



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Thyroid

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

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

info@downs-syndrome.org.uk.

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

The Down Syndrome Medical Interest Group (DSMIG)

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

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

Thyroid conditions are more common in people who have Down's syndrome when compared to the general population. The chance of having a thyroid condition increases as people get older.

People who have Down's syndrome should have their thyroid tested every year (or more often if needed) throughout their life.

What is the thyroid gland?

The thyroid gland is at the front of the neck just below the Adam's apple. The gland makes a number of different hormones; the main ones are thyroxine (T4) and triiodothyronine (T3). These hormones help the cells in the body work properly. They help to control the body's energy levels and they play a part in physical and mental development.

Hypothyroidism

Hypothyroidism is a type of thyroid condition that is common in people who have Down's syndrome. This condition is also known as having an underactive thyroid gland. It happens when the thyroid gland does not make enough thyroid hormones.

If a person has an untreated underactive thyroid gland, they may have the following symptoms:

- Slowing of growth
- Excessive weight gain
- Lethargy
- Sensitive to cold
- Dry skin
- Constipation
- Hair loss

If tests show you have an underactive thyroid, your GP may prescribe hormone replacement medication. It may take a little while to get the dose of medication right. You will probably have to take thyroid medication for the rest of your life. Over time, the amount of medication you need to take may change.

Hyperthyroidism

Hyperthyroidism a type of thyroid condition that is a little more common in people who have Down's syndrome than in the general population. This condition is also known as having an overactive thyroid gland. It happens when the thyroid gland makes too many thyroid hormones.

If a person has an untreated overactive thyroid gland, they may have the following symptoms:

- Weight and muscle loss
- Increased appetite
- Heat intolerance
- Diarrhoea
- Anxiety
- Tremor

If tests show you have an overactive thyroid, your GP may prescribe anti-thyroid medication to stop the body making too many thyroid hormones. In some cases, surgery to remove part of the thyroid gland or the use of radioactive iodine to reduce the gland's functioning might be required.

How is the thyroid gland checked?

The thyroid is checked by having a blood test. A health professional will take a blood sample from a vein in the arm. Taking a blood sample from a vein is sometimes called '*venipuncture*'.

For most people this will happen at their GP surgery. Sometimes a blood sample will be taken at the local hospital.

Some people will find having blood taken from a vein difficult. It is sometimes possible to have a finger prick test instead of a blood sample being taken from a vein. Ask your GP if finger prick testing is available in your area.

The blood sample will be sent to a laboratory for testing.

The GP surgery will contact you to discuss what the laboratory has found.

For some people an unfamiliar and noisy GP surgery or health setting can be overwhelming even if they have visited the place before. Having a blood sample taken does not always have to happen in a health setting. Some families arrange for a community nurse to take a blood sample at home, at school or at the local children's centre. It is always worth asking if there are other places (not health settings) where a person can have a blood sample taken.

Although all staff qualified to take a blood sample should be able to manage the person giving the sample sensitively and calmly, some parents and support workers have found that they have had a better experience with particular professionals (e.g. a phlebotomist, a senior nurse or a learning disability nurse).

There are further suggestions about supporting people to have a blood test towards the end of this resource.

How often should the thyroid be checked?

All newborn babies should have a heel prick blood test for thyroid.

Babies should be tested again for thyroid when they are between 4 to 6 months old.

From the age of 1-year-old people who have Down's syndrome should have a thyroid test every year (or more if needed) for the rest of their lives.

DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

	Birth - 6 weeks	Special checks under 2 years	Preschool checks	School age
Thyroid blood tests	Newborn routine heel prick - blood spot test	Age 4-6 months and then every year from the age of 1 year or more often if clinically indicated: Venous thyroid blood test including thyroid antibodies or Fingerprick TSH test		
Eye checks	Newborn routine check including congenital cataract check.	Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or short sight	Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity	Repeat vision test every 2 years, or more frequently if recommended by optometrist or ophthalmologist or if concerns
Visual behaviour to be monitored at every review particularly in first year				
Hearing checks	Universal newborn hearing screen	Full audiological review by 10 months including hearing test impedance check.	Annual audiological review or more frequently and if indicated 2 yearly audiological review or more frequently if recommended	
Growth monitoring	Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts		Height and weight should be checked and plotted on Down syndrome growth charts at least annually (BMI checked if concern regarding overweight)	
Heart checks	By age 6 weeks, formal heart assessment including Echocardiogram	At all ages low threshold for reviewing heart status if signs or symptoms develop		From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease
Breathing checks	Enquire at every review for uneven breathing during sleep and poor quality sleep. Screen with an overnight pulse oximetry once in infancy and yearly until the age of 5, or at any age if there are symptoms or concerns. Low threshold for detailed sleep studies if symptoms persist, despite normal tests.			
Blood checks	Within the first three days of life, full blood count and blood film to check for a serious blood disorder	If blood film is abnormal treatment or monitoring may be required		

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk

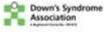
Down syndrome insert © DSMIG 2020

If in doubt, think thyroid!

If you notice any significant changes in the person you support, it is always worth arranging a GP appointment to have their thyroid checked. People who have Down's syndrome may have difficulties telling you how they feel. Changes in mood, routine, behaviour and/or appetite may be a sign that someone is unwell.

Thyroid easy read

We have made an easy read resource about thyroid. Here are some example pages to give you an idea of how it is laid out and the information in it. You can download the complete resource at our website.

 <p>Down's Syndrome Association A Registered Charity No. 1031714</p> <p>Health Series</p>  <p>Thyroid Easy Read</p>	<p>Easy Read Health Series www.downs-syndrome.org.uk</p> <p>About this leaflet</p> <p> This leaflet is made by the Down's Syndrome Association</p> <p> It is in Easy Read. Easy Read means easy words with pictures to help everyone understand.</p> <p> We ask Having a Voice groups to help us make Easy Read Information</p> <p> Having a Voice groups are groups of people with Down's syndrome. They help people have their say.</p> <p>  Having a Voice groups make sure the Easy Read information is easy to understand.</p> <p> You can find out more about Having a Voice on the Down's Syndrome Association website.</p>
<p>Easy Read Health Series www.downs-syndrome.org.uk</p> <p>What is the thyroid and what does it do?</p>  <p>The thyroid gland is in the front of your neck.</p>  <p>The thyroid gland makes hormones. This is what hormones looks like in our bodies.</p>  <p>Hormones are chemicals inside of our bodies. These chemicals are healthy. They make sure our bodies are working properly.</p>	<p>Easy Read Health Series www.downs-syndrome.org.uk</p> <p>Sometimes your thyroid gland might not work properly</p>  <p>An underactive thyroid means that your body is not making enough hormones. It is working too slowly.</p>  <p>An overactive thyroid means that your body is making too many hormones. It is working too fast.</p>  <p>Hormones are important as they make sure that our bodies are working properly.</p>

Supporting people to have blood tests

We know from enquiries to our Helpline that some children and adults who have Down's syndrome may find giving blood samples difficult. Fear of needles is common in the general population, so it stands to reason that people who have Down's syndrome should experience it too, particularly if they find it harder to understand why they need to go through the procedure and/or they have been put off by having a bad experience having a blood test in the past.

A parent neatly sums up the issue:

'If you were not sure what was going on and someone tried to stick a needle in your arm, how would you feel?'

Here are some tips that may help children and adults have a better experience when giving a blood sample. None of the tips and ideas here are new; they have been gathered from various sources including parents and health professionals. They have worked for some children and adults used in various combinations.

Preparation

People sometimes find with the new and unfamiliar difficult. Familiarising a person with what is going to happen can help to reduce anxiety and prepare them for giving a blood sample. The amount of preparation needed will be different from person to person; sometimes it's a fine line between preparing a person to allay their worries and unintentionally creating anxiety because the forthcoming procedure is being blown out of proportion. There are lots of tools that people have found useful in helping someone to prepare for giving a blood sample; these include social stories, easy read information, photo books or videos.

A man who has Down's syndrome needed to go the hospital for the first time to give a blood sample. His support worker talked to him about what was going to happen and then she arranged for him to have a trial visit to the hospital and to meet the doctor, the person who was going to take his blood sample. Whilst they were at the hospital, they took some photos of the building. When they got home, they made a story book using the photos as a reminder for the man about what to expect when he went to give a blood sample. They also used one of the photos on his visual timetable.

Many hospitals will have DVDs explaining what happens when a blood sample is taken. Find out if you can borrow a DVD from your local hospital. An example of a video about giving a blood sample (produced by Derby Teaching Hospitals NHS Foundation Trust) can be found on YouTube. Enter the following title in the search box: *Having A Blood Test – Learning Disabilities Version*.

For younger children it may help to rehearse what will happen with their favourite doll or teddy bear. You can bring the toy along to your child's appointment so that they can go through the procedure first. This may provide your child with reassurance.

Rewards

Rewards can work wonders. Remember to include rewards for getting through the procedure in any social stories, picture books or visual timetables that you use with the person who is giving a blood sample. Heaps of praise during and after blood is taken will help. If in doubt, resort to a bit of bribery.

Positioning and distractions

Positioning and distractions can make the process easier for children and adults. The right position can help them feel safe and secure, make it easier to distract them (e.g. if they are looking at you rather than at the person about to take blood) and make the task easier for the person taking the blood sample. Providing a distraction during blood taking may help to reduce anxiety (e.g. an iPad, favourite toy or game, iPod and headphones, an activity book involving having to find objects, singing, engage the person in a conversation about something they are passionate about.)

Medication

Local anaesthetics (e.g. creams such as 'Emla' cream) can be used to numb the skin and reduce pain before blood is taken. Ethyl chloride is an alternative to anaesthetic cream; it acts as local pain relief when sprayed onto the skin. It has no anaesthetic properties, but rather works as a vapo-coolant. A thin film of liquid is sprayed onto the skin, which makes the skin cold and less sensitive as the liquid evaporates.

Who Can Help?

Some families arrange for the Community Nurse to visit their child at school to carry out a desensitisation programme. Other parents have found the services of a play worker or play therapist useful. Talk to your local hospital or GP about this. A play worker can visit your child at home and go through the process of giving a blood sample with them. Your local Community Learning Disability Team (CLDT) can be a good source of advice. CLDTs usually have clinical psychologists and Learning Disability Nurses who can work with adults with learning disabilities around needle phobia. There is further information about CLDTs towards the end of this resource.

Can the blood taking be combined with another procedure to make it less stressful?

If a person is having an operation, ask the anaesthetist at the pre-op session about the possibility of taking a blood sample whilst they are anaesthetised.

A Final Note

These tips may help someone you support to find it easier to give blood samples. They are not a magic wand that can be waved with instant success. For some people, just getting them to a point where they feel comfortable with the setting and staff, where blood may eventually be taken, can be a lengthy process. This is before you reach the stage of the person being happy to undergo the full procedure. Realistically, we know there are going to be some children and adults who will always struggle with giving blood whatever measures are put in place to help them.

Supporting people to take medication

Pill cases split into times of the day or days of the week can help people to know when to take their medication.

People who have Down's syndrome are very good at keeping to routines once they have learnt them. Teaching a person to take medication with meals, or a specific meal, may be helpful for some people. This could be reinforced by using a visual timetable that includes a reminder for the person to take their medication.

Some people have difficulty swallowing tablets or capsules. Your chemist can advise about taking medications and whether an alternative option is available. They may also be able to give suggestions about how to remember to take medication.

Additional information for health professionals

If your health professional would like further information about thyroid condition and people with Down's syndrome, there are some useful links towards the end of this resource. In particular, please see '*Thyroid disorder in children and young people with Down syndrome – Surveillance and when to initiate treatment*'.

The UK Down's Syndrome Medical Interest Group (UK DSMIG) are happy to take enquiries from health professionals. Please note DSMIG will **not** take enquiries directly from parents/supporters.

Additional information for parents/supporters

If you, as a supporter/parent, have further questions about thyroid, you can call DSA's Helpline (Tel: 0333 1212 300). If an information officer is unable to answer your question, they can make a referral to DSMIG. Please note DSMIG can provide general advice about health issues but they are not able to comment on individual test results.

Further information and resources

DSA

Information for GPs – Thyroid

<https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/>

Thyroid – Easy read

<https://www.downs-syndrome.org.uk/download-package/thyroid/?highlight=thyroid>

Going to the chemist – Easy read

<https://www.downs-syndrome.org.uk/download-package/ltwyw-series-going-to-the-chemist-er/?highlight=chemist>

Other organisations

Thyroid disorder in children and young people with Down syndrome – Surveillance and when to initiate treatment (UK Down's Syndrome Medical Interest Group)

<https://www.dsmig.org.uk/>

Blood tests for people with learning disabilities: making reasonable adjustments (Public Health England)

This resource contains examples of changes made by health professionals to make having a blood test easier for people who have learning disabilities

https://www.ndti.org.uk/uploads/files/Blood_tests_for_people_with_learning_disabilities.pdf

Annual health checks for people who have Down's syndrome (aged 14 years plus)

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

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

Who can have one?

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

The benefits of annual health checks

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

How to get an annual health check

- The GP may get in touch with the person who has Down's syndrome to offer an annual health check but this doesn't always happen.

- A person who has Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

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

What happens next?

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

Who attends the annual health check?

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

How long should an annual health check be?

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

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

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

What happens after the annual health check?

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

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people who have Down's syndrome.

GP's learning disability register

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

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

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

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

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

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

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

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

Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable

adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

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

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

Publication date 2020

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

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

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

Contact us

Down's Syndrome Association

National Office

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

t. 0333 1212 300

f. 020 8614 5127

e. info@downs-syndrome.org.uk

w. www.downs-syndrome.org.uk

Wales

t. 0333 1212 300

e. wales@downs-syndrome.org.uk

Northern Ireland

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

t. 02890 665260

f. 02890 667674

e. enquiriesni@downs-syndrome.org.uk



WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of DSA members and supporters.



www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



© Down's Syndrome Association 2017