



**Down's Syndrome  
Association**

A Registered Charity No. 1061474

**Health Series**



## **Managing sleep issues in children**



The  
Down Syndrome  
Medical Interest  
Group

**A Down's Syndrome Association publication**

## Our resources and Information Team are here to help

Please see our website for up-to-date information: [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on

[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

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## The Down's Syndrome Medical Interest Group (DSMIG)

This resource has been produced in collaboration with the Down's Syndrome Medical Interest Group (DSMIG).

DSMIG was launched in 1996 and is a registered charity. It is a network of healthcare professionals – mainly doctors – from the UK and Republic of Ireland whose aim is to share and disseminate information about the medical aspects of Down syndrome and to promote interest in the specialist management of the syndrome.

**Many parents will tell you that their child's sleep is a big problem. Helpful advice on how to deal with these problems can be hard to find and many parents tolerate disruptions night after night in the hope that their child will eventually just grow out of it.**

**In addition to the disruptive effect such problems have on the sleep of parents and other family members, they can seriously affect the ability of both the child and parent to function properly the next day and, in the case of children, their learning may be affected and behaviour problems may also develop.**

**These sorts of effects are perhaps even more important to recognise in children with a learning disability as they may add to the child's developmental problems, or they may be misinterpreted as part of the condition or thought of as the child "just being difficult".**

**This booklet provides some basic information about children's sleep. It also outlines the most common childhood sleep problems experienced by children with Down's syndrome and describes the most effective ways of dealing with them as well as where to go for further help.**

## Typical sleep requirements in children

There is much variation between different children but, generally, as children get older, they require less sleep. In the first few weeks of life, they may sleep for around 16 hours and this gradually reduces to around 13 hours when they are 2 and reduces further as they get older. In the first few weeks of life, around half children's total time asleep will occur during the night and half during the day. Later, the proportion of daytime sleep decreases until eventually, at around 3, all their sleep is occurring during the night. By about 18 years of age, people usually sleep on average 7-8 hours a night and stay at about this level for the rest of their life.

## Sleep states

Once it was thought that sleep was a single state distinguished only from waking. However, we now know that sleep is divided into two very different states: REM (or Rapid Eye Movement) sleep and Non-REM sleep. These states can be identified by monitoring brain waves, eye movements and muscle tone.

REM sleep is a relatively active state for the brain. Your eyes make quick movements during this sleep state (hence its name) and breathing and heart rate are irregular. Brain waves become busy and resemble those recorded in someone awake and alert. Blood flow to the brain is increased. However, your muscles are effectively paralysed. It is during this sleep state that most dreaming occurs. Much of sleep is taken up with REM sleep in very early development, suggesting that this type of sleep is important in early learning and memory.

One view is that most of the restorative function of sleep occurs during Non-REM sleep. During this state, you lie quietly with a regular heart rate and breathing. Non-REM sleep consists of four stages which represent progressive levels of sleep from drowsiness to very deep sleep from which it is difficult to be woken.

## How sleep develops in children

Sleep patterns begin to develop in babies before birth. Beginnings of primitive REM (or 'active') sleep can be seen at about 6 or 7 months' gestation, and Non-REM (or 'quiet') sleep between 7 and 8 months' gestation.

In new-born babies, as in adults, the two states can be identified. During active sleep, the baby twitches, breathes irregularly and their eyes can be seen to dart about under the eyelids. Smiling also occurs. Quiet sleep has not yet divided into four stages. Some sleep is a mixture of active and quiet sleep. This is called 'indeterminate' or 'intermediate' sleep.

At around 2-3 months, a sequence of sleep stages can be identified and by 4-6 months, all sleep stages occur and a clear 24-hour sleep wake rhythm has normally started to develop.

## A typical night's sleep

By around 4-6 months of age, a child's night time sleep cycle will be pretty well developed and will resemble that of an adult.

Most of the first half of the night is spent in the deeper stages of Non-REM sleep and most of the REM sleep occurs towards the end of the night.

An important feature of the child's sleep cycle is that a number of brief wakings occur during the night. These are quite normal and everyone experiences these at any age. However, we usually wake and return to sleep so quickly that we are not aware that we woke in the first place. Problems arise when a child will not go back to sleep on their own after these wakings. More will be said about these wakings later.

## How common are sleep problems?

A wide range of sleep problems exist as described shortly. However, among the most common problems are difficulties settling children to sleep and repeated waking during the night with children demanding their parents' attention. Frequent settling problems have been reported to occur in at least 20 percent of 1 to 2 year olds in the general population and frequent night waking in about 25 percent. Figures are higher for children with learning disabilities. For those with learning disabilities other than Down's syndrome, around 80 percent of children are reported to show some type of sleep problem. Children with Down's syndrome fall somewhere in the middle with problems reported in around half.

## Why should we be concerned about sleep problems?

Research has shown that persistent sleep disturbance can cause a number of problems.

Children with very disturbed sleep are more likely to have behaviour problems than children who sleep well. Sometimes the sleep problems are part of a child's more general behaviour disturbance. As with any of us, if a child is not getting enough sleep at night, this is likely to affect them during the day causing such difficulties as irritability, overactivity, aggression, learning problems and impaired attention and concentration. As already stated, these effects are even more important if present in a child with a learning disability as they may add significantly to the level of delay already experienced and also may be misconstrued as part of the child's condition or them just being "difficult".

In addition to the detrimental effects on the child, having a child with a sleep problem is likely to have a disruptive effect on the sleep of parents and other family members. Mothers of children with a sleep problem report higher stress levels, increased irritability, poorer marital relationships and more negative attitudes towards their spouses, their child and themselves. Having a child with a learning disability can sometimes be stressful; the addition of sleep disturbance is likely to add significantly to parents' difficulties. It is essential, therefore, that help with sleep problems is provided as soon as possible. Ideally they would be prevented from happening at all.

Sleep problems can also have a detrimental effect on a child's physical wellbeing.

## Types of sleep problems

Virtually all sleep problems which occur in children in general are seen in children with Down's syndrome and children with other learning disabilities.

There are no sleep problems which are specific to children with Down's syndrome. However, as will be described later, they may be particularly prone to developing certain types of sleep disturbance.

Some sleep problems have a physical cause; others have a behavioural basis. Some are more likely to occur at certain ages, whereas others may appear during childhood and then persist throughout most of the individual's life if treatment is not provided.

It is very important to identify the sleep disorder causing a sleep problem rather than trying to treat the problem in its own right. For example, just as there are many possible reasons why someone is breathless, there are many possible causes of sleeplessness. Treatment depends on the underlying cause. The most common sleep problems experienced by children with Down's syndrome are described below. Approaches to management are described later.

## Behavioural sleep problems

Behavioural sleep problems are among the most common sleep problems in children, including those with Down's syndrome. Some of these were mentioned earlier. They include difficulty in settling the child to sleep, repeated night time waking with demands for parents' attention, early morning waking and insisting on sleeping with parents.

There are many ways in which these problems can develop, varying somewhat from child to child. In some cases, a child may have challenging behaviour and the night time problems are just another aspect of this. In other children, the presence of a physical or medical disorder (such as an ear infection or other painful condition) may disturb their sleep. More commonly, the settling and night waking problems develop as a result of children never having learnt to fall asleep without their parents being present. Therefore, when they wake up in the night, they are unable to re-settle themselves and demand their parents' attention.

It is important to say that what may be a problem in one family may not be in another. However, what may not be a problem when children are young, may become a problem when they are older and the longer a behaviour has been going on, the harder it is to change.

## Obstructive sleep apnoea (OSA)

Studies have consistently shown that children with Down's syndrome are more prone to OSA than children in the general population. This is due to various physical characteristics associated with the condition including floppy muscles in the throat, enlarged tonsils and adenoids and a smaller upper airway.

OSA occurs as a result of the upper airway at the back of the throat becoming blocked repeatedly during sleep. Each time this occurs, breathing stops for a time and the child is

then woken up by the struggle to breathe. These interruptions in breathing ('apnoeas') may occur many times during the night (or during daytime naps) causing sleep disruption and poor quality sleep. It is the frequency of these events which determines the severity and whether treatment is necessary.

Night time features include combinations of loud snoring or coughing or choking noises, restless sleep, sleeping with the head tipped back (to try to open up the airway), other unusual sleeping positions, repeatedly interrupted breathing, excessive sweating and possibly bedwetting. However, these behaviours can occur in the absence of OSA and so careful assessment is needed.

Sleep studies involving measuring oxygen levels and sometimes other physiological measures can be helpful in establishing a diagnosis and the severity of the problem. These tests can usually be organized by your paediatrician. Daytime consequences of OSA include excessive sleepiness, behaviour changes and impaired concentration and poor memory.

There is evidence to suggest that OSA is under-recognised in the general population and probably more so in individuals with Down's syndrome. About 2 percent of children in general have some degree of OSA (usually because of the relatively simple matter of enlarged tonsils and adenoids). In contrast, the figure is more like between 50 and 80 percent in children with Down's syndrome.

## **Combinations of behavioural and physical sleep problems**

Some children may have both a physical and a behavioural sleep problem and it is possible that one may perpetuate the other. Careful assessments need to be carried out to establish the nature of the problems present and treatment tailored accordingly. A multi-disciplinary approach is almost certainly needed in such cases. The physical problem should possibly be treated first and the behavioural problem tackled afterwards.

## **Other sleep disorders**

Many other types of sleep disturbance are now known to exist in both children and adults. Here is not the place to list them all; those already mentioned have been selected because of their special relevance to children with Down's syndrome. That said, however, because many of these other sleep disorders are common, they might well occur in conjunction or instead of those described above. Examples include sleepwalking or sleep terrors, head banging, night time fears, nightmares and bedwetting. Epileptic attacks can occur during sleep too. Children with Down's syndrome can be very restless sleepers and move around a lot during sleep. This may be a part of a sleep problem or may not. Some of these conditions eventually stop of their own accord but others need special treatment which can often be effective. Further details are provided in the recommended reading at the end of this resource.

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## Management of sleep problems

Before being able to manage a sleep problem, it is useful to carefully describe the symptoms by using a sleep diary kept over a week or two preferably. If help is needed from health professionals, they will find this information very useful. The type of treatment needed for a sleep problem depends on the specific nature of the problem. A sleep problem with a physical cause, for example OSA, will require a very different approach to, say, a settling or waking problem. Methods for treating behavioural sleep problems will be described first and methods for treating OSA will be outlined towards the end of the section. First, a word or two about medication.

### Medication

Medications for sleep problems are among the most commonly prescribed drugs by doctors. This is somewhat surprising as research has shown they are of limited value. There has been much recent interest in the use of melatonin in the treatment of sleep problems in children including those with developmental disabilities such as visual impairment, attention deficit hyperactivity disorder and autistic spectrum disorders. Some of this research has shown beneficial effects, however, further high quality research is needed to fully understand its effectiveness. This is especially the case in children with Down's syndrome. Sedative drugs (mainly antihistamines), either prescribed or bought over-the-counter, have been shown to have limited short-term effects and provide no lasting benefit. Also they can cause an irritable and "grizzly" state especially the next day and do not provide a child with the opportunity to learn to go to sleep at bedtime unaided and to return to sleep after waking during the night. The best current advice is that they are best reserved for very short-term use where really necessary and as a preparation for starting behavioural treatment.

### Behavioural approaches

More specific and individually designed behavioural approaches may be needed for some sleep disorders and these techniques have been shown to be particularly effective. Many of these problems are a result of parents' difficulties in setting limits and/or children never having learned to fall asleep on their own. Behavioural techniques aim to change the way parents react and deal with the problem. A brief overview of the techniques used for the individual problems of settling, night waking, early waking and sleeping with parents is given below. More information is provided in the recommended reading mentioned at the end of this resource.

### Settling to sleep

A consistent routine throughout the whole day is very helpful for children in general. Starting a bedtime routine as early on in a child's life as possible is definitely a good idea. This should be carried out at the same time every night and consist of relaxing, pleasurable things like having a bath, perhaps a warm drink, a nice story and then being tucked up in bed with a kiss before the light is turned out. It should be a winding down period, without anything exciting happening like boisterous games. If the same routine is used every night, children learn to associate it with sleep and know that sleep is coming soon and will start to unwind, relax and become ready for sleep.

It is most important to teach children to fall asleep on their own from a young age. Not doing this often leads to sleep problems later on. It is vitally important that a parent being present does not become a cue for falling asleep otherwise every time your child wakes up they will need you to fall asleep again. It is important that your child falls asleep in bed and not downstairs e.g. in front of the TV.

As was mentioned earlier, all children wake up during the night, and if things are different from when they went to sleep, they may be less likely to fall asleep again. If your child has got into the habit of not falling asleep without you being present, there are two methods for teaching him to fall asleep on his own. These are the checking method and the gradual withdrawal approach. A description of these methods is given below.

## Checking method

If, when you put your child down, he settles happily you can leave the room. If they start to cry, go in after 5 minutes (less if the crying distresses you) and gently but firmly resettle them with as little touching as possible. Leave again. If the crying persists, go back at gradually increasing intervals and use the same resettling routine. You may have to go in many times to begin with but this will get fewer each time until they eventually fall asleep rapidly on their own. By doing this, your child will learn to fall asleep on their own and will no longer require you there. Things will probably get worse before they get better, but within a few nights, your child should be falling to sleep on their own fairly quickly.

## Gradual withdrawal approach

Alternatively, you can gradually increase the distance between you and your child over successive nights (e.g. stand beside cot or bed, stand a bit away, stand in the door, stand outside the door etc.) until your presence is no longer required for him to fall asleep. This approach may take a bit longer than the checking method but it can be more acceptable to some parents as it involves less crying!

Rewards and incentives speed up the learning process!

But two vital rules are:

- At no time should a reward be taken away once it has been earned.
- There should be no bargaining about the required behaviour and no giving in.

There are some other points worth bearing in mind:

- Nightlights and comforters can be a useful cue for sleep and, for example, if a child appears to be afraid of the dark.
- Late afternoon naps should be avoided to ensure the child is actually sleepy when put to bed.
- To set an earlier bedtime, you can gradually bring the bedtime routine earlier and earlier, by say 15 minutes, over successive nights until the desired bedtime is reached.

Firmness and consistency are vital for these approaches!

## Night waking

The following should be helpful if your child wakes repeatedly at night and demands your attention.

- The first thing is to check they are okay and see if there is a reason for having woken up, for example, being cold or having a wet nappy. Obviously it is very important to know if your child has a medical condition that can disturb them at night such as an asthma attack or an epileptic seizure.
- If you are satisfied that things are alright, then settle them in exactly the same way as bedtime i.e. using the checking method or gradual withdrawal approach, so that he learns to go back to sleep in the same way.
- If your child is old enough to get out of bed, take them back every time! It only needs one time for them not to be taken back to make the situation worse and for them to learn they need to cry for just a little longer for you to give in.
- Generally speaking, leaving a child completely alone, to cry themselves to sleep, is not a good idea. Although in theory this might work after a few nights, it seems too harsh for most parents who, with support, feel happier with the other behavioural methods just described.
- For older children who come into your bedroom, hanging something noisy on your door can be useful so that you know each time they come in and you do not wake up in the morning and find them in your bed!
- Try to avoid night time drinks or giving much attention in other ways, as this can make night waking a habit.

Again, firmness and consistency are vital.

## Early waking

If your child's early waking and demanding attention or making lots of noise is a problem:

- Wherever possible, try to encourage them to go back to sleep and avoid any encouragement to stay awake i.e. avoid noisy activities.
- Reduce light and noise and other external stimuli to reduce the chance of waking early.
- Praise should be used to encourage children to stay in their own bed and entertain themselves until a reasonable hour.
- A lamp on a timer can be an additional necessary cue for when it is acceptable to disturb mum or dad. Alternatively, a clock radio playing music on a timer may be more useful in the summer when it gets light early.
- Sometimes, children just need less sleep than you might expect. In these cases, try gradually putting bedtime later so that they wake later.
- As the last phase of sleep can become displaced to a daytime nap, it is best to avoid morning naps when a child is waking too early.

## Sleeping in parents' bed

Some parents are happy to have their child in bed with them and others are not. Neither is right or wrong. However, as said earlier, it is worth remembering that what may not be a problem to you now, may become a problem in the future and the longer a behaviour has been going on, the harder it is to do something about it later on. If you have decided that you do not want your child in your own bed, leave the child in their own bed or, if they get up and come to your bed, take them back every time and resettle as at bedtime. Again, something noisy hanging from your door may be necessary to alert you. You may have to do this several times on the first few nights but eventually your child will learn to go back to sleep on their own. Be persistent.

## Summary of behavioural approaches

The most important points about behavioural techniques for settling problems, night waking, early waking and sleeping with parents are:

- Ensuring the bedroom is conducive to sleep e.g. comfortable bed, correct temperature, darkened quiet room, not too stimulating.
- Establishing a consistent evening and bedtime routine ending with your child relaxed and ready for bed.
- From an early age, teaching your child to fall asleep on their own without you being present, avoiding the reinforcement of settling and waking problems by giving in to demands for drinks, food, more stories etc.
- Rewarding good night time behaviour.
- Trying to avoid taking your child into your bed for sleep.
- Avoiding prolonged naps in the late afternoon.
- Avoiding caffeine containing drinks.
- Restricting TV/DVDs/video in the bedroom around bedtime.
- Being kind but firm and consistent!

These principles can be difficult to stick to in the middle of the night but they do work if you are persistent.

Firmness and consistency are the keys to success. If you need to give in, do so straight away but do not give up. Perhaps another technique will be more appropriate, or try again when you are feeling stronger.

There are an increasing number of sleep clinics being set up around the UK which deal with behavioural sleep problems. They are usually run by health visitors who help plan a programme based on these techniques and offer support whilst you are carrying it out. This can be very helpful and can make it easier than tackling the problem on your own.

## Management of sleep related breathing problems

Unlike the problems just described, OSA requires a medical approach to treatment as the cause is physical. Paediatricians would usually be the first port of call and in most cases

they will arrange an assessment for your child. They will refer onto an Ear, Nose and Throat (ENT) surgeon or respiratory physician for specific treatment if necessary.

As mentioned earlier, where children in the general population are concerned, the most usual cause of obstructive sleep apnoea is enlarged tonsils and adenoids and, therefore, the most effective treatment is their removal. In children with Down's syndrome, the situation is more complicated and each case needs to be investigated on an individual basis. The cause of the airway obstruction can vary from one child to another. Some children may just grow out of the problem on their own. In some cases, removal of the tonsils and adenoids may improve matters sufficiently but in others it may not. Where it proves ineffective, there are other surgical interventions which may be appropriate.

For adults in the general population, the most common and effective form of treatment for obstructive sleep apnoea syndrome is a procedure known as Continuous Positive Airway Pressure (or CPAP for short). This involves wearing a mask which is placed over the nose and mouth during sleep through which air is pumped continuously to keep the airway open therefore preventing obstruction. Individuals find that the beneficial daytime effects outweigh the inconvenience of wearing the mask. It has been used successfully in a preliminary way with children including some with Down's syndrome. However, as one might imagine, there are often problems with compliance, especially if the procedure cannot be properly explained to the child. More research is needed into effective forms of management in children with Down's syndrome.

## Recommendations

If you are concerned about your child's sleep you should contact your Health Visitor, School Nurse, GP or Paediatrician. Health professionals should be aware of which issues to look out for, in particular:

- Sleep problems should be routinely enquired about by health professionals, not only because of the immediate distress that a sleep problem can cause to the child and other family members, but also because treatment of the sleep problem might have a beneficial effect on the child's learning and behaviour.
- In the case of children with Down's syndrome, healthcare professionals should enquire about both sleep disorders of a behavioural origin and those caused by physical factors especially OSA. Combinations of the two types of sleep problems may well occur.
- The possible effects of persistent sleep problems on other members of the family should be considered carefully. Distress, depression and sometimes marital problems can result from long-standing sleep problems for which no effective help has been sought or provided.
- Community and hospital services ought to be alert to the possibility of severe sleep disorders in children with Down's syndrome. Appropriate psychological, physiological and other clinical investigations need to be available. Treatments appropriate to the individual case should be provided as early in the child's development as possible. Effective treatment is very likely to benefit the child and family as a whole.

## Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

### Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

### The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

### How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

### What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

### **Who attends the annual health check?**

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

### **How long should an annual health check be?**

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

### **What areas of health should be looked at as part of the annual health check?**

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

### **What happens after the annual health check?**

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

## **Information about health issues for GPs**

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

## **GPs learning disability register**

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

**It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.**

## Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

**If a patient with Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.**

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## Resources

For further advice on managing sleep problems in general, the following books written for parents should be useful:

Ferber, R. (2013). ***Solve Your Child's Sleep Problems***. Vermilion.

Riha, R.L. (2007). ***Sleep: Your Questions Answered***. DK publishing.

Stores, G. (2008). ***Childhood Sleep Disorders: The Facts***. Oxford University Press.

Further more detailed information may be found in the following published articles:

Hill, C.M. et al (2016). ***Prevalence and predictors of obstructive sleep apnoea in young children with Down syndrome***. *Sleep Medicine*, 27-28. 99-106.

Esbensen, A.J., Beebe, D.W., Byars, K.C. & Hoffman, E.K. (2016). ***Use of Sleep Evaluations and Treatments in Children with Down Syndrome***. *Journal of Developmental & Behavioral Pediatrics*, 37(8):629–636.

Stores, R. J. and Stores, G. (2014). ***The significance of aspects of screening for obstructive sleep apnoea in children with Down syndrome***. *Journal of Intellectual Disability Research*, 58: 381–392.

Stores, R. and Stores, G. (2004). ***Evaluation of Brief Group-Administered Instruction for Parents to Prevent or Minimize Sleep Problems in Young Children with Down Syndrome***. *Journal of Applied Research in Intellectual Disabilities*, 17: 61–70.

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Author:

Dr Rebecca Stores, University of Portsmouth School of Health Sciences and Social Work.

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The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

## Contact us

### Down's Syndrome Association

#### National Office

Langdon Down Centre,  
2a Langdon Park, Teddington,  
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

w. [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

#### Wales

t. 0333 1212 300

e. [wales@downs-syndrome.org.uk](mailto:wales@downs-syndrome.org.uk)

#### Northern Ireland

Unit 2, Marlborough House,  
348 Lisburn Road,  
Belfast BT9 6GH

t. 02890 665260

f. 02890 667674

e. [enquiriesni@downs-syndrome.org.uk](mailto:enquiriesni@downs-syndrome.org.uk)



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[www.dsworkfit.org.uk](http://www.dsworkfit.org.uk)



[www.langdondownmuseum.org.uk](http://www.langdondownmuseum.org.uk)



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