



Start With

Positive Outlook

A handbook to help you and your loved ones live confidently with

TYPE 1 DIABETES



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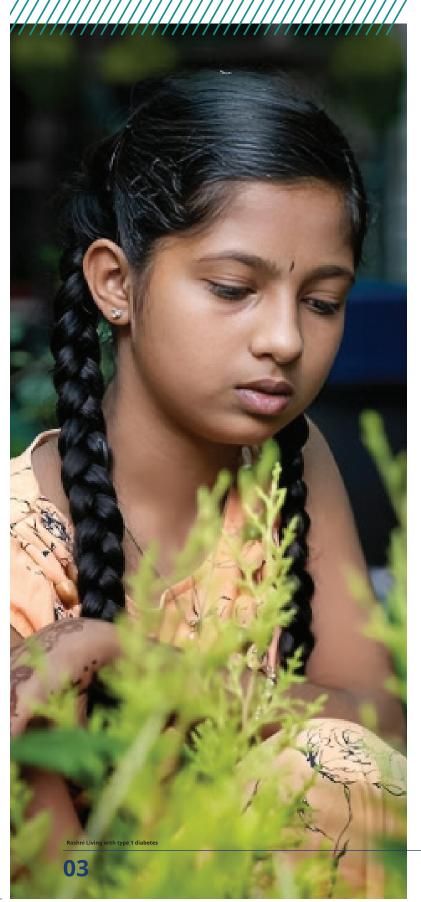
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A WORD FROM ROSHNI WHO HAS TYPE 1 DIABETES¹

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Dear Parents,

My name is Roshni and I am sixteen years old. When I was only four years old, I was diagnosed with type 1 diabetes. I can only imagine how difficult it must have been for my parents when they found out that I had this condition. They were new to diabetes and didn't know how to take care of me. I was too young to understand the situation and it was challenging for all of us.

However, I want to assure you that there is hope and life can be beautiful even with diabetes. My doctors helped us a lot and through one-on-one counselling, I met many children who were like me. It was a relief to know that I was not alone, and I gained confidence to live and dream big. My doctors not only treated me but also helped me to grow in different fields and showcase my talents. I know it can be tough to see your child not being able to eat sweets, but let's focus on the positive aspect that he/she is able to eat all the food that keeps them healthy. I urge you to stay positive and always remember that you are not alone. Encourage them to try new things, explore their interests, and set ambitious goals. With proper care and the management, diabetes should not limit their potential.

Sincerely, Roshni



About This HANDBOOK

- This booklet is for you if you're going through a diagnosis of your child with Type 1 Diabetes, or have already been diagnosed with it. It will also answer many of your questions, if you're the relative or caregiver of someone with Type 1 Diabetes.
- Whatever your situation is, you might be going through a huge range of emotions. Among them could be anger, shock or fear.

YOUR CHILD CAN DARE TO DREAM NEWER DREAMS

Having Type1 Diabetes doesn't mean that one can't achieve thier dreams, whether your child wants to be a parent, pilot, scientist, or anything else! It shouldn't define or limit them.

TYPE 1 **DIABETES BASICS**^{1,2,3}









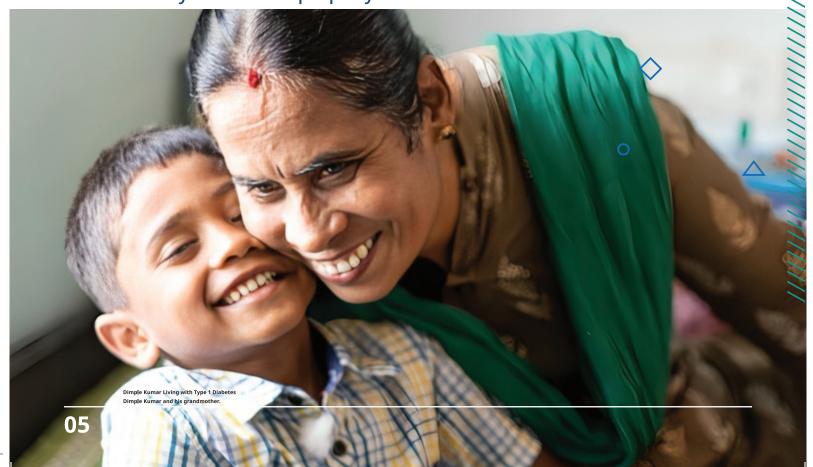
(P) What is Type 1 diabetes?^{1,2,3}

Type 1 diabetes is a chronic disease that occurs when your body cannot make insulin or makes very little insulin. Type 1 diabetes can be managed by following your healthcare professional's advice.

Type 1 diabetes - What's going on in your body?

When you have type 1 diabetes, your immune system attacks cells in the pancreas that produce insulin, the hormone that helps cells take up glucose, which is then converted to energy for the body's cells.

To understand how type 1 diabetes affects the body, we need to • understand how insulin and blood glucose levels affect the body's ability to function properly.





Symptoms of Type 1 diabetes¹

 In most cases, type 1 diabetes develops early in life and is often diagnosed during childhood.¹



IF YOU OR A LOVED ONE EXPERIENCE ANY OF THESE SYMPTOMS² PLEASE SEEK MEDICAL SUPPORT IMMEDIATELY



Tiredness & fatigue

As energy from glucose cannot reach your bodys cells



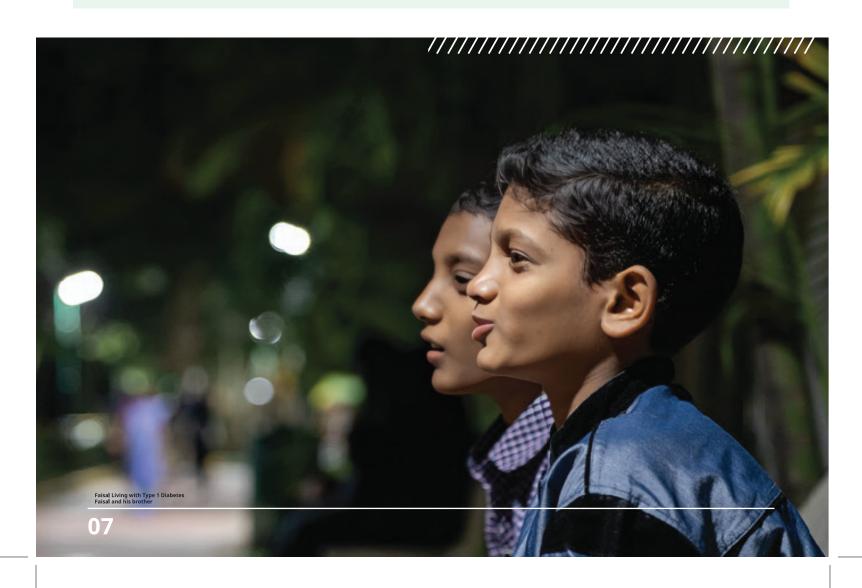
Diabetic Ketoacidosis

As ketones are released when body uses non-glucose energy sources



Blurry vision

Caused by high glucose levels in the fluid of your eye



WHAT CAUSES TYPE 1 DIABETES?



- The disease starts when the immune system attacks cells in the pancreas that produce insulin, the hormone that helps cells take up glucose, which is then converted to energy for the body's cells. As more insulin producing cells in the pancreas are destroyed, blood glucose levels increases and the symptoms of type 1 diabetes begin to appear.¹
- Genetic and environmental factors are suspected to play a role in why a person develops type 1 diabetes.¹

DIAGNOSING TYPE 1 DIABETES

- If your child show signs of having type 1 diabetes, your doctor may use blood or urine tests to diagnose it. There are several ways this can be done. An initial test can be a simple blood glucose test. If test results are above normal and one has the common symptoms, one may be diagnosed with type 1 diabetes.^{1,2}
- If one does not have the common symptoms, but blood glucose or urine blood glucose levels are high, additional blood tests can be taken to measure HbA1c levels. HbA1C is a measure of how well controlled your blood glucose has been over three months, and it gives a good idea of how high or low, on average, your blood glucose levels have been. This chart shows the blood glucose cut off levels for diagnosing Type 1 Diabetes.

Indicator	Diabetes
Fasting plasma glucose	126 mg/dl or greater
Casual or random plasma glucose & symptoms	200 mg/dl or greater
HbA1C	6.5% or greater



LIVING WITH TYPE 1 DIABETES

Since type 1 diabetes can develop quickly without any clear warning signs, getting a diagnosis may come as quite a shock.⁵ The best thing that you can do is take control of the situation and learn as much as possible about type 1 diabetes, the treatment options and how it can affect daily life. Talk to your doctor for more information and advice. There are also many resources available for and by diabetes communities worldwide. The more you know, the more prepared you will be to deal with the challenges ahead.

With good management of blood glucose levels and an overall healthy lifestyle, most people with type 1 diabetes can live a long and active life.



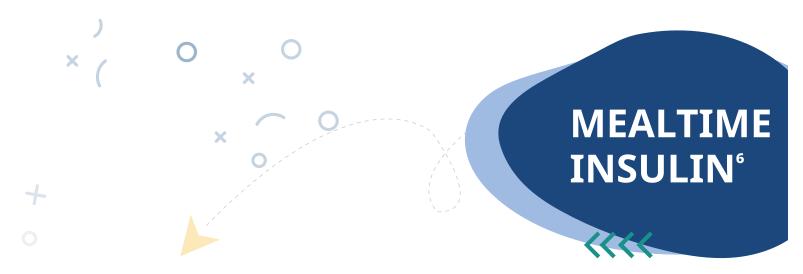
WHAT IS INSULIN TREATMENT?

• Insulin is the treatment for type 1 diabetes¹. Without it, people with type 1 diabetes wouldn't survive¹. Insulin treatment aims to get as close as possible to the natural insulin response of someone without diabetes. This can help people with type 1 diabetes keep insulin levels balanced and maintain healthy blood glucose levels, which is important to avoid associated short and long term problems.





- Intermediate acting- Acts for 12- 24 hours and usually has a peak.
 - Long Acting Acts for 20-24 hours and peak is there.
- Ultra long acting Acts for 36 42 hours with minimum peak.



- Regular (short-acting) insulin- It needs to taken 20 30 minutes before food and acts upto 8 hours
- Rapid-acting insulins-Rapid-acting insulins should be given ideally 10–15 min before meals or immediately before meals and have shorter duration of action (5 hours)
 - Ultra-rapid-acting insulins- They act even more fast and can be given immediately before meals (2 min before* and 20 minutes after starting the meal)

MONITORING

THE MAIN GOAL OF MANAGEMENT OF TYPE 1 DIABETES IS ACHIEVING BLOOD GLUCOSE LEVELS IN TARGET RANGE ALONG WITH OPTIMAL GROWTH AND DEVELOPMENT OF CHILD. THREE WAYS TO ACHIEVE THESE

SMBG – Self Monitoring of blood glucose by glucometer.



- It should be assessed at least 6 times a day or as your doctor recommends.
- Recommended target glucose values are between 70–180 mg/dl any time, with a narrower fasting target range of 70–144 mg/dl.

CGM – Continuous Glucose Monitoring



- Although CGM use helps in better HbA1C but CGM accuracy is an important consideration, especially in the hypoglycemic range,, so blood glucose testing by prick is needed in such situation. Infact blood glucose testing by prick is recommended in both hyper and hypoglycaemia but CGM gives invaluable information as how various foods, activities and insulin levels effect blood glucose.
- One can use CGM on continuous basis and also intermittently.

HbA1c (Glycated hemoglobin)



- It is a test which gives average blood glucose levels of last 2-3 months.
- Target HbA1C for most young people with diabetes should be <7.0%. In case of very young children or in special situation your doctor may suggest, individualized targets.</p>



FIRST QUESTIONS

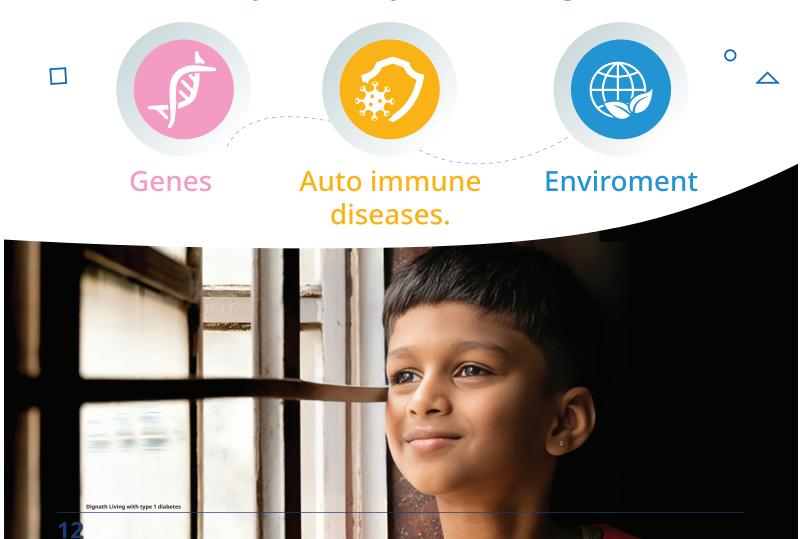
Q. DID WE, AS PARENTS, DO SOMETHING WRONG THAT RESULTED IN OUR CHILD HAVING TYPE 1 DIABETES?



NO

- 1 Type 1 diabetes is an autoimmune disorder.1
- 2 There are many children with type 1 diabetes where there is no one in thier family having type 1 diabetes.8
- 3. It is different from type 2 diabetes.9

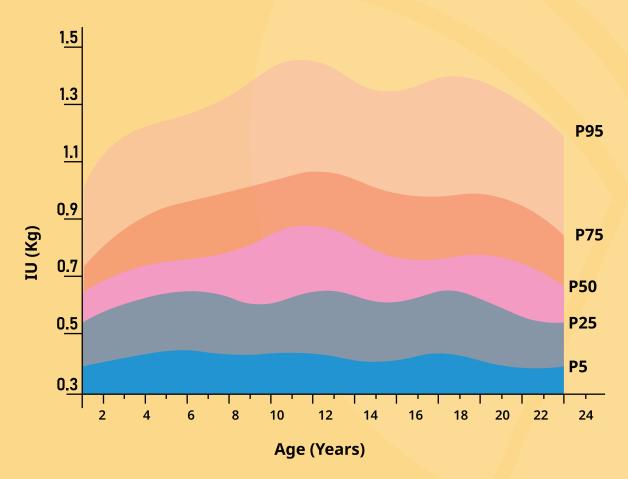
So don't blame yourself for your child's diagnosis.



Q. DOES AN INCREASED REQUIREMENT OF INSULIN

in children with Type 1 Diabetes indicate that something is wrong?

- The most important goal for children and people with diabetes is keeping near- normal blood glucose levels in order to feel well and avoid long-term diabetes complications. Need of insulin may differ depending on age, weight, food and activity.¹⁰
 - In children with type 1 diabetes insulin dose increases as the child grows with increase in height and weight followed by decrease after puberty.¹⁰
- Insulin doses also increase in temporary situation like Illness, Stress, Surgery.¹¹



Insulin requirement per kilogram body weight and day (IU/kg): all patients; diabetes duration >2 years; 5th, 25th, 50th, 75th, and 95th percentile¹²

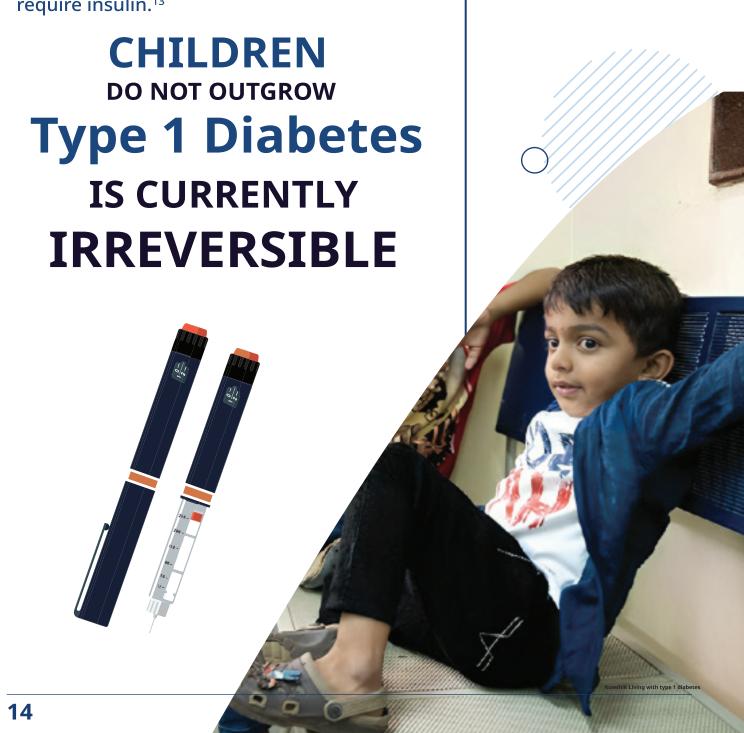
Q. IS IT POSSIBLE FOR CHILDREN WITH TYPE 1 DIABETES TO OUTGROW THE NEED FOR INSULIN ONCE THEY BECOME ADULTS?





NO

- Type 1 diabetes is different from type 2 diabetes and children and people with type 1 diabetes always require insulin.¹
- If type 1 diabetes occurs in adulthood, they require insulin.¹³



Q. CAN CHILDREN WITH TYPE 1 DIABETES HAVE ANYTHING SWEET?

- With the right amount of insulin and planning, children with diabetes can enjoy all the foods in moderation.
- Also, people with diabetes need fast-acting forms of sugar (orange juice, candy, or glucose tabs) to treat hypoglycemia (low blood glucose).¹⁵
- Some people may choose not to eat any sugar-rich foods for a variety of reasons- e.g. they do not like it. Others might plan and take extra insulin for a piece of cake on special occasions.¹⁴

Q. CAN CHILDREN WITH TYPE 1 DIABETES EAT ANYTHING SINCE THEY ARE ON INSULIN?

Balanced diet is essential for all children including children with diabetes.¹⁴

While some parents are afraid to indulge in occasional treats, others take an opposite approach.

Growing problem of today's world is obesity. Many children with type 1 diabetes are also becoming overweight, which means we have to fight both diabetes and the obesity.



Q. IS TYPE 1 DIABETES CURABLE?¹⁶



NO, CURRENTLY, IT IS NOT



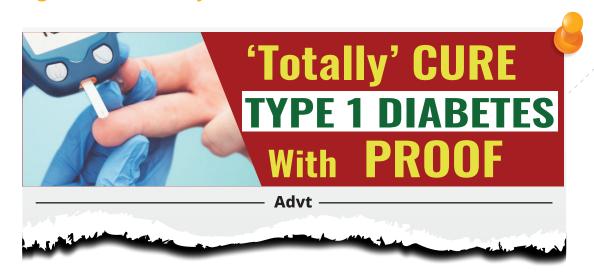
When a child is newly diagnosed with type 1 diabetes, parents want a cure¹⁷ and once they start searching for cure. Many things appear to be working but they work due to

Honeymoon
period. 18
(When body produces some insulin for some time – 1 month – 6 months in most cases)

Excessive exercise.

Diet rich in low carb options.

• We all know Diet and exercise are essential part of diabetes management, but they are not substitute of insulin.



- Beware of such advertisements.
- Please keep monitoring blood glucose level on daily basis.
- Please continue with your insulin and other treatment as prescribed.
 - Or Discuss with your doctor and diabetes educator.

Q. IS IT TRUE THAT TYPE 1 DIABETES CAN BE CURED THROUGH STEM CELL THERAPY?



- There are many centers even in India which are offering it and the cost is enormous.
- Autoimmunity is not addressed in this process and so it is not completely successful.
- Fact is this process is still in TRIALS.¹⁹



We are on our way yet have not reached our destination, so please wait. Ask your treating doctor before going for any treatment.



Q. DOES HAVING TYPE 1 DIABETES MEAN CHILD IS LIKELY TO GET ILL?²⁰

- Having type 1 diabetes does not mean you're likely to catch more infections than usual²¹ if your child has kept blood glucose levels in normal range.
- The significance of illness for children with diabetes is that it can make the management of blood glucose levels more difficult – mostly high but low also and this can result in

Feeling more sick- So you'll have to take extra care, particularly if your child is sick.

LEARN ABOUT SICK DAY RULES²¹



Check your blood glucose level every 1-2 hours necessary (even more frequently for pregnant women & children).



Never completely stop insulin. insulin dose needs to be adjusted according to blood glucose values



Make sure you take in enough carbs and drink enough fluids. If your glucose level is high, stick with sugar-free drinks. If your glucose is low, drink carb-containing drinks.



Check your blood or urine ketone levels every 4 hours. Take rapid-acting insulin if ketones are present. Remember to drink plenty of water to flush out the ketones out of your system.

Q. IS IT TRUE THAT CHILDREN WITH **TYPE 1 DIABETES CANNOT HAVE FUN OR GO OUT?**

NO, IT IS NOT TRUE

We all carry wallet, cell phone, toothbrush and pair of clothes when we go out to stay with friends and relatives.

What needs to be added to the kit²² is as follows:



Your Insulin, syringe, pen.







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TYPE 1 DIAGNOSIS & HOW YOU'RE FEELING





YOU MIGHT:23

Feel sorry for yourself and ask 'why me'?

Feel angry and want to lash out at people.

Feel grief because you don't see your child as a healthy, carefree person anymore. Go into denial about your diagnosis.

These reactions are somewhat normal²² if you are able to do your duties and daily tasks. Talk to your healthcare provider for sometime, and people in similar situations. In case , your symptoms are incapacitating (you are unable to do your essential daily work) , take professional help

- Living with T1D can be challenging at times, but with the progress made in medical science and technology, it is now more manageable disease.
- Each day may present different circumstances, requiring careful planning and adjustments to ensure you or your child can continue to live life to the fullest with type 1 diabetes. Daily management of type 1 diabetes involves regular monitoring of blood glucose levels to avoid severe high or low blood glucose levels and associated complications. If blood glucose levels fall outside the target range, it may be administer insulin necessary carbohydrates. Despite careful attention, people with type 1 diabetes can still experience dangerously high or low blood sugar levels, but with proper care and management, they can continue to live healthy and fulfilling lives.



ADVOCACY GROUPS



THIS IS COMPILATION OF OPEN RESOURCES.
YOU CAN FIND COMMUNITIES AS PER YOUR REGION

- 1. Indian Society of paediatric and adolescent endocrinology
- https://ispae.org.in/
- 2. Type 1 Diabetes Foundation of India
- Type 1 Diabetes Foundation of India | t1dfindia
- 3. Diabesties
- **◯** D1ABESTIES | When Passion Meet Purpose and Purpose Meets People (diabesties.foundation)
- 4. Diabetes Fighters' Trust, Gaziabad
- D Fighter Trust D Fighter Trust (dfighterstrust.org)
- 5. Yog Dhyan Foundation
- The Yog Dhyan Foundation: Empowering Lives



- 6. Blue Circle Foundation
- **☑** Blue Circle Diabetes Foundation
- 7. Juvenile Diabetes Foundation, Mumbai
- ➡ Home Three Juvenile Diabetes Foundation, (jdfmumbai.org)
- 8. Nityasha Foundation
- Nityaasha Foundation a registered, charitable trust
- 9. Idhayangal trust
- Idhayangal.org, Idhayangal





NEW WORDS EXPLAINED¹

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- You may come across some words that are commonly used when discussing the treatment and management of type 1 diabetes.
- We've created an alphabetical list of these words, grouped by topic, to help you understand them better.

SCIENTIFIC TERMINOLOGY

AUTOIMMUNITY:24

Immune responses against a person's own healthy cells and tissues. In type 1 diabetes, the autoimmune response targets the insulin-producing beta cells of the pancreas.

• • • •

BETA CELLS:24

▶ These cells are located in the pancreas, and their primary function is to synthesize, store and release insulin. In type 1 diabetes, beta cells are destroyed and with them the body's ability to produce insulin.



GLUCAGON:²⁴

A hormone produced by the alpha cells in the pancreas that raises blood-glucose levels. It's available by prescription, and may be used to treat severe low blood glucose (hypoglycaemia).

HbA1C:²⁴

▶ Measuring HbA1C in the blood is used to reflect average blood-glucose levels over a period of three months in people with diabetes.

INSULIN:24

▶ A hormone produced in the pancreas, which regulates the amount of glucose in the blood.

LIVING WITH TYPE 1 DIABETES

Basal:24

 Basal insulin (also known as background insulin) keeps blood-glucose levels stable during periods of fasting, such as between meals or during sleep. It plays a vital role in managing type 1 diabetes.

Blood Glucose Monitoring:24

• Monitoring lets a person know when insulin may be needed to correct high blood glucose or when carbohydrates may be needed to correct low blood glucose. Knowing your blood-glucose levels and acting accordingly are among the most important ways to manage diabetes.

Bolus:24

People with type 1 diabetes need to take short/ rapid / ultra rapid acting insulin with a meal or snack, to cover an expected rise in blood-glucose this is called a bolus.

Carbohydrate Counting:24

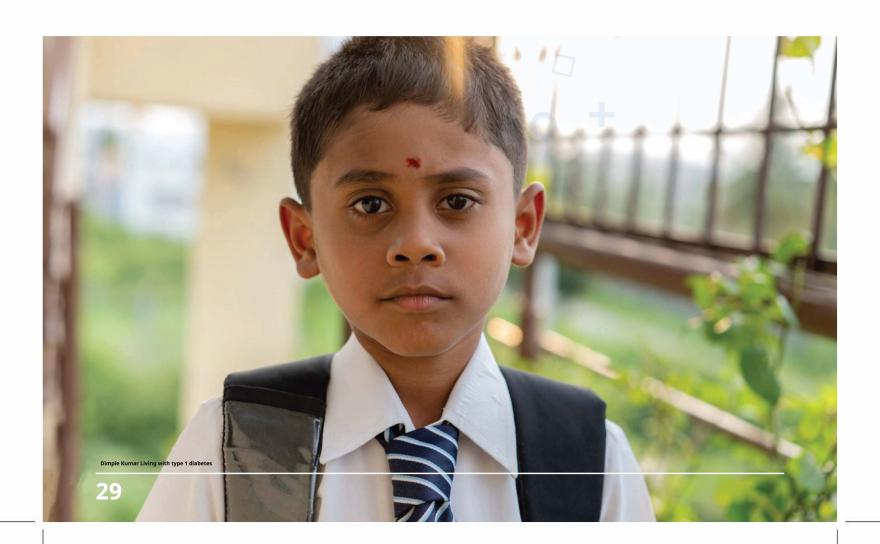
People with type 1 diabetes must count each carbohydrate gram they eat or drink. Based on that count, they dose insulin using an "insulin-to-carb" ratio, which helps them maintain stable blood-glucose levels after eating. The Insulin-Carb-ratio is individualized for each child according to age, sex, pubertal status, duration of diagnosis, and physical activity and your doctor will help you find it. This ratio changes as the child grows

Continuous Glucose Monitor (CGM):24

This device will automatically track your blood-glucose levels every few minutes, day and night, allowing users to see whether their levels are trending high or low before they become dangerous. CGM use has significantly improved diabetes management, helping people avoid blood-glucose highs and lows and the complications that these bring.

Honeymoon Phase:²⁴

For some people, there is a period of time shortly following type 1 diabetes diagnosis when the pancreas is still able to produce enough insulin. It typically lasts a few months to a year post-diagnosis, after which the person with type 1 diabetes is dependent on external insulin to survive.





DIABETIC KETOACIDOSIS (DKA):24

• A life-threatening condition due to uncontrolled high blood glucose levels and shortage of insulin, causing symptoms like dehydration, nausea and vomiting, confusion and difficulty breathing.

HYPERGLYCAEMIA:²⁴

• This is the term for high blood glucose. It is important for people with type 1 diabetes to be aware of their blood-glucose levels and keep them within a normal range, to avoid the complications that can ensue.

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HYPOGLYCAEMIA:²⁴

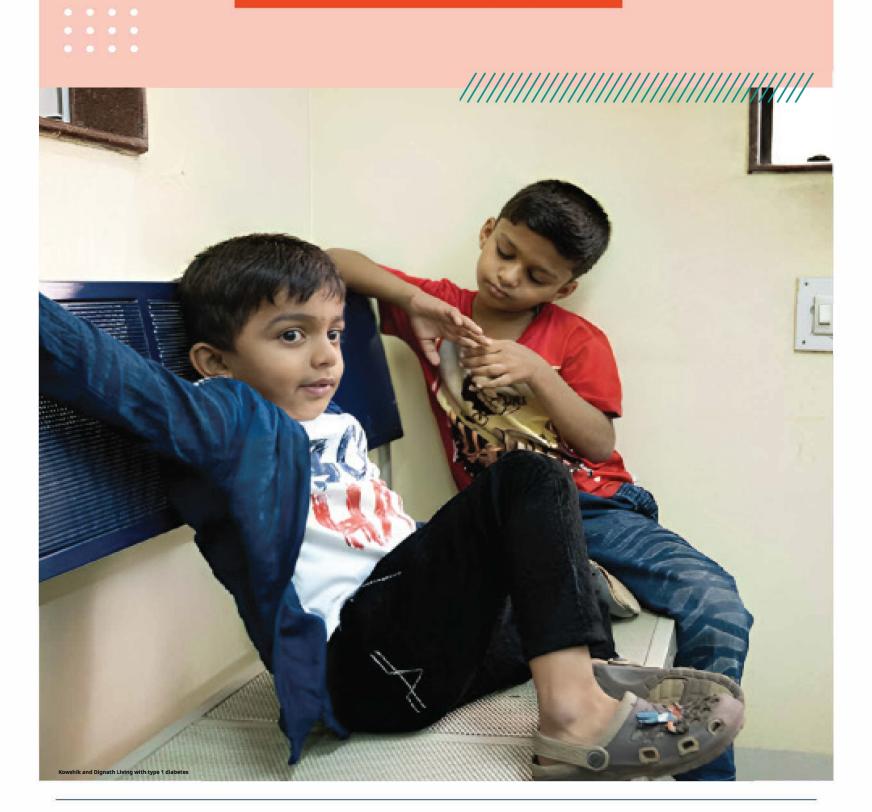
• This is the term for low blood glucose and can arise if one takes too much insulin. Most of the time, low blood glucose is caught early on with symptoms such as sweating, fatigue, hunger and/or irritability. Action is then taken to bring the blood glucose back to normal range.

HYPOGLYCAEMIA UNAWARENESS:24

Some people cannot tell when their blood glucose is too low. This is called "hypoglycaemia unawareness."

We have compiled a list of additional resources to help you navigate Type 1
Diabetes (T1D) at all stages of life. These resources, available online at <u>Welcome</u>
to the Novo Nordisk Education Foundation(nnef.in) include educational tools
and printable resources, which we hope will be useful and informative.

https://nnef.in/



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