleep.
- A 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. However, 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 needs 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 wakes 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 getting up and taking 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.

WARNING!

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. Find other ways to encourage good behaviour.

Our guide to <u>Understanding your child's behaviour</u> has ideas to help with behaviour. Call our freephone helpline for a free copy on 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 member, 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. She still comes to us some nights and asks us to take her back to bed, so only needing a small amount of attention." **Parent carer**

CRYING AT BEDTIME

Sometimes children cry to get their parents' 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. However, a disabled child is likely to be crying because something is preventing them from sleeping. For example:

- 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 a 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 by injuring themselves, so it is not safe to leave them.

There are two 'techniques' commonly used to tackle problem crying at bedtime.

GRADUAL RETREAT – 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. Say your 'goodnight phrase', for example "it's sleep time". Try to avoid touching them, any 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.

RAPID RETURN

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.

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.

Remember consistency is key – keep going, it does work!

BE PATIENT AND FIRM

- It is common for a child's sleep behaviour to start to improve and then 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 fading, which is why it is a good idea to put your child to sleep in a darkened room.

AVOID SCREEN TIME BEFORE BEDTIME

The blue light that comes from computer screens, mobile phones, iPads and other devices 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?

In the UK melatonin 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 GP. In some areas there is a 'shared care' agreement so that GPs can give repeat prescriptions for melatonin. However, the consultant will always be 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 14). 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.

Helping your child sleep

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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, or call our freephone helpline who can look for you on 0808 808 3555.

SLEEP WORKSHOPS

Sleep 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. Contact runs online sleep workshops for families. In some areas you may be able to get help with a one-to-one sleep counselling service.

Our <u>Helping your child sleep workshops</u> are run by trained sleep practitioners. Please see our website for dates.

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 to <u>Getting help with social care services – England</u>, 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.

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. Our helpline can provide details of national parent support groups on 0808 808 3555.

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 to <u>Claiming Disability Living Allowance for children</u> has further information. It's available free from our helpline on **0808 808 3555**, or to download from our website.

OTHER USEFUL CONTACTS

The Sleep Charity

Offer sleep workshops or parents. Sleep workshops are generally bought in by other organisations to support their families, funded by grants or commissioned by local authorities. Helpline: 03303 530 541 thesleepcharity.org.uk

Sleep Scotland

Helps families of children with additional needs or with severe sleep problems. Access to sleep counsellors.

sleepscotland.org

The National Autistic Society

Information and strategies to help with sleep for people affected by autism spectrum disorders. 0808 800 4104 autism.org.uk

Scope: Sleep right

Sleep workshops, telephone help and home visits, where appropriate, in certain areas of the country – contact them for details. 0808 800 33 33 scope.org.uk/sleep-right

Sense

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

Early Support Information on Sleep

This guide was produced as part of the Early Support materials, and contains more detailed information on helping your child sleep and strategies to support you. Search for the title on the website below. councilfordisabledchildren.org.uk

Cerebra Sleep Advice Service

One-to-one telephone support and help with organising sleep workshops. 0800 328 1159 cerebra.org.uk

Parenting NI

Support, education, counselling, and training for parents who are stressed and or dealing with behavioural issues. 0808 8010 722 parentingni.org

FURTHER READING

You can buy these books or you may be able to borrow them from your library. Although they are older sleep practitioners recommend them. If you look online you will see more book which may be helpful:

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

GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

Ø 0808 808 3555

- Info∂contact.org.uk
- (h) www.contact.org.uk
- (c) twitter.com/contactfamilies
- (f) facebook.com/contactfamilies
- youtube.com/contactfamilies

Contact Head Office 209–211 City Road London EC1V 1JN

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

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