



**Down's Syndrome  
Association**

A Registered Charity No. 1061474

## Health Series



# Diabetes



The  
Down Syndrome  
Medical Interest  
Group

A Down's Syndrome Association publication

## Our resources and Information Team are here to help

Please see our website for up-to-date information: [www.downs-syndrome.org.uk](http://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](mailto:info@downs-syndrome.org.uk).

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

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## The Down's Syndrome Medical Interest Group (DSMIG)

This resource has been produced in collaboration with the Down's 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.

**We know that children with Down's syndrome are four times more likely to develop diabetes than other children, so about 1 child in 60 with Down's syndrome will also develop diabetes. It has been reported that, as a group, children with Down's syndrome tend to develop diabetes earlier than other children in the general population. Diabetes occurring in children with Down's syndrome is most likely to be type 1 diabetes, which is a condition where the immune system attacks and destroys the insulin producing cells in the pancreas. However, some people with Down's syndrome will have type 2 diabetes. In this resource we will describe the differences between type 1 and type 2 diabetes and provide some information about the treatments.**

**There should not be any difference in the care given to people with or without Down's syndrome, except that those with Down's syndrome are likely to require a greater degree of supervision and monitoring by health professionals and carers.**

## What is diabetes?

Much of the food we eat is turned into glucose to provide our bodies with energy. The pancreas, an organ that lies near the stomach, makes a hormone called insulin to allow this glucose to be used. When you have diabetes, your body either doesn't make enough insulin or can't use its own insulin as well as it should. This causes glucose to build up in your blood, which acts on many organs to produce the symptoms of the condition. In the long-term, if it is not carefully controlled, diabetes can cause health complications in a variety of organs, including the heart, eyes and kidneys.

### Main symptoms:

**Increased thirst (polydipsia)**

**Passing urine more often – especially at night (polyuria)**

**Extreme tiredness**

**Weight loss (in Type 1 diabetes)**

**Blurred vision**

## Tests for diabetes

Blood glucose meters can quickly measure the amount of glucose in a drop of blood from a finger prick sample. Blood glucose levels should be between 4-6 millimoles/litre. People with some or all of the symptoms (e.g. with increased thirst, passing urine more often, weight loss, blurring of vision) will require a single blood glucose test that may be taken on an overnight fasting (i.e. no food or drink for at least 10 hours before) or daytime non-fasting sample. To diagnose diabetes, the blood glucose concentration must be  $\geq 7$  in the fasting sample or  $\geq 11.1$  in the non-fasting sample. Diagnosis in people who don't have symptoms requires two blood samples on different days. If the results are not clear, an oral glucose tolerance test can provide further information. This involves taking a drink of glucose (up to 75gms – the amount is determined by the weight of the person being tested) after fasting overnight for 10-14 hours and measuring blood glucose levels at the start and after 2 hours to test how well the insulin producing cells in the pancreas are working.

## Types of diabetes

**There are two major types of diabetes: Type 1 and Type 2**

### Type 1 diabetes

Type 1 Diabetes is caused when the immune system mistakenly recognizes the beta cells in the pancreas, which makes insulin, as foreign invading cells and destroys them. This is called autoimmunity. About 10% of cases of diabetes in the UK are type 1 diabetes. The condition generally develops in a younger age group, usually children or young adults, and may occur even earlier in those with Down's syndrome. The signs and symptoms will usually be very obvious, developing quickly, usually over a few days or weeks. All people with type 1 diabetes require insulin injections to stabilize blood sugar levels. Pen injectors can be used easily, by dialling in the amount of insulin needed.

## Treatment of Type 1 diabetes

Some children develop a relatively serious medical condition termed diabetic ketoacidosis (DKA). These children are often dehydrated and have too many ketones in their blood. Doctors will gradually correct the dehydration and ketone excess over about 48 hours with intravenous fluids and insulin. Once stable or if not showing symptom of ketoacidosis, they are placed on daily insulin injections given under the skin (subcutaneous). Usually people are given four injections a day to keep blood sugars as stable as possible. Diabetes specialists and families try to keep blood glucose levels between 4-8mmol/l for as much as the time as possible, but it is difficult for someone with diabetes to manage this all the time. There is evidence that the closer patients can keep their blood sugars to non-diabetic levels of 4-6mmol/l, the more they can reduce the likelihood of damage to other organs in the body.

In order to keep an eye on the day to day management of diabetes, children with type 1 diabetes and their families are encouraged to check blood glucose levels about four times a day using finger-prick blood tests and a glucose meter, most of which have memories to record results so that they can later be reviewed by a carer or health professional. In this way insulin treatment can be adapted to ensure blood glucose is not running too high (hyperglycaemia) or too low (hypoglycaemia). Doing regular blood tests to estimate the correct dosage of insulin is very important.

Many people with Down's syndrome can be taught to manage their diabetes independently, or with some support from carers. They can be taught to check their blood glucose levels using a glucose meter, and to give their own injections. As well as teaching the person affected, their carers, friends and family can be taught to recognize the symptoms of hypoglycaemia and treat them with glucose or glucagon.

In recent years, there has been a move to use insulin pumps in some children with diabetes. The pumps give very small doses of continuous insulin that can be programmed to vary on an hour by hour basis. At meals, a dose of insulin can be dialled up and given to cover the carbohydrate content of that meal. Pumps are especially useful in very young children and those in whom hypoglycaemia (low blood sugars), because of treatment difficulties, are causing significant management problems. The site of insulin pump infusion lines need to be changed on a 2-3 day basis, meaning fewer injections, although regular blood testing is still mandatory. Insulin pumps should be considered on a case by case basis for children with diabetes and Down's syndrome.

## Who is at risk of Type 1 diabetes?

Currently there is no way of predicting who will develop type 1 Diabetes, or of preventing it. A combination of different genes and some factors in our environment that are, as yet, incompletely identified combine early in life to cause type 1 diabetes.

## Autoimmunity

In many cases diabetes occurs alongside problems with thyroid function. This may be hypothyroidism (underactivity) or less commonly hyperthyroidism (over activity) of the thyroid gland. This is because both problems are caused by the body producing antibodies which destroy vital tissues, the thyroid gland in hypothyroidism and insulin producing cells of the pancreas in diabetes. This autoimmune process seems more likely to develop in people with Down's syndrome, although the reasons for this are not yet clear. Other autoimmune problems such as alopecia and vitiligo may also co-exist. Markers in the blood called antibodies are a sign that a person is at increased risk of autoimmune disorders. It is not until about 80% of insulin producing cells have been destroyed that the clinical symptoms of diabetes appear. There is also an association between Type 1 diabetes and an increased risk of coeliac disease (gluten intolerance), in children with and without Down's Syndrome.

## Genes for type 1 diabetes

There has been a huge increase in information regarding the genes underlying type 1 diabetes. It is now known that combinations of more than 40 genes contribute to susceptibility to the condition. By far the most important genes are called HLA genes and they help control the immune system. A gene on chromosome 21 has been identified. However, we do not know if this discovery has significance in adding to what we know about diabetes in people with Down's syndrome, trisomy 21, who have 3 copies of this gene.

## Type 2 diabetes

Type 2 diabetes is the most common type of diabetes in the general population. It occurs in an older age group, typically those over 40, when the pancreas does not produce enough insulin to meet the body's needs or the insulin is not used effectively by the body's cells. The condition develops more insidiously and is commonly associated with lifestyle factors.

## Treatment of type 2 diabetes

Type 2 diabetes is often connected to being overweight and this can also be the case in Down's syndrome where managing weight in later life often seem to be a problem. Healthy eating, weight control and exercise can help with prevention. If diabetes develops, a sensible change to healthier eating, with advice from a dietetic specialist, and increased physical activity should improve blood glucose levels and cause the diabetes to improve. Some type 2 diabetics require tablets, in addition to diet. There are several different types of tablets that can be tried. Insulin injections might be considered in some people.

## The effects of diabetes

In addition to symptoms caused by high blood glucose levels, such as thirst and passing more urine, diabetes can cause harmful effects to other areas of the body. Long term problems can occur with the eyes, feet, kidneys, heart and blood vessels. Regular checks

should be carried out to look for early signs of these complications so they can be treated, and to ensure the best control of blood sugar possible.

People with Down's syndrome and diabetes should have particularly careful diabetic management, for support with trying to maintain optimum blood glucose control and to minimise the risk of developing further medical complications. The good news is that evidence suggests that children with Down's syndrome and type 1 diabetes often achieve very good blood glucose control.

## Annual health checks for people with Down's syndrome (aged 14 years plus)

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

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

### Who can have one?

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

### The benefits of annual health checks

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

### How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

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

### **What happens next?**

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

### **Who attends the annual health check?**

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

### **How long should an annual health check be?**

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

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

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

Diabetes should be considered as part of a comprehensive and thorough annual health check.

### **What happens after the annual health check?**

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

## **Information about health issues for GPs**

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

## GPs learning disability register

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

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

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

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

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

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

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

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

## Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you



are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

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

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

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

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

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

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