

A type 1 diabetes diagnosis

Whether you, or someone close to you, has been diagnosed with type 1 diabetes it can be a shock. Getting your head around type 1 diabetes doesn't happen on a schedule, and explaining the condition to friends can seem daunting at first, but having people who understand can help.

If you don't feel comfortable explaining type 1 diabetes to your friends, or you want to learn more about your friends diagnosis, this leaflet will provide you with the tools to discuss type 1 diabetes with confidence.

JESS AND LILY

Jess is 14 and was diagnosed with type 1 diabetes in 2012. She is an aspiring athlete and regularly competes in athletics competitions. Jess knows Lily from her athletics training.

JESS

I was diagnosed when I was 8. I was young and wasn't sure how to tell people. It felt awkward. Having type 1 changed my routine and my classmates noticed so they learnt a bit about the condition. Six years on, I have no issue telling new people about type 1. I think it's important that people you see regularly know what it is even if they don't have all the details. Everyone in my year at school knows I have it. My close friends know more, like what to do if I'm having a hypo.

LILLY

Jess told me about her type 1 when we met. I don't think it makes a difference to our friendship at all. I know what to do if she has a hypo and am there if she needs any help. My advice to a friend of someone with type 1 is to remember that it doesn't make them any different.

You don't have to keep checking that they're okay!

Getting to know type 1 diabetes

What is type 1 diabetes?

Type 1 diabetes is where your body can no longer make a hormone called insulin. Without insulin, the level of glucose (a type of sugar) in your blood becomes too high. This means that you need to take regular doses of insulin to manage your blood glucose levels.

Type 1 diabetes can affect anyone, at any age, and it is not caused by a poor diet or an unhealthy lifestyle.

What happens to your body when you have type 1 diabetes?

In type 1 diabetes, your immune system – which is meant to protect you from viruses and bacteria - attacks and destroys the beta cells in your pancreas that produce insulin. Insulin is what enables the glucose from your food to move from your blood into your cells, giving you energy. When vou don't produce insulin, vour glucose levels rise and vour body can't function properly.

What causes type 1 diabetes?

We don't yet know what causes type 1 diabetes, but we're dedicated to finding out.

Currently, scientists think that type 1 diabetes is caused by a combination of your genes and other, non-genetic factors. In fact, we know of more than 50 genes where a small difference in your DNA code can change your chances of developing type 1 diabetes. But even in identical twins, who share the same DNA, one twin may develop type 1 diabetes and the other may not!

So scientists are looking for other factors that may trigger type 1 diabetes in people who already have a higher genetic risk, such as viruses and hormones.

How is it treated?

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

But you're not like anybody else. And neither is your type 1 diabetes. Regular check-ups and appointments with your diabetes clinic will allow them to build up a picture of you, your type 1 diabetes, how you like to manage it and which treatment will suit you best.

The treatments you may be offered are things like:



A **blood glucose meter**, which is a small medical device that checks the amount of glucose in vour blood.



A continuous alucose monitor (CGM) which gives information about your glucose levels every few minutes from a sensor worn on the body. It can warn you when your levels are going out of range using alarms.



Flash glucose sensing, which uses a sensor with a probe just under the skin. It gives you a graph of your glucose levels and tells you whether your levels are going up or down. It can warn you when your levels are going out of range using alarms.



Insulin injections, which combine an insulin pen and needles. There are many different types of insulin, and most people with type 1 diabetes in the UK combine the use of two insulins.



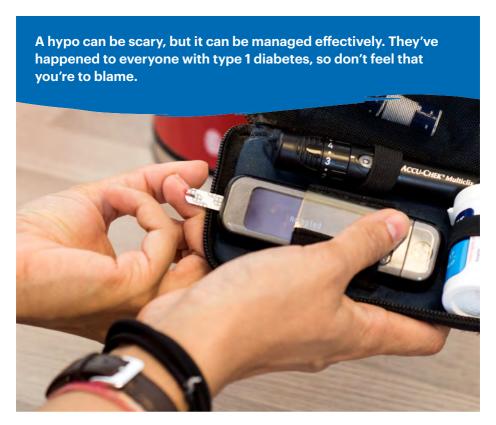
An **insulin pump**, which delivers short acting insulin through a cannula every few minutes in tiny amounts, 24 hours a day.



Getting to know hypos & hypers

Managing a hypo

When your blood glucose level drops below 4mmol/L, this is called hypoglycaemia, or a 'hypo' for short. There might be times when you have too much insulin in your bloodstream. This may be because you accidentally injected more than you needed, because you've been very active, because you haven't eaten, you've drunk too much alcohol or you've had less carbohydrate than you thought. Sometimes there doesn't seem to be any cause, but you still need to treat the hypo.



How do I know when I'm having a hypo?

Symptoms are different for everyone - you may not get any at all but they're things like:

- **Shaking**
- Sweating
- **Dizziness**
- Hunger
- **Blurred vision**
- Difficulty concentrating
- Feeling anxious
- Changes in behaviour

What should I do if I think I'm having a hypo?

Check your blood glucose level. If it's low, eat or drink something that contains fast-acting carbohydrates to bring your blood glucose within range. In general, 15 grams of carbohydrate will bring your blood glucose level up by about 3 mmol/L. That's about 3 jelly babies, or five glucose tablets, or 300ml of non-diet soft drink/150ml fruit juice. Though tempting, remember that chocolate is not fast-acting, so not the best choice!

You should always check your blood glucose 10-15 minutes after you have treated your hypo. Remember to wash your hands or use a cleaning swab to get an accurate reading as there might be some hypo-treatment left on your fingers. If your level is still low, you should eat another 15 grams of carbohydrate and check again in 10-15 minutes.

You can't always predict when your blood glucose is going to drop too low so you need to carry a hypo treatment with you at all times (jelly babies, glucose tablets, etc).

What happens after a hypo?

Your blood glucose levels might run high for many hours after a hypo. This might be the effect of what you ate to try to sort out the low blood glucose level, or it might be your body trying to protect you from another one.

How can I avoid hypos?

By checking your blood glucose levels throughout the day, it'll help you and your doctor or healthcare team work out when you need less insulin and when you might need more.

What happens if I don't get any symptoms?

Some people don't get any hypo symptoms, and just don't realise they're having one. This is called hypo unawareness.

Feeling a bit spaced-out or vague might be your only sign. If that sounds familiar to you, it's important to let your doctor or healthcare team know if your blood glucose level is dropping below 4 mmol/L regularly (more than three to four lows in a week, or less if you are newly diagnosed).

GETTING HELP IN AN EMERGENCY

Sometimes, your blood glucose might drop so low that you can't treat the hypo yourself. This may happen if you have hypo unawareness, you ignore the symptoms, or you're not quick enough to act.

It's a good idea to teach your family and friends how to recognise and treat a hypo so they can treat you. They should only give you something to eat or drink if you can respond to their commands. If you can't, they'll need to call 999 or give you an injection of glucagon.

Glucagon is a hormone which triggers a release of stored glucose from your liver. This injection (called GlucaGen) is available with a prescription from your doctor. Talk to your doctor or diabetes team about this injection and whether you should have one at home, or train a family member or friend on how to give this, if you need it.

Hopefully you'll never need anyone to do this, but it's brilliant to know there's always a back-up plan.

You might also want to consider wearing a diabetes identifier (such as a piece of medical alert jewellery) in case of an emergency.

What is a hyper?

This happens when you haven't taken enough insulin to match the carbohydrate that you've eaten, which means that your blood glucose level will be too high. This is known as hyperglycaemia, or a 'hyper' for short.

Like hypos, hypers are a fact of life for people with type 1 diabetes - it's pretty difficult to keep your blood glucose within range all the time. Again, it happens to everyone.

A hyper might not make you feel ill like a hypo does. But it can make you feel ill in the long run.

Can I avoid hypers?

You can help avoid them by regularly testing your blood glucose and matching your insulin to food intake and exercise as closely as you can. If you're worried about how often you have high blood glucose, talk to your healthcare team about 'time in range' so they can discuss targets with you.

There are technologies that can help you, like **continuous glucose monitors** and **flash glucose sensing**, but the most important thing is to test regularly and keep talking to your diabetes team. They're on your side, and their job is to help you manage your type 1 diabetes so it affects you as little as possible.



JDRF is here for you!

Whether you're at secondary school, sixth form or university, JDRF has created resources to support you.

Please visit our web page **'Understanding Type 1 Diabetes: A Guide for Young People'** for more information about type 1 diabetes and how to get involved with the type 1 community (including the best type 1 blogs, vlogs, podcasts, and Instagram accounts to follow). The online type 1 diabetes community is a great place to connect with other young people living with type 1 from all around the globe!

If you'd like to plan for attending university, or for more information about managing type 1 diabetes away from home, check out our online **Uni Toolkit**. Here you can read about applying through UCAS, studying abroad, alcohol, and much more.

Emotional Wellbeing

We understand that living with type 1 diabetes can be really tough. Many people with type 1 diabetes say that talking with others who have experience of the condition is very helpful. There are many resources, helplines, support groups and a large online community that can help you to feel supported at any stage on your type 1 diabetes journey.

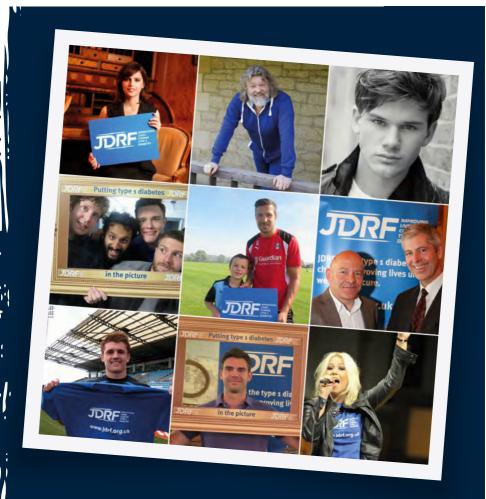


Others with type 1 diabetes are usually happy to help those who have been newly diagnosed. If you'd like to see what online forums and community support there is, please visit our web page

'The type 1 diabetes community'.

If you'd like to learn more about 'diabetes burnout', diabulimia, and keeping an eye on your emotional wellbeing, please visit our web page **'Emotional Wellbeing'**.

jdrf.org.uk/information-support/



JDRF Celebrity Ambassadors

JDRF is grateful to have support from many talented and high-profile celebrities living with type 1 diabetes, from Hollywood actors to international sports stars. Their backing is helping to raise awareness of type 1 diabetes and the work that we do.

To learn more about our celebrity ambassadors please visit our 'Celebrity Supporters' web pages.

Discovery Events

Why not attend one of our Discovery events? Whether you're newly diagnosed or have lived with type 1 diabetes for some time, come to a Discovery event and meet local young people with a connection to type 1.

You can even bring your own friends along! We cover themes such as type 1 technology, food and nutrition, sport and exercise and living well with type 1 diabetes.

If you can't attend in person, why not watch a virtual event from your computer at home? There are lots of ways to join, and you can even watch recordings of all our previous events on JDRF UK's **youtube channel** today. Ask your parents/guardian and browse our list of **local events** at **https://jdrf.org.uk/discover** to book a free place, or drop us an email at **discoveryevents@jdrf.org.uk**.



The cure and you

Every day, our researchers all around the world are learning new information about type 1 diabetes. Information is power - the more we know, the faster we can work towards treatment, prevention and cure.



It's an exciting time.

Scientists, researchers and people with type 1 diabetes are working together to eradicate the condition entirely. In the meantime, our research has helped improve the treatment of type 1 diabetes. Just 50 years ago people had to inject with longer, thicker needles and glass syringes. Now, most people use a more convenient lightweight injector pen!

Genetic research has taught us a lot about who is at risk of developing type 1 diabetes, but we still don't know why some people at risk get type 1 diabetes, while others never do. We're also working on discovering how insulin beta cells grow, how they stay healthy and how we can give new ones to people with type 1 diabetes. If we can identify the beginning of the autoimmune attack. we might be able to avoid people needing insulin treatment.

How can I help?

There are so many different ways you can help JDRF. So, what's your preference?

Fundraising



How about a challenge? Marathons, mountain climbing or how about your own cycling challenge? Whether it is an in person event or one of our virtual challenges – the sky really is the limit and we have something to suit absolutely everyone!



Raising money is a great way for the whole school, college or university to show support and raise awareness for those with type 1 diabetes in your school. Whatever you decide to do, our fundraising team will be on hand to support you with anything you need to make your fundraising a big success.



We have a fundraising guide for ideas and more information about organising your own event. You can download or order this and anything else you need from our **fundraising materials** page at **jdrf.org.uk/get-involved/fundraise/**.





Volunteering



Whether you want to enhance your CV, meet others to build your social network or be part of an exhilarating national event, we have an opportunity for you. Write an article for our blog, speak about type 1 diabetes at your local school, cheer on our marathon runners or share a professional skill - whatever you're interested in, explore how you can help us and become part of our team today.



Our Youth Ambassadors Programme is a great way for anyone aged up to 25 years old to get involved with JDRF. There are a variety of tasks and projects that we will ask you to be a part of, including events and even fundraising!



If this sounds like something you'd be interested in please email volunteering@jdrf.org.uk.

We are JDRF: the UKs type 1 charity

Until the day we find a cure, we are committed to making life better for anyone affected by type 1.

To work towards a day when there is no more type 1 we:

- Fund world-class research approved and administered by our international research programme to cure, treat and prevent type 1 diabetes.
- Make sure research moves forward and treatments are delivered as fast as possible.
- Give support and a voice to people with type 1 and their families.
- Lead a global movement to create a world without type 1.

Juvenile Diabetes Research Foundation Ltd (JDRF) is a charity registered in England and Wales (No. 295716) and in Scotland (No. SCO40123). Registered address: 17/18 Angel Gate, City Road, London EC1V 2PT. Registered as a company limited by guarantee, in England and Wales (No 2071638).



Contact us: T: 0207 713 2030 E: info@jdrf.org.uk W: jdrf.org.uk

