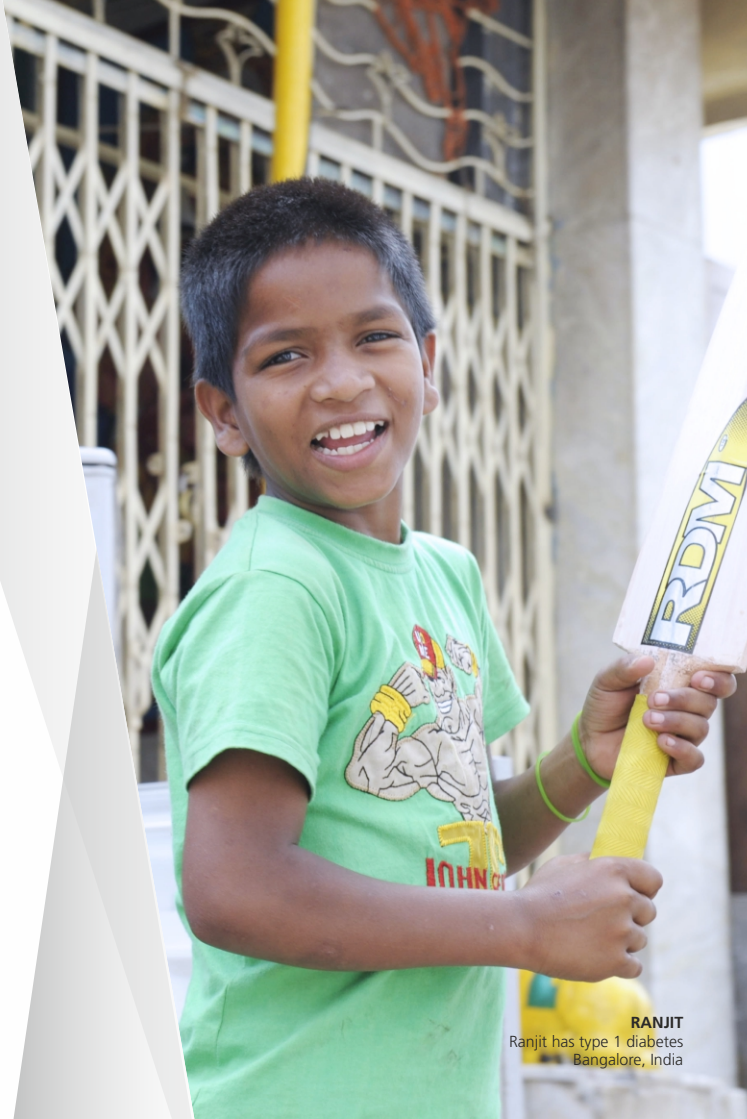
Type 1 diabetes and your child

FAQs for parents of children with type 1 diabetes newly diagnosed



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Finding out that your child has type 1 diabetes can be quite distressing for you and your child. Along with the physical impact, there is also a deep emotional impact. While learning about type 1 diabetes and its management, there are multiple questions which come into your mind. Here are some answers to the most common questions that parents have when they find out their child has type 1 diabetes.

While there is currently no cure for diabetes, research is underway. Perhaps in the near future with the advancement of knowledge, a cure may be found. But for now, it is important to manage diabetes by controlling the blood sugar values and reducing the risk of complications. Do not be carried away by unsubstantiated claims of a cure mentioned by well-meaning friends and relatives.

Q 1. Why did my child develop type 1 diabetes?

The exact cause of type 1 diabetes is not known. We do know that it's not caused by eating too much sugar or any other thing. It can run in families, but there are many times when a child may be the only person in the family to develop type 1 diabetes. It is a condition in which the beta cells of the body are destroyed. Beta cells are found in the pancreas and they produce insulin.

Children with type 1 diabetes can live long, healthy lives with proper treatment which includes their daily dose of insulin, regular monitoring of blood glucose levels along with a balanced diet and regular exercise.

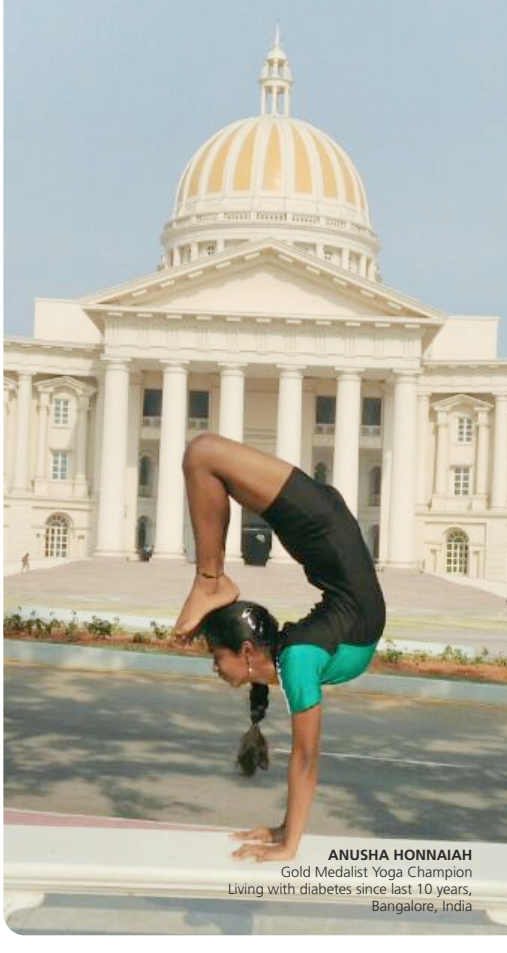
Q2. Is it my fault that my child got diabetes?

Most parents of children who have been newly diagnosed with diabetes live with this guilt. It is very important to understand that the disease is not a result of anything you may or may not have done. Also, till now there is nothing which can be done to prevent it either. It is an autoimmune disease in which the body's own immune cells destroy the beta cells.

Parents are the biggest sources of strength for children cope with diabetes. Strong and positive parents can help children lead healthy and successful lives despite diabetes.

Q3. How long does my child need to take insulin?

We all need insulin to grow and live. For people with type 1 diabetes, their bodies do not make insulin on a continuous basis and hence they need to take it from external sources till a cure is made available.



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After being diagnosed with type 1 diabetes, once the insulin is started, some children with type 1 diabetes may undergo a honeymoon period[1]. This is the time when parents start looking for alternative therapies for their child. In this phase the pancreas is still able to make some insulin and the need of external insulin may reduce dramatically. The honeymoon period is variable, lasting from a few weeks to months. There is no documented case of type 1 diabetes where the honeymoon phase has lasted forever and the need of external insulin has been eliminated and hence it is very important to understand that insulin is the only treatment option currently available for type 1 diabetes.

Q4. How much Insulin is safe for my child?

Insulin is a natural hormone which all of us need. Your doctor will calculate the first insulin dosage for your child taking into consideration the weight, age, diet and treatment goals. Insulin requirement is different for different children and the best insulin dose is a matter of trial and error. Monitoring blood sugar levels on a continuous basis will help you and your doctor to see how food, exercise and insulin affect sugar levels. This helps to adjust the insulin dose to achieve near normal blood sugar goals.

Two important things to understand are

- The Insulin dose for the child will increase in the growing years with increase in height and weight. This is normal
- Self-adjustment of the insulin dose according to diet is fine under the guidance of the treating physician as long as the weight of the child is normal according to its height and age.

Q5. Is there any easy way to take insulin?

Insulin as a medicine cannot be taken by oral route ie as pills because insulin gets destroyed in the gastrointestinal tract. The traditional and most predictable method for taking insulin is by subcutaneous injections, administered into the layer of fat between the skin and the muscle. With type 1 diabetes, one needs to take insulin on a daily basis. One can take insulin in many ways:

- Syringe • Pen • Pump

The most widely used methods of insulin administration include vials and syringes and insulin Pen delivery devices into the subcutaneous tissue.

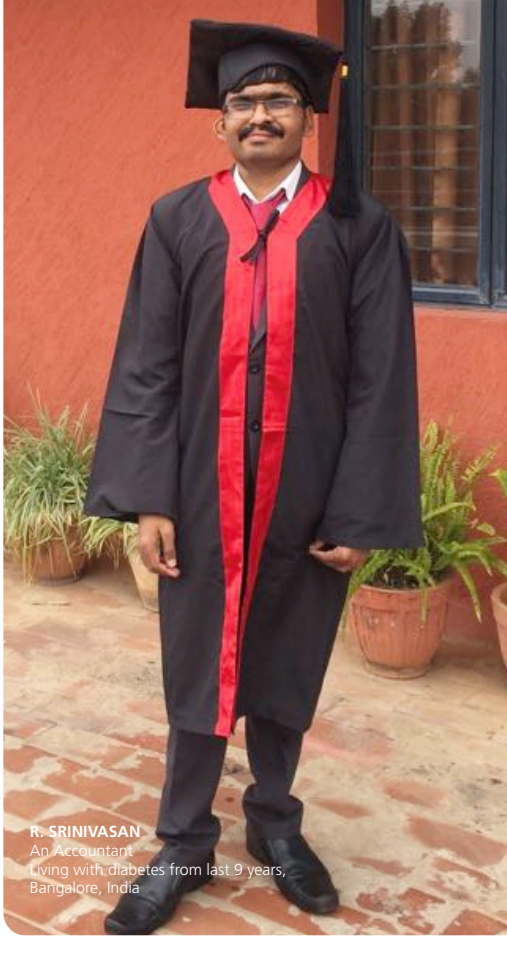
Q6. Why do children with diabetes need 4-5 insulin injections per day while others take only 1-2 insulin injections per day?

The goal of treatment is to maintain the best possible level of glucose control by providing the appropriate insulin at the appropriate time to help them live healthy, long and near normal lives.

In general, there are two types of insulin treatment plans:[2]

1. Intensive insulin treatment - in this regimen, the child needs to take three or more doses of short-acting insulin along with the main meals per day and one or two doses of long-acting insulin for maintaining the requirement of insulin throughout the day. The doses of the short-acting insulin can be adjusted according to the food eaten and activity. Although it seems tough, but this regimen is best for children and adolescents as there is an absolute insulin deficiency in children with type 1 diabetes. This regimen provides control with flexibility.

2. Conventional insulin treatment – in this regimen, two doses of premixed insulin (short and long acting e.g. 30/70) or other combinations split mix are given before breakfast and dinner. Children on this regimen need to have a fixed diet at a particular time, with minimum variations in activities, to achieve optimal glucose control. This regimen, although seems to be easy, but it is very difficult for children to have a fixed diet and activity throughout the day.



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Q7. If my child stops eating everything sweet, still will he / she need insulin?

The fact is that all foods provide carbohydrates. Whenever a person eats any carbohydrates, blood glucose rises. If there is enough insulin present in the body naturally or provided by injections, the carbohydrates will be utilized and consequently the blood sugar will not rise. However, if your body is producing less insulin or not utilizing it efficiently, then the blood sugar is bound to rise even if you do not eat sweets at all.

Q8. What is the most suitable age for a child to take over his or her own daily management?

Ultimately, every child needs to learn self-management of type 1 diabetes as he or she grows up and becomes independent. It is suggested that children with type 1 diabetes can participate in diabetes management from the beginning in a positive way according to his or her age.

A child in the pre-kindergarten years, may be able to participate in his or her own care by indicating food preferences, checking blood glucose, and choosing a finger-prick[3] or injection site. In next few years[4] children can manage their injections successfully in later periods by sharing the responsibilities, such as preparing the injection, choosing the site, etc. The ADA (2004) states that the child can start taking responsibility for insulin administration at around 10–12 years of age, but that this responsibility should be given gradually.

Studies have demonstrated that parental involvement is necessary throughout childhood and adolescence to assure appropriate[5] self-management and blood glucose control.

The goal should be a gradual transition toward independence in management through middle school and high school.[6]

Q9. Can children with diabetes do well in studies?

Diabetes is a disorder which can be managed and does not have any effect on academic performance, if managed well. There are ample examples where a child with type 1 diabetes has become a doctor, an engineer, or a sports person and excelled in the chosen field. One very important thing is that since a child spends more than 1/3rd of his/her day at school, teachers should know about diabetes in the child and also know about the management of hypoglycaemia and hyperglycaemia. This is going to be helpful for the child.

Q10. Can my child get married and what are the chances of his/ her child to get affected by type 1 diabetes?

Children with diabetes can definitely have a life partner and can also have babies. There are ample examples of young men and women with diabetes, having a healthy baby.

It is always good to look upon positive aspect of the statistics available. Any decision should me made depending upon your wish for your life , your health (as discussed with your doctor) and not just on statistics.

- If father[7] has type 1 diabetes, risk of child developing diabetes is 1 in 17 (ADA)
- On the other hand, if the mother[8] has type 1 diabetes and is 25 or younger when the child is born, the risk is reduced to 1 in 25 (4 percent) and if the mother is over age 25, the risk drops to 1 in 100

As a parent, we always think and try to provide best for the child, but we need to understand that marriage is a decision of two adult individuals, It is always better as parents, that we focus on making our children educated, self-dependant and good human beings and the rest follows.

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Key things you need to learn/do following your child's diagnosis of type 1 diabetes

Please ensure that you feel confident in the following aspects of your child's diabetes and have informed the relevant people of your child's diagnosis. If you have any questions or concerns, speak to your healthcare professional.

Injections

Ensure you feel confident injecting your child with insulin and know what dose is required and when

Blood glucose monitoring

Ensure you feel confident using the blood glucose meter and know when to test and what the results mean

Meal planning

Ensure you understand how to balance food intake with insulin doses

Managing low blood glucose

You will need to ensure that you have a supply of sugary snacks or fruit juice at home to help manage episodes of low blood glucose (hypoglycaemia).
Your child should also carry supplies with them at school or away from home (e.g. Hypobox)

Contacts

Ensure you have the contact details of your doctor and nurse. It is important to know whom to contact in case of emergency. You and your child should carry these contact details at all times.

Whom to tell

Ensure you inform anyone involved in your child's care about their diagnosis of type 1 diabetes:

- Assistants/caregivers
- School teachers
- Other members of your family

The 'What about diabetes at school?' information leaflet can help you to explain your child's condition and their needs to teachers

Diabetes Dictionary

Autoimmune disease: A disorder in which the body attacks its own cells. In type 1 diabetes, the body mistakenly damages beta cells in the pancreas that make insulin, resulting in high blood glucose.[1]

Basal insulin - See 'Long-acting insulin'.

Beta cells - Cells in the pancreas that make insulin.

Blood glucose - The concentration of sugar in the bloodstream - the body's main source of energy.[2]

Bolus insulin - See 'Rapid-acting insulin'.

Carbohydrate - Type of food that provides the body with energy. Carbohydrates are mainly sugars and starches that are broken down into glucose, a simple sugar that the body's cells use as fuel.[3]

Carbohydrate counting - Carbohydrate counting is one of the many meal planning options for manging blood glucose levels used by people taking mealtime insulin.

Dawn phenomenon - The early-morning (4 to 8 a.m.) rise in blood glucose that occurs in some people.

Diabetic KetoAcidosis (DKA) - A serious life-threatening condition, where the body is unable to use the blood glucose for energy because of lack of insulin. So the body starts to burn fat as fuel instead. This breakdown of fat leads to the production of ketones and a build-up of acids.[4,5] Nausea and vomiting are typical symptoms. Checking ketones in the urine blood can help to distinguish DKA from other causes.

Fasting blood glucose (FBG) - This is the blood sugar level after not eating anything for at least 8 hours. This test is often used to help diagnose diabetes.[6]

Glucagon - A hormone that raises the levels of blood glucose in the body by releasing stored glucose (glycogen) from the liver.[10] Injectable glucagon may be given when a child has episodes of severe hypoglycaemia.

Glucometer - Device to check blood glucose levels at home.

HbA_{1c} - This is a blood test to measure blood glucose to estimate levels of control over the past 2–3 months and is a marker of the risk of developing complications.[6] HbA_{1c} is formed when glucose and haemoglobin in the blood come together. When glucose sticks to haemoglobin, the haemoglobin becomes 'glycosylated', also known as HbA_{1c} or A1c. Levels in healthy individuals usually go up to 5.6%.

Hormone - A chemical released in the body which helps to control functions in other cells in the body. Insulin is a hormone which helps cells to remove blood glucose from the bloodstream so other cells can use it as fuel.[6]

Hyperglycaemia - This term is used for high blood glucose or sugar. This occurs in diabetes when there is a lack of insulin so glucose is not removed from the bloodstream.[5]

Hypoglycaemia - This term is used for low blood glucose or sugar. Hypoglycaemia can be triggered by taking too much insulin, inadequate food intake or by participating in unusually strenuous or prolonged activity or exercise.[7]

Insulin-dependent diabetes - This term was used in the past to describe type 1 diabetes.[2]

Juvenile onset diabetes - This term was used in the past to describe type 1 diabetes.[2]

Ketones - Chemicals produced when there is a shortage of insulin in the blood and the body breaks down body fat for energy. High levels of ketones can lead to diabetic ketoacidosis and coma.[2]

Lancet - A spring-loaded device used to prick the skin (typically on a finger) with a small needle to obtain a drop of blood for blood glucose monitoring.

Long-acting insulin - This type of insulin is usually given once or twice a day to provide a constant supply of insulin.[4]

Monogenic diabetes - This is a rare type that is often misdiagnosed as type 1 or type 2 diabetes. Different types of monogenic diabetes include neonatal and MODY (maturity onset diabetes in the young). The body has more than 30,000 individual genes. Mutations in more than 20 genes have been linked to monogenic diabetes.

Non-insulin dependent diabetes - This term was used in the past to describe type 2 diabetes.[2]

Oral AntiDiabetics (OAD) - Oral medications that help to control blood glucose (e.g metformin). They are generally used for type 2 diabetes, sometimes in addition to insulin.[7]

Pancreas - An organ in the body that stretches across the back of the abdomen behind the stomach. The pancreas is where insulin and digestive enzymes are made.[2]

Post-Prandial BLOOD Glucose (PPG) - The level of blood glucose measured 1 to 2 hours after eating.[2]

Prefilled (disposable) insulin pen - This type of pen comes with the insulin already in it. These pens are thrown away when all the insulin doses have been used.[8]

Premixed insulin - A mixture of a rapid-acting insulin and a long-acting insulin, usually injected before breakfast and dinner.[4]

Pump - A device that delivers insulin via a tube that is inserted under the skin in the abdomen.[4]

Rapid-acting insulin - This type of insulin acts quickly. It is typically given around mealtimes to help manage blood glucose levels.[4]

Reusable (durable) insulin pens - This type of pen requires cartridges to be inserted. When all the doses are used, the cartridges are thrown away and replaced.[8]

SMBG - Self Monitoring of blood glucose levels at various times of day like , Fasting, Post Breakfast, Pre Lunch, Post Lunch, Pre Dinner, Post Dinner and at 3.00 AM.

Type 1 diabetes - This type of diabetes occurs when the body produces little or no insulin at all. It is caused by an autoimmune disorder, in which the body attacks the beta cells in the pancreas that make insulin.[1] Type 1 diabetes is the most common form of diabetes in children.[9]

Type 2 diabetes - This type of diabetes occurs when not enough insulin is being made by the beta cells in the pancreas or the body stops using insulin properly. This type is more commonly diagnosed later in life.[2]

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For more queries about living with diabetes, you can write to us at:

diabeteseducatorindia@novonordisk.com

For queries regarding treatment, ask your doctor

For more information, you can visit our websites at:

http://cdicindia.org/

http://nnef.in/

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