

# Down's syndrome resources for health and social care

1 November 2023

## Who we are

The Down's Syndrome Association (DSA) is the leading charity supporting individuals who have Down's syndrome across England, Wales, and Northern Ireland.

We have been registered as a charity for more than 50 years and have a long-standing history of providing information, advocacy, training, and support to people who have Down's syndrome of all ages, their families and the professionals who work with them.

We have expertise to share in areas of health, education, employment, and social care and work extensively with professionals who provide direct services and researchers in the field of learning disability, both here in the UK and internationally.



The DSA regularly engages with The Department of Health and Social Care, Department for Education, NHS, NICE and other Government departments, and public bodies on responding to policy initiatives that should improve service provision for people who have a learning disability. We submit responses to public consultations and engage pro-actively on key policy issues which affect people who have Down's syndrome.

We include the voices of people who have Down's syndrome within all of our activities, aided by the Our Voice network. As well as guiding the work of the DSA, Our Voice members provide services for other organisations.

Our support frequently begins prenatally and extends to support through all life stages encompassing early development and education, transition into adult life and additional support on ageing and end of life, when needed.

If you have any questions, you can call our Helpline (tel: 0333 1212 300) or email using: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

## Health and people who have Down's syndrome

It has long been recognised that people who have Down's syndrome experience poorer health outcomes than are seen in the general population. Children and adults who have Down's syndrome face significant barriers regarding their health support including a lack of understanding among health professionals about Down's syndrome and the more common health conditions in this group of people.

We believe it is crucial that all health practitioners working with people who have Down's syndrome understand the common health issues they experience as well as how they might struggle to communicate their symptoms, location of pain and feelings about their health condition.

To support you as a health or social care professional, we have put together this resource that brings together all of DSA's health-related resources along with relevant resources that have been produced by the UK and Ireland Down Syndrome Medical Interest Group (DSMIG) and other organisations.

DSMIG are happy to receive enquiries from health professionals on clinical issues relating to Down's syndrome – [dsmig.org.uk](http://dsmig.org.uk)



## Alex's story

### A case study of a multi-disciplinary approach to a health crisis that had a positive outcome

My name is Alex and I have Down's syndrome. I live in a supported living house in Devon with my friends who have other learning disabilities.



A few years ago, I was rushed into hospital because I had a very high temperature, and I was finding it hard to breathe. I went in an ambulance with a flashing light because I was so ill and everyone was worried about me. I was very frightened. The ambulance people were very nice, and they told me not to worry and that I would be OK.

By the time I got to hospital, I was so ill, I couldn't speak properly. Mum and Dad were told it was very serious. The doctors told me the infection was in my heart and lungs and I would have to have an operation to fix it. They said it was spreading fast through my body, but they had strong medicine that would kill it. They told me that I would have to go to another hospital to have my heart fixed but they had to wait until the infection got a bit better before I could travel in the ambulance.

I went in another ambulance to Plymouth. I was feeling so poorly and very frightened. I thought I was going to die, and I kept saying that to the doctors. My brother was allowed to stay with me the night before my operation and the doctor who mended my heart came to see me to tell me not to worry because he was going to fix my heart. He told me I was strong and that I could fight the infection. In the morning my Dad was allowed to go with me into the room where they put me to sleep.

I had to have two heart operations because the infection was so bad, but I am much better now. I was in hospital for 13 weeks and on a breathing machine for a lot of days because I was so poorly. Everybody on the CICU ward clapped when I came round from the breathing machine, and they gave me a Harry Potter wand because I had been listening to the stories all the time to keep strong. I couldn't speak or move my arms and legs for a while but I am back to normal now and I hope I can go back to my job with the police soon.

I know I would have died without the doctors and nurses who helped me to understand what was happening to me.

**I am so glad that everyone who looked after me understood about infections in Down's syndrome and how quickly they can get very serious.**

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# Health Resources General

## DSMIG Personal Child Health Record (PCHR) Insert

Growth and development are different in children who have Down's syndrome, so a separate insert is recommended to ensure that issues are identified more easily. The insert contains health information, a schedule of health checks covering birth to 18 years, information about development and growth/weight charts. The insert is available here:

[Personal Child Health Record \(PCHR\) – DSMIG](#)

[You and your baby - Down's Syndrome Association \(downs-syndrome.org.uk\)](#)

## Care pathways

Examples of Down's syndrome specific care pathways are available here:

[Service Provision and Commissioning – DSMIG](#)

## Developmental Journal for Babies and Children who have Down's Syndrome

This Developmental Journal for Babies and Children who have Down's syndrome is a set of charts that families use to record what their child is able to do as time passes and they learn new things. It has been written to help parents and the professionals who work with them and is a tool to help families track and understand development in their child. It is available here:

[Downs Syndrome Development Journal - Early Support \(councilfordisabledchildren.org.uk\)](#)

## Paediatric service specification

A draft service specification, developed by DSMIG and the Royal College of Paediatrics and Child Health, is available here:

[Service Provision and Commissioning – DSMIG](#)

## Triage and treatment

Children who have Down's syndrome may have some physiological and behavioural differences that make it difficult to assess how sick they actually are.

Tips for Triaging and Treating Children is available here:

[Infections and Immunisations – Down's Syndrome Association \(downs-syndrome.org.uk\)](#)

## GP Annual Health Checks and health screening

Young people (14+ years) and adults who have Down's syndrome are entitled to a free Annual Health Check with the GP.

People who have Down's syndrome should be offered the chance to take part in all national health screening programmes (including cervical and breast screening).

## Resources:

*Annual Health Check*

*Annual Health Checks for Teenagers And Adults – Checklist For GPs*

*The Importance of Health Screening*

**The resources listed above may be found here**

[Health and Wellbeing – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Blood tests

Some children and adults who have Down’s syndrome will struggle with blood tests and will require additional preparation, support, and reasonable adjustments.

### Resources:

*Having a Blood Test*

The resource listed above is available here:

[Thyroid - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Easy Read

DSA has produced the following accessible health-related resources to support the good health and well-being of people who have Down’s syndrome:

- Staying Healthy
- Going To The Chemist
- Going To The Doctor
- Thyroid
- Knowing About Neck Problems
- Emotional Well-being
- Healthy Eating
- Reasonable Adjustment Digital Flag and Consent Form
- Supporting Me to Make a Decision – Quick Guide
- Making Choices
- Coronavirus Vaccine
- Staying Well and Healthy
- Coronavirus: What is it? How to Stay Safe
- The New Normal
- Staying Safe
- Social Distancing
- Return to Work

The resources listed above may be found here:

[Easy read information – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Pain

Pain is often poorly assessed in people with a learning disability ([LeDeR](#)). People who have Down's syndrome may have difficulties telling you about their pain/illness and where it hurts. Pain may not be understood, or communicated as pain, but as another feeling such as discomfort or worry. There is some evidence to suggest people who have Down's syndrome may be more sensitive to pain but that it takes a while for people to express (in whatever way) how they are feeling. Those around the person may have to look for non-verbal clues that indicate they are unwell or feeling uncomfortable (for example: changes in mood, routine, appetite, and behaviour). If a person is feeling unwell or in pain, but they find it hard to express this, they might feel upset, anxious or have low moods.

The DisDAT tool (or Paediatric Pain Profile in children) can help to identify non-verbal signs of pain.

### Resources:

<https://www.stoswaldsuk.org/how-we-help/we-educate/education/resources/distress-and-discomfort-assessment-tool-disdat/>

<https://ppprofile.org.uk/>

## Frailty

The Rockwood Clinical Frailty scale, used to identify frail patients, is NOT appropriate for use in patients who have Down's syndrome or other causes of learning disability, as it does not take into account pre-existing conditions or disabilities.

## Reasonable Adjustment Flag

Consideration must be given to reasonable adjustments that might be needed by a person who has Down's syndrome when accessing healthcare. Each person's needs will be different.

The Reasonable Adjustment Flag is a national record that shows a person needs accommodations and may include details about their impairments and necessary adjustments. There is further information about the Reasonable Adjustment Flag here:

[Reasonable Adjustment Flag - NHS Digital](#)

The Our Voice Network helped to produce an easy read resource about the Reasonable Adjustment Flag along with an accompanying consent form. This is available here:

[downs-syndrome.org.uk/easy-read-information/](https://downs-syndrome.org.uk/easy-read-information/)

## Mental capacity

Health professionals must be mindful of the importance of following the Mental Capacity Act (MCA) Code of Practice around capacity, supported decision making and best interests decision making with their patients who have Down's syndrome.



These elements of the MCA often appear overlooked:

- People who have Down's syndrome are not always provided with support and information to make decisions – the MCA allows for people to be supported to make decisions.
- If the person does not have capacity now, can work be done by social care staff over time in the provision of information and support to enable them to make that decision in the future?

Where capacity is in doubt or lacking, proper procedures should be adhered to in order to avoid individuals being left to make highly detrimental choices that effect their overall health and wellbeing over the long term

**Resources:**

*Supporting Me to Make a Decision – Quick Guide*

The resource listed above may be found here:

[Easy read information - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

*Who Decides – Decision Making From 16 (video)*

*Making Decision Post 16*

*Decision Making And Lasting Power of Attorney*

*Mental Capacity Act FAQs*

The resources listed above may be found here:

[Children, Families & Education – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

*Making Choices*

The resource listed above may be found here:

[Easy read information – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)



# Down's Syndrome - Health Condition/Issue Specific Information and Resources

## Infection including respiratory & immunisation

People who have Down's syndrome differ from the general population in their response to infection. They may be more susceptible to some serious infections especially respiratory and when they do get infections may have more problems fighting them. Infections therefore may be more frequent, prolonged, and are more likely to need medical attention, including hospital admission.

Children with serious infections may present atypically. They may not 'appear' to be unwell, so checking with their parents/carers about what is usual for them is important.

The insert for the Personal Child Health Record (PCHR) contains information about infection. The PCHR insert is available [here](#)

### [You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

As part of the GP Annual Health Check for teenagers and adults the nose, oral cavity and lungs should be examined. Patients should be checked for:

- Blocked nasal passages
- Lower airway disease

GPs should ask the patient about sleep apnoea which may be due to a hypoplastic pharynx or nasal congestion.

#### Resources:

*Preventing Infection in Children*

*Respiratory Infections*

*Tips for Triaging and Treating Children*

The resources listed above may be found here:

### [Infections and Immunisations – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

*Nasal Congestion/Catarrh*

The resource listed above may be found here:

### [Ears, Nose, Throat and Teeth – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)



## Immunisation

Children who have's Down syndrome may be particularly susceptible to infections and it is very important they are offered the recommended universal immunisations as well as, the Flu vaccine every year from the age of 6 months and the Pneumovax II at the age of 2 years.

The insert for the Personal Child Health Record (PCHR) contains information about immunisation. The PCHR insert is available here:

[You and your baby - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

Immunisations should be checked at the GP Annual Health Check for teenagers and adults. Due to congenital heart disease and reduced immunity most teenagers and adults are eligible for Influenza and Pneumococcal vaccination. All teenagers (12 plus years) and adults should be offered COVID vaccination.

### Resources:

*Immunisation*

The resource listed above may be found here:

[Infections and Immunisations – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Leukaemia

Both Acute Myeloid and Acute Lymphoid Leukaemia occur in children who have Down's syndrome more commonly than in the general population and have roughly equal incidence.

In addition, some babies who have Down's syndrome are born with a unique pre-leukaemic condition called 'Transient Leukaemia of Down syndrome' (TL-DS). This condition, which is also sometimes called "TAM", can develop into Acute Myeloid Leukaemia in early childhood. It is similar to Leukaemia but is a temporary condition that usually resolves without any treatment as the baby gets older.

Children who have Down's syndrome should have their blood count and blood film checked within the first three days of birth, to identify any serious blood disorders. An abnormal blood count/film may indicate the presence of TL-DS.

The insert for the Personal Child Health Record (PCHR) contains a schedule for blood checks. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

In addition, all new-borns who have Down's syndrome should be examined for signs of TL-DS, which include organ enlargement, liver dysfunction and skin rashes

### Resources:

*Leukaemia*

The resource listed above may be found here:

[Leukaemia – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Cardiovascular

About half of all children who have Down's syndrome are born with a heart condition. All children must have a thorough heart examination, including an echocardiogram, by six weeks of age to enable prompt treatment.

The insert for the Personal Child Health Record (PCHR) contains a schedule for heart checks. The PCHR insert is available here:

[You and your baby - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

A cardiovascular examination should be carried as part of the GP Annual Health Check for adults and teenagers as follows:

- Auscultation – particularly if imminent dental procedure
- A single ECHO should be performed in adult life.
- Adults with a pre-existing structural abnormality should be informed of current prophylactic antibiotic protocols.
- Blood pressure and heart rate

### Resources:

*Cardiac disease in Down Syndrome: literature review and international expert consensus in collaboration with Down Syndrome International (DSI)*

*Cardiac Conditions*

The resources listed above may be found here:

[The Heart – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Hearing and vision

### Hearing

Temporary or long-term hearing loss will affect many people who have Down's syndrome at some point in their lives. Well over 50% of people who have Down's syndrome have significant hearing impairment, which can range from mild to profound. Sensorineural and/ or conductive loss may be present at any age. If undetected it is likely to be a significant cause of preventable secondary disability. The main cause of conductive loss is persistent OME, glue ear.

The insert for the Personal Child Health Record (PCHR) contains a schedule of hearing checks from birth to school age. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

Research highlights the need for audiology and speech and language therapy services to work together as soon as a child is diagnosed with severe, ongoing hearing difficulties (further information is available at the link below).

A audiology assessment should also be carried out at transition from child to adult services and every two years thereafter.

### **Resources:**

*Hearing (Children & Adults)*

*Supporting Adults to Have Hearing Tests – Tips for GPs*

*Supporting Adults to Have Hearing Tests – Tips for Carers*

*Hearing, Learning and Down's Syndrome - Summary of research into early hearing loss and language abilities in children.*

*Nasal Congestion/Catarrh*

The resources listed above may be found here:

[Ears, Nose, Throat and Teeth – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

## **Vision**

People who have Down's syndrome are more likely to have difficulties with their eyesight – up to half will need to wear glasses. It is vital that children, young people, and adults have regular eye checks to minimise the effects of any sight difficulty they have.

Even when people are wearing correctly fitted glasses, they will still have poor visual acuity. In practice this means their world lacks firm details and sharp contrasts. This is the case for everyone who has Down's syndrome.

The insert for the Personal Child Health Record (PCHR) contains a schedule of eye checks from birth to school age. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

Teenagers and adults should have a full assessment by an optician/optometrist at least every 2 years (or more frequently if a change in vision is suspected).

Ophthalmic issues such as cataract, glaucoma, keratoconus, and refractive errors need to be checked. If examination is difficult, refer to specialist optician or ophthalmologist for assessment.

Vision should be discussed as part of the GP Annual Health Check.

### **Resources:**

#### **Visual Acuity**

*Seeing The World Differently*

*Visual Acuity: How I See the World*

*Visual Acuity: Think Big, Think Bold*

*Video – Visual Acuity – What Is It and Why Does It Matter*



## **Resources:**

### **General**

*Eye Conditions in Children*

*Children – Vision, Eye Tests and Glasses*

*Adults – Vision, Eye Tests and Glasses*

The resources listed above may be found here:

[Eyes - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

### **Dental**

People who have Down's syndrome do not have any unique oral health conditions but there are some conditions which are more common. In children who have Down's syndrome, the eruption of teeth may be delayed, and they will not necessarily appear in the same sequence as other children. It is advisable to register children with a dentist as soon as teeth erupt in the mouth.

The insert for the Personal Child Health Record (PCHR) contains information about teeth. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

Children and adults who have Down's syndrome appear to be more susceptible to gum disease (periodontal disease). This may be because of impaired immunity. Good oral hygiene and regular check-ups with a dentist will help to reduce the chance of developing gum disease.

Teenagers and adults should have an annual dental review where the following should be considered:

Look for signs of oesophageal reflux.

Poor oral health is linked to an increased risk of aspiration pneumonia and should be actively managed.

Cardiovascular Examination for Adults:

- Auscultation – particularly if imminent dental procedure
- A single ECHO should be performed in adult life
- Adults with a pre-existing structural abnormality should be informed of current prophylactic antibiotic protocols
- Blood pressure and heart rate

## **Resources:**

*Oral Health Care for Children*

The resource listed above may be found here:

[Ears, Nose, Throat and Teeth – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Sleep

Sleep disturbance is common in people who have Down's syndrome and may occur for multiple reasons including Obstructive Sleep Apnoea (OSA).

Sleep apnoea occurs more commonly in children who have Down syndrome. Symptoms of sleep apnoea include gasping, momentarily stopping to breathe or snoring whilst sleeping. It is recommended for all children who have Down syndrome to have their oxygen levels checked overnight, whilst asleep, at around the age of six months and then once a year until the age of 5. This is to ensure that their breathing pattern and oxygen levels are normal.

The insert for the Personal Child Health Record (PCHR) contains a schedule for breathing checks. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

Sleep issues may go undiagnosed because of diagnostic overshadowing and/or people may not realise, or be able to express, that they are experiencing poor sleep.

Sleep should be checked as part of the GP Annual Health Check for adults and teenagers. GPs should ask about sleep apnoea and consider Epworth sleepiness score and refer for sleep studies if appropriate.

### Resources:

*Managing Sleep Issues in Children*

*Sleep Issues in Adults*

*Sleep Poster*

*Relaxation audio*

The resources listed above may be found here:

[Sleep – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

## Musculoskeletal

Musculoskeletal issues are quite common in people who have Down's syndrome. There are different reasons for this including low muscle tone, lax ligaments, and hypermobile joints.

Children who have Down's syndrome have an increased risk of autoimmune conditions. Autoimmune conditions are caused by a malfunction in the body's natural defence systems against infections.

Children who have Down's syndrome are more commonly affected by arthritis. There is an increased risk of an inflammatory form of arthritis in children who have Down's syndrome (sometimes referred to as 'Inflammatory arthritis of Down's syndrome' or 'Down's arthropathy'). Inflammatory arthritis of Down's syndrome is an under-recognised condition that, if untreated, results in chronic disability and functional impairment. Children may not easily express the pain that they are experiencing. A change in a child's ability to perform daily living activities, e.g., in their handwriting or walking abilities may be an indication of early onset arthritis.

The insert for the Personal Child Health Record (PCHR) contains information about arthritis. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

Adults who have Down's syndrome may be more at risk of osteoporosis. Some adults may develop osteoporosis and arthritis at an earlier age than is seen in the general population.

At the GP Annual Health Check for teenagers and adults, the following should be assessed/reviewed:

- Joints
- Mobility
- Physical activity
- Postural care (if immobile)
- Feet and need for orthotic support

Consider the possibility of arthritis, including Down syndrome arthropathy (more commonly found in children), and osteoporosis.

#### **Resources:**

*Orthopaedic Issues*

*Inflammatory Arthritis in Children*

The resources listed above may be found here:

[Bones and Muscles – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Neck instability / Atlanto Axial Instability (AAI) (also see separate information for Musculoskeletal issues)**

Underlying neck instability is more common in people who have Down's syndrome than in the general population. It is more commonly diagnosed in childhood. The majority of cases remain stable radiologically and do not develop clinical complications.

The insert for the Personal Child Health Record (PCHR) contains information about neck instability. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

Practitioners should be aware of the symptoms which might indicate that a person who has Down's syndrome is at risk of neck instability.

These include:

a) Warning symptoms

- Pain anywhere along the neck
- A stiff neck which doesn't get better quickly
- Unusual head posture ('wry neck' or torticollis)
- Alteration in the way a person walks so they may appear unsteady
- Deterioration in a person's ability to manipulate things with his/her hands

b) Poor neck control

Difficulty holding the head up, holding the head at an unusual angle, difficulty nodding or looking up and down and/or difficulty turning the head in certain directions.

Anyone with the above signs could have underlying neck instability and be at increased risk of neck dislocation. Minor impact involving the person with the symptoms may cause spinal damage (e.g., tripping up or a jolt).

Routine cervical - spine X-ray is not recommended.

At the GP Annual Health Check for teenagers and adults, there should be an assessment for neurological deficit, which may indicate spinal stenosis.

Investigation of choice is MRI. Plain films are not helpful in diagnosing or ruling out AAI.

### **Resources:**

*Neck Instability*

*Knowing About Neck Problems (Easy Read)*

The resources listed above may be found here:

[Bones and Muscles – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Endocrine

### Thyroid

In people who have Down's syndrome there is an increased prevalence of hypothyroidism at all ages (rising with age) with a small increase in hyperthyroidism.

The insert for the Personal Child Health Record (PCHR) contains a schedule for thyroid blood tests and some information about thyroid. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

All newborn babies should have a heel prick blood test for thyroid, and they should be tested again for thyroid when they are between 4 to 6 months old. From the age of 1 year old, a thyroid function test should be done every year (or more often if clinically indicated) for the rest of life.

Thyroid should be tested as part of the GP Annual Health Check for adults and teenagers. Thyroid should be considered if the person has accelerated weight gain, is generally unwell or where there is a possible diagnosis of depression or dementia. Those with existing thyroid disease, diabetes, anaemia, or symptoms of possible coeliac disease should be offered a coeliac antibody test as part of their Annual Health Check.

#### Resources:

*Thyroid*

*Thyroid (Easy Read)*

*Having a Blood Test*

*Guidelines on Thyroid Disorder in Children and Young People with Down Syndrome – Surveillance and When to Initiate Treatment*

The resources listed above may be found here:

[Thyroid – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

### Diabetes

Children who have Down's syndrome tend to develop diabetes earlier than other children in the general population. In children it is more likely to be Type 1 diabetes. Type 1 diabetes is relatively more common in people who have Down's syndrome.

Some children develop a relatively serious medical condition termed diabetic ketoacidosis (DKA).

Some people who have Down's syndrome will develop Type 2 diabetes.



Type 1 diabetes should be checked for at the GP Annual Health Check for teenagers and adults. Those with a diabetes diagnosis should be offered a coeliac antibody test as part of their Annual Health Check.

### **Resources:**

*Diabetes*

The resource listed above may be found here:

[Gastrointestinal and Diabetes – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk/gastrointestinal-and-diabetes)

## **Feeding and breastfeeding**

Almost all mothers who want to can breastfeed or provide breast milk for their baby. For some mothers, breastfeeding is established easily, but others may find it takes a little more time, patience, and perseverance. Support should be available to help mothers who want to breastfeed their child. Many hospitals employ a lactation consultant or have midwives with a particular interest in feeding.

For some babies, feeding gets easier as they grow older, and they will be able to be fully breastfed. Some mothers choose not to breastfeed or find that because of their circumstances, breastfeeding is not right for them.

Some babies have health conditions which affect feeding. Babies with gastro-intestinal tract (GI tract) conditions who need an operation will not be allowed to feed at first and will get nutrients intravenously.

Some babies with heart conditions may be unable to feed immediately because they are tired or breathless. At such times, mothers can express breast milk by hand or pump to build up their milk supply. Their milk can be given to their babies by naso-gastric tube when the babies are well enough.

With patience, and following surgery for any medical conditions, babies can often eventually fully breastfeed.

The insert for the Personal Child Health Record (PCHR) contains information about feeding. The PCHR insert is available here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk/you-and-your-baby)

## **Resources:**

*Biting and Chewing*  
*Straw Drinking in Children who have Down's syndrome*

The resources listed above may be found here:

[Speech, language and communication – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

*Congratulations on the birth of your baby*

The resource listed above may be found here:

[You and your baby – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Diet and nutrition**

The following should be considered, and checked as appropriate, as part of the GP Annual Health Check for teenagers and adults:

Weight, height

Feeding (including physical difficulties, swallowing, aspiration risk)

Diet and nutrition

Fluid intake

Smoking

Alcohol

Substance misuse

## **Resources:**

*Supporting Healthy Eating – Tips for Parents*  
*Healthy Eating – Easy Read*

The resources listed above may be found here:

[Healthy Lifestyle and Physical Activity – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Gastrointestinal

Some gastrointestinal conditions are more common in people who have Down's syndrome.

Issues in the gastrointestinal tract can either be due to abnormal structure i.e., the organs are formed differently from usual, or may be because part of the tract is not functioning properly. Children who have Down's syndrome are more likely to have issues in both of these areas in comparison to the rest of the population. Some of these are serious and are likely to cause immediate difficulties in the new-born period. Other issues may not be so serious, but nevertheless cause considerable concern.

In some of the conditions, issues will develop slowly and may not be picked up by parents or health professionals for some time. Some may have obvious symptoms, but others may have subtler symptoms that may be easier to miss and put down to behavioural and/or psychological issues. Less obvious symptoms may be overlooked as the person experiencing them is unable to, or finds it difficult to, explain what they are feeling. For many people who have Down's syndrome, a change in their behaviour may be the first sign that something is wrong.

Children who have Down's syndrome may be more susceptible to digestive difficulties such as reflux, diarrhoea, and constipation.

### Resources:

*Gastrointestinal – Children*

*Gastrointestinal – Adults*

The resources listed above may be found here:

[Gastrointestinal and Diabetes – Down's Syndrome Association \(downs-syndrome.org.uk\)](http://downs-syndrome.org.uk)

## Constipation and continence

Children who have Down syndrome are usually daytime toilet trained by the age of 3.5 - 4 years old. If a child is still in nappies at 4 years old, then they need to be seen by a medical specialist to make sure that their bladder and kidneys are working properly.

Constipation is common in children who have Down syndrome. This may be a particular issue for those children with lower muscle tone and those who take less exercise. Fluid intake and diet may also contribute to constipation. In most cases it is not due to any underlying bowel condition and can be managed as it would be in any child.

The insert for the Personal Child Health Record (PCHR) contains information about constipation. The PCHR insert is available here:

[You and your baby – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

If constipation is present since birth, or is severe and persists despite simple measures, then further investigation is needed. Very occasionally thyroid condition (which is again common for children who have Down’s syndrome) may be a cause of constipation.

Urinary continence and constipation should be considered and checked as part of the GP Annual Health Check for adults and teenagers. People who have Down’s syndrome are at high risk of constipation, which can become very severe, leading to faecal impaction, perforation, sepsis, and death. Constipation must be actively managed, and complications must be considered with changes in symptoms or behaviour. Constipation may be associated with coeliac disease and thyroid.

**See information about Thyroid and Coeliac Disease.**

**Resources:**

*Gastrointestinal – Children*

*Gastrointestinal – Adults*

The resources listed above may be found here:

[Gastrointestinal and Diabetes – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Coeliac disease

Although coeliac disease can occur more frequently in people who have Down’s syndrome, routine screening is currently not recommended. Symptoms of coeliac disease include bowel problems, tiredness, or a change in behaviour. There should be a low threshold for checking for coeliac disease.

Coeliac disease should be considered during the GP Annual Health Check for adults and teenagers as follows:

Screen clinically by history and examination annually.

Testing (coeliac antibody test) in those with suspicious symptoms or signs, including:

- Disordered bowel function tending to diarrhoea or to new onset constipation
- Abdominal distension
- General unhappiness and misery
- Arthritis
- Rash suggesting dermatitis herpetiformis
- Test all those with existing thyroid disease, diabetes, or anaemia

**Resources:**

*Coeliac Disease*

The resource listed above may be found here:

[Gastrointestinal and Diabetes – Down’s Syndrome Association \(downs-syndrome.org.uk\)](http://downs-syndrome.org.uk)

## **Epilepsy – seizures**

It is estimated that around 1 in every 10 people who have Down’s syndrome will develop epilepsy at some point in their lives, compared to around 1 in every 100 people who do not have Down’s syndrome. Just under half of people who have Down’s syndrome, and who have epilepsy, develop it when they are less than a year old mainly with Epileptic Spasms, but other types of seizure can occur, most often in teens or early adult years, though they can also occur in later life. Alzheimer’s disease in people who have Down’s syndrome may be associated with the onset of seizures for the first time in that person’s life.

**Resources:**

*Epilepsy*

The resource listed above may be found here:

[Epilepsy – Down’s Syndrome Association \(downs-syndrome.org.uk\)](http://downs-syndrome.org.uk)

## **Skin**

Down’s syndrome is associated with an increased frequency of some common dermatoses, and specifically with some rarer dermatological disorders. This may be due to a number of factors including inefficient physiological processes and immune and genetic dysregulation.



The following should be considered and checked as appropriate as part of the GP Annual Health Check for Adults and Teenagers:

Eczema

Dry skin

Fungal skin or nail infections

Folliculitis

## **Female health and menstruation**

The stages of puberty are the same for girls who have Down's syndrome as other girls. Breast development starts first (age range 8-13 years) followed by pubic hair growth, then the first period. The average age for 1st period in girls who have Down's syndrome is 12 years 6 months (in the general population it is approximately 13 years).

Occasionally the usual sequence of pubertal changes is not followed, and the start of periods has been seen as the first sign of puberty in young women who have Down's syndrome.

Menstrual periods should be reviewed as part of the GP Annual Health Check for teenagers and adults. GPs should 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 at an average of 44 years of age.

The symptoms of menopause may look similar to those of dementia. Women who have 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.

## **Cervical and Breast Screening**

People who have Down's syndrome should be invited to take part in all national health screening programmes.

Access to cervical and breast screening should be discussed as part of the GP Annual Health Check for teenagers and adults. Where appropriate the GP should provide advice and education re breast examination.

Breast cancer is much less common in women who have Down's syndrome – around 10 times less frequent than in other women. Therefore, the risk is small but still present and if there is a family history of breast cancer the risk will be higher. The low risk of breast cancer in contrast to the possibility that a woman who has Down's syndrome may be less likely to report early symptoms of breast cancer both need to be considered when breast screening is offered.

## **Resources:**

*Puberty, Adolescence and Sexual Health*

The resource listed above may be found here:

[Sexual Health – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

*The Importance of Health Screening*

The resource listed above may be found here:

[Health and Well-being – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Testicular health**

Testicular cancer is more common in men who have Down’s syndrome.

If the person is not able to do this himself, examination of the testicles should be included as part of the GP Annual Health Check for teenagers and adults. Where appropriate, education and advice about testicular examination should be offered.

## **Resources:**

*Puberty, Adolescence and Sexual Health*

The resource listed above may be found here:

[Sexual Health – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

*The Importance of Health Screening*

The resource listed above may be found here:

[Health and Well-being – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Sexual health general**

Puberty and sexual health are areas of development for a child who has Down’s syndrome that should be thought about, discussed, and planned for. It is best if this is done in advance and support should continue throughout their adult life.

Relationship and sex education (RSE) is important in providing people who have Down’s syndrome with the tools to understand their own body and crucial in protecting individuals from abuse.

It is important that vulnerable children, young people, and adults are protected but this should not be at the cost of respecting their human need to love and to be loved, to have friends and to express their sexuality (in ways that suit them, and which are acceptable). People who have Down's syndrome have the right to express their emotions and sexuality and to develop relationships. This is an important part of having a full and equal life and is based on their right to independence and choice.

As part of the GP Annual Health Check the following should be considered and checked as appropriate:

Sexual health and infection risk

Contraception

Sexual abuse and/or exploitation

### **Resources:**

*Puberty, Adolescence and Sexual Health*

The resource listed above may be found here:

[Sexual Health – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

*Let's Talk About Relationships and Sex: Teenage Resources*

*Let's Talk About Relationships and Sex: Trainer Package*

The resources listed above may be found here:

[Relationships and Sex Education – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

## **Ageing**

People who have Down's syndrome are living into their fifties and sixties with small numbers living into their seventies and beyond. There is evidence to suggest that people may experience the biological symptoms of ageing at an earlier age than is seen in the general population (e.g., age-related sensory impairment and musculoskeletal issues).

Woman over 40 should be checked for hot flushes and menopausal symptoms as part of the GP Annual Health Check for adults as they have an earlier onset of menopause compared to women in the general population at an average of 44 years of age. The symptoms of menopause may look similar to those of dementia. Women who have 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.

## Resources:

*Getting Older*

The resource listed above may be found here:

[Ageing and Dementia – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Mental health and well-being

People who have Down’s syndrome are susceptible to the same physical and mental ill health as anyone in the population. However, whilst certain biological differences coupled with environmental stresses may make mental health issues more likely, they are not inevitable. As with all of us, there are things that can promote positive mental health and reduce the likelihood of issues arising. For example, facilitating positive relationships and empowering people through providing choice and opportunity and keeping physically active.

Common behaviours in people who have Down’s syndrome may be mistaken for poor mental health. For example, self-talk has historically been misdiagnosed as evidence of psychosis. We now know that self-talk is developmentally appropriate and that it can serve a number of useful purposes. If it moves along a continuum into becoming disruptive to everyday life, then the person may need to be supported with strategies to help reduce the impact.

Any sudden behaviour change is always a cause for concern and may be a sign that the person needs additional support. Some behaviours that may indicate that things are not right for the person include:

- Loss of skills or needing more prompting to use skills
- Social withdrawal
- Irritability
- Avoidance
- Agitation
- Loss of interest in activities they usually enjoy

There may be things that can help such as reducing demands on the person, putting in extra support and structure, using visual prompts and supports, breaking information and tasks down into manageable segments.

Mental health should be considered as part of the GP Annual Health Check for teenagers and adults with awareness on the part of the GP of the following:

- Psychological problems often present as deterioration in self-help skills or behaviour change. Need to exclude depression, thyroid disorder, and hearing impairment.
- Depression is common in older adults, often as a result of bereavement and/or changes in living situation.

- Behaviours of distress (previously called challenging behaviour, or behaviour that challenges) is often incorrectly treated with psychotropic medications, with resultant issues related to side effects including over-sedation, confusion, and constipation. Consider behaviours of distress as a form of communication. Causes of distress need to be identified, including physical health causes, mental health causes and social or environmental causes. Medication should only be used when necessary.

### **Resources:**

*Depression in People with Down's syndrome  
Bereavement*

The resources listed above may be found here:

[Depression and Bereavement – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

*Mental Health – An Introduction  
Mental Health - Anxiety and Stress  
Mental Health - Depression  
Mental Health – Obsessive Compulsive Disorder (OCD)*

The resources listed above may be found here:

[Down's syndrome with Complex Needs – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

*Supporting Emotional Well-being for Parents and Supporters  
Well-being – What Does It Look Like and What to Look Out For  
Film About Relaxation  
Relaxation Audio  
What Is Well-being? (Easy Read)  
What Is Mindfulness? (Easy Read)  
Let's Talk About Feelings (Easy Read)  
Bullying (Easy Read)  
Anger (Easy Read)  
How Am I? (Easy Read)  
The Stress Bucket (Easy Read)  
Changes That Can Happen in Families (Easy Read)  
Top Ten Tips for Well-being (Easy Read)  
Things You Can Make (And buy) (Easy Read)*

The resources listed above may be found here:

[Emotional Well-being – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Autism

The incidence of autism in children who have Down's syndrome is substantially higher than in children who do not have Down's syndrome (who do not have other genetic conditions that are associated with higher incidence of autism).

Presentation of autism has characteristics specific to the genetic condition of Down's syndrome (as do many other genetic conditions). These characteristics are reported in a number of research studies, whose findings indicate that children who have Down's syndrome tend to show relatively milder social difficulties. It is important that clinicians are aware of this difference if children who have Down's syndrome and autism are to be correctly diagnosed and eligible for specialist intervention and education services.

### Resources:

*Down's Syndrome and Complex Needs – Autism*

*Down's Syndrome and Complex Needs – Autism – Assessment and Diagnosis*

The resources listed above may be found here:

[Down's syndrome with Complex Needs – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## Regression

Regression is a term that is used to describe the loss of previously acquired developmental skills in an individual. This can be in the areas of daily living, language, motor abilities/function, or social interaction. Regression typically occurs in adolescence/young adulthood and can occur over weeks to months or more quickly. There are some similarities with the presentation of autism and Alzheimer's disease however the age of the person would be the key indicator. Autism would usually be apparent at an earlier age and Alzheimer's at 40+.

Regression can also be referred to as Down syndrome regression disorder (DSRD), Down syndrome disintegrative disorder (DSDD) or unexplained regression in Down syndrome (URDS) and these terms are sometimes used interchangeably. The cause of regression is thought to differ among individuals and there is ongoing research to look at causation and treatment options.

It is important to determine the reason(s) for a person's regression as this will inform any treatment. There is no one singular treatment for a person with regression as no case of regression is exactly like the next. Any tests carried out would be based on an individual's symptoms and determining the most likely cause of the regression.

## Resources:

*Regression in People Who Have Down's Syndrome*

The resource listed above may be found here:

[Down's syndrome with complex needs – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

Walpert, M.; Zaman, S.; Holland, A. *A Systematic Review of Unexplained Early Regression in Adolescents and Adults with Down Syndrome*. *Brain Sci.* 2021, 11, 1197. <https://doi.org/10.3390/brainsci11091197>

Handen, B.; Clare, I.; Laymon, C.; Petersen, M.; Zaman, S.; O'Bryant, S.; Minhas, D.; Tudorascu, D.; Brown, S.; Christian, B., on behalf of the Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS). *Acute Regression in Down Syndrome*. *Brain Sci.* 2021, 11, 1109. <https://doi.org/10.3390/brainsci11081109>

The resources listed above may be found here:

[Research Support – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

*Regression In People Who Have Down's Syndrome Conference (Recording)*

The resource listed above may be found here:

[Regression in people with Down syndrome conference - YouTube](https://www.youtube.com/watch?v=...)

## Dementia

Adults who have Down's syndrome are far more likely to develop dementia and the onset of dementia begins at a much younger age than in the general population. Clinical onset is uncommon before age 40 years.

Incidence rises from 9% of adults who have Down's syndrome aged 40-49 years to 32% of adults aged 50-59 years (Coppus et al, 2006).

Dementia is an underlying cause of death in more than 70% of adults who have Down's syndrome aged over 35 years (Hithersay et al 2018).

McCarron et al (2014) report a cumulative incidence of dementia of 90% by the age of 65 years.

The early signs of dementia are often ignored and are put down to an "individual having Down's syndrome" (diagnostic overshadowing) – this means that some people present very late for a diagnosis.



Conversely, assumptions are sometimes made, meaning that any change is assumed to be dementia when it is something else (which would be treatable via a different type of intervention). There is a need for a differentiated diagnosis, which correctly identifies and suggests interventions for other causes of decline in middle to older age.

This would include:

1. Life stresses, especially a bereavement
2. Depression
3. Changing sensory impairments
4. Confusion brought about by an infection
5. Untreated thyroid condition
6. Menopause in women
7. Musculoskeletal issues and changes in mobility due to issues with joints
8. Side-effects or interactions between other prescribed medications, which may need review

[British Psychological Society](#) good practice guidance suggests carrying out baseline assessment for dementia by age of 30 for all people who have Down's syndrome. The frequency of prospective monitoring for dementia should be matched to rising risk with age; every two years for those in 40s; and annually for those 50+.

As part of the GP Annual Health Check for adults, GPs should be aware of the symptoms of dementia such as decline in function, memory loss, ataxia, seizures or urinary and/or faecal incontinence whilst bearing in mind differential diagnosis.

GPs should check that people with a diagnosis of Alzheimer's disease have had depression, hypothyroidism, visual impairment, deafness, and social/ environmental changes excluded in the first instance.



# Social care

Children and adults who have Down's syndrome have a right to have their needs assessed by the local authority to ascertain if they have eligible needs that might be met by the provision of social care.

Carers have the right to ask for a separate assessment of their needs.



## Resources:

### Assessments - adult social care

*Overview of Social Care Assessments*

*Asking for a Needs Assessment*

*Preparing for a Needs Assessment*

*Getting the Care and Support Plan Right*

*Support Planning – Person Centred*

*Needs Assessment – Supporters Guidelines*

*Supporters Booklet*

*Assessments – How They Should Work – Case Studies*

The resources listed above may be found here:

[Housing and Support for Adults – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

## **Assessments - carers**

*Asking for a Carers Assessment*

*Preparing for a Carers Assessment*

*Getting the Carer's Support Plan Right*

The resources listed above may be found here:

[Housing and Support for Adults – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Cuts and complaints**

*Complaints to a Local Authority*

*Reduction to a Support Package*

*Capping/Rationing of Carers Short Breaks*

The resources listed above may be found here:

[Housing and Support for Adults – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Housing**

*Housing Choices*

*Arranging Housing*

*Financing Housing*

*Tenancy Agreements*

*'Top Up' Payments Towards the Cost of Residential Care*

*De-Registration of Care Homes by Local Authorities*

*Common Problems*

*What is Supported Living?*

*Supported Living: A Parent's Experience*

The resources listed above may be found here:

[Housing and Support for Adults – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

## **Easy read**

*Choosing Where to Live*

*What is Supported Living*

*Choosing Who to Live With*

*Getting Ready to Move Out*

*Getting Help in Your Home*



*Choosing Where to Live*  
*What is Supported Living*  
*Choosing Who to Live With*  
*Getting Ready to Move Out*  
*Getting Help in Your Home*  
*Becoming More Independent*  
*Paying Bills*  
*Staying Safe*  
*When There is a Problem*  
*Supported Living: Our Stories*  
*Listen to Me: 13+ Transition*

The resources listed above may be found here:

[Housing and Support for Adults – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

## **Support**

*Support Planning – Person Centred*  
*Types of Support – The Options*  
*Paying For Support*  
*What to Expect from Good Support*  
*Information for Support Staff*

The resources listed above may be found here:

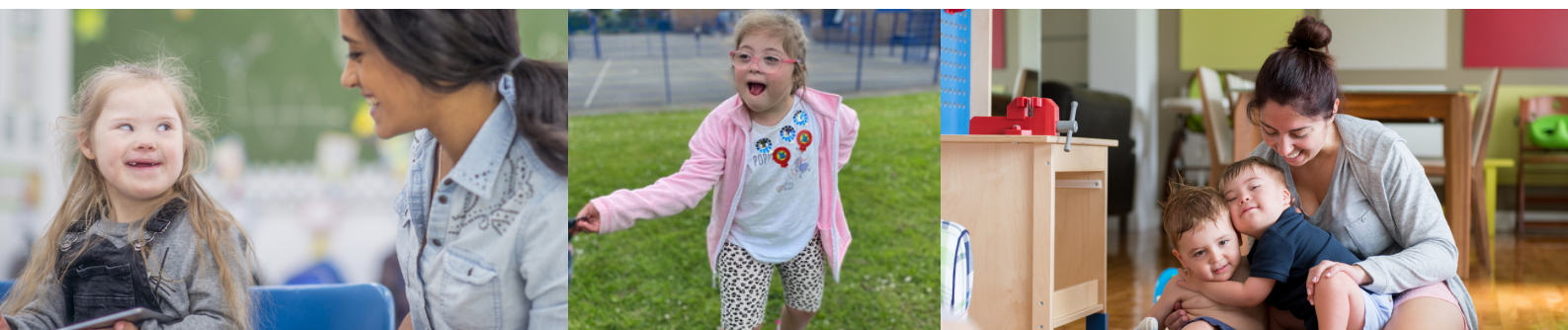
[Children, Families & Education – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

## **Children’s Social Care**

*A Quick Guide to Social Care for Children in England*

The resource listed above may be found here:

[Children, Families & Education – Down’s Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)



# Education

The benefits to learners who have Down's syndrome of an inclusive education have been documented over the last 30 years. Inclusive primary education became well established for the majority of learners who have Down's syndrome during the 2000's (less so for those learners with more complex needs and dual diagnoses) although more variable (regionally) at secondary stage. The DSA is committed to children and young people having the option to attend local community schools and colleges however complex their needs may be.

Some learners' needs are met in specialist settings. Teaching and learning recommendations for learners who have Down's syndrome should apply to all types of school and college settings.



## Resources:

### Back to school

*Back to School Checklist*

*Making A Transition Book*

*Making A Holiday Book*

*All About Me – Personalised Books*

*What Should I Expect from My Child's School*

*Becoming School Ready – Transition from Reception to Year 1*

*How to Build a Relationship with Your Child's School*

*School Transport Factsheet*

*Education, Health, and Care Plans (EHCP)*  
*Education, Health, and Care (EHC) Needs Assessments*  
*Education Rights Post 16*  
*EHCP Annual Reviews (Video)*  
*Advice for Parents Entering the Education System (Video)*  
*Back to School Checklist for Educators*  
*Early Years Factsheet*  
*Primary Factsheet*  
*Secondary Factsheet*  
*Further Education Factsheet*  
*Supporting Children to Learn*  
*What Works to Support Children and Young People Who Have Down's Syndrome (Video)*  
*How to Include Learners with Intellectual Disabilities in Your Classroom (Video)*  
*Vision and Learning*  
*Seeing The World Differently – Explaining How Vision Impairments Affect Children Who Have Down's Syndrome*  
*Strategies For Supporting Vision Impairments*  
*Hearing And Learning*  
*Childhood Communication (Easy Read)*  
*Visual Acuity – What is it and Why Does it Matter (Video)*  
*DSi International Guidelines on the Education of Learners with Down Syndrome*  
*How Can Teachers Build a Good Relationship with Parents? (Video)*  
*How Can Parents Build/Maintain A Positive Relationship with Schools? (Video)*

## **Inclusive education**

*What Does the Term Inclusive Education Mean? (Video)*  
*Why Inclusion Matters In Education (Video)*  
*Talking About the Education Campaign – Our Voice (Video)*  
*Let's Talk – What Makes an Inclusive School (Video)*  
*Inclusive Education – A Discussion on the Concept and Practice in the Classroom (Video)*  
*How Can an Inclusive Atmosphere Be Best Created in the Mainstream Setting? (Video)*  
*Steps for Developing Inclusive Practice for Pupils who have Down's Syndrome in Your Setting*  
*What is Inclusive Education?*  
*What are the Principles of Inclusion?*  
*How Can We Work Towards Including All Children?*  
*How Can Teachers Ensure That Learners Who Have Learning Disabilities Are Included with Their Peers?*  
*What Is Your Ethos When It Comes to Inclusion and Inclusive Education?*  
*Evaluation of Inclusive Practice for Students with Down's Syndrome in Devon Secondary Schools – Academic Year 2008-2009*  
*What Is the Role of Learning Support Assistants?*  
*What is the Role of the LSA in Ensuring All Learners Are Included with Their Peers?*  
*Supporting Teenagers*  
*What Is Down's Syndrome? (resources for children and young people)*

## **Whole school inclusion**

*Being Included and Discrimination – Your Rights Under the Equality Act*

*The Equality Act 2010 and Schools*

*Top Tips for an Inclusive Sports Day*

*Top Tips for an Inclusive Residential Trip*

*How Can Outdoor Learning Support Inclusion?*

*A Discussion About How the DSA Supports Inclusion Within Sports and Leisure Activities (Video)*

## **Inclusion success stories**

*Isla: Taking Part in School Productions*

*Harry: Taking Part in YMCA Youth Club*

*Morgan: Taking Part in Youth Club and Social Activities*

*Beatrice: Taking Part in School Swimming Lessons*

*Tanzie: Taking Part in a School Residential Trip*

*Harshi: It's Ok to Talk to Me*

*Dylan: A Great Sporty Experience at School*

*Betsy: Inclusion in Her Local Dance Class*

*Swansea FC and Down's Syndrome Football*

*Meet Jack Hale – Special Olympics Skier (Video)*

*David and His Taekwondo Teacher Talk Inclusion (Video)*

*Introducing DSActive Tennis (Video)*

*Perry and The Charlton Upbeats (Video)*

*Sam: My Experience of Sport at School (Video)*

*Joe: My Experience of Cheerleading at School (Video)*

## **Medical information**

*Neck Instability in People Who Have Down's Syndrome*

*Knowing About Neck Problems (Easy Read)*

## **School leadership**

*Leading for Inclusion*

*How Can SENCOS and Leaders Support Teachers to Include Learners with Intellectual Disabilities?*

*How can policy for inclusion at the strategic level, be best implemented & supported in classrooms? (Video)*

*What is the Role of the SENCO? (Video)*

*Why should the policy of the inclusion of all learners be adopted by all schools? (Video)*

*What do Leaders Need for Inclusion to be Taken Seriously?*

*Leave No One Behind: Including All Children and Young People*



## **Developing an aspirational and inclusive curriculum for all**

*The Teacher's Role in Creating an Inclusive Curriculum (Video)*  
*Planning for an Inclusive and Accessible Curriculum*  
*How to Support Pupils to Learn About Disability*  
*DSi Inclusive Education Guidelines – Curriculum Modification*  
*Supporting Communication in the Classroom*

## **Planning for independence**

*Who decides? Decision making from 16 years old (Video)*  
*Further education*  
*Education rights post 16*  
*Planning for adulthood and transition*  
*Making choices and encouraging independence*  
*Supporting teenagers*  
*Growing up: thinking about being an adult (Easy Read)*  
*DSi Inclusive Education Guidelines - Lifelong Learning*  
*Angharad: preparation for adulthood*  
*Emma: going to college*  
*Tanzie: travel training (video)*  
*Catherine: about dreams (video)*  
*Samuel: my job as a swimming coach*  
*Making decisions post 16*  
*The Mental Capacity Act FAQs*  
*Mental capacity and decision making*  
*Bank accounts and managing money*

## **Early years education**

*Early years factsheet*  
*Lorni: how I benefited from my early years intervention*  
*DSi Inclusive Education Guidelines - Early Years*  
*How do I pick which school is right for my child? (video)*  
*Advice for parents entering the education system (video)*  
*'All about me' personal books*  
*Transition from EYFS into Year 1*  
*Supporting early communication*  
*The role of the Speech & Language Therapist for babies and pre-schoolers*  
*Speech and language therapy activity videos*  
*Activity tutorials*  
*Developing language at mealtimes*

*Straw drinking advice*  
*Biting and chewing*  
*Supporting motor skill development*

## **Ensuring your rights**

*Education, health and care (EHC) plans*  
*Education, health and care (EHC) needs assessments*  
*Education rights post 16*  
*School transport*  
*Annual reviews*  
*Rights under the Equality Act 2010*  
*31 March deadline for post 16 education, health and care plans (EHCPs)*  
*Using legislation and guidance to make a difference for children and young people (video)*  
*The Down Syndrome Act 2022*  
*The lived experiences of parent carers of children with learning disabilities attending mainstream education (Emma Foley, researcher)*

## **Behaviour**

*Understanding behaviour resources*  
*Using positive behavioural support guide*  
*DSi inclusive education guidelines: encouraging behaviour for learning*  
*Tips for behaviour management*  
*Supporting emotional well-being*  
*Sleep*  
*Gastrointestinal and diabetes*

## **Friendships**

*Being part of a Circle of Friends at school: Catherine's story*  
*Circle of Friends meetings: Molly's story*  
*Hand in hand: forging bonds and friendships together*  
*#MyFriendsMyCommunity films*  
*Relationships and sex*  
*Our Voice*  
*Let's Talk: Natty, friends and friendship*  
*Let's Talk: Bullying - supporting children and young people who have Down's syndrome*  
*Supporting children and young people to learn about Down's syndrome*

## **Inclusive homework**

*Inclusive homework: adventures in learning at home*

## **Teacher training**

*About Down's syndrome (Including terminology guide)*

*Supporting children to learn*

*DSA Education resources*

*Professional learning on Down's syndrome*

*Planning for inclusive practice (DSi guidelines extract)*

*Amy's story: volunteering at her local school*

*Bethan's presentation on what helped her at school*

*Support in my mainstream school: Brogan's story*

*What works in practice (guidelines reproduced with permission of Sarah Geiger and the Barnet Down Syndrome Leading Edge Group)*

*What can an inclusive lesson look like?*

*How can we support early career teachers who are including a learner(s) with an intellectual disability?*

*How can student teachers have an inclusive mindset?*

*How are student teachers equipped to teach learners who have intellectual disabilities?*

*How can early career teachers best prepare for a diverse class?*

*What obstacles are faced by NQTs entering a diverse classroom?*

*How can a mindset of being ready for inclusive education improve a new teacher's practice?*

*How can teachers ensure that learners with intellectual disabilities in their class are included?*

*How can teachers be supported to develop as inclusive practitioners?*

*How can we best work with peripatetic staff?*

*What is the role of the Speech and Language Therapist?*

*What is the role of the Occupational Therapist?*

*How can teachers build a good working relationship with parents?*

*What is the role of the SENCO?*

## **Planning for transitions**

*Transition planning (DSi guidelines)*

*Transition planning: how do I choose what's right for my child?*

*Education, health and care needs assessments*

*Starting school*

*Primary school*

*Becoming school ready (from Year R to Year 1)*

*How can parents make the right decision on secondary school?*

*Secondary school (including useful questions to ask)*

*Transition to secondary school*

*Teenagers...what next?*

*Easy read: Listen to me - thinking about 13+ transition*

*Further education*

*31 March deadline for post 16 EHCPs*

*Fostering independence*

*Supporting teenagers*

*Making everyday decisions post 16*

*Planning for adulthood and transition*

*Social care transition assessments*

*DSi International guidelines*

The resources listed above may be found here:

**[Education Project – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)**

**[Children, Families & Education – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)**

## Employment

The DSA has a successful employment project, WorkFit.

You can find out more about WorkFit here:

[WorkFit – Down's Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)



For additional information, support and training, visit our website, email us or call our Helpline.

Our Helpline is open **Monday to Friday, 10am - 4pm** and can be reached on **0333 1212 300**.



## CONTACT US

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