

# Type 1 Diabetes: A Guide for Families

## What is type 1 diabetes?

Type 1 diabetes is a disease caused by a lack of insulin. Insulin is needed to allow sugar to move from the bloodstream into the cells to be used for energy. Nutrients in food are changed into a sugar called glucose. People with type 1 diabetes cannot make insulin, and without insulin, glucose is “stuck” in the bloodstream, leading to a high level of glucose in the blood. Type 1 diabetes affects about 1 in 400 children, adolescents, and young adults under 20 years of age. Currently, once diagnosed, type 1 diabetes is a lifelong disease that cannot be cured. However, the administration of insulin is a very effective treatment for type 1 diabetes.

## What causes diabetes?

Type 1 diabetes is caused by the inability of the pancreas to produce insulin. Insulin is produced in special cells (called beta cells) in the pancreas, which is an organ located in the belly. In children with type 1 diabetes, the immune system “misbehaves.” Normally, the immune system produces special proteins called antibodies that defend the body against infections, but in type 1 diabetes, the immune system attacks its own beta cells by producing antibodies against them. This ongoing attack results in over 90% destruction of beta cells, which may occur quickly or over a period of years, and ultimately leads to an inability to produce adequate levels of insulin.

## Symptoms

The symptoms of type 1 diabetes are largely due to the lack of energy caused by an inability to use the nutrients eaten and by the high sugar levels in the bloodstream pulling water from the body into the bloodstream and spilling into the urine, causing dehydration (lack of fluids). These symptoms include:

- Hunger, at times extreme, and associated with weight loss
- Increased thirst and increased urination – the latter can be missed in infants who are not toilet trained, because parents may not realize that they are in need of more frequent diaper changes; also, “accidents” in a toddler and older children previously toilet trained may be overlooked
- Fatigue
- Irritability or unusual behavior
- Blurry vision (not a common symptom but can occur if the sugar is very high)
- If untreated, the following symptoms can occur that require immediate medical care: nausea, vomiting, belly pain, rapid breathing and drowsiness, and loss of consciousness

## How is type 1 diabetes diagnosed?

The diagnosis is made when a child has classic symptoms of diabetes as described above with abnormally high blood sugar levels and ketones in the urine. Diabetes can also be diagnosed by a test that reflects what the average blood sugar has been in the blood over the previous 3 months. This test is called hemoglobin A1c (HbA1c). A result that is 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 his/her doctor right away, and the doctor can easily check for sugar in the urine or obtain a drop of blood from the 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 the blood sugar, because you may not do it correctly and/or the home meter may not be working properly.

Before a child develops full-blown type 1 diabetes, a phase of prediabetes may be present.

## How is type 1 diabetes treated?

Diabetes is treated by giving back the very hormone that is missing, called insulin. Insulin is given as several daily injections with small syringes 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 can be inserted by the parent or the affected child. Treatment is aimed at normalizing blood sugar levels, but this is not a simple task, and patients need to check blood sugars 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 that is then inserted into a home glucose meter. A healthy diet is also very important in type 1 diabetes, and insulin dosing needs to be matched with the amount of sugar (called carbohydrate) taken in. Being physically active is also key, and insulin often needs to be reduced at times of physical activity.

Some people with insulin pumps also wear continuous glucose monitors that measure the levels of sugar in the fatty space under the skin through another catheter.

Islet cell and pancreas transplantation is an experimental treatment carried out in adults only and in very limited settings throughout 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 di-

abetes 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. Diabetes cannot be predicted with certainty; however, special blood tests are available to measure the risk of diabetes in an unaffected relative of a person with type 1 diabetes.

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