

# Begin with Hope

Your Guide to Living Confidently with Type 1 Diabetes (T1D)



## Who We Are

As the leading global type 1 diabetes research and advocacy organization, Breakthrough T1D helps make everyday life with type 1 diabetes better while driving toward cures. We do this by investing in the most promising research, advocating for progress by working with government to address issues that impact the T1D community, and helping educate and empower individuals facing this condition.





#### We Are Here to Help

Living with T1D can be challenging, but you don't have to manage it alone.

When your diagnosis is new, you may at times feel scared. We have information, resources and tools to help you take on the challenges of T1D and live healthier and happier.



#### About this Guide\*

This guide—Begin with Hope—is Breakthrough T1D's booklet for people who are newly diagnosed with T1D and their loved ones.

Begin with Hope offers a general introduction to navigating life with T1D. People just like you who are living with T1D, as well as doctors, nurses, and other diabetes care experts, wrote the guide.

Visit us at BreakthroughT1D.org to find more resources and information about life with T1D.

<sup>\*</sup>Begin With Hope is for informational purposes only, and should not be used in place of medical advice from a professional healthcare provider.

# **Table of Contents**

Who We Are	2
T1D Basics	4
Managing T1D	6
Blood Sugar Basics	6
Insulin Basics	7
Counting Carbohydrates Basics	8
Low Blood Sugar or Hypoglycemia	9
High Blood Sugar or Hyperglycemia	11
Diabetic Ketoacidosis	13
The Emotional Side of a T1D Diagnosis	14
Additional Resources	15

# Type 1 Diabetes Basics

Type 1 diabetes (T1D) is a chronic disease. This means that it doesn't go away. Anyone can be diagnosed at any age, though it often is diagnosed in children or teens.

The causes of T1D aren't fully known, but it isn't something that you or your loved ones could have prevented. Type 2 diabetes (T2D) is the most common form of diabetes. It is different from T1D. T2D is caused by factors such as aging, family history, sedentary lifestyle, and obesity.

Living with T1D isn't easy but it is manageable. With the right help and information, you or your loved one can lead a fulfilling, active life.

# How Your Body Gets Energy

Your body breaks down food into sugar (also called "glucose").

Most of this sugar goes into your bloodstream. This is so it can travel to your cells and be used as fuel. The sugar in your blood needs a hormone to help it enter cells. That hormone is insulin, and it acts like a key that unlocks the door so sugar can enter your cells.

Insulin is made by an organ called the pancreas. When sugar enters the bloodstream, your body releases insulin into the bloodstream, too.



## When You Have T1D

When you have T1D, your immune system prevents your pancreas from making enough insulin. This means that your cells can't get the fuel they need, and the sugar in your blood can get too high or too low.

## Signs of Type 1 Diabetes



Increased Appetite



Frequent Urination



Unexplained Weight Loss



Heavy Or Labored Breathing



Extreme Thirst



Fruity Odor on the Breath



**Drowsiness** or tiredness



Dry Mouth



Sudden Vision Changes



# **Managing T1D**

Managing T1D involves three main steps: checking blood sugar, taking insulin, and counting carbohydrates.

## Checking Blood Sugar



Blood sugar levels need to be checked frequently during the day and overnight.



One of two **devices can be used:** A blood glucose meter/glucometer or a continuous glucose monitor (CGM).



With a blood glucose meter, you usually place a **small drop of blood** (usually from the fingertip) on a test strip in the meter.



With a CGM, a sensor is placed just under the skin. This **sensor measures tissue-glucose levels** in real time and relays them to a receiver.



**Illness can make blood sugar levels fluctuate.** Check blood sugar more often when you're sick.

## **Blood Sugar Basics**

With T1D, the amount of sugar in the blood can be too high or too low. This can lead to health problems.

## What is a Healthy Range?

Everyone is different, but for most people with T1D, the goal is to keep blood sugar between 70 and 180 milligrams of sugar per deciliter of blood (mg/dL). This is known as a blood sugar range. Talk with your healthcare provider about the right blood sugar range for you or your loved one.

## **Insulin Basics**

People with T1D need to take insulin to survive. This is because their bodies do not make it or do not make enough of it. Insulin is available only by prescription. Insulin—which helps to lower blood sugar— is not a cure for diabetes.

## Taking Insulin

A person with T1D can take insulin through injections, pumps, inhalers, or automated insulin delivery systems (also called Artificial Pancreas/AP systems).

There are five main types of insulin, categorized by how quickly they work in the blood stream and how long their effects last: rapid-acting, regular or short-acting, intermediate-acting, long-acting, and ultra-long-acting.

## Caring for Insulin



Refrigerate unopened insulin.



Store opened insulin at **room temperature** and never near extreme heat or extreme cold.



Check insulin **expiration date** before using. Discard expired insulin or insulin that has discoloration or particles.

#### T1D TIP

Talk to your healthcare provider about which options for checking blood sugar and which options for insulin and insulin administration will work best for you or your loved one.



# **Counting Carbohydrates Basics**

Carbohydrates, or "carbs," are nutrients in the food we eat and drink. The body uses insulin to break down carbs and turn them into sugar for the body to use as energy.

When you have T1D, it's important to know how many carbs you consume each time you eat or drink. This is so that you can determine how much insulin you need to take at any given time.

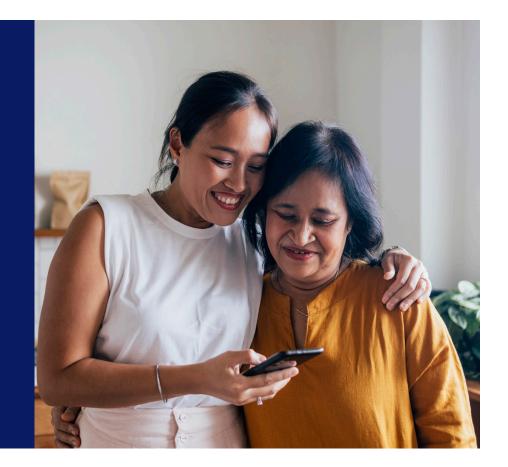
Your healthcare provider will help you figure out what kind of insulin dosage you need each day, and how often you should take it. For the names of websites or applications that can help you count carbs, go to the Additional Resources section of this booklet (begins page 15).

#### How to Count Carbs

- Find nutrition labels on foods and drinks to figure out the total grams of carbs per serving.
- Use measuring cups and spoons or food scales to count carbs more accurately. Be sure you use liquid measuring cups for liquid and dry measuring cups for dry foods.
- Use smartphone apps and websites that make it easier to add up carbs.
- Create a list of what you most often eat and drink and their carb counts. You can use the list to more easily add these carbs to your daily total.

## T1D TIP

Nutrition labels also tell you how many grams of sugar are in a food. You don't need to count these sugars separately as they are already included in the total grams of carbs per serving.



# Low Blood Sugar or Hypoglycemia

When you have too little sugar in your blood, it is called low blood sugar (also called "hypoglycemia").

Low blood sugar usually means anything lower than 70 mg/dL.

You can have low blood sugar by taking too much insulin, taking insulin at the wrong time, or not eating or drinking enough. You can also have low blood sugar during or after physical activity. It can also happen late at night when someone is asleep—this is when muscles are rebuilding with glycogen (the form of glucose your body stores).

It is important to recognize the signs of low blood sugar as when blood sugar is low, you or your loved one may lose consciousness or have a seizure.

## Signs of Low Blood Sugar



**Sweating** 



Headache



**Blurry Vision** 



**Unusual Behavior** 



**Shaking or Dizziness** 



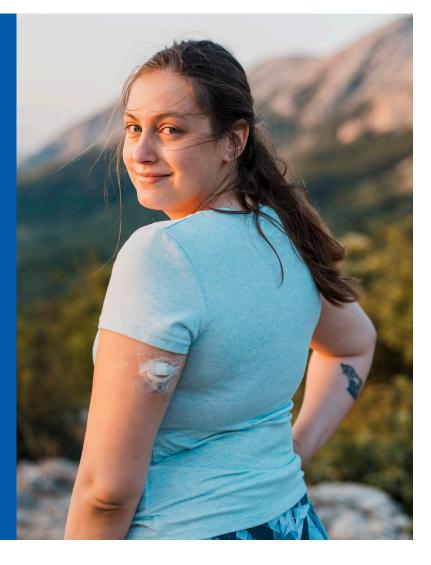
**Hunger or Nausea** 



**Difficulty Concentrating** 



**Poor Coordination** 



If you notice these symptoms, check your or the person's blood sugar. If blood sugar is below 70 mg/dL or the target range, follow your healthcare provider's instructions. You can also review the following directions.

# **How to Treat Low Blood Sugar**

Treating low blood sugar depends on the state of the person with T1D.

## If the person is conscious and able to safely eat, drink, and swallow

Eat or drink 15 grams of fast-acting sugar (see "Be Prepared to Treat Low Blood Sugar" below to learn more).

- Wait 15 minutes, then recheck blood sugar.
- If blood sugar is still too low, repeat the first two steps until blood sugar is in range.

If the person is unconscious or is having a seizure (unable to safely eat, drink, and swallow)

Stay calm.

- Treat with a dose of glucagon (see "What Is Glucagon?" below to learn more).
- Turn the person on their side.
- Call 911 and stay with them until emergency help arrives.
- Call the person's caregiver or emergency contact.

## What is Glucagon?

Glucagon (pronounced "glue-kuh-gone") is a hormone used in emergency situations (the person has a seizure or loses consciousness). It can be given by injection, auto-injection pen, or dry nasal spray. Like insulin, it is available only by prescription.

#### Be Prepared to Treat Low Blood Sugar

Have fast-acting sugar on hand at all times. Fast-acting sugar includes fruit snacks, juice boxes, or glucose tablets or gels.

Have glucagon that is easy to access. It may make sense to have glucagon at home, at school or work, and in the car or as part of your travel supplies.

Be sure that others are aware of you or your loved one's T1D, understand how to spot and treat low blood sugar, and have what they need to treat it.



# High Blood Sugar or Hyperglycemia

Having too much sugar in your blood is called high blood sugar (also called "hyperglycemia").

For most people with T1D, a blood sugar level of 180 mg/dL or greater is high.

You can have high blood sugar after not taking enough insulin for the amount of carbs you eat or drink.

Caffeine, intensive exercise, and medication can cause high blood sugar, as can things beyond your control, such as hormonal changes, illness, and stress.

If left untreated, high blood sugar can lead to Diabetic Ketoacidosis, and long-term complications to the eyes, heart, kidneys, and nerves.

Signs	of High Blood Sugar	Signs of Long-Term High Blood Sugar	
	Extreme thirst	<b>**</b>	Cuts or Sores that Do Not Heal
	Increased hunger		Infections
	Frequent Urination	<u> </u>	Unexplained Weight Loss
\$	Having Trouble Seeing or Concentrating		

If you notice these symptoms, check your or the person's blood sugar. If blood sugar is **above 180 mg/dL or the target range**, follow your healthcare provider's instructions. You can also review the following directions.

# **How to Treat High Blood Sugar**

Treating high blood sugar depends on whether the person's blood sugar is above 180 mg/dL or above 240 mg/dL and/or they are exhibiting certain serious symptoms.

# If the Person's Blood Sugar is Above 180 mg/dL but Below 240 mg/dL

- Check insulin pump or infusion site for blockages.
- Take a "correction dose" of insulin (see "What Is a Correction Dose?" below to learn more).
- Drink water and rest.
- Recheck blood sugar in one hour.
- If blood sugar remains high, contact your healthcare provider.



#### If the Person's Blood Sugar is Above 240

Also check for ketones in blood or urine.

#### If Ketones are Present

- The person may be in Diabetic Ketoacidosis.
- Call the person's caregiver or emergency contact.

If the Person has Ketones and/or the Person has Fruity Breath, Exhaustion, Confusion, Nausea or Vomiting; or the Person Loses Consciousness

- The person is likely to be in Diabetic Ketoacidosis or dangerously close to it.
- Call 911 and stay with them until emergency help arrives.
  - Call the person's caregiver or emergency contact.

#### What is a Correction Dose?

This is insulin you take to lower your blood sugar when it is too high. It's sometimes called a "correction factor." Your healthcare provider will help you figure out the right correction dose for you. The right dose depends on what type of insulin you take and how you take it.

## **Diabetic Ketoacidosis**

Diabetic Ketoacidosis ("die-uh-bet-ick key-toe-acid-oh-sis," also called "DKA") is a medical emergency and must be treated immediately.

It happens when your cells can't get fuel from the sugar in your blood and break down fat instead. This creates ketones, acids produced in your liver and released into your blood when your body breaks down fat for energy. When ketones build up, it leads to too much acid in the blood. This is called acidosis.

#### Signs of DKA



Extreme Thirst Or Very Dry Mouth



Extreme Exhaustion Or Fatigue



Chest Pain



Frequent Urination



Dry Or Flushed Skin



Fruity Odor On The Breath



High Blood Sugar (Above 240 Mg/Dl)



Nausea, Vomiting, Or Abdominal Pain



Confusion Or Difficulty Paying Attention



Ketones In The Urine Or Blood



Difficulty Breathing

#### Be Prepared to Check for Ketones

- Have a blood or urine ketone test kit on hand.
- Read the package when there isn't an emergency to learn how to use it.
- To make sure you understand the instructions, do a sample check in consultation with your healthcare provider when you believe ketones are not present (blood sugar is in range).
- Check expiration dates on kits and discard expired strips.



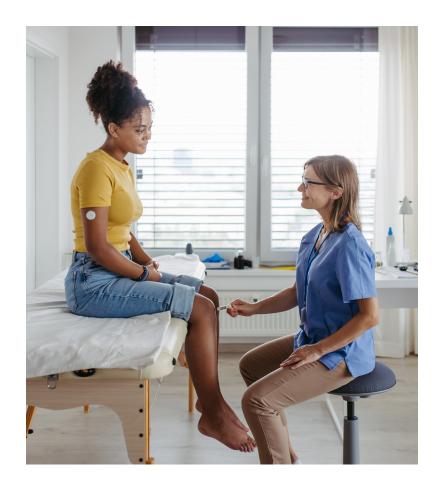
# The Emotional Side of a T1D Diagnosis

When someone has T1D, it often affects their mental and emotional health. It can affect other family members, too. This is known as "diabetes distress."

#### Signs It May Be Time to Seek Help

If you feel like you need help to cope with diabetes distress, consider reaching out for help. You or your loved one may need some extra support if the following apply:

- No Motivation or Refusing to Check Blood Sugar, Take Insulin, Count Carbs, or Actively Manage T1D
- Newly-Troubled Relationships with Family and Friends
- No Desire to Spend Time with Loved Ones
- No Interest in Hobbies or Activities that Were Once Enjoyable
- Constant Feelings of Stress or Anxiety
- Changes in Appetite and Ability to Sleep



If you or your loved one is experiencing these or other signs of diabetes distress, talk to your healthcare provider about whether it could be time to seek help from a mental health professional.

#### Finding Help

To find a mental health professional who has expertise in diabetes distress, visit the American Diabetes Association's Mental Health Provider Directory at professional.diabetes.org/mhp\_listing.

You can also scan the QR code to the right.



## **Additional Resources**

We hope you have found Begin With Hope to be an easy-to-understand source of the information you absolutely need to know starting on day one of a T1D diagnosis.

When you are ready, you may want to learn about other, more specialized topics relevant to T1D, as well as Breakthrough T1D.

Visit **BreakthroughT1D.org** to find these and other helpful resources.

More Newly Diagnosed Support

BreakthroughT1D.org/newly-diagnosed

**Personal Support** 

BreakthroughT1D.org/t1d-community

Life with T1D

BreakthroughT1D.org/t1d-resources

Health Insurance, Explained

BreakthroughT1D.org/t1d-resources/insurance

**Daily Management** 

BreakthroughT1D.org/daily-management

Breakthrough T1D Near You

BreakthroughT1D.org/chapter-finder

Join the Breakthrough T1D Online Community

BreakthroughT1D.org/t1d-community

**Breakthrough T1D Events** 

BreakthroughT1D.org/discover-events

Volunteer

BreakthroughT1D.org/volunteer

**Activate Change** 

Breakthrough T1D. org/advocacy

Find a Clinical Trial

BreakthroughT1D.org/clinical-trials



#### Disclaimer

Breakthrough T1D does not provide medical advice. Any content accessed through "Begin with Hope" is for informational purposes only and is not intended to be a substitute for professional medical advice.

As the leading global type 1 diabetes research and advocacy organization, we help make everyday life with type 1 diabetes better while driving toward cures. We also want to support you in living your best life with diabetes. As such, our content is intended to provide support and tips for living well with diabetes.

The information we provide is not intended to cover all possible uses, directions, precautions, drug interactions, or adverse effects. Please contact your doctor or other qualified health provider with any questions you may have regarding your diabetes or any medical condition.

Do not disregard professional medical advice because of something you have read on BreakthroughT1D.org, any 3rd party site or any non-medical literature.

If you think you may have a medical emergency, call your doctor or 911 immediately.

Breakthrough T1D does not recommend or endorse any specific tests, providers, products, procedures, opinions, or other information that may be mentioned on our website or by one of our sponsors.



You can also follow us on:







