



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Oral health care for 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

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.

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

Much of the information provided in this resource focusses on cleaning teeth. You may feel that this is a seemingly trivial aspect of your child's health and one that does not warrant step by step instruction.

Nevertheless, sometimes the simplest things can result in the greatest benefit. This resource is a basic guide to understanding the oral health needs of your child; this can be expanded upon by forming a good relationship with the dental team.

Establishing good dental habits, including getting your child used to the dental environment at an early age, can reduce the likelihood of dental problems in the future. There are some dental issues which occur in the general population that are more common in people with Down's syndrome. These issues, and the reasons for their being more common, are discussed towards the end of the resource.

Prevention is better than cure – oral hygiene

Tooth brushing

Dental plaque is a sticky substance full of bacteria which sticks to teeth. Plaque is not always visible as it is tooth coloured making it hard to efficiently remove. If your child has crowded teeth there are more areas which are hard to reach and hence cleaning can be more difficult.

Your child may dislike having their teeth cleaned and may initially find use of a toothbrush difficult because they have not yet developed fine motor skills. However, it is important to be persistent with this issue.

When your child's first tooth erupts get them used to having a toothbrush in their mouths. Very soft bristle toothbrushes can be purchased; gentle cleaning of these first teeth will initiate good habits and routine. Even gentle cleaning with a napkin can stimulate the gums and help baby acclimatise to tooth cleaning.

Soft bristle toothbrushes for children can be bought for their varying ages, try to stick to toothbrushes with small heads; these can make access to tricky areas easier. The following products, available commercially, can help when you are cleaning your child's teeth and/or supporting them to learn to brush their own teeth:

- Double headed brushes
- Brush handle grip
- Non flavoured toothpastes
- Finger brushes
- Finger bite guards to protect the fingers of parents brushing children's teeth.

To start with you will need to brush your child's teeth for them. Find a comfortable position for both of you, where you have a clear view of the whole mouth. You may try cradling your child, where their head is resting in your arm or get them to rest their head on your lap whilst kneeling on the floor. Don't be afraid to pull the cheek away from the mouth to gain a better view. The cheeks are very stretchy and you shouldn't hurt them by doing so. To gain further access to the back of the mouth try to get your child to close their mouth a little; this will enable you to retract the cheek much further. Alternatively stand behind your child. It can be helpful to use a mirror so that they may observe your actions.

Brushing technique

This is an example of a good brushing technique:

Step 1: Place the toothbrush beside the teeth at a 45-degree angle.

Step 2: Gently brush teeth, only a small group of teeth at a time (in a circular or elliptical motion) until the entire mouth is covered.

Step 3: Brush the outside of the teeth, the inside of the teeth, the chewing surfaces, and in between each tooth.

Step 4: Gently brush the tongue, back to front in order to remove bacteria and freshen breath.

Step 5: Repeat steps one through four at least twice daily. Aim for about two minutes per brush. Electric toothbrushes have timers which can be useful.

Initially this should all be performed by you but as your child gets older they ought to get involved. Start by allowing them to brush their own teeth while you brush yours. Your child may not have perfected the brushing technique so you can give their teeth another brush after they have had a go. All children up until 7 years of age should have an adult brushing their teeth at least once a day. Children with Down's syndrome may need an adult to brush for them even after 7 years of age.

When visiting the dentist or dental hygienist bring your child's toothbrush along so they can observe how you are doing. They will be able to demonstrate and give advice on how to alter or improve techniques.

There are also brushes available to purchase that have 2 or 3 sides of bristles and will clean a number of surfaces at once. Distractions such as music, DVD's and brushing at bath time can help.

Remember, persistence and motivating your child is key. Try to make this boring routine into a game. Reward charts can be useful, where encouragement is given if teeth are brushed twice daily.

Disclosing tablets are made of a vegetable dye that stains plaque a different colour (often blue and pink). They are chewed; the solution should be licked around the teeth then spat out, followed by one rinse. This not only highlights areas that need re cleaning but can be fun for children (if a little messy!). These can usually be obtained from your dentist, local pharmacist or supermarket

Interdental cleaning (cleaning between the teeth)

If brushing has been mastered, it is worth introducing something to clean in between the teeth. It is impossible for the toothbrush to reach all of the minute spaces between each tooth meaning that less than 50% of the tooth surfaces are being cleaned. Again this can be very difficult and fiddly on your own teeth let alone when you are trying to clean

someone else's teeth. A good option is little interdental brushes, they are similar to toothpicks but have tiny bristles that pick up plaque and food debris. They come in different sizes to fit different gaps between the teeth; your dentist can advise you about the right size and the best way to use these.

Fluoride and Diet

Despite the fact that decay is not a prominent problem for people with Down's syndrome, fluoride and diet control are still important for the dental health of your child in reducing the risk of decay, particularly if the teeth have weaker enamel (Hypomineralisation).

Toothpastes

Most toothpastes now contain fluoride (a naturally occurring mineral that strengthens tooth enamel); fluoride is an important part of preventing decay. The following table summarises what you should use for your child. Your dentist may also be able to offer advice and provide additional preventative support.

Age-specific Advice

0 - 3 years

- Breast feeding provides the best nutrition for babies
- From six months of age infants should be introduced to drinking from a cup, and from age one year feeding from a bottle should be discouraged
- Sugar should not be added to weaning foods
- Parents should carry out all tooth brushing
- Use only a smear of toothpaste containing no less than 1,000 ppm (and up to 1500ppm if advised by a dentist) fluoride
- As soon as teeth erupt in the mouth brush them twice daily and register your child with a dentist
- The frequency and amount of sugary food and drinks should be reduced and, when consumed, limited to mealtimes. Sugars should not be consumed more than four times per day
- Sugar-free medicines should be recommended

3 - 6 years

- Brush last thing at night and on one other occasion
- Brushing should be led by and supervised by an adult
- Use a pea-sized amount of toothpaste containing 1,350-1,500 ppm fluoride
- Spit out after brushing and do not rinse
- The frequency and amount of sugary food and drinks should be reduced and, when consumed, limited to mealtimes. Sugars should not be consumed more than four times per day
- Sugar-free medicines should be recommended

7 years and above

- Brush twice daily
- Brush last thing at night and on one other occasion
- Use toothpaste (1,350 to 1,500 ppm fluoride)
- Spit out after brushing and do not rinse the mouth
- The frequency and amount of sugary food and drinks should be reduced and, when consumed, limited to mealtimes. Sugars should not be consumed more than four times per day
- Use a fluoride mouth rinse daily (0.05% sodium fluoride) at a different time to brushing (you may need to monitor use of mouth rinses). Get your child to spit out the excess but not rinse, this ensures that the maximum benefit of the fluoride is utilised.

Dietary considerations

If your child is following a diet because they have a particular medical condition, talk to your GP before following the advice below.

Sugar in the diet feeds the plaque bacteria and creates acid which can cause decay. Cutting out all sugar is unrealistic; instead try to lower the amount, and more importantly, lower the frequency of sugar intake. It is frequent sugary snacks that don't give the mouth a chance to get rid of the harmful acid that causes decay. If sugary foods are kept to main meal times the damage to teeth is reduced. Alternative snacks such as carrots and celery may be an option.

If your child is taking medication which has a high-sugar content; ask your GP or pharmacist if a sugar free alternative is available.

Some parents dip dummies/pacifiers in sweet substances for their baby to suck on. This is extremely destructive to the developing teeth and should never be done. The same should be said for sweet drinks in beaker cups; the front teeth are constantly bathed in sugar resulting in rampant caries (rapid decay). If used correctly straws can be a useful way of protecting teeth from acidic and sweet drinks and can reduce the acid attack from these.

Prevention is better than cure – finding the right dentist

Your child's first appointment

It is preferable to find a dentist as soon as your child's first teeth erupt.

As previously mentioned there is no dental condition that is unique only to people with Down's syndrome. Therefore, there is no reason why a general dental practitioner should not take care of your child.

Alternatively, a paediatric dentist will have had much more contact with children in general and know how to treat and deal with them in an appropriate manner. They should also have more experience of providing dental care to children with special needs.

It can be beneficial to have an initial appointment just to get your child used to the environment of the dental waiting area and surgery. There are many strange noises, smells and people that are all new. At the back of this booklet there is a form attached, to be filled in and sent to your dentist prior to your first appointment. It has been devised to help your dentist and your child. It gives you the opportunity to provide a little background information. As a result, the dentist can make adjustments and be fully prepared for your child's individual needs. Positive first dental experiences are very important; bad experiences may lead to a phobia of dentists. Also your attitude towards dentistry will play a role in how they feel, so try and keep any negative feelings hidden from your child.

During this first appointment your dentist should gain a very thorough medical history from you about your child's present and past medical status.

Medical History

Recording of an accurate medical history and regularly updating it is very important for everyone, particularly for the population with Down's syndrome who experience a greater incidence of certain health conditions and whom may be less able to self-report health problems. When giving this it is important not to miss anything out, it is done to ensure your child's safety and although it may not seem dentally relevant, it is still very important.

As well as your child's safety, medical histories can reveal medications or conditions that will influence dental health. For example: anti-epileptic drugs, used to control seizures, can cause swollen gums (gingival hyperplasia) and dry mouth (xerostomia).

Cardiac (heart) disorders

Historically, antibiotics would have been given to individuals with heart problems prior to dental treatment to prevent a condition called infective endocarditis (inflammation of the inner tissues of the heart).

Recently guidelines have been produced by the National Institute for Clinical Excellence (NICE) which recommend that most people with heart problems do not require antibiotics prior to dental treatment.

If your dentist is unsure as to the appropriate course of action; ask your child's cardiologist for their advice in writing.

Treatment options

After an examination the dentist can note any special oro-facial (relating to the mouth and face) and dental characteristics that your child has. Any predictable or current problems can be discussed in detail. If your child has poor occlusion (the manner in which the upper and lower teeth come together when the mouth is closed), a specialist orthodontic opinion may be recommended.

Orthodontic means the correction of irregularities in the alignment of teeth. Treatment can involve extraction of teeth and the wearing of orthodontic appliances (braces) for long periods of time. Orthodontic treatment can help correct the alignment of teeth e.g.

if there is overcrowding but some children may be less able to tolerate the necessary procedures/appliances.

Your dentist will discuss the most appropriate treatment options with you and your child for any problems that can be addressed.

Dental considerations in people with Down's syndrome

Development of the Jaws

The jaws and palate (the roof of the mouth) are often small in children with Down's syndrome. The lower jaw can protrude which contributes to poor jaw alignment. The upper jaw is small in relation to the lower jaw and this may affect the way the teeth meet on biting and closure (occlusion).

The palate is often V shaped and has a high arch where food can lodge and be a cause of chronic infection. This anatomical shape can also cause problems with fitting orthodontic appliances and dentures (if required).

The abnormal position of the lower jaw, tongue and open bite encourages mouth breathing which can contribute to your child having a dry mouth. Having a dry mouth can encourage bacteria to grow and may lead to dental decay, gum inflammation (red and swollen gums), discomfort and bad breath.

Tooth eruption

The way in which your child's primary (milk teeth) and permanent teeth develop may affect the occlusion.

In most children, teeth usually erupt in a predictable sequence and time; but this can be disorderly and delayed in children with Down's syndrome. The 1st tooth in children with Down's syndrome typically erupts at 12 to 14 months but can be up to 24 months. A child with Down's syndrome may be 4 or 5 years old before all the baby teeth have erupted. Permanent front teeth and 6 year molars may not erupt until 8 - 9 years of age (Desai et al Oral Surgery Oral Medicine Oral Pathology Oral Radiology 1997; 84: 279 - 285).

Primary teeth are often retained (don't fall out), therefore delaying the eruption of permanent teeth. This can cause problems with spacing between teeth and may require the advice of a Paediatric Dental Specialist or Orthodontic Specialist. If primary teeth are retained they may wear down with time.

Teething

Some children may not have any of the typical symptoms of teething whilst others may find it more painful. Symptoms may include raised temperature, irritability, increased chewing, reddened gums, facial rash and poor sleep.

It is possible that a child with Down's syndrome may react more passively than other children and not alert you to these symptoms. You are best placed to notice any changes in your child's behaviour. Every child is different; you may have to try several

approaches to help alleviate your child's discomfort before you hit on the right one. If any symptoms are causing concern, talk to your GP or dentist.

Missing teeth (Hypodontia) and tooth development abnormalities

Missing primary and permanent teeth is a common feature in children with Down's syndrome and any teeth present are often smaller both in crown and root. They may develop an unusual shape such as a peg-shaped incisor. The most commonly missing teeth are the lateral (second) incisors. Developmentally, the teeth can show signs of what is called hypoplasia where the surface of the enamel is affected. The enamel surface may be pitted; and this encourages plaque and stain retention.

Dental Disease

Tooth decay

Tooth decay is also known as dental caries, and it is the most common dental disease. People with Down's syndrome, although not immune to caries, do have a lower incidence. One theory is that this is the result of delayed eruption of teeth – so it's not all bad! However, there may be developmental weaknesses in the teeth which can erupt with weaker enamel (hypomineralisation).

Gum disease

Periodontitis is the dental word for gum disease and it is caused by plaque bacteria. Gum disease destroys the supporting structures that hold your teeth in the mouth and can lead to tooth loss. This is a condition that is seen more often in people with Down's syndrome and is thought to be linked to the weaker immune system. Although this is a disease that mostly affects adults, children with Down's syndrome may experience rapid, destructive periodontal (gum) disease. The most common sign of gum disease is bleeding gums. The gums may appear red and puffy.

Bruxism (tooth grinding)

Some children with Down's syndrome may grind their teeth. Grinding or 'bruxing' teeth can just be habitual without any other cause. It is usually more of a night time problem than an all-day problem. It is important not to overlook that grinding can sometimes be as a result of toothache and it would be worth having a dental check up to exclude any dental causes. If this is the case, solving the dental problem may resolve the grinding.

Grinding teeth habitually over long periods of time causes tooth wear making the teeth shorter and sometimes leads to dental pain as the nerve of the tooth can become exposed. Because of the increased muscle tension, grinding can also lead to headache and jaw ache. The usual treatment for grinding (although it doesn't always work) is to fit a bite guard. This can be made of soft or hard acrylic and fits over the biting surfaces of the upper or lower teeth. This entails having an impression taken by the dentist and the bite guard is then manufactured. It then relies on the patient's ability to wear and tolerate the bite guard. Bite guards are usually worn at night but there is no reason why they couldn't be worn during the day.

Additional health issues that may impact on oral health

Children with Down's syndrome may be prone to digestive difficulties including gastro-oesophageal reflux. This occurs when food that has already passed into the stomach and beyond comes back up into the oesophagus and may be vomited up. The acid content from the stomach may contribute to tooth erosion. There is further information about gastro-oesophageal reflux in our resource about gastrointestinal issues.

Some children with Down's syndrome will require tube feeding which may reduce the production of saliva. Reduced saliva may lead to an increased build-up of plaque and tartar (a form of hardened plaque).

Some children have restless or disturbed sleep because they can't breathe properly. They may have a blocked nose, enlarged tonsils/adenoids, or a small mouth cavity. In a very small number of cases, children stop breathing (sleep apnoea) for short periods when they're sleeping. This may lead to a dry mouth and increased decay. It has been suggested that in some people sleep problems may be a cause of tooth grinding. If your child has sleep problems, seek help from your GP. There is a DSA resource about sleep issues in children.

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.

Glossary

Bruxism: tooth grinding

Crown: the enamel-covered part of a tooth above the gum

Dental Caries: tooth decay

Fluoride: a naturally occurring mineral that strengthens tooth enamel

Gingival hyperplasia: swollen gums

Hypodontia: missing teeth

Hypomineralisation: weakened enamel

Hypoplasia: where dental enamel doesn't form completely

Incisor: a chisel-edged tooth at the front of the mouth

Infective endocarditis: inflammation of the inner tissue of the heart

Interdental-cleaning: cleaning between the teeth

Lateral: second

Malocclusion: the teeth are not aligned properly

Occlusion: the manner in which the upper and lower teeth come together when the mouth is closed

Oro-facial: relating to the mouth and face

Orthodontic: the correction of irregularities in the alignment of teeth

Palate: the roof of the mouth

Periodontal Disease / Periodontitis: gum disease

Plaque: soft sticky film of bacteria

Rampant caries: rapid decay

Retained root: the embedded portion of a tooth

Tartar: tartar (a form of hardened plaque)

Xerostomia: dry mouth

Copy this page and send to your dentist before the first appointment

To (name of dentist),

My son/daughter (child's name) has his/her first appointment with you soon.

(Name) has Down's syndrome. Here are a few things you may find helpful to know:

Concerning health:.....

Concerning medication:.....

Concerning behaviour:.....

Special Interests (favourite TV programme or character):.....

Specific dislikes:.....

Concerning sensitivities such as sound, light, texture, smell:.....

I am/my child is worried about the following:.....

Many thanks

(Your name)

References

Delivering Better Oral Health: An evidence-based toolkit for prevention Department of Health/ Public Health England /British Association for the Study of Community Dentistry. 3rd edition March 2017

Delivering Better Oral Health: A quick guide to a healthy mouth in children, Public Health England, March 2017

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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.

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