DOWN'S SYNDROME ASSOCIATION

DSMIG UK & IRELAND
The Down Syndrome Medical Interest Group

Diabetes and People who have Down syndrome

October 2026



A Down's Syndrome Association publication

What is Diabetes?



Diabetes is caused by your body either not making enough insulin or not using the insulin it has as well as it should. Insulin is a hormone that is required to allow glucose (that we get from the food we eat) to be absorbed into the cells for energy. When there is not enough insulin and the glucose builds up in the blood, it causes the symptoms of diabetes.

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.

Symptoms of Diabetes

A useful mnemonic is the 'four 'T's:

- **Thirst (drinking more than usual).**
- **Toilet (peeing lots).**
- **Thin (losing weight).**
- **Tiredness.**

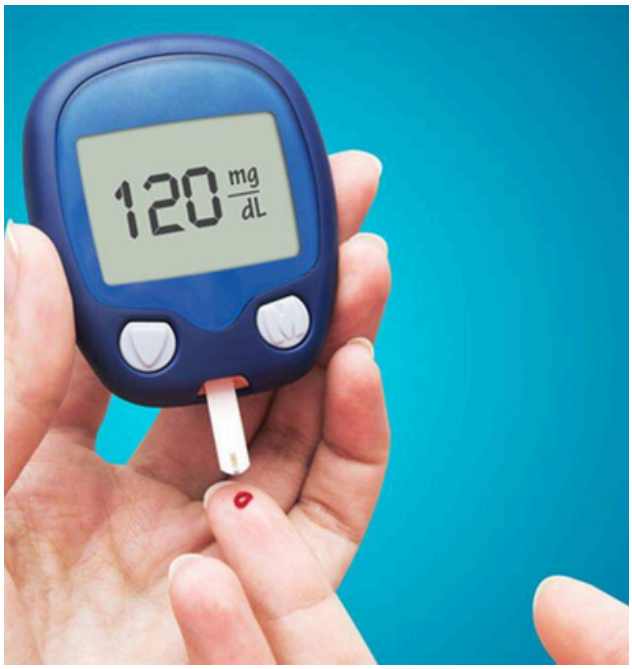
Tests for Diabetes

Blood glucose meters are used to measure the amount of glucose in a finger prick blood sample.

This could be a fasting blood test first thing in the morning or a daytime non-fasting sample.

To diagnose diabetes, the blood glucose concentration must be equal or above 7 in the fasting sample or equal or above 11.1 in the non-fasting sample.

A normal fasting blood glucose level should be between 4-6 millimoles/litre.



In adults, a GP may request a blood test called HbA1c which measures Glycated Haemoglobin (not to be used to diagnose diabetes in children).

The value to diagnose diabetes is greater or equal to 48mmol/mol.

If the results are not clear, then an oral glucose tolerance test can provide further information. This involves drinking a set amount of dissolved glucose (usually 75 grams) and measuring blood sugars after a two-hour period to see 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 by the immune system mistaking the beta cells (which makes insulin in the pancreas) as foreign and destroying them.

This is called autoimmunity. About 10% of cases of diabetes in the UK are type 1. The condition generally develops in children or younger adults and may occur even earlier in those who have Down syndrome.

The signs and symptoms will develop quickly, usually over a few days or weeks.

Treatment





All people with type 1 diabetes require insulin given subcutaneously (under skin) to stabilise blood sugar levels.

The insulin can be given by pen injectors or using an insulin pump.

Usually, people on injections have four a day to keep blood sugars as stable as possible.

Blood glucose levels should then be ideally maintained between 4-10mmol/l however 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.

Everyone with Type 1 diabetes is given the option of using a continuous glucose monitoring system (CGMS) which involves having a sensor inserted under the skin approximately every 10 days. This means that insulin treatment can be adapted to ensure blood glucose is not running too high (hyperglycaemia) or too low (hypoglycaemia). Some people elect to still use finger prick blood tests to monitor glucose levels.



Many children and young people now use insulin pumps to administer the insulin, and these have the capacity to interact with the CGMS system to continuously control blood glucose levels. This would replace the need for four injections a day but requires a new cannula being inserted every three days.

Patients or carers still need to programme the pump to give a bolus dose of insulin (a single larger dose given all in one go) to account for the carbohydrate in meals and snacks. The ratio would be decided by the hospital diabetes team. Insulin pumps should be considered on a case-by-case basis for children and young people with type 1 diabetes and Down syndrome.

Some people who have Down syndrome can be taught to manage their diabetes independently, but they may need significant support from carers especially if using a pump system.Carers, friends and family can be taught to recognize the symptoms of hypoglycaemia and treat them with glucose or glucagon.

Diabetic Ketoacidosis (DKA)

Some children and young people develop a relatively serious medical condition called DKA. They are often dehydrated and have too many ketones (chemical made by the body breaking down fat) in their blood. Doctors will gradually correct the dehydration and ketone excess over 24-48 hours with intravenous fluids and insulin.

To reduce the frequency of DKA at diagnosis, all children suspected of diabetes should be referred to their local hospital on the same day diabetes is suspected (NICE Guidelines).

Who is at Risk of Type 1 Diabetes?

Type 1 diabetes occurs in people with a particular combination of immune system genes and the trigger in the environment is unknown.

Screening for islet autoantibodies has been shown to identify people at risk early and reduce the chance that diagnosis will only be made when they become seriously ill with DKA. Several studies across the UK offer screening and as people who have Down syndrome are at increased risk of developing type 1 diabetes, screening should be considered.

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 gradually.

Treatment

Type 2 diabetes is often connected to being overweight and this can also be the case in people who have Down syndrome who might struggle to manage their weight. Healthy eating and exercise can help with prevention however if diabetes develops the person may need to adapt their diet with advice from a specialist.





Increased physical activity can improve blood glucose levels and positively impact diabetes however some people with type 2 diabetes may require tablets in addition to dietary changes. Insulin injections might need to be considered for some people.

The Effects of Diabetes

The common symptoms of high blood glucose levels include feeling thirsty and passing more urine.



Long term problems can occur in the following areas:

- **eyes**
- **feet**
- **kidneys**
- **heart**
- **blood vessels.**

It is important that people have regular checks to identify early signs of complications and treat quickly.

Ensuring the best control of blood sugar possible will lessen the risk of problems.

The evidence suggests that children who have Down syndrome and type 1 diabetes often achieve very good blood glucose control.

People who have Down syndrome and diabetes should be carefully monitored to minimise the risk of developing further medical complications.

Autoimmunity

Diabetes can occur alongside other autoimmune conditions. This is where the immune system mistakenly attacks healthy tissues and these are more common in people who have Down syndrome. The reasons for this are not clear.

In diabetes the insulin producing cells of the pancreas are attacked.

The autoimmune process can also affect the thyroid gland causing hypothyroidism (underactivity) or less commonly hyperthyroidism.

Other autoimmune problems such as alopecia (hair loss) and vitiligo (loss of skin pigment) may also co-exist.

There is also an association between Type 1 diabetes and an increased risk of coeliac disease (gluten intolerance), in children with and without Down syndrome.

Resources

Easy Read

Getting on with Type 1 Diabetes — Beyond Words

Getting on with Type 2 Diabetes — Beyond Words

Other

Diabetes UK

Improving care for people with diabetes and a learning disability

NHS

Diabetes

Reviewed and updated August 2026

Authors: Dr Kath Gillespie, Diabetes and Metabolism Unit, University of Bristol.

Dr Liz Marder, Consultant Community Paediatrician and Medical Advisor to the DSA; member of the DSMIG UK and Ireland.

Julian Hamilton-Shield, Professor of Diabetes and Metabolic Endocrinology, University of Bristol and Bristol Royal Hospital for Children.





CONTACT US

Down's Syndrome Association

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

0333 1212 300

info@downs-syndrome.org.uk
training@downs-syndrome.org.uk
downs-syndrome.org.uk

Wales
wales@downs-syndrome.org.uk

Northern Ireland
enquiriesni@downs-syndrome.org.uk



A Down's Syndrome Association publication
© Down's Syndrome Association 2026

Photosymbols®
Professional Licence 6132156530743