Breakthrough T1D™
Formerly JDRF

A new type 1 diabetes diagnosis

breakthrought1d.org.uk

We are here for you from when you first hear the words ‘type 1 diabetes’

There’s a lot to learn after a new type 1 diabetes (T1D) diagnosis. Whether you’re an adult, a parent or carer of a newly diagnosed child, it’s normal to feel overwhelmed and a bit lost. We’re here to help and we’ll guide you through everything you need to know.

You can feel sure that whatever you’re going through, you’re not the only one. Keep talking to your diabetes healthcare team, your family and friends and reach out to us at Breakthrough T1D to get the help, advice and the reassurance you need. We have information and tools to help you take on the challenges of T1D and live healthier and happier.

What is T1D and what causes it?

Type 1 diabetes is an autoimmune condition that affects over 400,000 people in the UK. T1D occurs when the immune system mistakenly attacks and destroys the insulin producing beta cells, which are crucial for converting glucose from food into energy. Like many autoimmune conditions, we're not yet clear why this happens. However, we do know that T1D is not caused by diet or lifestyle, and there's nothing you could have done to prevent it.

What is insulin and what does it do?

Insulin is a hormone that is made by beta cells in the pancreas. When you eat, insulin is released to stop the levels of glucose (a type of sugar) in your blood going too high and becoming dangerous. When you have T1D, your body can no longer produce insulin, so you have to inject or infuse it yourself.

How to manage T1D?

In simple terms, you manage T1D by trying to keep the amount of glucose in your blood within a target range. Your diabetes healthcare team will tell you what to aim for, but the target range is usually between 3.9-10.0 mmol/L.

When you eat something that has carbohydrates in it, you need to inject insulin to stop your blood glucose level going too high. To do this you need to know how much carbohydrate you are eating so you take the right amount of insulin. This is called carb counting. Speak to your diabetes healthcare team to find out what courses and education can support you.

You need to monitor your glucose levels, with a blood glucose meter, or continuous glucose monitor (CGM). If they're too low, you need to eat something containing fast acting carbohydrates to bring them back up.

Should I be aiming for perfect glucose levels?

There are lots of things that can affect your glucose levels as well as eating carbohydrates, including exercise and movement, hormones, temperature, periods, stress and illness. A lot of these factors are outside of your control, so don't be hard on yourself if you don't reach your targets all the time.

What current treatments are there?

Treating type 1 diabetes involves replacing the insulin that your pancreas doesn't make and monitoring your blood glucose levels.

Regular check-ups and appointments with your diabetes healthcare team and your GP will allow them to build up a picture of you, your T1D, how you like to manage it, and which treatment will suit you best.

Everyone with T1D should be able to access specialist diabetes clinicians. If you are not in touch with a diabetes healthcare team, please ask your GP to refer you as soon as possible.

The treatments you may be offered currently include:

A blood glucose meter:
This is a small medical device that checks the amount of glucose in your blood.

A continuous glucose monitor (CGM):

A CGM uses a sensor attached to your body to send glucose readings to a smart phone or reader. It can warn you when your levels are going out of range using alarms.

Insulin injections:

These combine an insulin pen and needles.
There are many different types of insulin, and most people with T1D in the UK combine the use of two types of insulin.

An insulin pump:

This delivers short acting insulin every few minutes in tiny amounts, 24 hours a day. The insulin flows through a cannula which sits under the skin.

Hybrid closed loop (HCL):

HCL systems link together certain pumps and CGMs. It takes readings from a continuous glucose monitor and uses an algorithm to tell an insulin pump how much insulin to deliver. It does this 24 hours a day.

Click to learn more about T1D
tech and treatments

Carb Counting

Carb counting is working out how much carbohydrate (carbs) is in your food and adjusting your insulin dose accordingly.

Why do you need to count carbs when you have T1D?

When you eat or drink carbohydrates, your body breaks them down into glucose to give you energy.

You need to know how many carbs you're eating so that you can take the right dose of insulin to stop your blood glucose levels going too high (by not taking enough insulin) or too low (by taking too much insulin).

What kind of carbs are there and what do I need to count?

There are two main types of carbohydrate that you need to be aware of when you have T1D:

Starches

- potatoes
- peas
- beans
- rice
- bread
- pasta

Sugars

- natural sugars in fruit or milk
- added sugar in cakes and cookies

These carbohydrates are released into the bloodstream differently. Starches release slowly over time so the rise in blood glucose will be more gradual. Sugar releases more quickly, so will cause more of a spike in blood glucose levels.

Working out how much insulin to take

To work out how much insulin you need to take, you'll need to know your insulin to carbohydrate ratio. Your diabetes healthcare team will tell you what your ratio is.

Carb counting and making calculations can be tricky at first. Don't worry if you're not good at maths, over time you will get used to how many carbs are in certain foods, especially if they're your favourites and you eat or drink them often. Speak to your diabetes healthcare team to find out what courses and education can support you.

Carb counting and insulin pumps

Insulin pumps and hybrid closed loop systems can make carb counting easier because you can enter the amount of carbs you're going to eat and it calculates how much insulin you need.

How do I know if I’m getting carb counting right?

A good way to see if you’re on the right track is to check your blood glucose before you eat and then several hours after eating, ask your diabetes healthcare team what your blood glucose levels should be. This will help you see if your estimate was right.

Don’t worry too much if you’re not getting everything right all the time – you’re only human and carb counting is not always an exact science. Remember that other things can affect your blood glucose levels as well as carbs, like doing exercise, being unwell or being too hot or cold.

If you’re struggling with carb counting – or any aspect of your type 1 management – ask for help. You don’t have to manage it all on your own so speak to friends, family and your diabetes healthcare team.

Click to find out more about how to carb count and where to get support

Hyperglycaemia (Hyper)

Hyperglycaemia (hyper) is when glucose levels are too high (usually above 10 mmol/L).

Symptoms include:

- Being more thirsty
- Peeing more often
- Headaches
- Being tired
- Stomach pain
- Unexplained weight loss
- Having blurred vision
- Experiencing recurrent infections
- Nausea and/or vomiting
- Fruity-smelling breath

Hypers may happen due to:

- Taking too little insulin or missing a dose
- A hypo being over-treated
- Stress
- Illness
- Menstruation
- Some forms of exercise

What to do?

High blood-glucose readings happen sometimes without an obvious reason but may be caused by one of the reasons above.

If blood-glucose levels are high for just a short time, emergency treatment won't be necessary. If it stays high, action needs to be taken to prevent diabetic ketoacidosis (DKA). This is when a severe lack of insulin upsets the body's normal chemical balance and causes ketones to be produced.

It's good to talk to your friends, family, work or school about how to recognise and treat a hyper.

Click to find out more about hypers

Hypoglycaemia (Hypo)

Hypoglycaemia (hypo) is when glucose levels are too low (usually below 3.9 mmol/L).

Symptoms include:

- Sweating
- Drowsiness
- Glazed eyes
- Lack of concentration
- Aggression or tearfulness
- Hunger
- Going pale

People may not always notice that they are hypo, this is known as hypo unawareness.

What to do?

The aim of treating a hypo is to restore a safe level of glucose in the blood. These are some common ways to quickly elevate sugars:

- A cup of fruit juice or non-diet soft drink
- Three to five glucose tablets
- Sweets like jelly babies

It's good to talk to your friends, family, work or school about how to recognise and treat a hypo.

Hypos may happen because:

- Too much insulin has been administered
- A meal or snack has been delayed or missed
- Not enough carbohydrates eaten
- Unplanned physical activity

Sometimes there is no obvious cause.

Click to find out more about hypos

The honeymoon period

Type 1 diabetes can be easier to manage in the first few months after diagnosis, which is known as the honeymoon phase or period.

What is the honeymoon period in T1D?

T1D happens when the immune system destroys the insulin-producing beta cells in the pancreas. This is a slow process, meaning people with T1D can still have some functioning beta cells for some time after their diagnosis. These surviving beta cells continue to function as normal, which can make T1D easier to manage at first. You may need less insulin during this time and experience more stable blood glucose levels. Not everyone with T1D will have a honeymoon period and it only happens just after you've been diagnosed.

How long does the honeymoon period last?

The honeymoon period lasts for different lengths of time for different people, but it is always temporary. It most commonly lasts between a few months and a year, but some people can experience it for a few years. Eventually the immune attack will destroy most of your beta cells. When this happens, you may need to start taking more insulin.

Click to learn more about the honeymoon period

Needle phobia

What are the signs of needle phobia?

It’s normal to dislike needles, but a fear or dislike becomes a phobia when it leads to problems. When you have a needle phobia, coming into contact with a needle may cause you to feel:

- Scared
- Tearful
- Hostile or agitated
- Dizzy or faint
- Like you want to run away

How can needle phobia affect T1D management?

When you have T1D it’s difficult to avoid needles. There are needles in injection pens, finger prickers used with blood glucose meters, glucose sensors, as well as the cannulas used with insulin pumps. If you have a phobia of needles, you might start avoiding them. This might stop you getting the insulin that you need.

Is it possible to manage T1D if you have needle phobia?

You can still manage T1D if you have needle phobia, you might have to do things a little differently. You can take steps to overcome your phobia and put strategies in place. This might be:

- Getting someone else to help you inject
- Finding ways to prepare mentally and emotionally for injections
- Having a special routine around injections that makes you feel more comfortable

How can I try and overcome my needle phobia?

Here are some tips to help you relax around needles. Everyone is different, so you may want to try a few of these techniques to see what works for you:

- Relaxation
- Distract yourself
- Keep needles sharp by changing them often
- Reach out to your diabetes healthcare team for support

Click to learn more about needle phobias and where to get support

My child has been diagnosed with T1D

When your child is diagnosed with T1D, it can come as a shock and the information you need to learn can feel overwhelming. However, you don't need to go through this alone. There is lots of support out there, from your child's diabetes healthcare team, other parents and carers of children with T1D, school and nursery staff and us here at Breakthrough T1D, who are here to support you and your family every step of the way.

Click to find out more about how we can support you and your child

School and T1D

Going back to or starting school after a T1D diagnosis may seem daunting, but with some planning and preparation it is entirely possible for your child to enjoy school life and participate in all activities.

As soon as the diagnosis is confirmed, make an appointment to see your child's teacher to discuss a care plan. The aim is that everyone around your child should know what your child is expected to self-manage, when they'll need help, and the signs they need to be aware of that show your child's blood sugar is low.

Click to take a look at our 'School Pack' which includes information for teachers and parents on how to support a child with T1D in educational and social settings

We’re here for you

Whether you’ve just been diagnosed or have been living with T1D for some time, we have created a wide range of events and information resources to support you in managing your condition and to help you connect with the T1D community.

From newly diagnosed kits to T1D technology information, all our resources can be accessed for **free**

If you have any questions about our resources, please reach out to the Community Engagement team at **outreach@breakthrought1d.org.uk.**

Community events

Come together with the T1D community at one of our free community events!

Our events, known as Breakthrough T1D Discovery Days, offer a supportive environment where you can connect with others, learn about the latest research and technology, and hear inspirational talks from people living with T1D.

Our events also feature technology exhibitions, where you can explore a variety of devices to manage your T1D and find out what works best for you.

> *Thank you very much for this event - it has been absolutely brilliant and so informative and also very comforting for a newly diagnosed person like me!*

Females and Type 1 Virtual Discovery Day attendee

> *I came to the event not knowing what to expect. Travelling here made us realise we have a brilliant support system.*

Liz, Cardiff Discovery Day attendee

Click to check out our upcoming Discovery Days

How you can help

No one should face T1D alone. Join us in taking breakthrough action for the entire T1D community. However you choose to support us, you'll be helping to create a world without T1D.

How you can help

Get your local community involved: Fundraise at work, school or your community group and raise awareness at the same time

Play the Breakthrough T1D lottery: For just £1 per entry, you could win the weekly top prize of £25,000

Take part in an event: Take on a marathon, sponsored walk, or attend a ball

Do your own fundraising: Find your own perfect way to raise money, from holding a bake sale to a sponsored skydive

Volunteer: Speak about T1D in your local community, cheer at an event or share a skill - whatever you're interested in, we have a role for you

Donate: Give a one-off gift or a regular donation

Click to find out more about how you can get involved

We are Breakthrough T1D, the leading global type 1 diabetes (T1D) research and advocacy charity. Together we're driving breakthroughs towards a world where no one lives with T1D. Until then, we help make everyday life better for the people who face it.

Contact us

Telephone: 020 7713 2030

Email: info@breakthrought1d.org.uk

Breakthrough T1D™
Formerly JDRF

Registered with FUNDRAISING REGULATOR