



DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

A parent and carer's guide to
TYPE 1 DIABETES

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WELCOME

Finding out your child has type 1 diabetes can be a shock. With so much information out there it can be difficult to know where to start, but we're here to help.

This guide introduces the key things you need to know, so your child can lead a full, active life with diabetes. There are tips on how to make day-to-day life easier for the whole family, facts about diabetes and how to treat it, and we talk about the care your child should get from their paediatric diabetes team. You'll also hear from other parents on how they and their child manage type 1 diabetes. Plus, we've put together a list explaining medical words at the back.

Of course, if you've got any specific questions about your child's diabetes, please ask your paediatric diabetes team. And we at Diabetes UK are always here to help – just drop us an email or pick up the phone. Check out the back cover for ways to get in touch.

What is type 1 diabetes?

Type 1 diabetes is a condition where your child's blood sugar – or glucose – level is too high because their body can't make a hormone called insulin.

It develops when the insulin-producing cells in someone's pancreas have been destroyed. We all need insulin to live, as it allows glucose in our blood to enter our cells and fuel our bodies.

When your child has type 1 diabetes, their body still breaks down the carbohydrate from food and drink and turns it into glucose. But when the glucose enters the bloodstream, there's no insulin to allow it into the body's cells. This leads to glucose building up in their bloodstream and causes high blood sugar levels.

Watch our **What is type 1 diabetes?** video for more info at diabetes.org.uk/pg-what-is-type-1

Causes

It's normal to wonder if something could've caused your child to develop type 1 diabetes. The truth is that we know very little about why a child develops it. But there's nothing you could've done to prevent it.

What we do know is that it's an autoimmune condition. This means that the body has damaged its own insulin-producing cells, so they stop working. Once the cells stop, they don't start again. This results in type 1 diabetes.

We now know that both environmental factors and genetics can play a part in the development of type 1 diabetes. So if someone in your family has type 1, there's a slightly higher chance of your child developing it. But most people with type 1 diabetes have no family history at all.

Treatment

Your paediatric diabetes team (see page 33) will work with you to plan the best treatment for your child.

Type 1 diabetes is treated with insulin injections or by using an insulin pump. A healthy diet and keeping active are also really important – see page 39 for more on this.

You and your child will need to use a blood glucose meter to regularly check their blood sugar levels.

You'll learn how to manage their blood sugar levels by balancing the amount of insulin they take to the food they eat and the activity they do.

Managing diabetes requires planning and effort, and it can feel like a lot at the beginning. Parents often tell us it's like a rollercoaster ride. But don't worry about being perfect all the time – sometimes blood sugar levels are too high, sometimes too low, sometimes just right. It's all about doing the best you can and trying to keep your child's numbers within range for as much time as possible.

It's normal to worry about what might happen if you get it wrong. But remember that your paediatric diabetes team of doctors, nurses and dietitians are there to help you.

Call our helpline

You can call our helpline on **0345 123 2399** or email **helpline@diabetes.org.uk**

With the right help and support, there's no reason why type 1 diabetes should stop your child from having a long and healthy life.



Questions



Is there a cure?

No, but research is transforming care and treatment and moving us closer to a cure. Visit diabetes.org.uk/pg-research to find out more about this.

Are there other types of diabetes?

There are two main types – type 1 and type 2.

Only about 8% of the 4.9 million people with diabetes in the UK have type 1. But when it comes to children, the vast majority have type 1. We're now starting to see some children with type 2 diabetes, but it's still quite rare.

Type 1 and type 2 are both serious conditions. But while there are things people can do to reduce their risk of developing type 2 diabetes, this is not the case for type 1.

Monogenic diabetes

If you have several close family members with type 1 diabetes, your child may have monogenic diabetes, which is caused by a change in a single gene. It's often treated slightly differently from type 1 diabetes, so speak to your paediatric diabetes team if your child has several relatives with type 1.

Neonatal diabetes

This is a form of diabetes diagnosed under the age of six months. Unlike type 1 diabetes, it's not an autoimmune condition. Neonatal diabetes is very rare, currently there are less than 100 people diagnosed with it in the UK. Genetic testing for neonatal diabetes is offered free of charge for all children diagnosed with diabetes before nine months of age.

Other types of diabetes

There are other, less common types of diabetes. To find out more, visit diabetes.org.uk/pg-types-diabetes

WELLBEING



Your family

This diagnosis may have affected the whole family. While you and your child have a lot to get used to, it's important to pay attention to how other family members are feeling too. Let them know that they can ask for help if they need it – whether that's from you, their school, GP or us. Our free online forum is open to everyone affected by diabetes, including family and carers.

Family relationships

At the beginning, you may put your other children's needs to one side to focus your attention on the child who's just been diagnosed with type 1 diabetes. This is completely understandable.

But it's important to acknowledge that your other children can be affected by this diagnosis too. While they may seem jealous of their sibling's 'special treatment', it could be because they're feeling

anxious. Maybe they're worried that their sibling could get really sick, or that they'll now get diabetes themselves.

Regular hospital visits and everything else that goes with managing diabetes also take up time.

This can have a longer-term impact and there can be more tension at home after one child has been diagnosed with type 1 diabetes.

Try to give each child individual attention and listen to what they have to say. Be sensitive to claims that it's not fair. If you feel it's appropriate, you could get siblings involved with diabetes care so they don't feel left out. Importantly, try not to put family life on hold.

If you have a partner

Don't feel guilty about putting each other first sometimes. It could be something as simple as grabbing a tea or coffee together and not talking about diabetes.

And if there's someone who understands your child's needs and can give you both a break, then make the most of the chance for some quality time together.

Separated parents

If you're separated from the other parent of your child, it can make things more difficult. You'll have to work together to make sure your child's diabetes is managed, whoever they're staying with.

Think about:

- How you let each other know about changes in your child's treatment or routine. Make sure you keep each other updated.
- How to involve new partners.
- Making sure both of you learn about managing your child's diabetes from your paediatric diabetes team. Second-hand information can be confusing.



Single parents

It can be tough to be a single parent managing a child with type 1 diabetes. It may feel like you're having to deal with all of this on your own.

It's worth thinking about if there's anyone who can support you emotionally or learn about your child's care so they can give you some time off when you need it. It's also good to think about who can help you in an emergency.

Wider family

Grandparents, aunts, uncles and close friends may have also been upset by your child's diagnosis. They may be asking for updates and want to help. Or maybe they've decided to leave you alone to concentrate on your child. Either way, it might feel a bit overwhelming.

You might want to keep one person up to date so that they can pass on news to the rest of the family, or use a group text or WhatsApp group.

People often want to help but need to be told how, so ask for specific help if you need it. Ask them to help you keep your child's life as normal as possible. And most of all, be honest about how you feel.

Coping with a diagnosis

Every parent and family copes differently with a diabetes diagnosis. The whole family has to acknowledge that your child's life has changed. And it's important to talk about it together.

Only your child knows exactly what they've gone through and how they feel, and each child will deal with their diagnosis differently.

They may blame themselves or see diabetes as a punishment. Talk to them about these things. It's better they talk about how they're feeling now than cover it up.

Keep an eye on your child and their mood. Your child could look like they're coping but be hiding how they really feel – and that could cause difficulties later.

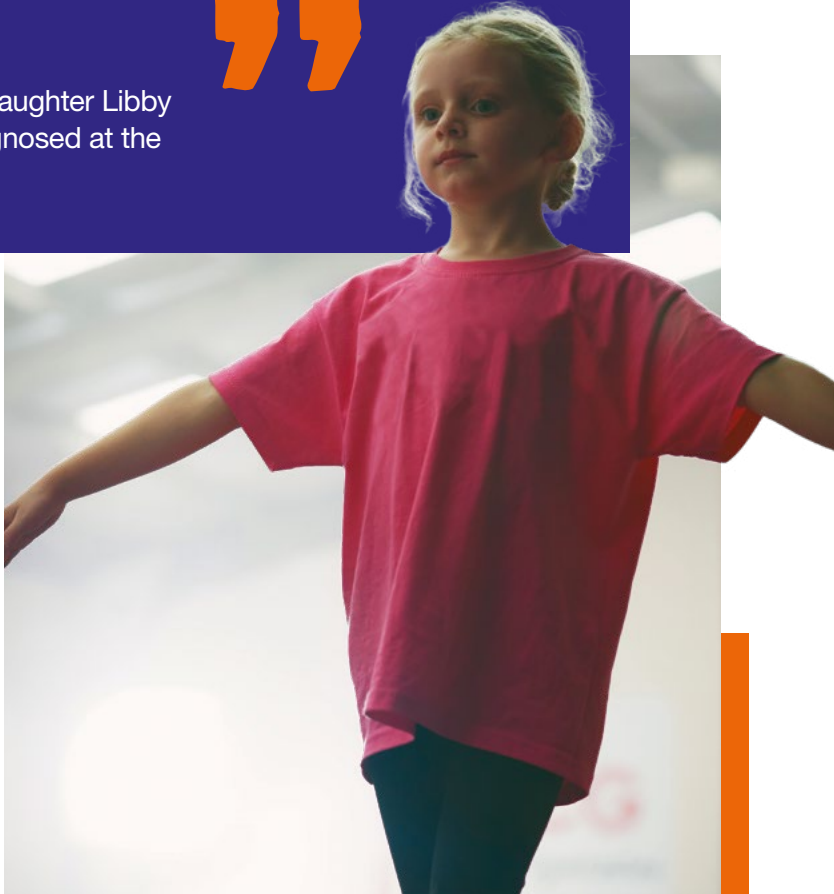
At the beginning, a diagnosis of type 1 diabetes can seem like a loss. Both you and your child could be grieving for the life you had before diabetes. This is natural and is part of coming to terms with the diagnosis. How long it takes is different for everyone and depends on how much support, both physical and emotional, is available. Allow your child to grieve in their own way. Don't hurry them.

“

People tell you you're strong, but you don't think you are. I was heartbroken. I would look at Libby when she was asleep and think "I've lost her and who she was." With time it got easier and now my outlook is changing. I thought I'd never get my little girl back, but she's here and diabetes is part of our life now. We manage it, while she also enjoys her childhood.

”

Jayne,
whose daughter Libby
was diagnosed at the
age of 3.



Tips for older children dealing with diabetes



- ✓ It's OK if they feel it's not fair that they've got diabetes – it's not! Acknowledge this, empathise with them and remind them that it's OK to ask for help.
- ✓ Some people find it helps to think of diabetes as being like a pet – it's part of your family but it needs to be cared for and looked after every day for it to live well.
- ✓ Remind them that there's no such thing as perfect blood sugars all the time. They just need to try their best to manage every day as it comes, and hopefully they'll find it easier to deal with over time.
- ✓ Meeting other people their age who are dealing with diabetes can help them to feel less alone. They might not realise how much this kind of support helps and people often tell us they wished they'd reached out much earlier.

We've got local groups for teenagers and young people. Find out more on our website at diabetes.org.uk/pg-local-groups

It's good to talk

One way to help is to encourage your child to talk openly to someone who'll listen and understand.

Having type 1 diabetes can feel lonely, so having the support of family and friends can be a great source of strength.

But many children, especially older children, don't like talking about it. It's the same for many adults.

It may be easier for them to talk to someone outside the home – maybe a grandparent, an aunt or uncle, or a good friend. It may also

help to keep a daily journal, to say how the day was, what was good and what was hard.

Young children need lots of love, comfort, cuddles and calm handling. If your child has been diagnosed very young, be aware that problems may surface later. Sometimes it's only when school starts that they really become aware that they're different to other kids. But it's important to bear in mind type 1 diabetes shouldn't stop your child doing anything their friends do.



After our son was diagnosed at the age of seven, we felt a rollercoaster of emotions. We felt guilty and terrified of how our son and our family would cope with this. We were devastated that our son had to now live with a lifelong condition and change his entire life.

Nikki and Zack



Looking after yourself

Getting help if you're struggling

- Speak to your paediatric diabetes team.
- Contact our confidential helpline. It's staffed by a team of highly trained advisors. Call **0345 123 2399**, or email **helpline@diabetes.org.uk** or **helplinescotland@diabetes.org.uk**.
- Connect with other parents of children with diabetes. Go to the Diabetes UK Facebook page (/diabetesuk), or the Diabetes UK Online Support Forum at **diabetes.org.uk/pg-forum**.



Try to get enough sleep

Worrying about your child's health after their diagnosis may be affecting your sleep. And if you're now doing nightly blood sugar checks, this can also make it harder for you to get a good night's rest. If you have a partner, or someone else at home who can help, then see if they can do some of the night checks to give you a break.

If your child is having a lot of nighttime highs or lows, or both, speak to your paediatric diabetes team. They might suggest strategies that can help, like changes to your child's insulin dose.

Find a community

Sharing experiences and talking to people who are also looking after a child with diabetes can really help.

Here are some of the ways you can get in touch with other parents or carers.

- Local groups.
- Our online forum.
- Family Weekenders, which are residential events for the whole family. For more info, visit **diabetes.org.uk/pg-type-1-events**

Work

If you're struggling to keep a balance between your job and looking after your child, speak to your employer.

You have the legal right to request flexible working hours once every 12 months, once you have been in post for 26 weeks, or to ask for emergency time off. Some employers may have other leave you can request, like parental leave, so it's useful to check.

Your employer can deny a request if they have a good business reason, but they have to offer you the ability to appeal.



“

I have been to one Weekender, which was very informative and useful. A standout benefit from it was the session for siblings. Aidan's brother Keir got a lot out of that and it was eye-opening as parents to understand that he sometimes felt that all our focus was (inadvertently) on Aidan at times when Aidan was needing lots more input and attention.”

Julie,
whose son Aidan
has type 1 diabetes.



CHECKS AND TREATMENT

Blood sugar checks

Your child's blood sugar level changes with insulin, food and activity levels, as well as things like being ill, feeling stressed or having growth spurts. Checking it regularly with a blood glucose meter will help manage their diabetes and can help avoid low or high blood sugar.

You can check your child's blood sugar by doing a finger prick test and using a blood glucose meter. Your paediatric team can explain how to do this and they will give you a meter and prescribe test strips. You'll prick their finger with a small needle called a lancet, put the blood on a test strip and use a blood glucose testing meter to give you a sugar reading. After the test, throw the needle into a sharps bin. Find out more about checking blood sugar at diabetes.org.uk/pg-testing

Many children use a monitor that measures their blood sugar continuously throughout the day and night, called a continuous glucose monitor, or CGM. They still need a blood glucose meter as a backup. Find out more about this on page 17.

Checking your toddler

It can be difficult getting blood from a toddler. It's good to explain what you're doing and that it may hurt a little, but it'll be over very quickly. You could encourage them to help if they're interested or have a teddy bear for them to practise on.



Tips for checking blood sugar using a blood glucose meter:



- ✓ Wash your child's hands with soap and water and dry thoroughly. Don't use wet wipes or alcohol wipes as they can affect the test result.
- ✓ Make sure their hands are warm, it's easier to get blood and it doesn't hurt as much.
- ✓ Prick the side of the pad of their finger. Avoid the middle or too close to a nail.
- ✓ Use a different finger and area of the finger each time.
- ✓ If you have difficulty getting enough blood, wait five seconds with their hand facing towards the ground, before applying gentle pressure.
- ✓ Keep a diary of their results or track them in an app. This can help you spot trends, which you can discuss with your child's diabetes team.

When to check:

- Before a main meal.
- Before bed.
- If they feel unwell
 - see page 29.
- Before and after physical activity, and sometimes during
 - see page 54.
- If they feel or you notice any hypo warning signs
 - see page 24.
- Any time they feel their blood sugar levels could be high or low.

Blood sugar checks should become part of you and your child's routine. Checking them regularly helps to build a picture of what's happening with their blood sugar levels. Their ideal range will be individual to them, and you can agree on target levels with your child's diabetes team.

As a guide, the target blood sugar ranges for type 1 diabetes are:

- on waking: 4–7mmol/l
- before meals throughout the day: 4–7mmol/l
- 90 minutes after meals: 5–9mmol/l.

You won't be within these targets all the time and that's OK. Sometimes you might know why the levels have gone up or down, but other times you won't. Don't blame yourself, it happens to everyone. Your paediatric diabetes team are there to help if it's worrying you.

Continuous glucose monitoring (CGM)

CGMs are small sensors worn on the skin that measure your child's sugar levels, without needing to prick their fingers.

They don't measure blood sugar levels like a standard glucose meter. Instead, they measure the amount of sugar in the fluid surrounding the body's cells. The results aren't always the same as a finger prick result. There's a small time delay,





especially after eating or exercising, so it's a good idea to check with a finger prick test if you're thinking of changing your child's treatment when you're checking – like if they're having a hypo or they might need more insulin.

A CGM measures your child's sugar levels continuously throughout the day and night and can alert you to highs and lows.

There are two types of CGM:

- **Real time:** Checks blood sugar levels at any time. You can download results.
- **Retrospective:** You can't check in real time, but you can download results and look back at them.

Pros of CGMs

- Track your child's sugar levels throughout the day and night.
- See trends, like when their sugar levels are starting to rise or drop, so you can take action earlier.
- Fewer finger prick checks, in general.
- Help improve your child's HbA1c level – their average blood sugar levels for the last two to three months – as insulin doses can be tailored.
- Reduce hypos as you can see a downward trend before they actually go hypo.
- Set an alarm to alert you when your child's levels are high or low.

Cons of CGMs

- Information overload, which can be overwhelming.
- Still need to do some finger prick checks.
- Some children might not like wearing the sensor.
- You or your child need to be motivated to use the data for the best diabetes management.

Flash glucose monitoring

There are a few different models of CGM available. All CGMs send information instantly using Bluetooth. With a flash glucose monitor, or Flash for short, you'll only see the blood sugar readings when you scan your child's sensor with a smartphone or display device.

The Flash monitor available in the UK is called the FreeStyle Libre 2. The pros and cons are similar to those for CGM.

You can buy your own CGM, but all children should now be able to get one on the NHS. It's best to speak to your paediatric diabetes team for advice on whether a CGM or a flash glucose monitor would be helpful for your child.

Time in range

Time in range is the percentage of time your child's blood sugar level is within a 'target' range, as agreed with their paediatric diabetes team.

If your child has a CGM or flash glucose monitor, it'll tell you what their time in range is every day. This can be helpful to see what food and activity level causes their blood sugar to rise or fall, and for spotting trends. But it can also put added pressure on you and your child.

Their time in range might not be as high as you'd like. But try not to think of it as 'good' and 'bad'. It's helpful to remind yourself that sometimes blood sugar levels go up or down for reasons beyond your control, so you're not failing. The general aim is to be in range for 70% of the time, but this can be difficult to achieve, especially for children. And your child's paediatric diabetes team are there to help if anything's worrying you.



Tips for coping with needle phobia:



- ✓ Ask your child's team to prescribe the shortest, thinnest needles available.
- ✓ Look into injection aids, like the TickleFLEX®, which help to make injecting more comfortable and worry free.
- ✓ Ease any discomfort by numbing the area with ice first, gently pinching the injection area before starting, and rotating injection sites.
- ✓ Use a distraction like getting your child to count, sing, hug a toy, or watch a video while injecting or breast or bottle-feed babies and young children.
- ✓ Incorporate insulin injections and finger pricks into their routine, so it becomes like brushing their teeth.
- ✓ Get them involved, if they want to be, like choosing which finger to inject or reading the blood glucose meter.
- ✓ Remind your child that it's OK to have fears and talk about them openly.
- ✓ Get your child to try a mindful breathing exercise – you can find examples online.
- ✓ Reward them with a sticker on a sticker chart, or other small prizes.

Giving your child injections generally gets easier over time, so try not to worry. As long as you're open with them and your paediatric team, there's a good chance your child will start to become more comfortable with the process and routine.

Dealing with needle phobia

When your child has type 1 diabetes, needles become part of everyday life. It can take some time for everyone to adjust to this.

But if your child is scared of needles, then it can start to interfere with their care, making injections and blood sugar checks a stressful experience for everyone involved.

It can be tempting to skip an injection if your child's upset or angry. This isn't a good idea, as it's important to keep their blood sugars in check to keep them healthy and well. Nobody's entirely sure what causes a phobia and it can be difficult to explain. But there are lots of steps you can take to try and ease your child's fears.

Insulin

The carbohydrates, or carbs, your child eats are broken down into sugar in their blood. They're in starchy foods, like bread, potatoes, rice, flour and pasta, as well as fruit, some dairy products, sugar and other sweet food.

When your child has type 1 diabetes, they don't make any insulin, which helps move sugar from the blood into our cells for energy. So they need to take it via injection or pump.



At first, Libby cried every time we came at her with a needle to test her blood sugars or inject her insulin, but then she just accepted it.

She's a lot more aware now that we've got the technology and that makes things a lot easier for her.

Jayne,
whose daughter
Libby was diagnosed
at the age of 3.



Injecting

Your child will normally inject insulin with an insulin pen, which your paediatric diabetes team will show you how to use. The places to inject are usually the thigh, top of the bottom, stomach or upper arm, where there's more fatty tissue. Here are some tips:

- Decide where you're going to inject and get prepared with all your equipment to hand.
- Make sure the top of the needle is filled with insulin by squirting two units of insulin upwards into the air from the insulin pen.
- Always use a new needle. Reusing a needle makes it blunt and painful to inject with. It can also cause lumps to appear under the skin.



It's important to remember:

- Insulin must be kept at temperatures lower than 30°C (86°F), but ideally around 2–6°C (36–43°F).
- To store unused insulin in the fridge, but keep it away from the freezer compartment, as it could get damaged.
- To keep insulin you're currently using at room temperature, away from direct sunlight or heat sources.
- To throw away any insulin that's been open for 28 days or more.
- To avoid injecting into an area that your child will immediately use for activity. It'll make the insulin act more quickly and make a hypo more likely. For example, don't inject their leg just before football, try the stomach instead.

Insulin pumps

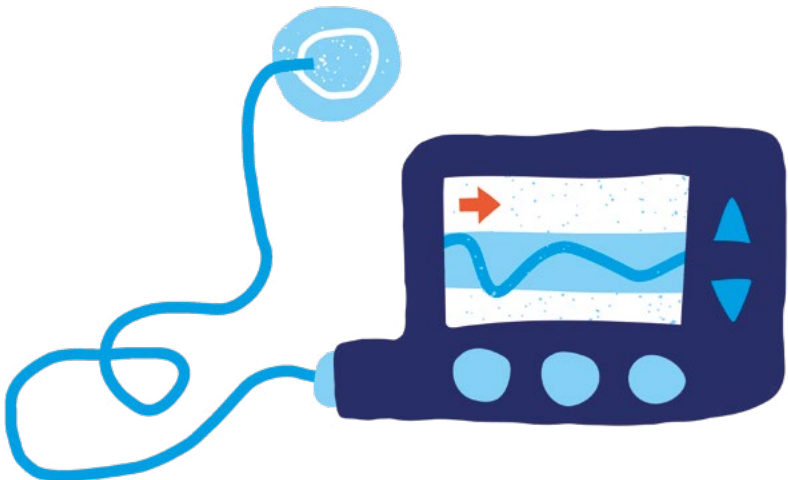
An insulin pump is an alternative to injections. It continuously supplies your child with insulin around the clock, through a tiny tube called a cannula inserted under the skin.

Pros

- Blood sugar levels are more likely to stay in target range, with fewer highs and lows.
- Your child won't need to inject as often.
- You can tailor their insulin more easily before, during and after exercise.
- Your child will have more flexibility in what, when and how much they eat.
- Better accuracy when you're bringing down their high sugar levels, as you don't have to give whole units – for example, you can give 2.8 units.

Cons

- Your child will need to wear their pump most of the time. For those wearing a tethered pump, which is attached to their body by another small tube that connects to a cannula, they'll need to take it off when swimming or showering.
- The infusion set can sometimes get blocked, so you might need to change it at short notice or switch back to injecting temporarily.
- You'll need to make time to learn about their pump, especially at first.
- There's a small risk of infection from the cannula.
- Your child will still need to inject sometimes.



HYPOS, HYPERS AND ILLNESS

Hypos and hypers

Hypos and hypers are when your child's blood sugar levels are too low or high. It can be hard to balance their levels all the time, but if you both know what the symptoms are, you'll be able to do something about it.

Hypos

A hypo, or hypoglycaemia, is when your child's blood sugar level is too low, generally below 4mmol/l.

Your child is likely to have a hypo at some stage. You won't always know why, but these things make them more likely:

- Missing or delaying a meal or snack.
- Not having enough carbs for insulin at their last meal.
- Strenuous activity without having extra carbs or reducing their insulin dose.
- Taking more insulin than needed.
- Hot weather.
- Injecting into a site that is just about to be used for activity, like the arm before playing tennis.

Symptoms

They're a bit different for everyone, but the most common signs are:

- trembling, feeling shaky, and sweating
- being anxious, irritable or tearful
- looking pale
- palpitations and a fast pulse
- lips feeling tingly
- blurred sight
- feeling hungry or sick
- tiredness
- having a headache or being unable to concentrate
- confusion.

Treating a hypo

Hypos need immediate treatment and acting quickly can stop them from getting worse. If you notice symptoms or a blood sugar test shows your child's levels are too low, treat the hypo immediately.

Tips for treating a hypo:



- ✓ Get your child to stop what they're doing.
- ✓ If there's time, check their blood sugar levels. If not, get them to treat first and check them later.
- ✓ Treat with something sugary to eat or drink. It could be some glucose tablets, Jelly Babies, glucose gel, or a non-diet drink. Avoid chocolate as the high fat content slows down how quickly the sugar's absorbed.
- ✓ Check their blood sugar levels in 10 to 15 minutes to see if they're back above 4mmol/l. If not, give them more sugary food or drink.
- ✓ Some children need longer-acting carbs too once their blood sugar level is above 4mmol/mol, like fruit, biscuits, a small sandwich or their next meal, if that's due.
- ✓ If your child is having a severe hypo, use the glucagon injection kit provided by your diabetes team. They should tell you how much to inject and how to do it.

Your child's diabetes nurse will be able to advise on how much food or drink your child needs to treat a hypo. Plus, it's also worth checking food and drink labels to see how many carbs they contain, as this can change.

Hypos can sometimes happen when your child is playing sport or being active. Make sure their teammates or coach know the signs and that they have hypo treatment with them at activities.

Hypos at night

Low blood sugar levels can happen at night. If they do, your child might not always notice the symptoms or wake up straight away, so their blood sugar levels may drop further. If the hypo still doesn't wake them up, they may be very tired or have a headache the next morning.

If you think they might be having hypos at night, check their blood sugar levels during the night. If the checks suggest they're having hypos, you may need to speak to your paediatric team about changing their insulin dose.

Hypo anxiety

If you or your child worries about having hypos, just know that it's completely normal. But if this worry becomes too much and leads to anxiety, then it's important to understand more about what's causing it. Here are a few steps you can take to help with anxiety.

- Learn more about hypos and why they happen. If you and your child understand what's going on inside their body, you might not worry as much because you know exactly what's happening.
- Start logging your child's hypos. You might be able to see patterns or something you can change in their routine.
- Try relaxation techniques like mindful breathing to help calm you or your child when they're having a hypo.
- Talk to your child's paediatric team. They'll have come across it before and will be able to offer advice on how to cope.
- CBT, or cognitive behavioural therapy, can teach you how to cope with stressful situations, like hypos. You can find services through your GP or try apps that guide you through meditations or breathing exercises.



- Find others who understand exactly what it's like via our online support forum, or local groups.
- Call our helpline and speak to a trained advisor who understands the ins and outs of life with diabetes.
- Consider whether tech like an insulin pump or a CGM is right for your child. They can help track blood sugar levels or keep levels in range more often, reducing the chance of hypos.

And keep in mind that children's lives are unpredictable and fast-paced, so you can't anticipate everything as a parent. You and your child will develop a sense of the things that could affect their blood sugar levels as time goes on, and you'll become an expert at managing them.

Hypers

A hyper, or hyperglycaemia, is when your child's blood sugar is too high. That's usually above 7mmol/l before a meal or above 9mmol/l two hours after a meal. If your blood sugar levels are very high, it can lead to diabetic ketoacidosis (DKA), which is a life-threatening emergency if it's not treated in time. See below for more about DKA.

There are lots of reasons your child might get hypers, but some of the common ones are:

- missing an insulin dose
- not having enough insulin for the carbs they've eaten
- feeling stressed
- being unwell
- overtreating a hypo.

Symptoms

- Weeing more than usual, especially at night.
- Being very thirsty.
- Headache.
- Tiredness.
- Irritability.

Treating a hyper

If your child's blood sugar level is high for a short time, you may not need to treat it. But if your child uses a pump or their blood sugar levels stay high, you may need to:

- check your child's blood for ketones. See below for more on this
- follow your sick day rules if there are ketones, contact your paediatric diabetes team immediately
- check your child's pump set is working correctly, in case it needs changing. Your paediatric diabetes team will be able to advise on this
- make sure your child drinks plenty of sugar-free fluids, so they don't get dehydrated.

Recognising DKA

Consistently high blood sugar levels can lead to DKA. DKA is most likely to happen when your child is first diagnosed, if they're ill, if they're having a growth spurt, or if they haven't taken their insulin.

It's caused by consistently high blood sugar levels, leading to a severe lack of insulin in the body and the release of chemicals called ketones. If left unchecked,

ketones can build up and make your child's blood acidic. This can be life-threatening and is an emergency. You should have been given a ketone meter by your healthcare team and told how to use it.

DKA usually develops over 24 hours but this can be faster in young children or those using an insulin pump. If DKA is picked up early enough, it can be treated. So it's important to look out for the signs, which include stomach pain or being sick, breathing more quickly, drowsiness or confusion, and breath that smells of ketones, like pear drops.

If your child has high blood sugar levels and any of these signs, contact your paediatric diabetes team immediately.

Illness and infections

When your child is ill their blood sugar levels may go up, or down. A high temperature tends to make blood sugar levels rise, whereas diarrhoea and vomiting can make levels fall. Children can become very sick more quickly than adults, so don't delay in getting help or reassurance.

Illness is a common reason for developing DKA. So, it's important to check regularly for ketones when your child is ill. You need to check regularly throughout the day and night when they're ill – no matter what their blood sugar levels are. If you're worried and can't get hold of your paediatric diabetes team, take your child to the nearest A&E.

Read more about the signs and symptoms of DKA at

diabetes.org.uk/pg-dka

A&E

If your child needs medical attention for something other than diabetes, like an accident or injury, there could be a long wait. People are usually advised not to eat or drink in A&E in case they need surgery. However, you should tell staff when you arrive that your child has type 1 diabetes, and that they may need to eat to avoid a hypo. If you feel your child needs to eat or drink, check with the staff again.





Hospital stays

Here's what to do if your child needs to stay in hospital overnight:

- The hospital should provide the insulin your child uses. But take some with you in case there's a delay.
- Take your own supplies of diabetes equipment, like a blood-testing kit or pump supplies, and label any kits that belong to your child. The hospital probably won't have these.
- Check that the ward staff have spoken to your child's paediatric diabetes team. You can always call them yourself if you're not sure.
- Don't assume that everyone treating your child knows they have type 1 diabetes. It's better to be safe and keep mentioning it to any new staff who look after your child.
- While in hospital, your child's blood sugar levels may be higher or lower than normal. Stress, illness, trauma and longer periods of inactivity will affect their levels. Either you or the medical staff at the hospital need to check their levels more often and adjust their insulin if needed.
- Whether you want to manage your child's diabetes care while

they're in hospital, or your child wants to do it themselves, the hospital should support you. This includes support with using an insulin pump. You'll need to discuss and agree this with the hospital staff.

Vaccinations

As well as regular childhood vaccinations, your child should be offered an annual flu jab from the age of six months. Your GP surgery should contact you about this between September and December.

The pneumococcal vaccine was made part of routine childhood vaccinations in 2010. This vaccine is given as three doses at two, four and 13 months. A child born before 2010 won't have had it but will be eligible for the vaccine because of their diabetes.

Anyone with diabetes is strongly encouraged to get the coronavirus vaccine. All children over five are now eligible. Most children will be given their vaccine at school. Check the NHS website for more on this.

Be aware that some children's blood sugar levels go up after a vaccination, because the body is making antibodies.

Sick day rules and tips



Keeping your child's blood sugars levels as close to target as you can when they're unwell is important.

- ✓ Your child should keep taking insulin even if they don't feel like eating. You may need to change their dose.
- ✓ Check your child's blood sugar levels throughout the night. This is the only way to know if they're too high or too low.
- ✓ If your child's blood sugar levels are high, check for ketones.
- ✓ Keep your child hydrated with plenty of unsweetened drinks.
- ✓ Encourage them to eat little and often. If they're still not eating well, get them to sip sugary drinks, like fruit juice or non-diet lemonade, or suck on glucose tablets.
- ✓ Contact your paediatric diabetes team urgently if ketones are present or if your child is vomiting and unable to keep fluids down. You can also call them if you need help with insulin dosing during an illness.

CARE

Your paediatric diabetes team are on hand to help you manage your child's diabetes.

As well as explaining what you need to know about diabetes and how it's treated, they're there to listen to your concerns and provide advice. You and your child live with diabetes every day, so it's important that you're involved in decisions about their care and also have people you feel like you can turn to.

You'll probably see your team often in the first months after diagnosis, especially your PDSN, or paediatric diabetes specialist nurse. Here's a little more about each member of your team and what they do.

- Consultant paediatric diabetologist or endocrinologist – the doctor who has overall responsibility for your child's diabetes care. Your child will still see their GP for things unrelated to diabetes, but anything diabetes related will be handed over to their specialist doctor.
- Paediatric diabetes specialist nurse (PDSN) – they're usually your first point of contact for all things diabetes related.

- Registered dietitian with experience in children with diabetes – they'll help with food choices.

Care at the clinic

Your child will have an appointment at their paediatric diabetes clinic at least four times a year. It's usually part of the children's ward of a hospital, an outpatient centre, or a diabetes centre.

The appointment should be with your full team, so the PDSN, the paediatrician and the dietitian.

At every appointment, you can expect certain checks, like measuring height and weight, checking injection sites, and a blood test to check long-term diabetes management.



Questions



I sometimes don't understand what the doctor is saying. I'm too embarrassed to ask them to repeat. What can I do?

Don't be embarrassed – your doctor is used to people asking lots of questions and it's important you ask about anything that's worrying you. You can write down a list of questions before you go, or jot things down while you're there so you don't forget. Make sure you understand the answers before the doctor moves on, especially when it comes to test results.

My child hates the clinic and refuses the checks when we go there. What should I do?

Most clinics do their best to make children feel comfortable, but it can help to take something to keep them busy or give them a treat, like a favourite meal or movie, before or after. Ask your diabetes team for help if your child is refusing checks.

Sometimes there may be someone else at the appointment, like a medical student. If that worries you or your child, you can ask to be seen alone.

I'm not happy with my child's healthcare. What can I do?

Try to deal with small worries when they come up. It's best to discuss any ongoing problems with the person in charge of the surgery or clinic. If you're still unhappy, you can take your complaint further. There are different ways of doing this depending on where you live, but you can start by asking your hospital clinic or GP practice for a copy of their complaints procedure. You can also call our helpline and speak to one of our advisors about what to do next.

Type 1 essentials

These are the 10 things you should expect from your child's diabetes care. They include the care, checks and support you and your family need to make sure your child's diabetes is managed well.

1. Care from a specialist team

Your child's diabetes team should include:

- a consultant with experience in children's diabetes care
- a children's nurse with experience in diabetes
- a dietitian with experience in children's diabetes, who can advise on food choices and eating healthily
- someone who can help you and your child get advice about feelings or worries.

2. Regular and long-term checks

As well as blood sugar levels, your child will need other checks with their paediatric diabetes team. These tests will check diabetes management and look for other conditions. They should be done once a year to make sure your child stays as healthy as possible.

All children should get:

- a blood test to check their diabetes management, known as HbA1c, four times a year. This test measures your child's average blood sugars over the last two or three months
- regular checks of their weight, height and general health
- screening for other autoimmune conditions linked to diabetes, like coeliac disease and thyroid disease. See diabetes.org.uk/pg-screening for more information on these
- an opportunity to agree goals
- an opportunity to talk about emotions or things they might be struggling with.

Once a year, children over 12 should get:

- blood and urine tests to check kidneys
- digital photo of the back of their eyes (their retinas)
- blood pressure check
- foot check.



3. The right treatments

You should be told about all the available treatments, including new ones, and get the treatments that are right for your child. These might be:

- multiple daily injections (MDI)
- blood glucose and ketone meters and testing strips
- insulin pumps
- continuous glucose monitoring (CGM)
- carb counting.

4. Support so you can do it yourself

You and your family should be able to manage your child's condition yourselves, as much as you can. This means being equipped with the expert advice, education and information you need to do this.

This should include:

- high-quality information that your child can understand, in a way that works for them and you
- education so your child can learn how to manage their condition
- advice on eating well and keeping active
- 24-hour access to help and advice

- a key contact in your paediatric diabetes team
- the chance to regularly see a dietitian who can help with food choices.

Your child may also be able to get financial support from the government called Disability Living Allowance. Go to diabetes.org.uk/pg-dla to find out more.

5. Help with feelings and worries

Sometimes it may be difficult coping with everything that goes with diabetes. Talk to your paediatric diabetes team who'll be able to help. Your diabetes team should offer your child and family the chance to talk to a counsellor who's an expert in mental and emotional health, and knows about how diabetes can affect emotions and feelings.





6. The right care when you're in hospital

If your child has to go to hospital for any reason, you should have contact with a paediatric diabetes team. You should also be allowed to carry on managing their diabetes yourselves if you can.

7. A smooth transition to adult diabetes services

Moving from child to adult healthcare services is a big shift. The paediatric and adult diabetes services should work together to make sure the move goes as smoothly as possible. It should be done in a way that suits your child, and at an age that's right for them.

8. A say in the care you get

You and your child should be part of the decisions made about their care and how their diabetes is managed. For example, you should:

- be able to work with your doctor or paediatric diabetes team to make a plan for how your child's diabetes will be treated and managed
- get copies of letters that say what everyone has agreed to
- help them come up with the services that are right for you and your child.

You should also be asked to fill in a national Patient Reported Experience Measure survey, which collects information about the kind of care children with diabetes are getting.



9. Support at school

Your child should have all the support they need to do well at school. They should be able to take part in everything, including in the classroom, going on school trips, taking part in sports and after-school clubs. Your paediatric diabetes team should work with the school to make sure it happens. For example, they should:

- agree a healthcare plan with you and your child
- work out who'll make sure your child gets the diabetes care they need at school
- keep plans up to date and make sure everyone knows what's happening.

10. Equal opportunities

Your child should be given the exact same opportunities as everyone else.

If you feel like you're not getting the right care, speak to the people or the service involved. For example, your doctor or nurse if it's a healthcare issue, or a teacher or headteacher if it's a problem at school. Ask them for a meeting and take this list of essentials along with you to help you get your point across. You can also write down your concerns so you have them to hand.

FOOD

Your child doesn't need a special diet for their diabetes. The aim is for your child to make the same healthy food choices that are best for all children and to fit their insulin needs around this.

There are a few things to avoid though. Don't buy any food labelled 'diabetic.' It's illegal in the UK for companies to label products like this, but be careful with anything you buy online. These foods don't have any health benefits and can be high in fat and calories.

It's also best to avoid sugary drinks and fruit juices, especially when your child is thirsty. They can make blood sugar levels go very high, very quickly, so they're usually only recommended as a hypo treatment. Water or sugar-free drinks are fine, and water is the best option when your child is thirsty as it won't affect blood sugars.

Talk to your dietitian

Either at diagnosis or soon after, you and your child will see a registered dietitian who understands diabetes. You should see them

regularly after diagnosis. They will advise on healthy food choices and the nutrients your child needs, and will help make sure they have a happy, healthy relationship with food. They will also help you and your child learn how to count carbs.

All food will have an impact, but it's the carbs, or carbohydrates, in food and drink that will cause the biggest rise in your child's blood sugar level after eating.



These are the different types of carbs:

- **Starchy:** bread, potatoes, chapatti, rice, pasta, breakfast cereals, couscous, quinoa, yams, and cassava.
- **Natural sugars:** fruit and plain dairy products.
- **Added sugars (also called free sugars):** sweets, chocolate, cakes, biscuits, syrups and non-diet drinks.

Starchy carbs will raise your child's blood sugar levels, but they're important as they provide the body with fuel for energy and nutrients to help them grow. So they need to be eaten as part of a healthy diet, but balanced with the amount of insulin taken. Healthier choices of starchy carbs include wholewheat pasta, porridge oats, brown rice, wholegrain cereals, and sweet potatoes. This is because they contain more fibre, which is important for gut and heart health.

Cutting down on foods with free sugars – which are sugars added by you or the manufacturer, or found naturally in honey, syrups and fruit juice – will help manage your child's blood sugar levels. It's difficult to cut them out entirely, but try to swap in healthier choices, like water

and plain milk instead of energy drinks or fruit juices. You should continue to treat hypos with free sugars though – see page 24 for more on this.

Carb counting

This is a good way to manage your child's type 1 diabetes, whether they have injections or use a pump.

It means matching your child's insulin to the carbohydrate in their food and drink. So, if they want a bigger portion size, they can have it – as long as they adjust their insulin. Your diabetes team will help you work out your child's insulin-to-carb ratio. This will often change as they get older, so it's important to see your team regularly.

Once you get used to carb counting, it can mean more freedom and flexibility when you're preparing meals at home, grabbing food on the go or eating out.

But it's important to remember that carb counting doesn't change the fat or calorie content so, like all children, healthier food choices still matter for their long-term health.

How to count carbs

Carbs can be counted in two ways – in grams, or as carbohydrate portions (CP). One CP is usually equal to 10g of carbohydrate.

To work out the right amount of insulin for the carb amount, you'll need to know your child's

insulin-to-carb ratio, which will vary depending on their age, weight, activity levels and how sensitive they are to insulin. Your paediatric diabetes team can help you work this out.

There are four ways you can count carbs in food and drink.

1. Food labels – using the carb per portion value

Take this pre-prepared food label as an example. If you ate all of the ready meal, you would count 44.7g for carbohydrate. It's important to count the total amount of carbs, not the 'of which sugars' value. When using a per portion value, make sure it's the actual portion you're planning to eat.

Typical Values	100g contains	Each oven-baked meal (317g) contains
Energy	433kJ (103kcal)	1372kJ (325kcal)
Fat	1.7g	5.4g
Saturates	0.9g	2.9g
Carbohydrate	14.1g	44.7g
Of which sugars	2.0g	6.3g
Fibre	1.2g	3.8g
Protein	7.1g	22.5g
Salt	0.4g	1.3g

2. Food labels: using the carb per 100g value

You'll see food labels like the below on the back of foods like pasta or rice. When using the per 100g value, calculate the carbs for the actual amount of the food or drink you're going to have.

Typical Values	As sold 100g contains
Energy	1515kJ (360kcal)
Fat	1.0g
Saturates	0.2g
Carbohydrate	77.4g
Of which sugars	0.2g
Fibre	1.8g
Protein	8.5g
Salt	<0.01g

Divide the amount of carbs (77.4g, uncooked) by the weight (100g) and multiply by the amount you're eating. So if you're planning to cook 35g of rice per portion, the amount of carbohydrate would be 27.09g, not 77.4g.



Just remember, the cooked weight of pasta, rice and potatoes varies from the raw or pre-cooked weight, so check which values you're using. The label should tell you whether the nutritional information is as sold or as prepared.

3. Reference lists, visual guides and apps

Apps and books, like **Carbs & Cals**, help you estimate carbs, by listing the amount of carbohydrate in handy measures, like one bread roll, one medium banana or one scoop of ice cream.

4. Restaurant and café nutrition information

Many restaurants and cafés now list nutritional information for their products online and on menus. It should look similar to food packaging, but the values are average values and the dish that you're served may vary in size and content. So you'll need to use your judgement and experience, too.

Tips for carb counting:



- ✓ Your child's dietitian can give you a list of foods with the amount of carbs in them.
- ✓ **Carb Counter: A Clear Guide to Carbohydrates in Everyday Foods** (Collins Gem) is a small, handy guide with clear tables showing the carbs in everyday foods. It's available as an app too.
- ✓ You could also complete our carb counting module, which features parents of children with type 1 diabetes and their tips. Go to our Learning Zone here: diabetes.org.uk/pg-zone
- ✓ Digital scales can help you to get portion sizes right. Make sure they have a flat base, can be set to zero and are accurate to the nearest gram.
- ✓ Even if you don't weigh food every time, you should do it every six months or so as your child may eat bigger portions as they grow.

Snacks

Snacks used to play a big part in managing blood sugar levels for people with type 1 diabetes. But this isn't the case anymore now that insulin treatments are more flexible.

Healthy snacks like fruit, plain yogurt and vegetables can still provide important nutrition. But too many unhealthy snacks can lead to higher blood sugar levels, extra fat and calories.

Options in schools are generally healthier these days, but children might still bring unhealthy snacks in from home or from the shops nearby.

Type 1 diabetes doesn't mean your child can't have these foods but, as for all children, having too many of them isn't good for their health.

Young children

All young children need two to three snacks between meals. Their stomachs are too small to fit all the food they need into three meals a day. Young children with diabetes also need snacks to stop their blood sugar levels dropping between meals when they're playing and being active.

They may also need a snack before bed to keep blood sugar levels stable overnight.

Older children

Older children on MDI treatment – multiple daily injections – or children with pumps, may not need snacks to maintain their blood sugar levels. They may need extra insulin if they have a carb-containing snack, but snacks with no or a very small amount of carbs usually won't need insulin. But avoid snacks high in fat, sugar or salt as eating these often isn't good for their general health.

Treats and sweets

Having sweets and chocolate is part of childhood for most children and your child can have them too. But try to make them occasional treats rather than something they have every day, which is recommended for all children.

For your child, it might be better they have this sweeter food as part of a meal as they'll be taking insulin then anyway, but they'll need to include them in the carb count for the insulin dose. They will need extra insulin doses if they have sweets or chocolate outside of mealtimes.

It's best not to ban anything as it could lead to them eating secretly. Instead, make it less about their diabetes and more about how too many sweets and chocolates aren't

good for them, in the same way they're not good for anyone. It can also help if you find them some healthier snacks they like, too.

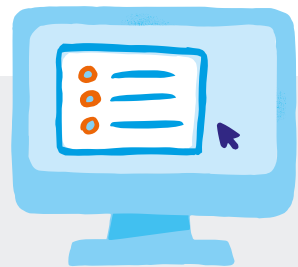
Instead of...	Try
Milk chocolate	One chocolate rice cake
Ice cream	Frozen banana or low-fat frozen yogurt
Crisps	Plain popcorn with added spices or cinnamon
Bread and dips	Carrots and celery with salsa or low-fat hummus
Fizzy sugary drinks	Water flavoured with mint or fresh fruit

For more healthy swaps, tasty recipes and loads of food tips, go to diabetes.org.uk/pg-enjoy-food

Be aware that some clinics recommend no snacking without insulin. Check with your own paediatric diabetes team.

Top tip

Download the free **NHS Food Scanner app**. It lets you scan your family's favourite foods and then swipe to see healthier swaps.



Dealing with food issues

It can be really worrying if your child refuses to eat – whatever age they are. If they're growing well, refusing food isn't likely to cause long-term problems, but you might still worry about hypos.

The best advice is to keep calm and try not to show them how frustrated or anxious you are. Children are good at picking up signals from parents and showing your anxiety can make things worse.

Try the following:

- Offer regular carb-containing meals and snacks. If they won't eat big meals, then go for small snacks. But try not to give a constant supply of snacks, as they'll be less hungry for meals.
- Keep mealtimes to 30 minutes. Then clear the meal away without offering something else.
- It's best to inject insulin or give a pump bolus before a meal. But if they're refusing to eat, you may need to inject or give a pump bolus dose straight after instead. Adjust the amount of insulin based on what they've actually eaten. If your child has had insulin and refuses to finish the meal, you can make up some of the missing carbs with

a drink of milk or yoghurt or custard for pudding, but try not to make a habit of doing this.

- Offer small portions or allow them to serve themselves, so you don't overwhelm them.
- Praise good eating behaviour.
- Try to not let your child drink 30 to 45 minutes before their meal's due, so they don't fill up on fluid.
- Be consistent. Everyone who feeds your child – parents, grandparents, nursery staff – should react to a refusal to eat in the same way. This gives them the same positive message about eating.
- Encourage your child to eat with other children who are good eaters. Children love to copy.
- Speak to your PDSN or dietitian for more advice on managing food refusal. You could also ask to speak to a psychologist.



Teenage food choices

Teenagers can go through phases with food, which can be frustrating. But it's important not to keep telling them what to eat. If they take insulin with food, that might be the best you can hope for a lot of the time.

If they want to have fast food with their friends, encourage them to go for smaller portions or healthier options. Many fast food places have information on their websites about carb content so you can check these.

Encourage your child to do regular physical activity (see page 50). Not only does it help with maintaining weight, but getting active will also help improve their mood and sleep, and reduce stress – not to mention help reduce their chance of developing diabetes complications later in life. Depending on the time of the activity, consider reducing the insulin dose at the meal before, rather than giving them an extra snack before they start.

Weight

As your child grows up, like many children, they may become more conscious of their weight.

But unlike most other children, they will need to be weighed and measured regularly at their

diabetes clinic. This needs to be done sensitively and respecting their privacy.

Unexpected changes in weight can be caused by poor thyroid function, which is more common in people with type 1 diabetes. So your child needs to have their thyroid checked every year too.

Missing or skipping insulin regularly leads to weight loss. A lack of insulin means the body can't use glucose for energy and this can lead to DKA (see page 24) in the short term, as well as long-term complications.

Teenagers may miss meals or be too strict about their eating, to control their weight. Discourage your child from missing meals to lose weight – it leaves them more likely to choose unhealthy snacks with limited nutrients when they do want to eat.

If you think your child is regularly missing insulin on purpose to control weight, or is becoming obsessed with how much they eat, speak to your paediatric diabetes team immediately. You can also find more information about disordered eating with diabetes on our website at diabetes.org.uk/pg-disordered-eating

It's important to know the warning signs if you're worried that your child might have an eating problem. Here are some common signs of disordered eating:

- increase in HbA1c or blood sugar levels going up and down a lot
- going into DKA or near DKA episodes
- severely restricting what food they eat
- binge eating
- secrecy about diabetes management
- trying to lose weight by making themselves sick or restricting insulin
- fear of weight gain and concerns about body image
- depression and anxiety
- fear of hypos
- denial of the seriousness of symptoms and conditions
- exercising a lot without eating enough to balance it out.

Questions

Can we still go out for family meals?

Yes. Once you can count carbs, you can adjust your child's insulin dose to match the carbs they eat.

Your child may choose foods that are higher in fat than you cook at home. And they'll probably eat over a longer period of time. As fat slows down the absorption of carbs in the bloodstream, foods like pizza, curry and fish and chips may take hours to affect your child's blood sugar levels. That means an injection or standard pump bolus dose may have finished working before all the carbs have been absorbed. So you may need to give more than one injection or an extended or dual wave pump bolus dose.

Your PDSN or dietitian can talk to you about this.

If you eat later than usual, it's generally OK to delay your child's insulin dose but again, talk to your PDSN or dietitian.



What about parties and sleepovers?

Your child can still go to parties or sleepovers. But sleepovers can make you worry about what they're eating and when because you can't help if their blood sugars become unstable. Here are some things that could help:

- Talk to the other parents beforehand to see what food will be provided and when.
- Remind them that your child can eat the same as everyone else but will need to have insulin with their food.
- Ask for sugar-free or diet drinks.
- Find out if there's any type of activity that might affect your child's sugar levels.
- If you can, try to find out what food is being served, so you can suggest the right amount of insulin.
- Make sure you swap numbers with the other parents, just in case.
- Talk to your PDSN or dietitian for more advice on parties and sleepovers.

I keep finding leftover food in my child's school bag and I'm worried they'll have a hypo if they don't eat everything I've given them. What should I do?

First of all, check you're not giving your child too much. Talk to them about why they're leaving the food, as there could be an underlying reason. If it's not about the quantity, maybe your child just doesn't like the food. Or they want to eat the same as their friends. Teenagers may not want to eat snacks if their friends don't. You could talk to your child's school to see if you can change meal and snack times so your child can fit in with their friends. Then talk to your PDSN or dietitian about the right amount of food and snacks for your child's age and activity level.

Your dietitian or PDSN can also advise you on the right dose of insulin to cover this.

PHYSICAL ACTIVITY



Being active

We know that being active has loads of benefits. And for children with diabetes, it's even more important. There are things you'll need to consider about your child being active, but they can still spend plenty of time getting out of breath, just like their friends.

Generally, children and young people should do at least an hour of moderate to vigorous physical

activity a day. That goes up to three hours for under 5s. This can include activities like brisk walking and active play, as well as sports and games, like skipping, dancing and swimming.

Keeping active isn't just about preventing excess weight gain. It helps children develop their co-ordination and build strong muscles and bones, increasing their strength and flexibility.

“

Our focus is on doing everything in the background to enable Moshe to do and be anything he wants. If he wants to be a circus acrobat, then so be it and we'll make sure that his sugar levels are managed in a way that allows him that freedom.

”

Mendy,
whose son Moshe
was diagnosed at 11 months old.

For children with diabetes, it can also help improve blood sugar levels and insulin sensitivity. And it lowers the risk of diabetes complications by improving blood pressure and cholesterol levels.

Plus, moving more can help with managing anxiety, increase self-esteem and confidence, improve mood, energy and sleep, and reduce stress and the risk of depression. This can lead to better concentration and learning at school, along with increased social skills.

Like all children, your child can still take part in all sorts of activities and sports. You'll just need to help manage their diabetes treatment around these activities.

Activity increases the amount of glucose used by muscles for energy. This means that being active may sometimes lower blood sugar levels.

Being active also helps the body to use insulin better. So regular exercise can help reduce the amount of insulin your child takes.



Tips for keeping your child active:



- ✓ Try to be active yourself – being a role model can really help and will also benefit your health.
- ✓ Encourage them to try different things – let them have a go and see what they enjoy.
- ✓ It doesn't need to be organised exercise – just being active and moving more is what's important. Any movement, no matter how informal, can have a huge impact. The playground, scooting to school, playing tag, running around in the garden, messing around in the paddling pool, walking to the shops with you – anything that gets them moving is good.
- ✓ If physical activity is a challenge or your child doesn't seem interested, try to split their exercise into shorter active sessions of 15 to 20 minutes of activity across the day, rather than doing an hour in one go.



Activity plan

Regular activity should be part of your child's routine, so it helps to have an activity plan.

Being active is likely to affect their blood sugar levels. And you may notice changes during or up to several hours after they've been active. Regularly checking before, during and after activity will help you understand the effect of activity on your child's levels. It could cause them to go low or high – or make no difference.

Activity may cause blood sugar levels to go down if:

- there's too much insulin working in your child's body
- the activity lasts longer than an hour

- the activity is strenuous
- there aren't enough carbs in the body.

Activity may cause blood sugar levels to go up if:

- they don't have enough insulin circulating in their body
- the activity is mostly anaerobic or competitive – so a competition or any activity that has short, sharp, bursts of movement, like sprinting, high jump or discus throwing.
- the body releases other hormones like adrenaline, which makes blood sugar levels rise. This is more likely if your child is doing vigorous or competitive exercise.

After physical activity

During any activity, your child uses up some of the glucose in their muscles and liver. They need to replace this or their blood sugar levels may drop. This usually takes around 12 hours, but can take longer after very strenuous exercise, or if they haven't eaten many carbs.

After exercise, your child's insulin may be more effective, so they may have low blood sugar levels. You might need to adjust their insulin or their food to prevent a delayed hypo, so talk to your paediatric diabetes team about having a plan for managing physical activity.

It's worth noting that this can be different for everyone, and it won't always be the same every time your child is active. Other things can play a part in affecting blood sugar levels, like weather, illness and hormones.



Tips for managing blood sugar levels when active

- If their blood sugar levels are above 14mmol/l, check for ketones. If there are ketones, don't let them do any activity until they no longer have them. And follow advice for managing ketones on page 28.
- If their blood sugar levels are high before exercise but without ketones, think about when your child last had insulin. They might need a small amount before exercise if it's been more than three or four hours since their last injection or pump bolus dose.
- If your child has had a severe hypo, they shouldn't exercise for at least 24 hours.
- Aim for blood sugar levels of at least 5mmol/l or more before any planned activity. This reduces the chance of a hypo.
- During exercise the blood flow to the muscles increases. This speeds up the action of the insulin. So, choose an injection or cannula site away from the muscles that your child is about to use the most.

- If you know your child will be active within one or two hours of an injection or pump bolus dose, you may need to reduce that insulin dose to avoid a hypo. If you don't reduce the insulin, they may need an extra snack before exercise. Talk to your paediatric diabetes team.
- If your child exercises for 60 minutes or more, they will probably need some extra carbs during the activity.
- All children should drink when they exercise. For activity lasting less than an hour, water or sugar-free squash is fine.
- Check out our website for more on blood sugar levels and exercise – diabetes.org.uk/pg-levels-exercise

Going professional

People with diabetes can do most sports and activities. There's no reason why your child can't enjoy sports or even go on to play sport competitively. Just look at British boxer Muhammad Ali, who was diagnosed at the age of the five and in 2018 became the UK's first ever professional boxer with type 1 diabetes. Or professional golfer Hannah McCook, who was diagnosed at the age of eight and has represented both Scotland and Great Britain at international competitions.

Some sports-governing bodies have restrictions on people with diabetes, but not many. Certain sports, like scuba diving, have strict guidelines for safety reasons.

Contact the relevant sporting body or a local sports group for more details.



Things to remember

Planned or unplanned activity

■ For planned activity:

If their meal is one or two hours before the activity, you may need to reduce your child's insulin dose, as well as having hypo treatments available, just in case. Give them a meal with low-fat carbs, like pasta, baked beans, porridge, milk or yogurt and fruit.

■ For unplanned activity:

Your child may need a carb-containing snack to help avoid a hypo. Always carry a snack, like a cereal bar, and hypo treatments, like glucose tablets, in case your child does an activity that isn't planned.

Timing

■ Activity within one or two hours after a meal:

Think about reducing your child's insulin dose with the meal they have before exercising.

■ Activity more than two hours after a meal:

Your child will usually need an extra snack, like a banana, a cereal or a cake bar, about an hour before starting the activity. How much they need depends on how long they'll be active.

Type of activity

■ Strenuous activity, like a football match:

Blood sugar levels may drop during the activity. If this happens, give your child some quick-acting carbs, like a sports drink or jelly sweets. Have some hypo treatment to hand throughout the activity.

■ Long activity, like a long bike ride:

Your child will need a mixture of quick- and longer-acting carbs, like fruit juice, sandwiches, cereal bars, fruit or biscuits. They can take these in a small rucksack along with something to treat a hypo, like glucose tablets.

You may be worried about your child being active, but it gets easier over time as you and your child start to understand their body and the effects of exercising better. Generally, the positives outweigh the negatives, as being active will help them lead a happier, healthier life.

Questions

I don't know which activity or sport is best for my child. What should we try?

There's no individual activity proven to be the best, so what's 'best' for your child is one they enjoy and are motivated to do regularly. Every child is different, so what works for one child might not work for another.

Balancing food, insulin and physical activity levels isn't easy, so be prepared in case they no longer enjoy an activity they used to. Try lots of different activities if you need to. Getting used to managing insulin with activity is likely to be trial and error at first.

Have the confidence to experiment and check your child's blood sugar levels to see how they're getting on. Your child's paediatric diabetes team can also help.

For more information about physical activity and diabetes and to hear more about playing professional sport with type 1 diabetes, visit

diabetes.org.uk/pg-activity



EVERYDAY LIFE

School

Diabetes shouldn't stop your child enjoying school and having the same experiences as any other child. It's important that the school works with you to make sure your child gets the care they need.

Many schools support children with diabetes very well. But some parents can have difficulties getting the care their child needs. This is wrong. No matter where you live in the UK, all schools have a duty of care to look after a child while they are at school.

To make sure your child gets the care they need, we've created two **Type 1 diabetes at school** packs – one for parents, one for schools.

These packs have all the basic information that you and your child's school need to make sure that your child gets the right care.

We have a lot more information for you and the school staff on our website too. There's more detailed information about everyone's roles and responsibilities. And there's specific information about trips and exams. There are also videos

made by young people themselves about diabetes at school.

Visit diabetes.org.uk/pg-schools-info or, if you'd like to order a pack by phone, call **0345 123 2399**.

You and your child's PDSN should give the school as much information as you can about your child's diabetes. Your PDSN can help you make sure the school knows how important it is to look after your child's diabetes. You, your PDSN and the school should work together to create an individual healthcare plan (IHP) that states what care your child needs, when they need it and who will help them. The IHP should be reviewed at least every year and whenever your child's needs change.

Find out who will be your main contact at school for your child's diabetes care and how you contact them. Always tell the school straight away about any changes to your child's diabetes.

If you don't get the support you need, call our helpline on **0345 123 2399**.



Travel

Diabetes won't stop you and your child from travelling anywhere. You'll just need to make the right preparations.

Travel checklist

- ✔ Carry diabetes ID and a letter from your paediatric diabetes team that says your child has diabetes and what medication they need.
- ✔ Take three times the amount of insulin and supplies as normal.
- ✔ In case of emergency, find out where you can get insulin at your destination.
- ✔ Check with your child's insulin manufacturer whether it's available at your destination and if it's sold under the same name. You can get prescriptions sent by courier with some companies.
- ✔ Flights might cross time zones. Check with your paediatric diabetes team if you need to make any changes to your insulin regimen, especially if the flight is over four hours.
- ✔ Hot or cold climates may affect how your child's insulin and glucose meter work. Check with your paediatric diabetes team.

Travel insurance

Most travel insurance policies exclude pre-existing conditions if they've not been detailed. So make sure you tell them about your child's diabetes when arranging your policy, even if they don't ask. If you don't, they could reject a claim. Find more travel advice on our website at diabetes.org.uk/pg-travel



I'll usually try to discuss the trip with my doctor or nurses and make sure that I have all the supplies I'll need. Research is definitely key, so I spend as much time as I can looking at things such as local healthcare, common foods, travel times, and of course any required paperwork. Things such as the cost of and availability of insulin in the destination are also very good to know.



Ted,
who was diagnosed at 16, is a photographer and travels often for work.

What to pack

- Check you have all your child's diabetes medication and equipment packed.
- Make sure you have their diabetes supplies in your hand luggage.
- Split diabetes equipment between both you and your child's hand luggage, in case a bag gets lost.

- Insulin must be kept in hand luggage as it can freeze in the hold.
- Pack snacks in case of delay.
- Take a letter from your doctor or nurse that details all of the medications (including insulin) and equipment you need to have with you.

Travelling with a pump or CGM

If your child treats their diabetes with a pump or uses a CGM, you must contact the airline before you travel. If possible, do this a few weeks before you fly.

The Civil Aviation Authority's Advisory Health Unit recommends that people with diabetes should always contact their airline before travelling to discuss medical devices they need to take on board an aircraft.

Some airlines need you to notify them of your medical equipment before the flight and fill in additional paperwork. If you don't do this, you might, in some cases, not be allowed to board the plane with your child's pump or CGM.

Pumps and CGMs can usually be put on airplane mode, but there's some caution about sudden changes in cabin pressure that can

cause unexpected delivery of insulin. If this happens, you may need to remove it and use an insulin pen. Your child may also need to check their blood sugar levels with a standard meter.

Also, you can't put all insulin pumps or CGMs through the X-ray machine or full-body scanner at the airport because X-ray waves can cause your pump or CGM to stop working properly. Make sure to check the manufacturer's instructions.

When carrying any medical equipment, you can get a Medical Device Awareness Card, which has information for airport security about diabetes and the equipment you need for your child to stop any confusion. Find out more and how to get one at diabetes.org.uk/pg-airport-tech

If your child gets ill abroad

Talk to your doctor for advice before you go, and get information from the tourist office, embassy or high commission of the country you're visiting about medical treatment there. Check whether the nearest hospital at your destination treats children and has someone who can interpret for you if needed.

Check your insurance policy and know exactly what you're covered for. Take a list of all your child's medication and use the generic name – not just the brand name.

Read more about dealing with illness on page 29.



I was first diagnosed with type 1 diabetes aged 16. I remember going to the diabetes centre and coming home with insulin needles, insulin pens, a blood sugar meter with loads of colourful lancets, and a book to read. The best way to describe it was like my whole life had just been turned upside down.

Shelby



TEENAGERS

Diabetes won't stop your child behaving like any other teenager. But being diagnosed with type 1 diabetes as a teen can be tough.



Your teenager may want to take total management of their diabetes. Or they may go the other way and feel they need you to look after them. Neither way is right or wrong. You have to do what feels comfortable for you both.

While it's important not to push them into too much responsibility too soon, don't hold them back if they want to handle it themselves.

Keep an eye on them and be prepared to step in and offer help when they need you.

Even if your teen wants to manage their own diabetes, it's still important that you're involved. Talk to them about how it's going to work and make a plan together. Explain that you trust them. Discuss any worries you have and how they can reassure you that they're doing OK.

Tips for dealing with teens

The teenage years are full of ups and downs for most families. These tips may help:

- **Pick your time.**

There's no point trying to talk when one of you is in a rush. Make sure you both have the time to talk about things properly, so you don't have a stop-start conversation. And don't talk to your teen when you're cross, if you can help it. In the same way, if you know they're in a bad mood already, try another time.

- **Pick your battles.**

If you're worried about several things, talk about the big worries first and come back to the others at another time.

- **Pick your way.**

A face-to-face conversation may make them so uncomfortable that they clam up and aren't honest with you. Try bringing things up gently, when you're going for a walk or you're in the car together. It can be easier for them to open up if they don't have to look at you while they're talking.

- **Pick your allies.**

Sometimes you're just not the best person to talk to your teenager and, at these times, they might want to talk to a family friend or relative. Make sure each of you knows who's talking to whom – and about what – so you're still aware of how your child is coping and so your teen doesn't think people are talking behind their back.

- **Pick your information.**

Think about what information your teen needs where you're going to get that from.

As your teenager gets used to dealing with diabetes, your paediatric diabetes team may suggest they come to the clinic on their own. It's important to talk to them about this and plan what's right for you both. Getting the balance right between your teen's independence and you being there for them when they need it is different for all families.

Tips to help you and your teen share responsibility at the clinic:



- ✓ Involve them in clinic visits at a level they feel happy with.
- ✓ Encourage them to ask and answer questions.
- ✓ Involve them in decisions about their care and treatment.
- ✓ Give them the chance to talk about their fears and worries.
- ✓ Encourage them to come up with their own solutions to problems, which you can then discuss with the doctor, PDSN or paediatric dietitian.

Teenage issues

As well as having more independence, teens may start experimenting with alcohol, drugs, smoking and sex, all of which can affect diabetes. It's important that you and your teen know how these things may affect their diabetes.

Alcohol

People with diabetes can still drink alcohol, but too much isn't good for anyone. It's recommended that no one has more than 14 units a week. If people drink 14 units a week, it should be spread over three or more days. Remember, these guidelines are for adults.

Alcohol makes a hypo more likely. Make sure your teen knows:

- not to drink on an empty stomach and to have a meal before drinking. If this isn't possible, they need to eat some carb-containing snacks, like a sandwich or crisps, while drinking
- to tell their friends about their diabetes and how to treat a hypo
- to carry diabetes ID with them, like a bracelet or necklace, as a hypo may be mistaken for being drunk

- after a few drinks, they may be less aware of hypo warning signs. They should try to drink in moderation
- to drink plenty of water or anything sugar free to avoid dehydration
- alcohol stays in the body for several hours. So a hypo may happen sometime later. After a night out, they should eat before bed, even if it's chips or a kebab on the way home.

Drugs

Illegal drugs or legal highs can all lead to problems with health, family, friends and the law. The ideal way of avoiding any problems is to avoid all drugs. But it's important to be realistic, so you and your teenager need to be informed.

Drugs affect people – and their diabetes – in different ways, depending on the type, amount and purity of a drug. Make sure your teen knows that:

- different drugs – legal or illegal – have different effects. They can all have serious effects on health and diabetes management
- a legal high doesn't mean that it's a safe drug. They can make you seriously ill and can cause death

- possessing illegal drugs can lead to a fine or imprisonment, as well as a criminal record that could affect job prospects. You can get more information from Talk to FRANK at www.talktofrank.com.

Smoking

Smoking increases the risk of heart and lung disease, and some cancers. Make sure your teen knows that:

- people with diabetes who smoke are twice as likely to have heart disease and circulation problems
- smoking can affect fertility and the chance of having a healthy pregnancy and baby
- smoking can stain your teeth and damage your skin
- smoking will increase the risk of getting the long-term complications of diabetes.



Sex

When you talk about sex with your child or teen, you also need to discuss it in terms of their diabetes. Make sure they know that:

- having sex is a form of activity so can cause a hypo
- high blood sugar levels can make thrush more likely. Keeping blood sugar levels in target range can help avoid this, but they need to see their GP if they have genital itching and discharge
- girls with diabetes can still take the contraceptive pill.

Pregnancy

Girls also need to be aware that while having diabetes shouldn't stop them having a healthy pregnancy and baby, it increases their risk of serious health complications during pregnancy and childbirth.

This is why we recommend that they plan for a pregnancy in advance and get the support they need from their GP and their diabetes team – before they come off contraception. If they do this, they're in a much better position to have a healthy pregnancy and are more likely to give birth to a healthy baby.

We have a lot more information about this on our website here: diabetes.org.uk/pg-pregnancy

University

Starting university or college is a big change for most young people. Diabetes shouldn't stop them from getting the most out of their time at uni. We've got lots of information for you – and your teen – to help them navigate student life.

As a parent of a child with type 1 diabetes, you'll probably have additional worries about how they'll cope – especially if this is the first time they've lived away from home.

As soon as they feel comfortable, encourage them to tell their new friends. This way, they'll know what to do if they have a hypo and have people around to support them.

Healthy eating on a budget can be a challenge. You'll find tips about eating at university on our website: diabetes.org.uk/pg-uni



I had a great experience at university. I had fantastic friends who I could vocalise and even joke with about my diabetes. They made me feel normal for discussing how I was feeling, which is hugely important. This made me feel more at ease, and although it wasn't easy, they helped me more than anything else.

Jim,
who was diagnosed
at the age of 2.



Tips to prepare you both for university:



- ✓ Make sure they tick the disability box on their UCAS application, so their university will have a record that they have type 1 diabetes and might need extra support.
- ✓ They'll need to move their GP if they're moving away from home. They can find their nearest GP on the NHS website: [nhs.uk/service-search/find-a-GP](https://nhs.uk/service-search/find-a-gp)
- ✓ It's worth applying for Disabled Students' Allowance (DSA). It's a scheme that helps cover some of the extra costs they might have because of a long-term illness. You don't have to pay it back and it's added on top of their student loan.
- ✓ Once accepted, they should get in contact with the disability department at their university, to make sure they know about their diabetes. They can often help with accommodation requirements, like needing a fridge.

MEDICAL WORDS EXPLAINED

Blood glucose meter

A device that checks your child's blood testing strips and stores the results of the tests.

Blood sugar levels

(also called blood glucose levels)

A measure of how much glucose (sugar) is in the blood.

Blood sugar targets

The blood sugar levels your child should aim for, measured in millimoles per litre (mmol/l), which you'll be told by your paediatric diabetes team.

Bolus insulin (bow-lus)

The rapid-acting insulin your child takes to cover the rise in their blood sugar levels when they eat and drink.

Cannula

A very thin and flexible tube, which sits under the skin and delivers insulin from an insulin pump.

Carbohydrate (carbs)

The body's main source of energy, which is broken down into glucose.

Carbohydrate (carb) counting

A very effective way of managing diabetes by individually matching your child's insulin to what they eat.

Coeliac disease (see-lee-ack)

A common autoimmune disease where the body reacts to gluten, the protein found in wheat, barley and rye, which damages the gut lining and affects how food is absorbed.

Continuous glucose monitoring (CGM)

A sensor worn just under the skin that measures blood sugar levels every few minutes.

Diabetic ketoacidosis (DKA) (key-toe-ass-ee-doh-sis)

Where a build-up of ketones (poisonous chemicals) causes the blood to become acidic. If not treated it can cause unconsciousness – and even death.

Diabetologist (die-a-bet-ol-a-jist)

A doctor who specialises in diabetes and is usually based in a hospital clinic or specialist diabetes clinic.

Diabetes complications

Health problems people with type 1 diabetes are at risk of developing in later life, including damage to the kidneys, eyes and nerves, and heart disease.

Dietitian (die-a-tish-an)

An expert in food and nutrition, who'll give you information and support to help you make changes to your child's eating habits if needed.

Glucagon (gloo-ka-gone)

For treating a severe hypo, a kit that includes either a syringe of sterile water and a vial of glucagon powder that you mix together, or a pre-filled pen.

Glucose

The sugar in the blood, which the body uses for energy.

GP

The doctor with the overall responsibility for your child's non-diabetes care.

HbA1c test

A blood test that measures blood sugar levels over two to three months.

Hyperglycaemia (hyper) (hy-per-gly-see-me-a)

When blood sugar levels are too high, usually above 7mmol/l before a meal or above 9mmol/l two hours after a meal.

Hypoglycaemia (hypo) (hy-poe-gly-see-me-a)

When blood sugar levels drop too low, below 4mmol/l.

Insulin pen

An easy-to-use injection device.

Insulin pump

Instead of injecting insulin, a pump delivers a steady flow of rapid-acting insulin around the clock through a cannula inserted under the skin.

Ketones (key-tones)

Poisonous chemicals that can build up in the blood if there isn't enough insulin in the body to allow enough glucose to enter the cells. A build-up can lead to diabetic ketoacidosis (DKA).

Lancet

A finger-pricking needle used for getting a drop of blood to check blood sugar levels.

Millimoles per litre (mmol/l)

A measurement that expresses the amount of glucose in the blood.

Multiple daily injections (MDI)

A routine of taking insulin, where your child has insulin injections four or more times a day.

Paediatric (pee-dee-at-rick)

The branch of medicine that deals with children, so paediatric doctors and nurses are specialists in treating and looking after children.

Paediatric diabetes specialist nurse (PDSN) (pee-dee-at-rick)

A nurse with a special expertise in diabetes and in working with children, who's usually your first point of contact and who'll give advice and support between appointments.

Paediatrician (pee-dee-a-trish-un)

A children's doctor with specialist expertise in diabetes who'll take overall responsibility for your child's diabetes care.

Quick-acting carbohydrate

Carbohydrate that acts quickly to raise blood sugar levels, for example glucose tablets, Jelly Babies and non-diet drinks.

Thyroid (thigh-royd)

A gland in the neck that produces hormones to regulate the body's metabolism. Thyroid problems are more common in people with type 1 diabetes.



A hand holding a white flag with the word 'MISSION' written on it. The background is a solid blue color.

MISSION

**We are Diabetes UK
and it's our mission
to tackle diabetes,
day in and day out,
until it can do no harm.**

It's why we campaign for better care,
give support in times of need and fund
ground-breaking research into new
treatments and a cure.

Diabetes doesn't stop, so neither do we.

This guide is FREE

As a charity, we rely on the generous donations of people like you to help us produce this vital information on living with diabetes.

To find out more about how you can help us, go to diabetes.org.uk/get-involved

Or, to make a donation to support our work, go to diabetes.org.uk/donate or send a donation via text.

Please text DUK to 70123 to donate £5 to Diabetes UK and help us do even more for people with diabetes.

You will be charged £5, plus one message at your standard network rate. Diabetes UK will receive 100% of your donation. Registered charity number England & Wales 215199 and Scotland SCO39136. If you wish to discuss this mobile payment, call 020 3282 7863.

By texting DUK to 70123, you are agreeing to us contacting you by phone and SMS to tell you more about our work and how you can support it (including financial support). To give £5 without receiving further contact by phone and SMS, text DUK NO to 70123.

You must obtain permission from the bill payer before sending a text message.

GET IN TOUCH

Call **0345 123 2399**

Email **helpline@diabetes.org.uk**

Visit **diabetes.org.uk**

Search **Diabetes UK** on Facebook,
Twitter, YouTube, Instagram and TikTok



We welcome your feedback. If any information in this guide has been particularly helpful or if you would like to suggest any improvements, please send your comments to: **helpline@diabetes.org.uk** or write to us at: Diabetes UK Helpline, Wells Lawrence House, 126 Back Church Lane, London E1 1FH.

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Our information is correct at the time of publication. It's not a substitute for seeing a healthcare professional, and isn't intended to replace the advice given by your diabetes healthcare team.

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