



**Down's Syndrome  
Association**

A Registered Charity No. 1061474

**Health Series**



## **Sleep issues in adults – for parents and supporters**

**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 the activities or where to start, 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).

**Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300**

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**Sleep issues are common in children with Down's syndrome. This may, in part, be due to neurological differences in the sleep centres of the brain.**

**While sleep issues in children with Down's syndrome have received a reasonable amount of attention, relatively little has been written about sleep in adults. Whilst anecdotal evidence suggests sleep issues may be common in adults, we do not yet have a clear picture of their prevalence. It is possible that sleep issues in adults often go undiagnosed.**

**Lack of, and/or poor sleep should always be considered as a potential reason behind loss of skills and changes in behaviour.**

**You should expect professionals to take your concerns seriously; poor sleep should not be overlooked as "just part of the syndrome"**

**There are currently no specific guidelines for the management of sleep disorders in adults with Down's syndrome and much of the available evidence is taken from studies carried out in the general population.**

## Sleep disturbance in adults

A small body of research and anecdotal evidence from parents and supporters suggests that sleep disturbance may be quite common in adults with Down's syndrome. We often hear about early waking, very light sleepers, difficulty falling asleep, waking during the night and falling asleep at different times during the day.

We believe all sleep issues which occur in the general population are seen in people with Down's syndrome. Some sleep problems will have a physical cause; others will have a behavioural or psychological basis. There are no sleep issues which are unique to people with Down's syndrome.

A person with Down's syndrome may not realise, or be able to tell you, they are suffering from poor or disturbed sleep. Symptoms and signs of disturbed sleep in the person for whom you care might include loud snoring, difficulty getting up, irritability, loss of skills, difficulties with attention and concentration and emotional outbursts.

## Sleep hygiene – developing a healthy routine

In addition to a propensity to disturbed sleep, some people with Down's syndrome may struggle to set their own boundaries around getting to sleep. Some sleep issues can be helped by encouraging better day-to-day sleeping routines (sometimes called sleep hygiene) and by making changes to the environment. Here are some ideas that may help the person whom you support get a better night's sleep:

- Establish and maintain a winding down routine towards the end of the day. If possible avoid challenging or upsetting tasks/activities/discussions in the evening.
- Establish and maintain a nightly routine at bedtime - some people find a photo schedule of their nightly routine helpful to keep them on track.
- A bedroom that is free of distractions (e.g. cut out any unwanted light or noise).
- Regulate bedroom temperature for comfort.
- Regular exercise and activities during the day.
- Try and avoid naps during the day.
- Avoid caffeine and other stimulants in the evening.
- Avoid exercise in the evening.

Sometimes people will need support to think about the consequences of staying up late regularly, particularly if this impacts on morning activities that they would usually enjoy.

If regular late nights are an issue for the person you support, you could do some work with them around how they feel after a good night's sleep versus how they feel after a bad night's sleep. You could turn this into an activity using visual materials (e.g. a feelings thermometer could be useful to help the person identify how they feel) and social stories. As with any learning, people with Down's syndrome need reinforcement and repetition to learn well. A learning disability nurse from the Community Learning

Disability Team (CLDT) (see information towards the end of this resource about CLDTs) may be able to help with advice and support in setting up a night time routine and behaviour support programme.

**The DSA runs a project for adults with Down's syndrome called Having a Voice. Here is what members of the Having a Voice group (South West) have to say about sleep:**

**We decided these things can help us get to sleep:**

- Drinking herbal tea
- Yoga
- Relaxing before going to bed
- Cutting out coffee
- Reading
- Having a bath to feel relaxed
- Relaxing music
- Routine
- Listening to audiobooks
- Watching a film

**We decided these things can stop us getting a good night's sleep:**

- Snoring
- Noise
- Other people disturbing you
- Eating late at night
- Pain and being ill (reflux and stomach pain)
- Drinking Coke (caffeine can keep you awake)
- Trying to sleep in a different bed or a new place
- Thinking
- Worrying
- Being too hot or too cold
- Mobile phones and iPads
- Having a dry mouth
- An uncomfortable bed

## Sleep disturbance in adults

If you think an adult has recently begun to suffer from poor sleep it is a good idea to look at whether anything has changed in their life, and whether this corresponds with the change in their sleep patterns. Has there been a change in their day to day routine, family life and/or social activities for example? Are they taking new medication and/or has the dosage of existing medication changed? If yes, might this be causing disrupted sleep? Is there anything that may be causing anxiety for the person which is affecting their sleep? Lots of people with Down's syndrome use self-talk (talk to themselves). It can be useful to listen in every so often to find out what's going on in a person's life to

try and find out if anything is worrying them. If there is an increase in self-talk and/or changes to where they are doing it and what they are saying, this may indicate that something is wrong.

At the same time, you should make an appointment with the GP to check if there are any underlying health issues that are contributing to, or causing, poor sleep. Sometimes a change in behaviour can be indicative of pain or other ailments that the person is unable to tell you about. For example, sleepiness may be an indication that a person is depressed and/or that they have an underactive thyroid (hypothyroidism). There are other health issues such as earache and the menopause that can also affect sleep. This is not a complete list of health issues that may affect sleep.

## Obstructive Sleep Apnoea (OSA)

OSA is common in people with Down's syndrome; it can occur at any age. People who suffer from OSA experience repeated interruptions in breathing during sleep. Relaxation of muscle and soft tissue in the throat leads to a partial (hypopnoea) or complete blockage (apnoea) of the airway. Apnoea is the term used when the airflow is completely blocked for 10 seconds or more and hypopnoea is the term used when there is a partial blockage resulting in airflow reduction of greater than 50% for 10 seconds or more. These interruptions in breathing may occur many times during the night (or during daytime naps) causing sleep disruption and poor quality sleep. In severe cases breathing may be interrupted every one or two minutes. It is the frequency of these events which determines the severity and whether treatment is necessary.

The raised incidence of OSA in adults with Down's syndrome may be due in part to various physical characteristics associated with the condition including floppy muscles in the throat, enlarged tonsils and adenoids and a smaller upper airway. In adults, obesity appears to be a common cause of OSA.

Signs that a person may have sleep apnoea include loud snoring, gasping noises, sleeping with the head tipped back (to try and open the airway) and other unusual sleeping positions, laboured breathing, excessive sweating, daytime sleepiness, morning fatigue (difficulty getting out of bed), excessive napping, fragmented sleep, irritability, poor concentration, behaviour changes, depression and impaired attention. Adults who show signs of sleep related breathing problems should be referred by their GP to a sleep specialist for careful investigation.

OSA can exacerbate gastroesophageal reflux disease which is a common condition in people with Down's syndrome. This is where stomach acid flows backwards in to the oesophagus. One of the most common symptoms of reflux is heartburn which is a burning sensation or a pain in the chest after eating. OSA can also put a strain on the heart and lungs and cause high blood pressure.

OSA can be detected via a sleep study performed at a sleep clinic. In some cases, sleep testing can be arranged in the home. Sensors are attached to different parts of the body to measure brain waves, blood oxygen levels, muscle tone and movement whilst the person sleeps.

There is an easy read resource 'Going for a sleep study' at the website of the 'Adult Down Syndrome Center':

<https://www.advocatehealth.com/health-services/adult-down-syndrome-center/resources/people-with-down-syndrome>

There is a list of UK sleep clinics at the website of the Sleep Apnoea Trust Association

## Management of OSA

If the person is overweight, they should be supported to try and lose some weight.

For adults in the general population, the most common form of treatment for OSA is Continuous Positive Airway Pressure (CPAP). This involves wearing a mask which is placed over the nose and mouth during sleep through which air is pumped continuously. This keeps the airway open and prevents obstruction.

A UK study of CPAP in adults with Down's syndrome and sleep apnoea demonstrated sustained and significant improvements in sleepiness, health status, behaviour and cognitive function with 12 months of CPAP use (albeit in a small number of participants) (*Hill et al, European Respiratory Journal. 2015;46 (suppl 59)*).

There is an easy read resource 'Going to get my sleep mask' at the website of the 'Adult Down Syndrome Center':

<https://www.advocatehealth.com/health-services/adult-down-syndrome-center/resources/people-with-down-syndrome>

Removal of tonsils (tonsillectomy) and/or adenoids (adenoidectomy) may be necessary. Sometimes more extensive surgery, such as repositioning of the top and bottom jaw (maxillomandibular) is required.

## Parasomnias

Parasomnias are characterised by unusual behaviours when sleeping, at the onset of sleep and when waking. They are categorised according to when they occur in the sleep pattern:

Sleep walking, night terrors and confusional arousals can happen during the deeper stages of **Non-Rapid Eye Movement (Non-REM)**. A confusional arousal is when a sleeping person appears to wake up but their behaviour is unusual or strange. The person may be disoriented, unresponsive, have slow speech or confused thinking.

Nightmares occur during **Rapid Eye Movement (REM)** sleep when dreaming occurs

Other parasomnias including head banging, head rolling, body rocking, sleep talking and teeth grinding can occur **in any sleep stage**.

We don't know how common parasomnias are in adults with Down's syndrome. Adults with parasomnias should be referred to a sleep specialist for investigation.

### Always talk to the GP about sleep issues

It is vital to talk to the GP if you are concerned about possible sleep issues in the person for whom you care because of the potential impact of inadequate sleep on their day to day life. There are many possible causes of sleeplessness and treatment depends on the underlying cause. The GP should take a thorough history of the person's health and their wider circumstances before a course of action is decided upon.

## General healthcare

### Making decisions: Mental Capacity Act (MCA) (2005) and Code of Practice

This law, which applies in England and Wales, sets out what should happen if someone is unable to make a decision for themselves. Its purpose is:

- To support individuals to make their own decisions wherever possible.#
- To protect those who cannot.

The Act is supported by a Code of Practice with specific guidance for professionals (e.g. social care, health, paid carers) who work with people who lack capacity. It is important for family carers to be aware of what the Code says.

The Act has five key principles to guide carers who have concerns over someone's capacity to make a decision:

- Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare and social care staff must always assume that a person has capacity to make a decision unless it can be established they do not.
- People must have support to help them make their own decisions. This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability. Types of support could include using a different form of communication, providing information in different formats (photographs, drawings, tapes) or having a structured programme to improve a person's capacity to make particular decisions (e.g. a healthy eating programme)
- People have the right to make decisions others might think are unwise - it does not mean they lack capacity. They may need further support to help them understand the consequences of their decision.
- It is important that any decision made on behalf of someone is made in their 'best interests' and that the person themselves and those who know them best are involved in the decision-making.
- A person making a decision on behalf of someone must always ask themselves if there is another option that would interfere less with the person's rights and freedoms.

There is information about making every day financial, health and welfare decisions post 16 years old at the 'families and carers' section of our website.

## Annual health checks

Every adult with Down's syndrome should have a comprehensive and thorough annual health check with their GP. Free annual health checks for adults with learning disabilities, with their GP, were introduced as a way to improve people's quality of life.

### Annual Health Check – Sleep

**Royal College of General Practitioners recommend that GPs should ask patients with Down's syndrome about daytime sleepiness and sleep apnoea as part of their annual health check. As appropriate, GPs should consider Epworth sleepiness score and sleep studies.**

**The quote below is taken from Syndrome specific medical health check guide – Down's syndrome (Royal College of General Practitioners, 2017)**

*'One third, if not the majority of those with Down's syndrome, have obstructive sleep apnoea (OSA), which may be due to a small jaw and upper airways combined with macroglossia, as well as blocked nose and most of all obesity. OSA can occur at any age and cause daytime sleepiness, behavioural change, loss of skills and other symptoms suggestive of depression or dementia. Complete an Epworth sleepiness score and refer for sleep studies. Weight loss if obese as well as CPAP mask overnight can dramatically improve the symptoms of OSA and the wellbeing of patients.'*

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 in 2008 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.

### 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'.

## Information about health issues for GPs

There is information on 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.

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age.

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

## 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 to ensure that services work equally well for everyone.

**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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## Health – sources of support

### GP

Your GP will be your main source of information and support. Your GP can make referrals for you to social services, other relevant health services and local support/information services.

### Community Learning Disability Teams (CLDTs)

CLDTs have been set up to serve the particular health needs of people with a learning disability and their family members, family carers and paid staff. CLDTs vary in size and make up but typically they will contain community learning disability nurses, a psychologist and a psychiatrist. You can discuss with your GP whether or not a referral to the local CLDT is appropriate. Some CLDTs take direct referrals from people with learning disabilities, their families or paid supporters thus cutting out the need to ask your GP to make a referral. You can find your local CLDT by searching online.

## How we can help

### Helpline

You can call our Helpline team Tel 0333 1212 300 or email us using [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk) if you have any questions about people with Down's syndrome and health issues.

### Training

We offer a range of training to help family members and practitioners understand and support people who have Down's syndrome throughout their lives. Please contact us at [training@downs-syndrome.org.uk](mailto:training@downs-syndrome.org.uk) to discuss your needs.

### Benefits

You can call Tel: 0333 1212 300 or email using [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk) to find out if the person for whom you care is receiving the benefits they are entitled to. If you call us, please ask to speak to a benefits adviser.

### Free membership of the DSA for adults with Down's syndrome

Adults with Down's syndrome are entitled to free membership of the DSA. Further information about membership can be found at our website in the 'support us' section.

### DSA resources

If you would prefer a hard copy of this resource, or any of the resources referred to, please call us Tel: 0333 1212 300 or email using [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

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Stuart Mills (DSA Information Officer) 2018

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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

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