

A booklet for medical professionals about supporting adults with Down's Syndrome through their Annual Health Check



Annual Health Checks for Adults with Down's Syndrome



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Background

An Annual Health Check is a targeted invitation for a yearly check-up of the health of an individual aged 16 and over with a learning disability living in Scotland which is undertaken by registered nurse or a registered medical practitioner, using the Scottish Annual Health Check (AHC) for Adults with Learning Disabilities guidelines.

The Scottish Government Health and Social Care Directorates have provided 'Directions' which provide a duty on Health Boards to provide Annual Health Checks to all people in Scotland aged 16 and over who have learning disabilities, using the Scottish Health Check for Adults with Learning Disabilities. You can access these [here](#).

NHS Education for Scotland (NES) Learning disability team have compiled resources and links on Turas relating Annual Health Checks, you can access these [here](#).

Why are Annual Health Checks important for Individuals with Down's syndrome?

Adults with Down's syndrome experience poorer health outcomes than are seen in the general population and are less likely to access healthcare therefore it is essential that practitioners are vigilant for conditions that are more common in adults with Down's syndrome.

Adults with Down's syndrome have a shorter life expectancy compared to the general population. Whilst life expectancy is increasing for people with mild learning disabilities which is approaching that of the general population, the mortality rates among adults with Down's syndrome is still 26 years younger than in the general population.

Mental illness, Dementia, chronic health conditions, and physical and sensory issues are more common in adults with Down's syndrome but they are less likely to receive regular health checks and access routine screening. Adults with Down's Syndrome have complex health needs, some of which they share with the general population and some of which are different. The interactions of physical, behavioral and mental health issues can often appear to be difficult to interpret when unfamiliar with an individual which can cause symptoms or illness to be overlooked and serious conditions present too late for prevention or treatment. This "diagnostic overshadowing" may lead to some health needs not being investigated early enough as new symptoms can often be rationalised as being part of the learning disability rather than explain new symptoms particularly with mental health issues (Mason 2004).

The introduction of annual health checks for adults with Down's syndrome is important for a number of reasons:

1. To improve their health outcomes
2. To help identify and treat medical conditions early.
3. To screen for health issues particular to adults with Down's syndrome
4. To improve access to generic health promotion for them
5. To develop relationships with GPs, practice nurses and primary care staff particularly after the comprehensive paediatric care finishes at the age of 18.

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Understanding the health needs of adults with Down's Syndrome

The following health areas should always be checked for all adults with Down's syndrome

- Monitor for any loss of **independence in living skills, behavioural changes** and/or **mental health problems**. Adults with Down's syndrome age earlier and quicker than the general population and there is a higher chance of early on set Dementia. Down Syndrome Medical Interest Group (DSMIG) has a resource on this you can view [here](#).
- **Vision** - Ophthalmic conditions such as cataracts, glaucoma, keratoconus and refractive errors need to be checked as individuals with Down's syndrome are at higher risk of Ocular defects. For this reason, a full assessment by an optician or optometrist should be carried out every 2 years. If the examination proves difficult for the individual with Down's syndrome we recommend you try using signs and visual supports to assist their understanding. There are several specialist opticians or ophthalmologist's across Scotland who specialise in working with individuals with learning disabilities. See Ability have practical support along with details of Opticians/Ophthalmologists available [here](#).
- **Visual acuity** - Even when individuals with Down's syndrome are wearing correctly fitted glasses they can still experience poor visual acuity and poor focus. In practice, this means their world lacks firm details and sharp contrasts. This is the case for everyone who has Down's syndrome. The Down's Syndrome Association (DSA) have a resource about the treatment of eye conditions in adults with Down's syndrome, you can access this [here](#). If a person's behaviour has changed, they appear confused and/or have lost skills, it is recommended that you check for any changes in vision. They may not be able to tell you that their sight has changed.
- **Audiology** - Up to 50-70% of individuals with Down's syndrome will experience impaired hearing at some point in their life. Hearing losses may be conductive, sensorineural or mixed in nature, and may be temporary or permanent. The patterns of hearing loss experienced by individuals with Down's syndrome change throughout life, with otitis media with effusion (glue ear) the most common cause in childhood, and sensorineural deafness becoming more prevalent with age. An Otoscopy examination should be carried out gently as individuals with Down's syndrome have short and narrow auditory canals. Audiological Assessment must be carried out every 2 years (including auditory thresholds, impedance testing). At all ages, individuals with Down's syndrome are predisposed to accumulation of wax which may also affect impedance testing and hearing.

- **Dental** - Individuals with Down's syndrome are at an increased risk for gum disease (periodontal disease). Even when they do not have a lot of plaque and tartar (calculus), they get periodontal disease more frequently than the general population due to having an impaired immune system which reduces some of the natural protections against the disease that individuals without Down's syndrome have.
- **Bleeding Gums** - Individuals who have sleep apnoea may be treated with CPAP (Continuous Positive Airway Pressure) which can have an impact on oral health. One side effect of this can be bleeding gums caused by having a dry mouth. CPAP wearers who breathe through their mouths at night can experience a dry mouth due to decreased saliva flow. Having a dry mouth can make it easier for oral bacteria to thrive potentially causing inflammation of the gums and contributing to gingivitis or gum disease. Regular dental check-ups and good oral hygiene are crucial for maintaining oral health while using a CPAP machine.
- **Heart** - Individuals with Down's syndrome have an increased risk of cardiac conditions. These are largely congenital but there is also an increased risk of acquired cardiovascular disease, partly due to other conditions associated with having Down's syndrome. DSMIG has produced guidelines to ensure that cardiac conditions can be diagnosed and treated promptly - you can view these [here](#).
- **Gut health - Coeliac disease** occurs more commonly in individuals with Down's syndrome with various studies reporting prevalence rates of 1-19% depending on age of sample and country of origin. Presentation is similar to that in the general population i.e. recurrent abdominal pain, reflux and vomiting, variable bowel habit (constipation or diarrhoea), flatulence, faltering growth and irritability. Screening for Coeliac disease should be carried out annually as clinical diagnosis may be difficult or delayed as associated symptoms are common in individuals with Down's syndrome and may be overlooked. It is important also to note that while symptoms may present typically the individual may not be able to recognise the level of pain or communicate discomfort, therefore it is important to have a low threshold of clinical suspicion and a heightened awareness of symptoms. Testing should be carried out in individuals with suspicious symptoms or signs, including disordered bowel function tending to diarrhoea or to new onset constipation, abdominal distension, general unhappiness and misery and for all individuals with existing thyroid disease, diabetes or anaemia.
- **Gut health - Gastroesophageal Reflux Disease (GERD)** where stomach acid flows backwards into the oesophagus is more common in individuals with Down's syndrome



of all ages although it often goes undiagnosed. GERD is common in individuals with Down's syndrome for several reasons; firstly the tone of the Lower Esophageal Sphincter (LES) between the esophagus and the stomach is lower in people with Down's syndrome; secondly risk factors for GERD such as Obesity and Sleep Apnoea are also more common in individuals with Down's syndrome. However, it isn't always possible to identify a cause. One of the most common symptoms of GERD is heartburn after eating. Other symptoms and signs include regurgitation of food, abdominal pain, hoarseness, cough, sore throat, aspiration, irritability, aggression, asthma, loss of enamel on the teeth and difficulty swallowing. Another issue for GERD in individuals with Down's syndrome is the issue of underreporting mild symptoms. It is not uncommon for individuals with Down's syndrome to be experiencing but not report heartburn. The chronic inflammation related to persistent heartburn can cause scarring and then narrowing of the esophagus. In this situation, the first symptoms may be vomiting after eating, weight loss, or difficulty swallowing. The narrowed esophagus does not allow food to pass appropriately into the stomach. Another important issue regarding not reporting the symptoms may be that the symptoms present in some other manner. Since GERD occurs more frequently when lying down for sleep, the discomfort of GERD may present as sleep disturbance. Whether related to poor sleep or the discomfort, a behavioural change may be the presenting symptom and the real cause is overlooked.

In addition to uncomfortable symptoms, GERD can lead to more serious conditions if left untreated, including Barrett's esophagitis (when there are changes in the lining of the esophagus that increase the risk of cancer) and scarring or narrowing of the esophagus that can lead to difficulties with food or liquid passing into the stomach.

Other concerning symptoms that may indicate GERD include weight loss, recurrent vomiting, difficulty or pain with swallowing, evidence of bleeding in the gastrointestinal tract and persistent symptoms despite treatment. If any of there is any evidence of these symptoms or an individual is having consistent restless sleep, or sitting upright at night it is always recommended that reflux is investigated.

- **Endocrine System** – There is an increased prevalence of hypothyroidism at all ages for individuals with Down's syndrome, rising with age with a small increase in hyperthyroidism. Thyroid Function blood tests (TFTs), including thyroid antibodies at least every 2 years and TFTs should be performed more often if there is evidence of accelerated weight gain, an individual is generally unwell, irritable or overly tired and if there is a possibility of depression or dementia. Type I diabetes is also relatively more common in adults with Down's syndrome (2%) and should also be checked for.
- **Immunisation** – Due to congenital heart disease and reduced immunity most adults are eligible for Influenza and Pneumococcal vaccinations.

- **Musculoskeletal Atlanto Axial Instability** - Atlantoaxial instability (AAI) also referred to as a Cervical Spine Instability (CSI) affects 10–20% of individuals with Down's syndrome. The condition is mostly asymptomatic and diagnosed on radiography by an enlarged anterior atlanto-odontoid distance. Symptomatic AAI, which affects 1–2% of individuals with Down's syndrome, manifests with spinal cord compression. It can present as acute or chronic cord compression, neck pain, reduced range of neck movement, torticollis, unsteadiness, deterioration in bladder/ bowel control as well as psychiatric/psychological. Routine Cervical -spine X-ray not recommended.
- **Alzheimer's Dementia** - (clinical onset is uncommon before 40 years) – It is recommended that if an individual with Down's syndrome is suspected to have or has been diagnosed with Alzheimer's disease that depression, hypothyroidism, UTI and deafness are excluded first as symptoms can be similar. Symptoms of dementia can include decline in cognitive function, memory loss, ataxia, seizures or urinary and/or faecal incontinence. Psychological conditions often present as deterioration in self-help skills or behaviour change. Depression is common in older adults, often as a result of bereavement and/or changes in living situation. We have information and resources available on our website relating to Dementia (these can be viewed [here](#)) and our Family Support Team can provide further guidance and support.
- **Respiratory** – For individuals with Down's syndrome, obstructive sleep apnoea (OSA) is a complex disorder with significant clinical consequences. OSA is seen frequently in individuals with Down's syndrome, and when present, it tends to be more severe. This increased prevalence is likely related to common anatomic abnormalities, including lower muscle tone and reduced airway size, and a greater risk of additional comorbidities such as obesity. Because signs and symptoms do not often correlate with respiratory disease, adults with Down's syndrome, should receive routine screening for OSA. Similar to the general population, polysomnography remains the gold standard for diagnosis. Check for blocked nasal passages, lower airway disease and lung function.
- **Menopause** - Check for hot flushes and menopausal symptoms in women over 40 as they have an earlier onset of menopause compared to women in the general population. Women with Down's syndrome with an early onset of menopause may also develop dementia at an early age. Women with Down's syndrome reach the menopause approximately 6 years earlier than the general population and are more susceptible to osteoporosis particularly if they are inactive.



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- **Sexual Health** - People with Down's syndrome need the same awareness and checks with regards to their sexual health as the general population. This will include information on contraception, smear tests, breast examination and testicular examinations.
 - **Blood Dyscrasias** - Individuals with Down's syndrome frequently show abnormalities in their blood cells which include the red cells, white cells and platelets. Some of the changes found in the blood cells of individuals with Down's syndrome can be associated with other medical complications seen among this patient population; many times, however, the same blood cell abnormalities are diagnosed without an apparent cause. In many instances the abnormalities resolve spontaneously after a period of time; this is especially common among newborn babies with Down's syndrome. Some patients will have persistent changes in the blood cells throughout their life. Sometimes the abnormalities seen in the blood cells in patients with Down's syndrome can lead to serious medical conditions; evaluation and treatment by a haematologist/oncologist may be necessary.
 - **Dermatology** - A variety of dermatological conditions are more common in individuals with Down's syndrome due to a combination of immune and genetic dysregulation and an inefficient physiological process. A variety of bacterial infections, fungi, or ectoparasite infestations are more common in people with Down's syndrome. Cutaneous bacterial infections (eg, angular cheilitis, folliculitis, furuncles, abscesses, secondary impetigo) are common with or without atopic dermatitis.
 - **Obesity and weight changes** - Individuals with Down syndrome have a higher likelihood of being obese than their typically developing peers. Sometimes it is the result of hypothyroidism which will result in symptoms, such as increased sleepiness, confusion, or mood changes. Individuals with Down's syndrome often have a Lower Resting Basal Metabolic Rate as having an extra 21 chromosome also causes an extra copy of a gene called CBS which affects metabolism. This coupled with hypotonia which causes poor gross motor movement are two of the main contributing factors that cause weight gain as individuals with Down syndrome use less energy when they are resting or sleeping than their typical peers do and therefore gain weight easily by consuming more calories than their bodies use. Strategies for treating and preventing obesity involve, eating smaller portion sizes, using healthy ingredients that increase bulk (like fiber, fruits, and vegetables), increasing water intake, eating fewer snacks between meals, empowering adults to monitor their own weight, preparing meals at home, not using food as a reward and introducing a daily exercise routine that is appropriate to the person's interests and skills. We have information and resources tailored to help adults with Down's syndrome maintain a healthy weight - these can be found on our website [here](#).

Supporting the communication needs of adults with Down's syndrome

Individuals with Down's syndrome can experience specific difficulties with using and processing spoken language. Poor auditory processing in conjunction with challenges in converting information to the long-term memory can lead to a lack of understanding, not knowing the vocabulary needed and difficulties with language structure. However, Individuals with Down's syndrome can often understand far more than they can communicate so the objective is to effectively support their communication needs so they can be fully included and understood.

The majority of adults with Down syndrome use speech to communicate. The most common communication challenges they experience are with other people not understanding their speech (speech intelligibility) they can also have difficulty with long conversations and complicated language. They may struggle to tell you full details about something that has happened to them or when retelling a story and may also struggle to ask for specific clarification when they don't understand something.

To effectively support communication with an individual with Down's syndrome it is best to start with finding out how they prefer to communicate and introduce aids or signing as required. Always speak/communicate directly with them first, be face to face and gain eye contact to support them to see and hear what you are saying. It is important to use short simple sentences, supported with visuals whenever possible, check their understanding regularly and give them time to answer. Using augmentative forms of communication such as signs and pictures is an effective way to support communication and understanding.

It is especially important to be encouraging and sensitive to their feelings as this supports their confidence and motivation with communicating. If you are uncertain about something they have said you can support this with using visuals/signs or clarify with their parent/carer if needed.

Preparing adults with Down's syndrome for their Annual Health Check

Preparation is key to carrying out a successful Annual Health Check. Adults with Down's syndrome often need more time to process and prepare for new experiences to avoid stress and anxiety. Below are some suggestions on how best to prepare the person for their Annual Health Check.

Invitation or pre check questionnaire

We have developed an easy read invitation questionnaire you can send prior to the appointment. This can be used to help prepare individuals for their Annual Health Check, give them a pictorial view of what will happen and allow prior discussion of any concerns or symptoms that may arise. It will also be a useful communication tool during the Annual Health Check for both the health professional and the adult who has Down's syndrome.

Easy Read Annual Health Check booklet

We have developed this resource to assist people with Downs' syndrome to understand their Annual Health Check and the processes throughout.

Make time to go over the questionnaire

Ensure that you allow time in the appointment to go over the answers to the questionnaire. Give the adult with Down's syndrome the opportunity to explain any issues in their own words and fill in any gaps that there might be. You may need to consider using visual aids to support them to communicate this.

Arrange blood tests or any other tests required prior to appointment

Where possible, arrange blood tests or any other tests that might be needed before the appointment. Getting blood taken can be stressful for some adults with Down's syndrome so having this done at the appointment might cause additional stress and make it harder to perform all the other parts of the health check.



Parent or Supporter attending

If the adult who has Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the Annual Health Check as well. If the parent/carer has legal welfare guardianship they can attend with the individual.

Our Family Support Team are here to support you

Our Family Support Officers based regionally across Scotland can provide information, resources and support to those attending their Annual Health Checks which includes attending with them where possible. They can also support you with more information if required, you can contact them on **0300 030 2121** or by emailing familysupportservice@dsscotland.org.uk.

After the Annual Health Check

At the end of the Annual Health Check appointment there are a few actions you can take to ensure that the adult with Down's syndrome is supported and receives the appropriate care for any issues discovered and understands the steps that can be taken to make them healthier.

Creating a Health Action Plan

We have included a sample Health Action Plan that can be completed during the health check appointment and taken away by the adult with Down's syndrome and their parent/carer. Having some written notes from the appointment will help the individual and those attending the appointment with them remember the key points that were discussed and any actions that need to be taken.

Involving adults with Down's syndrome in their health decisions

It is important to involve the adult with Down's syndrome in the making of this plan so that they are included in the decisions made and that they feel a sense of ownership of the plan. It is important to take time to explain the decisions that need to be made and outline the steps that will be taken using additional visual support aids if needed to support understanding and participation.

Follow up appointments

If there is the need for any follow up appointments ensure that you explain these and follow the same procedure as you did making the Health Check appointment e.g. if you confirmed the appointment with a letter or phone call do the same with any follow up appointments as well.

Scheduling the next Annual Health Check

Ensure that the adult with Down's syndrome or the person attending the appointment with them know the process for booking their next Annual Health Check.

Your Health Check Action Plan

Name			
Doctor			
Nurse			
Health practitioner			
Date			
Any medication changes			
My health need	What needs to be done?	Who will help?	When will this need to be reviewed?

Further information and useful links

- We have resources that focus on particular health concerns including Pain responses, Depression and Dementia - these can be found [here](#).
- The Down Syndrome Medical Interest Group (DSMIG) is a network of healthcare professionals from the UK, Republic of Ireland and further afield who work to promote equitable provision of medical care for all people with Down syndrome in the UK and Ireland by disseminating a wide range of information about the medical aspects of the syndrome and promoting interest in its specialist management. They are the only organisation to provide this type of medical-specific service in the UK. You can find out more about DSMIG and access resources on Down's syndrome specific health topics [here](#).
- Down's Syndrome Association (DSA) have resources and articles on a number of different health concerns including visual acuity and gastrointestinal issues- you can view these [here](#).
- See Ability have resources about eye care for people with learning disabilities - you can view these [here](#).

This book is designed to help you support an adult with Down's syndrome with their Annual Health Check.

Down's Syndrome Scotland provides information, support and training to families, carers and professionals who care for people with Down's syndrome.

If you would like to access further support please call us on 0300 030 2121.

For further information visit:

www.dsscotland.org.uk





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