

# Type 1 Diabetes: A Guide for Families

## What is type 1 diabetes?

Type 1 diabetes is a disease characterized by a high level of sugar in the blood caused by a lack of insulin. *Insulin* is a hormone (a special messenger compound) made in cells (called *beta cells*) in an organ located behind the stomach called the *pancreas*. Nutrients in food are broken down into a simple sugar called *glucose*, which is an important source of energy for the body. Insulin permits this glucose to move from the bloodstream into cells to produce energy. People with type 1 diabetes cannot produce insulin. Without insulin, glucose gets “stuck” in the bloodstream, causing high blood glucose levels.

Type 1 diabetes affects about 1 in 400 children, adolescents, and young adults. Currently, there is no cure. The disease is treated by administering insulin.

## What causes type 1 diabetes?

Type 1 diabetes happens when a person’s immune system “misbehaves.” The immune system produces special proteins called *antibodies*. Normally, antibodies protect the body against infections. However, in type 1 diabetes, the immune system produces antibodies that attack the beta cells in the pancreas. This process may occur quickly or over a period of years. When 90% to 95% of beta cells are destroyed, the body cannot produce enough insulin, and blood sugar levels rise.

## What are the symptoms of type 1 diabetes?

The symptoms of type 1 diabetes are largely caused by the body’s inability to use sugars from food to make energy; high sugar levels in the bloodstream cause sugar and water to spill into the urine. Symptoms may include

- Hunger, at times extreme
- Weight loss
- Increased thirst and urine production
- New onset of bed-wetting
- Dehydration (lack of fluids)
- Fatigue/irritability
- Blurry vision
- Yeast infections

If untreated, symptoms can occur that require immediate medical care, including nausea, vomiting, belly pain, rapid breathing and drowsiness, and loss of consciousness.

## How is type 1 diabetes diagnosed?

The diagnosis is made when a person has symptoms of diabetes with high levels of sugar in the blood and of sugar or ketones in the urine. Diabetes can also be diagnosed using a blood test called a *hemoglobin A<sub>1c</sub>*. This test measures what percentage of the hemoglobin in the blood has glucose attached to it and shows what the average sugar level has been over the prior 3 months. A result equal to or greater than 6.5% is suggestive of diabetes.

If you are worried that your child may have symptoms of type 1 diabetes, bring your child to a doctor right away. Your child’s doctor can check for sugar in the urine or obtain a drop of blood from your child’s finger to check the blood sugar level with a glucose meter (a small portable machine). We advise that you do not try to borrow a glucose meter from a relative or friend to check your child’s blood sugar because the result might be inaccurate or the home meter may not be working properly.

## How is type 1 diabetes treated?

Diabetes is treated by giving back the missing insulin. Insulin is often given as several daily injections using syringes or pens with very thin and short needles that make the injections almost pain free. The injections are most commonly given in the upper part of the arms, in the front of the thighs, and in the fatty skin of the belly. Insulin can also be given continuously via a small machine (often referred to as a *pump*) that gives insulin through a small plastic tube (called a *catheter*), which is placed under the skin by parents or children themselves. The goal of treatment is to normalize blood sugar levels. Patients need to check their blood sugar levels several times daily with a finger stick. To measure blood sugar, a small drop of blood is obtained using a very fine lancet device and then put on a strip, which is then inserted into a home glucose meter. Some people with type 1 diabetes also follow their glucose levels constantly using a continuous glucose monitor, which measures the levels of sugar in the fatty space under the skin through another catheter.

When children with diabetes do not get enough insulin, their blood sugar levels will run high (*hyperglycemia*). When they get too much insulin relative to food intake and activity level, their blood sugar levels can run low (*hypoglycemia*). When hypoglycemia is unrecognized or untreated, very low blood sugar levels can occur sometimes. When the blood sugar level is low, people with diabetes can experience confusion, loss of consciousness, and/or seizures.

A healthy diet is also essential for managing type 1 diabetes. Insulin dosing needs to be matched with the amount of sugars (called *carbohydrates*) eaten. Being physically active is also key. The insulin dose might need to be reduced at times of increased physical activity. Islet cell and pancreas transplantation can cure diabetes, but this technique remains experimental and is carried out mostly in adults in very limited settings. Recently, an insulin delivery system that matches insulin administration to glucose levels using a small computer in an insulin pump has been made available to people in the United States.

## Can type 1 diabetes be prevented?

Thus far, a strategy for preventing the development of type 1 diabetes is not available. Relatives of people with type 1 diabetes are at higher risk of developing type 1 diabetes compared with children and young adults who do not have any relatives with type 1 diabetes in their extended family. The development of diabetes in family members cannot be predicted with certainty, although blood tests that measure diabetes-related antibodies are available to assess the risk of diabetes in unaffected relatives of a person with type 1 diabetes ([www.diabetestrialnet.org](http://www.diabetestrialnet.org)), and research studies of prevention therapies are currently underway.

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