



Understanding Chromosome & Gene Disorders

Sleep problems

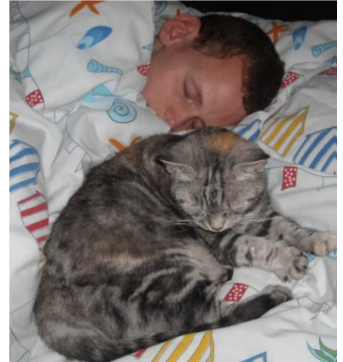


rarechromo.org

Getting enough sleep is vital for our physical, mental and emotional well-being

For parents of a child with a rare chromosome or gene disorder, one of the most challenging things is having a child that won't settle to sleep or stay asleep all night. For parents, trying to exist through lack of sleep is very difficult. You can often feel like a zombie the next day, which can make it very difficult to function, especially if you are also a working parent and you have other children. One child with a sleep problem can affect the whole family.

This guide has been written to help families find solutions to help their child to settle to sleep or stay asleep. Unfortunately, there is often no magic solution; but it is likely that there are things you can do which will make the situation a little better, even if it's not perfect. Of course, each child is different so what works for one child may not work in exactly the same way for another child, so it is worth experimenting with some of the ideas in this guide to see what might be most helpful for your child.



For children with sleep problems this can impact on the rest of the family, especially siblings, who may be sharing a bedroom with the child who has the disorder. However, some children with a rare chromosome or gene disorder sleep much better if they know someone else is in the room with them. The needs of all family members need to be balanced of course but experimenting with sleeping arrangements might be something that's helpful.

Have a bedtime routine

Everybody needs a good night's sleep. One of the most important things about settling a child with additional needs to sleep, is routine. For those with additional needs, routine is very important for all parts of their day including bedtime.

Setting up a bedtime routine would involve the same practices in the same order, every night. The routine should be calming and quiet, helping your child to transition between the daytime and night-time. So for example: a drink at a particular time, followed by a bath, teeth brushing, pyjamas, into bed, read a story, light out, kiss goodnight. The whole routine should not be too long; the routine needs to be something that your child can associate with bedtime and going to sleep; so ideally it should start half an hour or so before your child is going to fall asleep. Over time, just performing the first activity of your routine will act as a prompt that getting off to sleep is coming soon. If you have a regular routine with a definite endpoint you can re-use the endpoint (e.g. saying goodnight or a particular touch). If you need to re-settle your child during the night. This will help them to know that they are now expected to go to sleep.

Have an appropriate sleep environment

Make the bedroom a restful, pleasant and familiar place. TV and video games are distracting in the bedroom and also produce bright light which can give a signal to the brain to wake up, so if these must be in the room, unplug them. Children should be going to sleep in the same place every night. Children who fall asleep on the sofa, or anywhere that is not in their own bed, tend to have more trouble developing good sleep habits. Many of our families have found that using things like 'white noise' in the background can help their child to settle.

What is white noise?

White noise could be a fan, a radio or music CD, or something as simple as a ticking clock. When babies are in the womb, it is actually very noisy, they will be used to noise, so they might be more comforted by the whirring of a machine of some sort, rather than quiet. There are apps available to download on to your iPad, or android device for white noise sounds and relaxation music. Unfortunately for some children with a rare chromosome or gene disorder, noise is just what they don't need.

“ I remember when my son (dup15q) was very young, you couldn't use a lawnmower, vacuum cleaner, hairdryer, shaver or anything, without him screaming the place down! We didn't know at the time that he had glue ear and had frequent bouts of otitis media (middle ear infection). So it is always wise to get your child checked out for ears or other medical problems, if they are not sleeping well. ”

Sensory issues

Some children can have sensory issues and find it helpful to have particular sheets or mattresses which help with temperature regulations or weight. Darkness generally helps children to fall and stay asleep. Some children will go to sleep happily in a darkened room. If your child needs a light on during the night, try to use a low-level red coloured night light which won't be as disruptive. You may have to try lights on; lights off etc

for a while before knowing which is best for your child. Some children with rare chromosome or gene disorders sleep better in a very dark room, as often morning comes too quickly and they can be up too early, because the light coming through their bedroom window is telling them that it is time to get up. So a blackout blind or curtains with a blackout lining may help.



Think about the timing of sleep and being awake

While it is difficult to force your child to go to sleep at a particular time, you can if necessary, wake them up at the same time every day (including weekends) to help their sleep patterns become as regular as possible. If your child naps during the day try to avoid long naps too close to bedtime, since they will reduce your child's sleepiness at night-time. If your child tends to fall asleep during the day at times when you'd rather he or she did not, then try to plan stimulating activities for these vulnerable times and avoid activities which provide an opportunity for sleep (such as car journeys).

Make a difference between daytime and night-time

You might need to help teach your child that there is a difference between 'day' and 'night'. He needs to know that at night it is quiet, dark, calm and you are not in the mood for playing and interaction. In contrast, daytimes are noisier, more active and you and others are around to interact with him. How you behave, and aspects of your child's environment and what happens if he wakes during the night will help him to learn about the differences between daytime and night-time.

“ No naps! Naps are the ruin of a good nights sleep. Exercise and getting as much energy out of them as possible is what works for us. As well as 1ml of Melatonin to ease them into dreamland. ”

Monitors

A monitor can be a very useful piece of equipment. There are several monitors available to purchase, these can vary from monitors that you can listen to your child video monitors that you can listen and watch them monitors that go under mattresses to help with alerting parents to their child having a seizure.

Here are a few links to manufacturers of monitors:

■ **Vtech** baby monitors

Website: https://www.vtech.co.uk/brands/brand_view/babymonitor

■ **Embrace**

Website: <https://www.epilepsyalarms.co.uk/>

Wearable alarms and bed sensor alarms.

Exercise

Daytime exercise can make a big difference in helping children gain quality sleep at night. If your child is able to, encourage them to do some light exercise such as walking every day, or swimming.



Diet

Certain foods and drinks might be alerting and arousing and so not helpful for sleep. For example, caffeine and sugar are best avoided, especially from about 4pm. However, changing your child's eating and drinking preferences can be stressful and if they are used to having certain drinks or snacks near bedtime, suddenly switching to something different may be counter-productive. You could change to decaffeinated drinks. You could try gently phasing certain foods out over a period of days or weeks so that your child is consuming less and less sugar and caffeine overall without having anything suddenly taken away from them. For example, you could offer them one biscuit instead of two; put just half a spoonful of sugar in their tea or mix decaffeinated and caffeinated drinks together.

“ My baby (20months, 8p23.1 del) needs to have milk at 12mn, 3am and 6am. He will stay up until he gets his milk and resume sleeping after he finishes, sometimes he dozes off to sleep again while taking his milk in a bottle. ”

Behavioural Treatments

In addition to the above aspects of your child's sleep patterns/environment/behaviours which are likely to affect sleep there are many specific techniques which you can use to change your child's behaviour and help teach your child how to settle to sleep and stay asleep. These techniques involve you using various strategies to help your child to unlearn some sleep-related behaviours and/or learn some new sleep related behaviours. They are called behavioural treatments because they aim to address your child's behaviour (their sleep-related behaviour). Just because parents can use these strategies to help their children doesn't mean that parents have 'caused' the sleep problem in any way; some children, perhaps especially those with rare chromosome disorders just might need some extra help to learn how they can best get the sleep they need. There is research which suggests that these behavioural techniques are helpful for some children with rare chromosome disorders. Which particular strategy you choose will depend upon your child's particular sleep difficulties and your personal preference. You can read about the different strategies and techniques in the booklet listed below and in a very Website: <https://nassurreybranch.org/wp-content/uploads/2019/08/SLEEP-Encouraging-Good-Habits.pdf>

Practical advice about using behavioural treatments

Dr Luci Wiggs from Oxford Brookes University ran a sleep workshop for us at a Unique family event. She gave this useful practical advice using behavioural techniques for a child that constantly gets up in the night and comes out of their bedroom:

- Pick a good time to start addressing the issue; when you can stand a few nights increased disruption and you and your partner can share the load to lessen the burden.
- Warn neighbours what you are doing and say that things might be noisier for a couple of weeks (better to err on the side of caution). If you warn them, you will feel less worried about this, it really isn't something you have to apologise about, it's important for you both and your child to be getting as much of an uninterrupted night as possible, not you just creating unnecessary noise.
- Stick with your chosen strategy every night (or every time each night, if you need to use it multiple times each night). Consistency is the key to these things working.
- Sometimes these strategies work quickly, in a matter of a few days. Often they take longer. Generally, the slower you make changes to your child's current sleep behaviours, the slower you will see changes but the process might be met with less resistance and so is probably easier for you all at some level but only if you can keep being consistent and making small changes over several weeks. Try to keep a diary of your child's sleep whilst you are doing any behavioural treatments with your child. As well as writing down your child's sleep and wake times and their behaviour during the night-time period also note when your child is ill, if visitors are over or if there are any changes in the weather, temperature etc. as it is useful to notice any unusual patterns in sleep and see what they might be related to. Diaries are explained further below. A diary can also help you to see any small, gradual improvements in your child's sleep behaviour which you might not notice if you didn't write them down. Any improvement, however small, means that the strategy is working so stick with it! However, it's also worth noting that sometimes when you start a behavioural treatment your child's sleep problem might actually get worse for a few days – this too means it's working; your child has noticed you are making a change and is resisting the change! Noticing the change is the first step to improvements so stick with it!
- If you persist for a while but then abandon your strategy you are effectively teaching your child to persist with the very behaviour you are trying to change. So, if, one night you are both feeling exhausted and think it's unlikely that you have the strength to stick to the plan the best thing you can do is to forget the plan totally that night. That way, your child will learn that when you do embark on your plan you will see it through.

- If your child is able to respond to rewards, you could try giving him a reward in the morning (e.g. a star sticker or something else that your child will find rewarding). Over time you can gradually increase what he has to do to earn a reward. Of course this will only help, if a child understands the concept of rewarding good behaviour. If they do, it can be very motivating.

Sleep diaries

If you are worried about your child's sleep, keeping a sleep diary will help you to get an accurate picture of your child's sleep patterns. Sleep diaries can be helpful in identifying reasons why your child is not sleeping or has difficulties getting off to sleep. You should keep a sleep diary for two weeks in order to be able to identify any pattern emerging. You may find it helpful to share your sleep diaries with healthcare practitioners (such as your health visitor, paediatrician, sleep practitioner or clinical psychologist). A sleep diary will help them to begin to understand your child's sleep difficulties in more detail. Sleep diaries can be used to record the sleep patterns of children, young people and adults. Here are a couple of examples of a sleep diary:

Websites:

<https://library.sheffieldchildrens.nhs.uk/sleep-diary/>

<https://thesleepcharity.org.uk/information-support/children/sleep-diary-for-kids/>

<https://www.scope.org.uk/advice-and-support/keeping-sleep-diary>

Sleep Diary #it\$Bedtime

Keep track of each of your children's sleep patterns with this simple Sleep Diary. Most questions can be answered at bedtime. The rest you'll know the answer to at breakfast. Complete it each evening and morning. It will only take a minute.

Child's Name: _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Summary
What time did you start your bedtime routine?								
What time did your child go to bed?								
What time did they get to sleep?								
What time did they get up this morning?								
How many hours did they sleep?								
What activities did they do in the hour before they went to bed? (Did they read, watch TV, play with toys or video games, do homework?) Something else?								
Were they out during the night?								
Did bedtime go as planned, Yes or No								
How was their energy the next day? (On a scale of 1-5 = full of energy, 1 = no energy)								
What went well in getting them off to sleep?								
What got in the way of getting to sleep?								

Focus on what went well and try to build the things that get in the way of a good sleep.

safefood
 Practical mental health and eating disorder services for children and young people

Medication

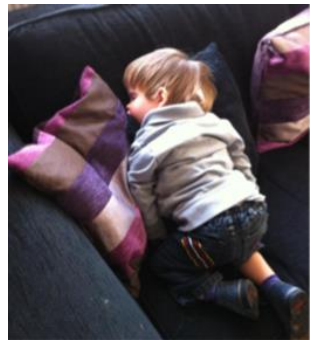
For some children with a rare chromosome or gene disorder - after everything else has been tried and failed it might be necessary to try some medication to help your child to settle. There are a variety of medications used for sleep in children. One of the most commonly prescribed to children with additional needs is Melatonin (not widely available for years, but now much more readily prescribed in the UK). Melatonin supplements are only available on prescription in the UK. For further information you should consult with your GP or Paediatrician.

What is Melatonin?

Melatonin is a hormone secreted by the pineal gland which has been shown to regulate sleep patterns in animals. There have been studies conducted which have shown that taking melatonin supplements can help to ward off jet-lag after long journeys. It is also thought that in some children, (for example those with autism spectrum disorder) their melatonin secretion patterns may be atypical. It is not that they don't produce melatonin, but that they don't produce the usual amount at the right times of day. Some foods are rich in melatonin such as oats, rice, sweetcorn, tomatoes, plums, bananas and brazil nuts, but current research is not clear whether a melatonin-rich diet could be effective in helping children to sleep. Melatonin can be helpful in settling a child to sleep, but not at keeping them asleep all night. Melatonin doesn't work for everyone. The results of a recent large study of children with various developmental disorders suggested that melatonin can be helpful in settling a child to sleep more quickly but that it doesn't increase the total amount of time that the children slept since the children tended to wake up earlier as a result of their earlier sleep onset. A different type of melatonin which is released slowly throughout the night is also available (and was not investigated in this study). This type of melatonin might be more helpful for keeping children asleep all night.

Identifying sleep issues

Sleeplessness is only one of the sleep problems you might encounter and sometimes the sleeplessness arises as a result of another sleep or medical disorder. Some children can suffer from night terrors, sleepwalking, excessive sleepiness, sleep-related breathing disorders or epilepsy, all of which can impact sleep, making night-times challenging. For some children with additional needs already taking medication for other conditions like epilepsy, this could also impact on sleep during the night and daytime. For medical advice talk to your GP or paediatrician. He/she may be able to give you some advice on what you could do to help your child to settle or stay asleep and suggest any appropriate investigations which are needed so that you can find out what is causing your child's sleep difficulty.



Night-time safety

For children that like to wander at night. Be sure to check that all of the doors to the outside of your house are locked and keys kept out of reach. Also make sure that all medications, sharps, etc. are kept in a locked cupboard and out of reach of your child. It may help to have a small bell on the door to their bedroom, so that you can hear the door opening when you are asleep.



Links

■ 10 Activities to Relax Your Child with Special Needs

Website: <https://bit.ly/2HWGyyL>

■ ADDISS

Website: www.addiss.co.uk/sleepseekersbooklet.pdf

For parents of children with ADHD (Attention Deficit Hyperactivity Disorder).

■ Autism sleeps

Website: <https://bit.ly/1gvBzVA>

A sleep tool kit.

■ British Snoring & Sleep Apnoea Association

Website: www.britishsnoring.co.uk

Telephone: 01284 717688

E-mail: info@britishsnoring.co.uk

■ Cerebra

Website: www.cerebra.org.uk

Helpline (freephone): 0800 328 1159

Email: sleep@cerebra.org.uk

Cerebra have a team of sleep practitioners who can offer help and advice on overcoming sleep problems such as anxiety at night and not being able to get to sleep, night enuresis (bedwetting), nightmares and repetitive movement disorders.

■ Cry-Sis

Website: www.cry-sis.org.uk/

Helpline: 0800 448 0737

Email: info@cry-sis.org.uk

A support and listening service for parents whose baby cries excessively.

■ Things to Try by NHS Fife

Website: <https://www.nhsfife.org/camhs-thingstotry/>

Gives practical information, tools and activities to respond helpfully to troubling behaviour and to help children and young people to flourish.

■ Special Kids Company

Website: https://specialkids.company/collections/childrens-zip-back?grid_list=grid-view

Special Kids Company: Special needs clothing and accessories for children

■ Sleep Council

Website: <https://thesleepcharity.org.uk/information-support/children/>

Raises awareness of the importance of a good night's sleep to health and wellbeing.

Provides helpful advice and tips on how to improve sleep quality.

Provides helpful advice on choosing the right bed for optimum sleeping comfort.

Sleep Council also produce a number of information leaflets and guides including the [Goodnight Guide for Children](#).

■ Sleep Action

Website: <https://sleepaction.org/>

Email: sleepsupport@sleepaction.org

Sleep Scotland is a charity which supports Scottish parents and carers of children and young people with additional support needs and sleep problems.

■ Young Minds

Website: <https://bit.ly/2DN3EoM>

Young Minds is the UK's leading charity committed to improving the emotional wellbeing and mental health of children and young people.

■ Birdhouse for Autism

Website: <https://www.birdhousehq.com/autism/>

This one is for mum and dad. A journal of your child's day – from wake-up to sleep time – to chart sleep, medications, doctor visits and therapy, meltdowns, and food intake. Have access to all your notes in one place, ideal for speaking to the professionals on your team and keeping everyone up to date and on the same page!



Books

The following books available from Amazon (www.amazon.co.uk), these are just some of the titles available ...



- Sleep better! A guide to improving sleep for children with special needs. By Durand, V. M.
- Teach Your Child to Sleep: Solving Sleep Problems from Newborn Through Childhood (Hamlyn Health) [Paperback] by the Millpond Sleep Clinic
- Healthy Sleep Habits, Happy Child: A step-by-step programme for a good night's sleep [Paperback] by Dr Marc Weissbluth
- The No-Cry Sleep Solution: Gentle Ways to Help Your Baby Sleep Through the Night: by William Sears and Elizabeth Pantley
- Solve Your Child's Sleep Problems by Richard Ferber
- Sleep Difficulties and Autism Spectrum Disorders - A Guide for Parents and Professionals by Kenneth J. Aitken

Apps for free.....

■ Headspace For Kids

Offers kiddie editions of its popular breathing and visualisation exercises. Customised for kids five and under, six-to-eight, and nine-to-12. Free (iOS) (Android) (Amazon)

■ Sleepy Sounds

Plays lullabies and soothing nature sounds on a loop, but it also displays an animated mobile to light up your kid's room. Free (iOS) (Android)

■ Sleep Meditations for Kids

if you can't decide between a story or meditation app, this could be the app for you. Yoga and Montessori teacher Christaine Kerr, founder of Calm for Kids, leads your child through a story meditation with soft music playing in the background. It's meant for kids ages 12 and below, but you may find yourself falling asleep to the app, too. Free (iOS)

■ Novel Effect

This app plays original music and sound effects to go along with select children's books. Just choose a book in the app and start reading. Its voice recognition software will pick up where you are in the story and start playing tunes. Books on the app include Where the Wild Things Are, Cat in the Hat, and Alexander and the Terrible Horrible No Good Very Bad Day. Free (iOS)

■ Kids Flashcard Maker

Make your own flashcards! Take pictures of items, add video and audio – this app puts it all together to create a one of a kind learning tool for children with special needs. Helps identify people, places and things in their direct environment plus it can be a great bit of technological fun for older children as well.



Inform Network Support



Understanding Chromosome & Gene Disorders

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Join Unique for family links, information and support.
www.rarechromo.org/join-us/

Unique is a charity without government funding, existing entirely on donations and grants. If you are able to support our work in any way, however small, please make a donation via our website at www.rarechromo.org/donate/
Please help us to help you!

While every effort is made to ensure that the information contained within this guide is accurate and up-to-date, Unique is not responsible for the reliability of any information contained herein. This information guide is provided solely as a convenience.

Unique mentions other organisations and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it.

This guide was compiled by Unique and reviewed by Dr Luci Wiggs, Oxford Brookes University, UK .

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