



Everyday life with **Type 1**  
**diabetes for parents**

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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 [www.diabetes.org.uk/pg-get-involved](http://www.diabetes.org.uk/pg-get-involved)

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

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# Everyday life with Type 1 diabetes for parents

**You're bound to be upset and have a lot of questions when your child is diagnosed with Type 1 diabetes. There's a lot of information out there and it can be confusing to understand what it all means. We'll help you get to grips with it.**

In this guide, we set the record straight, giving you the facts about diabetes and how you can treat it. We also tell you what you and your child can do to stay healthy, and list the care your child should get from their paediatric diabetes team.

We also hear from other parents on how they and their child manage life with Type 1 diabetes. We give you lots of tips to make your life easier – and there's a handy glossary at the back to help you get the most out of this guide.

If you sometimes find it all a bit overwhelming, there's a lot of support available to you, so don't be afraid to ask for help from your paediatric diabetes team. And, you can always send us an email or pick up the phone if you want to talk – see the back cover for ways to get in touch.

Armed with all the facts, and understanding what you, your child and your paediatric diabetes team need to do, means you can look forward to your child living a full, long and healthy life with Type 1 diabetes.



# What is Type 1 diabetes?

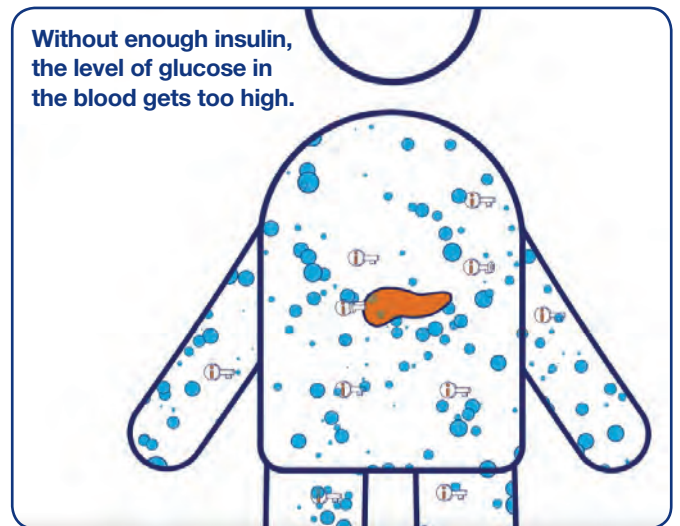
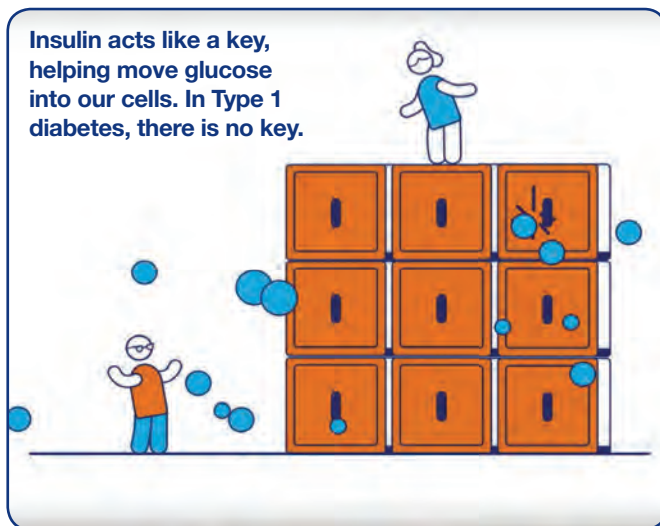
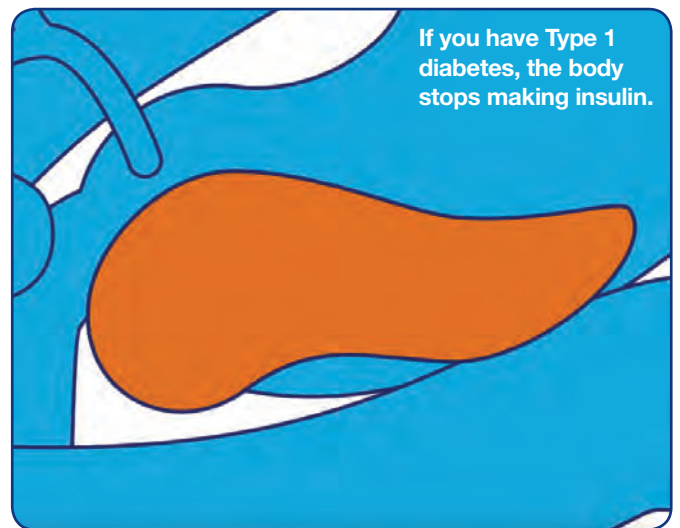
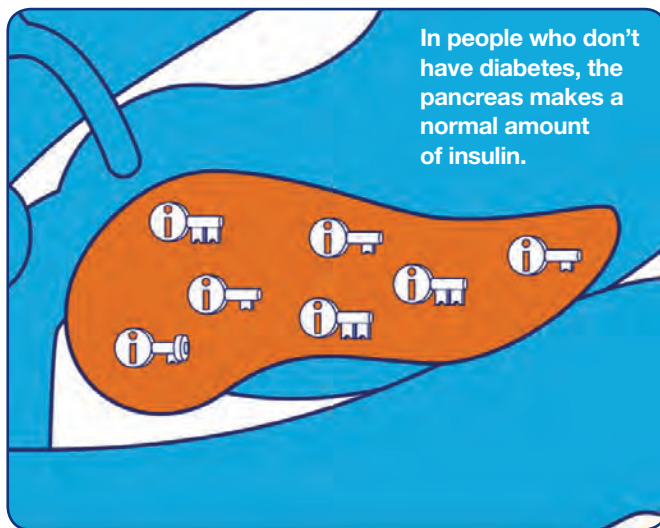
You're bound to be worried that your child has Type 1 diabetes, and you'll want to know more about it.

Your child has Type 1 diabetes because he or she can't make enough insulin. Until it's treated, this can make them very ill. Type 1 diabetes is an autoimmune condition. It develops when the

insulin-producing cells in your body have been destroyed and you can't produce insulin.

It's not caused by lifestyle.

Watch our What is Type 1 diabetes video at [www.diabetes.org.uk/pg-what-is-type-1](http://www.diabetes.org.uk/pg-what-is-type-1)





## Causes

Finding out that your child has Type 1 diabetes will have been a shock. This is natural, in the same way that it's natural to wonder what caused it. But, at the moment, we really know very little about why a child develops Type 1 diabetes.

What we do know is that it's an autoimmune condition. That means the body has damaged its own insulin-producing cells, so they stop working. Once the cells stop working, they can't start again. The result is Type 1 diabetes.

We don't know why this happens to some children and not others. Genes play a small part, as Type 1 diabetes is slightly more common when a parent, brother or sister has it. But there are many other unknown things involved.

You may blame yourself in some way and think you could've done something to prevent it. But you couldn't have. There's nothing you or anyone else did to cause this, and at the moment we don't know of any way it can be prevented.

## Symptoms

The main symptoms of untreated Type 1 diabetes are known as the 4 Ts and are:



**Toilet** – having to pass urine a lot, bedwetting by a previously dry child, or heavier nappies in babies.



**Tired** – being more tired than usual.



**Thirsty** – being really thirsty and unable to quench it.



**Thinner** – losing weight or looking thinner than usual.

## Treatment

Your paediatric diabetes team (see page 34) will work with you to plan the best treatment for your child. Type 1 diabetes is treated with insulin – either by injection, or by using an insulin pump. A healthy diet and physical activity are also really important – see pages 40 and 48.

You and your child will need to use a blood glucose meter to regularly check their blood glucose levels. We tend to call blood glucose by its other name, blood sugar. This is what we'll call it in this guide. You'll learn how to manage their blood sugar levels, and balance the amount of insulin they take with the food they eat and the activity they do.

Treating diabetes needs planning, attention and a lot of effort. It can be overwhelming, particularly at the beginning. Many parents say that it's like a roller-coaster ride – sometimes blood sugar levels are too high, sometimes too low, sometimes just right. This can be both frustrating and scary because, as a parent, you feel responsible for your child's health. Thinking about what might happen if you get it wrong can be very frightening.

Always remember that you're not on your own. Your paediatric diabetes team of doctors, nurses and dietitians are there to help you every step of the way. And, we're here too.

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.

### Need to know

In this guide you'll find information to help you and you'll also find out where to go for more detailed advice and support. A good place to start is our website, [www.diabetes.org.uk](http://www.diabetes.org.uk), or you can call our helpline on **0345 123 2399**. If you're in Scotland, call **0141 212 8710** or email [helpline.scotland@diabetes.org.uk](mailto:helpline.scotland@diabetes.org.uk)

## Some questions

### Is there a cure?

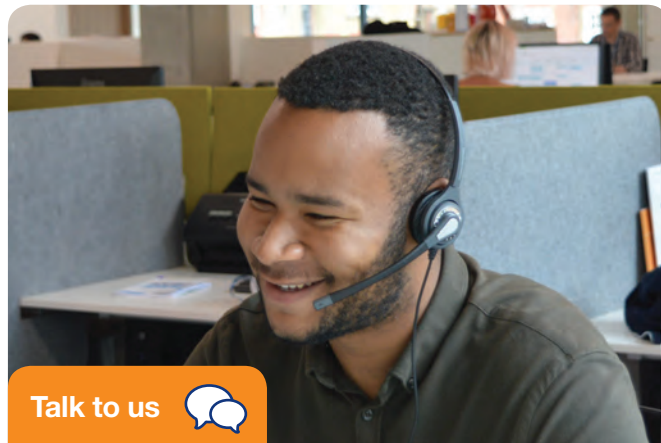
No, but there's ongoing research into transforming care and treatment, and to help find a cure. Go to [www.diabetes.org.uk/pg-research](http://www.diabetes.org.uk/pg-research) to see how we fund vital projects and the breakthroughs so far.

### Are there other types of diabetes?

There are two main types – Type 1 and Type 2. Of the 4.7 million people who have diabetes in the UK, only about 8% of them have Type 1. But, when it comes to children diagnosed with diabetes, the vast majority have Type 1.

Type 1 and Type 2 are different things, with different causes and different treatments. But they're both serious, life-threatening conditions.

There are also other types of diabetes, such as MODY (Maturity Onset Diabetes of the Young), but they're quite rare.



Talk to us 

Do you have a question about Type 1 diabetes? We can give information and advice on all aspects of living with diabetes. Get in touch for answers, support or just to talk to someone who knows about diabetes. Call our helpline on **0345 123 2399** or email [helpline@diabetes.org.uk](mailto:helpline@diabetes.org.uk). If you're in Scotland, call **0141 212 8710** or email [helpline.scotland@diabetes.org.uk](mailto:helpline.scotland@diabetes.org.uk)

## Meet Rachel and Alex

### Rachel looks back on Alex's diagnosis and the weeks that followed

"After a long evening of tests, Alex was diagnosed with Type 1 diabetes at 1am and the doctors told us he would need to stay in hospital. Alex was excited and saw it as a sleepover, whereas I knew I'd not be getting any sleep.

The first couple of weeks seemed like one long day. When Alex returned to school, I remember it took me over an hour to put his lunch box together because of the carb counting. I was frustrated and broke down in tears.

But, after a week or so, you adapt and adopt new techniques. I can now make Alex's lunch box in five minutes. I know all the carb values and I write them down on a piece of paper which I pop in his lunch box. Alex's maths has improved so much as



a result and he's top of his class. There are unexpected benefits as well.

Now we enjoy fundraising for Diabetes UK as a family – from bucket collections and cake sales to organising events at Alex's school. We are passionate about it.

Your life will never be the same but your family will find a new normal. You just have to make some changes and embrace it."





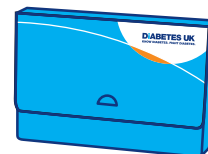
## Helping your child get the best care at school

Type 1 diabetes:  
Make the grade ★

### We all want our children to have a great time at school.

With Type 1 diabetes, there are some extra things to think about to make sure they do.

Our **free resources** are designed to help you and your child's school work together to give the best care. From practical information packs to help with planning successful school trips and exams, we're here for you every step of the way.



Our **Helpline** can give you support and information to help you make sure your child gets the best care at school.

Call **0345 123 2399**

Email [helpline@diabetes.org.uk](mailto:helpline@diabetes.org.uk)



Visit [www.diabetes.org.uk/schools](http://www.diabetes.org.uk/schools) to download or order your free resources.

**DIABETES UK**  
KNOW DIABETES. FIGHT DIABETES.

# Putting the record straight

People say lots of different things about diabetes – but not all of it's true. Knowing the facts about diabetes is important when it comes to managing it. There's so much information out

there, and it's often difficult to know what's right and what's not. This guide will help you learn more about diabetes and what you need to do to keep your child well.

Here are some of the most common myths about diabetes:



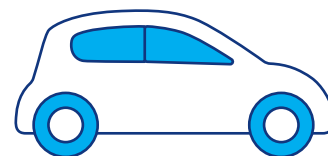
**Myth: “People with diabetes should eat diabetic foods”**

There's no need to eat special diabetic foods. They don't have any health benefits, are often high in fat and calories, and can give your child an upset stomach. In fact, companies aren't allowed to label their food and drinks diabetic anymore.



**Myth: “People with diabetes can't have sugar”**

That's not true. But your child's health will benefit with a balanced diet that's low in saturated fat, salt and sugar. See page 40 for more on healthy eating.



**Myth: “It's not safe to drive if you have diabetes”**

Your child can drive when they're older. So long as their diabetes is well managed, it's as safe for them as it is for anyone else out there.



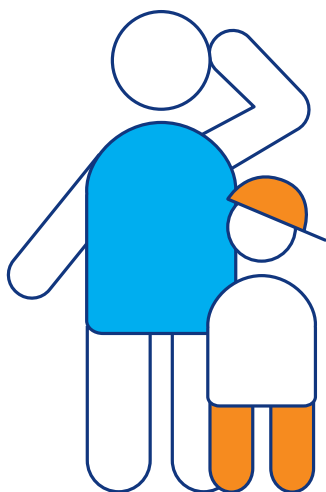
**Myth: “People with diabetes can't play sport”**

That's not true. It's good for your child to be active – physical activity and exercise have lots of health benefits and reduce the risk of diabetes complications. For more on exercise, go to page 48.



**Myth: “Having diabetes means you can't do certain jobs”**

Diabetes shouldn't stop your child from getting a job. The only job with a blanket ban for people with diabetes is the armed forces. Other jobs might have legitimate safety requirements that exclude people with Type 1. These decisions should be based on individual assessment.





# Wellbeing



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# Your family

**Your child's diagnosis will have affected the whole family. So, it's important that every member of the family is listened to and is able to get the help and support they need.**

You and your child may have strong feelings about the diagnosis and may react differently. But, remember, there's a lot of support available. Don't be afraid to ask for help.

## Family relationships

It's easy to forget your other children's needs when you're grappling with the news that one child has diabetes. But they'll also be affected by their brother or sister's diagnosis. They may feel that he or she is getting special treatment. They may also worry that their sibling will get really sick. And, they'll worry that they'll get diabetes, too.

Rivalry and jealousy are common in most families, and one child with diabetes can cause upset with other siblings. At the beginning, it's natural to focus on the child with diabetes. But regular hospital visits and everything else that goes with diabetes has a longer-term impact on all the family.



Brothers and sisters will always scrap. But there's a lot you can do to calm them down:

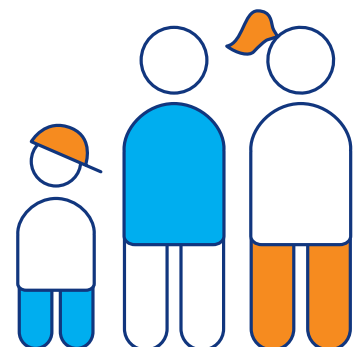
- Try to listen to both sides. Be sensitive to claims that it's not fair.
- Be clear about what you expect from each of them.
- Try to give them the same amount of attention.
- If you feel it's appropriate, get siblings involved with diabetes management so that they feel part of it.
- Try not to put family life on hold.

## Separated parents

If you're separated from the mother or father of your child, it can make things a bit more difficult if your child goes from one home to another. You'll have to work together to make sure your child's diabetes is well 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 always keep each other updated.
- How you'll 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 feel extremely tough if you're a single parent. It may feel like you're having to deal with all of this on your own.

### Think about:

- Who can you call if you need help?
- Who can help you in an emergency?
- Who can support you when you're struggling emotionally?
- Who can babysit when you need time off?
- Involving siblings in your child's care. But be careful not to give them too much responsibility.

## Wider family

Grandparents, aunts, uncles and close friends have probably also been very upset and worried about your child's diagnosis. They may be asking for updates and wanting to help. Or, they may go the other way and leave you alone to concentrate on your child and what you need to learn. Either way, it'll feel wrong to you sometimes.

### Some of the following are worth thinking about:

- Keep one person up to date. If lots of people want to know what's going on, one person can then update them. Otherwise, group texts, emails and using WhatsApp are a good idea.
- Ask for help if you need it. Whether that's looking after your other children, doing some shopping or walking the dog, people generally want to help but need to be told what to do.
- Think about the future. Type 1 diabetes is with your family from now on, so how best can your wider family help you? If your child used to stay over with relatives, then it's important they still do. If the grandparent, or whoever it is, is worried about looking after them now, try involving them in your child's care. You can bring them to clinic appointments if that helps them understand what's needed now. Most of all, be honest. Tell them how you feel. Ask them to help you keep your child's life as normal as possible.

## 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 with counselling skills, who have an extensive knowledge of diabetes. Call: **0345 123 2399** or email [helpline@diabetes.org.uk](mailto:helpline@diabetes.org.uk) or [helplinescotland@diabetes.org.uk](mailto:helplinescotland@diabetes.org.uk)
- Connect with other parents of children with diabetes. Go to the Diabetes UK Facebook page ([/diabetesuk](https://www.facebook.com/diabetesuk)), or the Diabetes UK Online Support Forum at [www.diabetes.org.uk/pg-forum](http://www.diabetes.org.uk/pg-forum)
- Join a Diabetes UK group. Go to [www.diabetes.org.uk/pg-groups](http://www.diabetes.org.uk/pg-groups) for more details.

### Need to know

- Take a few minutes to think about how each member of your family is dealing with your child's diabetes.
- If you're worried that diabetes is upsetting your family, get help.
- Look after yourself. You'll then be in a better position to look after your family.
- Be honest with your wider family. Let them know how they can help you and your child.

## Some questions

### Will my other children get diabetes?

Type 1 diabetes is caused by a combination of genetic and environmental factors.

If one family member has Type 1, there's slightly more risk of another family member developing it. But, many people with Type 1 diabetes have no family history of it at all – nor does anyone else in their family develop it. It's natural to worry that your other children will develop it, but try not to let this affect you too much.

Talk to your paediatric diabetes team or call our helpline on **0345 123 2399**. If you're in Scotland, call **0141 212 8710**.

# Coping with diagnosis

## How a child or young person reacts

It's often a confusing and frightening blur at the beginning. Your child will probably remember feeling ill, being suddenly taken to hospital and then waking up on a drip, surrounded by worried family and medical staff.

Unlike the usual illnesses of childhood, Type 1 diabetes won't ever go away. When your child realises this, it's likely they'll be upset and frightened. They'll probably wish they could turn back time and go back to the way things were.

### Different ways

Everyone – and every family – copes differently, but children are likely to copy the way that you cope. You can't expect a child to deal with it quickly or easily. You all have to acknowledge that their life has changed. Let them talk about it with you.

No one but your child knows exactly what they've gone through or how they feel. They may not have the words to explain it. They may blame themselves, or see diabetes as a punishment. Let them talk about it. It's better they talk about their worries now, rather than cover them up. If they don't talk now, it could all come back at a later date, maybe in their teens or twenties.

Some children choose to make little of their difficulties. They prefer not to mention it, ignore it or play it down. Each child has a different way of dealing with it, and some children will cope better than others. But it's important to keep an eye on them. Your child could look like they're coping well, but be hiding their true feelings, and that could cause difficulties later.

Being diagnosed with Type 1 diabetes can seem like a loss. And, like a loss, there's a time to mourn. Your child – and you – are grieving for the more carefree life they had before diabetes. This is natural and it's part of recovery. How long it takes is different for everyone and depends on how much support – both physical and emotional – is available. Allow children to grieve in their own way. Don't hurry them.

## It's good to talk

One way to help your child is to let them 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.

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 their immediate family – like a grandparent or good friend. It can also help an older child 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 crop up later. It's sometimes when school starts that they really become aware that they're different to other kids.

Type 1 diabetes shouldn't stop your child doing anything their friends do. But, it's better to acknowledge the difficulties as they come up, rather than pretending everything's OK.

If you want to talk through any concerns or get more information on any aspect of diabetes, call our helpline on **0345 123 2399**. If you're in Scotland, call **0141 212 8710**.

## How parents react

It can often come as a shock when your child is diagnosed with diabetes.

Most people don't know anything about it before diagnosis. But your paediatric diabetes team is there to help you. Don't be afraid to ask them questions and ask for support – you need to understand what diabetes is and how to look after it too.

It's OK to feel sad, angry and overwhelmed at the start because you might have to make a lot of lifestyle changes too.



It's normal to take a long time when coming to terms with the diagnosis. Don't force yourself to stop dealing with the different emotions that it can cause, but let yourself work through these at your own pace. It might help to separate the physical act of looking after diabetes from your emotional acceptance of it.

## Looking after yourself

### Get enough sleep

Getting enough sleep can be hard. And you might not be sleeping well if you're doing nightly blood sugar checks, or are just up worrying. If you have a partner or someone else to help you, try to come up with a way of alternating night-time responsibility.

If your child is having a lot of night-time highs and lows, speak to your paediatric diabetes team. They might suggest changing your child's insulin dose.

### Find a community

Finding people who are also looking after a child with diabetes can really help. Sharing experiences and talking to people who know what it's like can be really useful for emotional support.

A good way of getting in touch with other parents or carers is through our local groups at [www.diabetes.org.uk/pg-groups](http://www.diabetes.org.uk/pg-groups), or our online forum at [www.diabetes.org.uk/pg-forum](http://www.diabetes.org.uk/pg-forum). We also run family weekenders, where you can meet other families who have Type 1 diabetes. For more details, go to [www.diabetes.org.uk/pg-type-1-events](http://www.diabetes.org.uk/pg-type-1-events)



## Looking after your other family relationships

**If you have a partner:** Don't feel guilty about putting each other first sometimes. Try to find someone who can help and knows what your child needs so that you can spend quality time together. We know this can be hard, so even something small like bringing your partner a cup of tea can show you care.

**If you have other children:** Making some time for your other children is a really good way of making them feel important. Do something you'll both enjoy that can get you out of the house.

## Work

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

You legally have the right to request flexible working hours once every 12 months or ask for emergency time off, if you need it.

Your employer can only deny a request if they have a good business reason to say no, but they have to offer you the ability to appeal.

## Ask for emotional support

Looking after someone is hard, so make sure you ask for help if you need it. Our helpline is dedicated to helping anyone affected by diabetes. If you've been feeling stressed or anxious for quite a long time, see your GP. They'll be able to help you.

## Tips for dealing with diabetes

### Some older children may want to think about these ideas:

- 1 It's OK to admit that it's hard. In fact, it's good to do that. But also know that you can have more help if you need it.
- 2 Think of diabetes as being like a difficult or annoying relative, who you care for all the same. Sometimes they drive you around the bend, sometimes they're easier and sometimes you just cope with them really well.
- 3 Be kind to yourself. You're doing your best.

# Checks and treatment

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# SMART TESTING. SIMPLE SYNCING.

## WaveSense JAZZ™ WIRELESS



Results automatically sync from the AgaMatrix JAZZ WIRELESS Meter to the AgaMatrix Diabetes Manager App.



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[www.agamatrix.co.uk](http://www.agamatrix.co.uk)

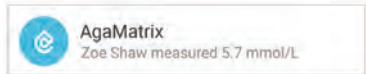
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DIABETES MANAGER



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Share individual results automatically in real time with family or carers.



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Send a preformatted report of results from a chosen timeframe at the press of a button.



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# Blood sugar checking

**As part of managing your child's diabetes, you'll need to check their blood sugar levels regularly. It's key to their day-to-day health. Checking blood sugar levels and doing something about the results can help avoid highs and lows. And, keeping on top of blood sugar levels helps prevent problems later on in life.**

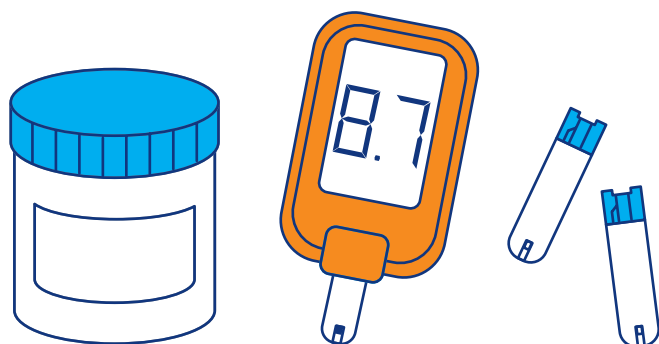
You'll need to know when to check for ketones, too – see page 19.

Checking blood sugar levels may be hard at times – for both of you – especially if your child is very young. So, follow our advice to make it as painless and straightforward as possible.

## Blood sugar checking

Your paediatric diabetes team will give you a blood glucose meter to check your child's blood sugar levels. You'll have different options to choose from. The meter will come with a finger-pricking device, a small supply of lancets and strips to check your child's blood.

The finger-pricking device takes a drop of blood from the finger, and the strips are what you put the drop of blood on to for the result. Your paediatric diabetes team will help you get these on prescription.



You may worry checking your child's blood sugar. When you prick their finger, it can hurt at first and take a bit of getting used to. Then, you might worry about what the levels will be and if they're on target. If they're not, it can be frustrating and even scary.

Blood sugar levels are measured in millimoles per litre, written as mmol/l. Many things affect levels – food, exercise, stress and even growth spurts. Sometimes you'll know why the levels have gone up or down, but at other times there's no reason. Don't blame yourself – it happens to everyone. But talk to your paediatric diabetes team if it keeps happening and it's worrying you.

## How to check

- Wash your child's hands and then make sure they are warm. Cold hands make it harder to draw blood. Then ask your child to hold their hand down towards the ground to make more blood flow to the fingers.
- Prick the side, rather than the tip, of your child's finger. It hurts less here. Don't prick too near the nail, and don't prick the index finger or thumb.
- There are other prickers that take blood from elsewhere – like the base of the thumb or arm. Speak to your paediatric diabetes team about whether these prickers are suitable for your child.
- Insert a strip into the blood glucose meter. Doing this will automatically turn on most meters.
- Put a drop of blood on to the strip.
- Make a note of the results. This will help you and your paediatric diabetes team see any patterns.
- You may need to calibrate the meter when you first use a new packet of test strips. Talk to your paediatric diabetes team about how to do this.



## When to check

It's recommended to check:

- before a main meal
- before bed
- if they feel unwell – see page 52
- before and after physical activity – sometimes during, too – see page 48
- if they feel or you notice any hypo warning signs – see page 29
- any time they feel their blood sugar levels could be high or low.

Your paediatric diabetes team may also ask you to check at other times too, like during the night. This is to get an overall view of your child's diabetes management. Checking blood sugars regularly helps to get a picture of what's happening with their blood sugar levels.

## Checking your toddler

It can be difficult getting a drop of blood from a toddler. Explain what you're doing and that even though it may hurt a bit, it'll be over very quickly. If they want to, encourage them to help or have a teddy bear that you – or they – can practise on.

## Blood sugar targets

The general target ranges are:

- 4–7mmol/l on waking up
- 4–7mmol/l before meals and at other times of the day
- 5–9mmol/l two hours after meals.

But your paediatric diabetes team may give you individual targets. You won't be within these targets all the time, but aiming for them will help your child manage their diabetes.



### Agreed blood sugar level targets



Waking up:

.....  
.....  
.....

Before meals at other times of the day:

.....  
.....  
.....

Two hours after meals:

.....  
.....  
.....

## Need to know

- Ask your paediatric diabetes team what blood sugar targets your child should aim for.
- Ask what to do about high or low results, and know the signs of DKA – see right.
- Check with the team about the best time of day to check, and if you need to check at night.
- Get free supplies on prescription. Check how you do this with your paediatric diabetes team.

## Some questions

### How important is it to keep a record of results?

It's really important. It helps you and your paediatric diabetes team see how well your child's diabetes management is working. It also helps you and your child work out how much insulin is needed. It doesn't matter how you do it – in a book or electronically – but it's important for getting good diabetes management.

## Checking for ketones

Ketones are poisonous chemicals that can develop if there isn't enough insulin in the body to convert blood sugar into energy. If they develop and aren't treated, they can make the body acidic. It's called diabetic ketoacidosis or DKA for short.

You must check for ketones if your child's blood sugar level is high – your paediatric diabetes team will tell you at what level. And, you need to check for ketones whenever your child is ill. Most children will check for ketones in the same way as checking blood sugar levels.

### Diabetic ketoacidosis (DKA)

These are the times DKA can develop:

- When your child is first diagnosed. Some children are only diagnosed when they become ill with DKA.
- When your child is ill.

- During a growth spurt or puberty.
- If your child hasn't taken their insulin.

It takes time for DKA to develop, so if your child has high blood sugar levels you generally have time to sort it out. But it can sometimes develop more quickly – particularly in young children and pump users.

## Signs of DKA

Watch out for:

- ketones in the blood or urine
- abdominal/stomach pain
- nausea/vomiting
- rapid breathing
- a fruity smell on the breath – a bit like pear drops or nail polish remover.

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

If you spot the signs early, you can give your child extra insulin and lots of fluids, which can help stop it getting more severe. Your paediatric diabetes team can tell you what to do.

If you don't treat it, DKA can make your child seriously ill and they'll need to go to hospital for a drip and an insulin infusion. So it's important to know the signs, and get help straight away if you're worried.





# Continuous glucose monitoring (CGM) and flash glucose monitoring

Both CGM and flash glucose monitoring can give your child a reading of their blood, as well as show trends, without pricking their finger. This can be helpful in establishing good management of blood sugar levels.



Using either CGM or a flash glucose monitor means your child wears a small sensor that sits just under their skin 24 hours a day, for a set period of time until it's replaced.

Speak to your paediatric diabetes team for advice on whether either a CGM or a flash glucose monitor would be helpful for your child.

## CGM

It shows trends in your child's blood sugar levels and alerts you to highs and lows. As a CGM measures every few minutes, it can make a graph to show your child's blood sugar levels over time.

There are two types:

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

A CGM has three parts:

- A sensor that sits just under your child's skin.
- A transmitter attached to the sensor that sends the blood sugar levels to a display device.
- A display device showing your child's blood sugar levels. Either a separate handheld device (standalone CGM) or a pump (integrated system).

A CGM comes with software to analyse results, so you can see patterns in blood sugar levels.

The sensor is usually worn for seven days before you need to replace it. You need to reattach the transmitter to the new one.

CGM doesn't actually measure blood sugar levels, but the amount of glucose in the fluid surrounding the cells. You'll sometimes hear this called interstitial fluid. This lags behind blood sugar levels a little. It's longer if blood sugar levels are changing quickly, for example after eating or exercising. So, you or your child will still need to do a finger-prick test to see if they need more insulin, or to confirm a hypo.

The CGM is calibrated by checking your child's finger-prick blood sugar levels generally twice a day.

## Tips for getting the use of a CGM

You might find it useful to use a CGM for a week or two. You can then look at the trends with your doctor or nurse to see if you need to make any changes to your child's treatment.

- 1 Speak to your paediatric diabetes team about whether they think it's worthwhile for your child.
- 2 As long as your clinic has a CGM, it can be given out on loan to you, so you don't need to worry about funding. But there could be a wait.
- 3 NICE recommends that if your child has high sugar levels despite adjusting their insulin and having a lot of support from your doctor or nurse, short-term use of a CGM might be useful.

## Pros and cons of a CGM

The pros

- Tracks blood sugar levels all through the day and night.
- Shows you levels at times you may not normally check and when your child is asleep at night.
- Shows trends when levels are starting to rise or drop. You can then take action earlier.
- Generally, not so many finger-prick checks.
- Can help improve your child's HbA1c – see page 25 – as you can tailor your child's insulin dose more carefully.
- Can help reduce hypos as you see a downward trend before it happens.
- Can set an alarm for high/low levels.

The cons

- Too much data could confuse or worry you or your child.
- You still need to do some finger-prick checks.
- Your child might not like wearing the sensor.
- You or your child, if able to, need to be motivated to use the data.

## Flash glucose monitoring

### What is it?

A flash glucose monitor is a small sensor that is worn just under the skin. We call it Flash for short.

The sensor records blood sugar levels continuously throughout the day. There's also a reader that you use to scan the sensor whenever you or your child wants to. The reader will show your child's blood sugar levels and whether they're going up or down.

Software lets you analyse the results and see patterns in the blood sugar levels.

Like the CGM, it's actually not your child's blood sugar levels it measures, but the amount of glucose in the fluid surrounding the cells, known as interstitial fluid.

The pros and cons of flash glucose monitoring are similar to those for CGM, and they can help improve diabetes management.

But, unlike a CGM, you can't set an alarm for high or low blood sugar levels, so it won't alert you or your child to a hypo.

## Need to know

- You need to calibrate most CGMs by checking your child's blood sugar levels, generally twice a day.
- You don't need to calibrate a flash glucose monitor.

## Some questions

### How can I get a CGM?

If you want a CGM long-term, it'll need funding. They're available on the NHS but not for everyone. The NICE guidelines recommend that CGM is offered to children and young people who:

- have frequent severe hypos
- have hypo unawareness that leads to adverse consequences like seizures or anxiety
- can't recognise or tell anyone they're going hypo because they're too young, have learning difficulties or similar.

And, NICE recommends that CGM is considered for:

- very young children
- children who do a lot of physical activity, for example at regional, national or international level
- children who have other health problems or are taking other medication that might upset their blood sugar levels.

You can buy one, but they're expensive – around £1,000 for a standalone system, or £500 if you already have a pump. Sensors are about £60 each. Speak to your paediatric diabetes team to see if your child is eligible under NICE criteria or SIGN guidelines if you live in Scotland.

### How can I get flash glucose monitoring?

Since April 2019, flash glucose monitoring has been made available on prescription across England to those who meet the criteria – no matter where they live. This follows announcements already about availability in Wales and Northern Ireland. Scotland has also agreed access, but the criteria will depend on the health board area you live in. Find out more about how to get Flash at [www.diabetes.org.uk/pg-flash](http://www.diabetes.org.uk/pg-flash)

# Using insulin

## Insulin is essential for your child's treatment.

There are different types of insulin, which have been made to replace the natural hormone that's no longer made by your child's pancreas.

Your child will use either a pump to deliver this insulin or need to have injections.

## Insulin injections

Your child will normally need to inject insulin four or more times a day. This is sometimes called basal bolus insulin or multiple daily injections (MDI).

They'll take a rapid-acting insulin – bolus insulin – before meals. And they'll take a long-lasting insulin – basal insulin – once or sometimes twice a day.

This means that the timing of meals, and the amount of food your child eats, can be flexible. It also means you can learn to adjust the amount of insulin to match how much your child eats – see page 41.

## Coping with injections

After diagnosis, you'll have been shown how to inject insulin. And, depending on your child's age and confidence, they'll have been shown this too. Your paediatric diabetes team will also have worked out with you which type of insulin is best for your child and when to inject.

You've probably now got a pen injector. They're fairly easy to use and there's a whole range to suit different types of insulin. The insulin needs to be injected under the skin, not into a muscle or vein. Once injected, it's taken into the bloodstream where it starts to work. Your child won't like the injections at first and will probably find they hurt a bit, as they'll be tense and anxious. It'll get easier and less painful as their confidence grows.

## Where to inject

There are four main sites:

- stomach
- bottom
- thighs
- arms.

Injecting the arm isn't right for everyone though, so your team will advise on what's best for your child.

It's vital your child rotates or changes injection sites. If you keep using the same site, small lumps can build up under the skin. They make it harder for your child's body to take in and use the insulin properly. They also don't look or feel very nice.

It's also important that you don't use the same spot within a site. By rotating injection sites and spots, you can help stop lumps appearing. Don't worry, any lumps that do come up will slowly disappear in time.

## How to inject

- 1 Make sure your hands and the area you're injecting are clean.
- 2 Eject a tiny amount of insulin in the air. This is called an air shot and makes sure the needle is filled with insulin.
- 3 Choose an area on your child that has lots of fatty tissue – like the top of the thighs or bottom.
- 4 Insert the needle at a 90 degree angle. If your child is very young – under 6 – or very thin, you may need to lift a skin fold before inserting the needle. If this is the case, make sure to lift rather than pinch the skin. Your paediatric diabetes team will be able to tell you if you need to lift a skin fold or not.
- 5 Put the needle in.
- 6 Inject the needle and count to 10 before removing it.
- 7 Release the lifted skin fold, if using this method.
- 8 Dispose of the needle safely.





## Some questions

### Why can't insulin be taken as a tablet?

That's because it's a protein and would be destroyed by the acids in the stomach. It has to be injected just under the skin so that it can be absorbed easily.

### Does insulin go off?

Yes it does. Clear insulin goes cloudy. Cloudy insulin sometimes goes lumpy and sticks to the container. Always check the expiry date and never use it past this date.

## Tips for helping your child with injections

- 1 Don't make your child do them until they're ready to.
- 2 If they want to take responsibility and inject themselves, then don't stop them.
- 3 If they start doing injections themselves, they still may not want to do them all the time, which is fair enough. So, be prepared to step in if and when they want you to.
- 4 Keep an eye on their injection technique as they won't always do them perfectly.

## Need to know

- Store any insulin that's not in use in the fridge at 2–8°C.
- Keep the insulin you're using at room temperature, under 25°C. This makes it more comfortable to inject.
- Don't let insulin get too hot. Avoid keeping it near a radiator, in direct sunlight or close to electrical devices.
- Don't let insulin freeze.
- Keep an eye on the expiry date. Don't let it go past this date.
- Transport insulin in a cool bag or flask.

## Insulin absorption

Avoid injecting into an area which your child will immediately use for activity. That's because it'll make the insulin act more quickly and make a hypo more likely – see page 29. For example, don't inject a leg just before football – inject somewhere like the stomach.

## Taking responsibility

There's no right age for your child to take over and do their own injections. Some children want to do it straight away, and others want to get used to the injections before doing it themselves. They need to make the decision in their own time. When they're ready, you can gently guide them.

It can really help a child to gain confidence at doing injections if they're around other children with diabetes. It's well worth thinking about going along to events run by your child's clinic or Diabetes UK. Medical staff are always on hand and they can see other children injecting.

You can find out more about our Type 1 Events for children, teenagers, adults and their families at [www.diabetes.org.uk/pg-type-1-events](http://www.diabetes.org.uk/pg-type-1-events)

## Some questions

### What should I do if my young child refuses injections?

It can be very hard to reason with a young child, but make sure they understand that there's no choice about the injection. You can give a choice in other ways: let them choose the injection site and spot, who does the injection, if possible, and where they sit. You could also ask them to choose a book or cartoon to watch while they have the injection. They may even like to help with the injection, like pushing the plunger.

Although it may feel right to let your child express their feelings and protest, don't let it go on for too long. Ask your paediatric diabetes team for advice, as they can suggest techniques too.

### How can I make injections hurt less?

They're more likely to hurt when the needle enters the skin slowly. So, try to push the needle through quickly. It can also help to hold an ice cube against the skin for a few seconds first.

### Need to know

- If you're unsure about injection technique, ask your paediatric diabetes team for help.
- If your child isn't rotating the site or spot, make a progress or reward chart to encourage them.

## Insulin pumps

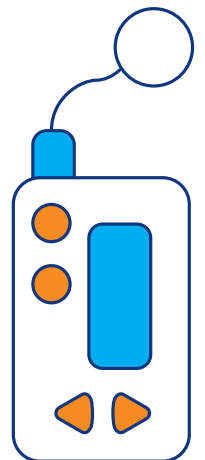
Some children use an insulin pump rather than have injections.

An insulin pump is about the size of a small iPhone and delivers a steady flow of rapid-acting insulin around the clock. It has a reservoir, which usually holds about two to three days' supply of insulin. There are two types: tethered pumps and patch pumps.

With tethered pumps, the insulin is generally delivered through an infusion set. This is a very fine tube that runs from the pump to a cannula (a thin and flexible plastic tube), which goes under the skin.

Patch pumps sit directly on the skin. The cannula of a patch pump can usually be left in for two to three days before it needs to be repositioned and replaced. Your paediatric diabetes team will show you how to do this. The pump is battery powered and will tell you when the power is low.

The pump delivers a varied dose of rapid-acting insulin throughout the day and night. The rate is pre-set to your child's needs, known as the basal rate. When your child has something to eat, you or they can give extra insulin, known as a bolus dose, by pressing a combination of buttons. Your child's paediatric diabetes specialist nurse (PDSN) or dietitian will teach you both how to work out the carbohydrate (carbs) in meals and snacks, so you can give the right bolus dose – see page 41. A bolus dose can also be given if your child's blood sugar levels go too high.



# Checks for long-term management

**As well as checking blood sugar levels, your child will need other checks with their paediatric diabetes team.**

The tests will check diabetes management and look for other conditions. These checks should be done at least once a year and are to make sure your child stays as healthy as possible.

## HbA1c check

These will check long-term diabetes management – over two to three months. It's usually done either at the clinic or before your child's appointment. It's measured in millimoles per mol (mmol/mol).

The recommended level for children is generally 48mmol/mol or lower. But targets are individual, so you may be given a different figure.

To find out about the other essential health checks your child is entitled to, go to [www.diabetes.org.uk/pg-type-1-essentials](http://www.diabetes.org.uk/pg-type-1-essentials)

## Other checks

Type 1 diabetes is linked to other autoimmune conditions, like thyroid problems and coeliac disease. So, your child will also be checked for these conditions.

### Thyroid tests

The thyroid is a gland in the neck just below the Adam's apple. It produces hormones to help regulate the body's metabolism, the chemical reactions that take place in the body's cells to convert food into energy. Thyroid conditions can develop when the body's cells attack the thyroid – which is similar to cells attacking the pancreas in Type 1 diabetes. That's why thyroid problems are more common in people with Type 1 diabetes.

There are two types of thyroid disorder:

### Hypothyroidism

When the body doesn't produce enough thyroid hormones.

Symptoms include:

- tiredness
- feeling cold all the time
- constipation
- more frequent hypos.

### Hyperthyroidism

When the body produces too many thyroid hormones.

Symptoms include:

- weight loss
- feeling warm all the time
- diarrhoea.

But, there are often no symptoms of a thyroid problem. So, your child needs to be checked when they're first diagnosed with diabetes, and then every year after that.

Both types of thyroid problem can be treated, but there's no cure.

### Coeliac disease

In coeliac disease, the body reacts to gluten – a protein found in wheat, barley and rye – that damages the gut lining and affects how food is absorbed. Symptoms include stomach ache, diarrhoea, constipation, anaemia, poor growth and unexplained hypos. But, sometimes, there are no symptoms.

Your child needs to be checked for coeliac disease when they're first diagnosed with diabetes and again



if they start to show any symptoms. Some hospitals check more regularly with a blood test once a year. If the test is positive, diagnosis is confirmed with a gut biopsy under general anaesthetic.

The only treatment for coeliac disease is a permanent gluten-free diet. You and your child will need to see a dietitian who can advise on both diabetes and coeliac disease.

Don't start your child on a gluten-free diet if you suspect they have coeliac disease. You must wait until you have a definite diagnosis. Following a gluten-free diet before a test for coeliac disease could give an inaccurate result.

For more information go to [www.coeliac.org.uk](http://www.coeliac.org.uk) and [www.diabetes.org.uk/pg-coeliac](http://www.diabetes.org.uk/pg-coeliac)

## Need to know

- Ask your paediatric diabetes team what the target is for your child's HbA1c.
- Check with them how often and where the test will take place.
- If you know your child has a blood disorder, tell your paediatric diabetes team. It may affect the accuracy of the test.

## Meet Andrew and Bia

### Andrew looks back at Bia's diagnosis, and how far they've come since

"When Bia was diagnosed with Type 1 diabetes at the age of 5, we were devastated. We had no idea what Type 1 diabetes was, or what it entailed. I managed to hold it together until the following morning. One of the cleaning ladies on the ward asked me about Bia. I said that she would never be able to remember a life without diabetes, then burst into tears. In true British style, she brought me a cup of tea.

Bia is now 11, and is incredibly strong and resilient – like all children growing up with Type 1. Recently, we decided to cycle 54 miles from Hayes to Brighton together with a local bike club. We did a few training rides building up to the big day. The ride was a microcosm of living with diabetes – managing blood sugar all day while exercising, carb counting for the snacks, ups and downs with her bloods being reflected in the hills, struggling at times, but never giving up. I was so proud of her. It took all day but she made it.



We want to show that this juggernaut that crashes unwelcome into people's lives can be used as a force for good. Type 1 diabetes doesn't mean everything has to change. Six years into our journey, being able to give people whose lives have been turned upside down by this diagnosis some hope makes any achy legs more than worthwhile."

# Understanding complications

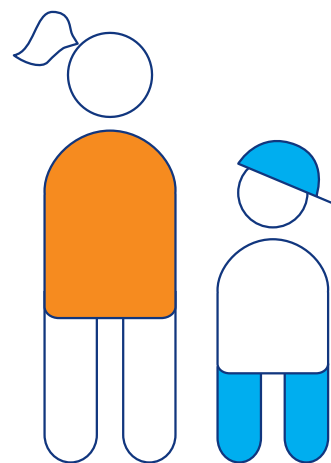
**Having Type 1 diabetes puts your child at risk of long-term complications, like heart disease, damage to the kidneys, eyes or nerves. It's completely natural that you'll worry about this.**

But the good news is that long-term complications are much less likely in people who keep their blood sugar levels as close to target as possible.

This doesn't mean you should panic or feel guilty if your child's blood sugar levels aren't always perfect. Nobody gets it right all the time. Having high blood sugar levels for short periods of time doesn't lead to a long-term problem.

As a parent, you'll want your child to follow a healthy lifestyle to make sure they have the best start in life. This is true whether or not they have diabetes. Doing your best to manage their diabetes well is part of making sure they have the best start in life, too.

You can find out more about diabetes complications and how they're treated at [www.diabetes.org.uk/pg-complications](http://www.diabetes.org.uk/pg-complications)



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Checks and treatment



# Hypos and hypers

## In this chapter

Low and high blood sugar levels	29
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Treating a hyper	32



# Low and high blood sugar levels

**It can be really hard balancing your child's blood sugar levels. Sometimes they'll go too high and sometimes too low. But if you both know what the symptoms are, you can do something quickly to put it right.**

When blood sugar levels go too low it's called hypoglycaemia or hypo for short. And, it's hyperglycaemia – or hyper – when it goes too high.

## Hypos

Blood sugar that's gone too low is usually below 4mmol/l. In people without diabetes, low blood sugar levels cause the body to stop making insulin and release stored glucose to get levels back to normal. But, with Type 1 diabetes, the injected insulin can't be switched off, so it'll keep working even when your child's blood sugar levels are too low. They'll get lower still unless you take action.



## Symptoms

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

- trembling and dizziness
- feeling hot or having cold sweats
- becoming anxious or irritable
- becoming pale
- palpitations and a fast pulse
- drowsiness
- blurred vision
- lack of concentration
- confusion
- feeling hungry or sick.

## Why they happen

It's not always obvious why hypos happen, but they're more likely if your child:

- takes too much insulin
- misses or delays a meal or snack
- hasn't had enough carbs
- is more active than normal.

You must treat a hypo as soon you recognise the symptoms – or if a check shows their blood sugar levels are too low. Act quickly before the hypo becomes more severe – see page 30.

## Treating a hypo

- Get your child to stop what they're doing. Ignoring a hypo will make it worse.
- If you have time, check their blood sugar levels. If not, get them to eat first and check them later.
- Give them something sugary to eat or drink. It could be a glucose tablet, sweets like Jelly Babies, GlucoGel® or a non-diet drink. These quick-acting carbs will quickly raise their blood sugar levels. How much you need varies from child to child. You can also give your child GlucoGel® if they're feeling drowsy or confused or you can't get them to eat or drink anything. But you shouldn't give it to your child if they're unconscious. Also, don't give your child chocolate because the high fat content slows down how quickly the sugar is absorbed.
- Sit them down until they feel better.
- Check their blood sugar levels in another 10 to 15 minutes to see if they're back on target. If not, give them more sugary food or drink.
- Some children need longer-acting carbs as well. This could be fruit, biscuits, a small sandwich or their next meal, if that's due. It helps to stop their blood sugar levels from dropping again. Ask your paediatric diabetes team if your child needs this kind of follow-up snack.
- As well as checking with your PDSN or dietitian how much food or drink your child needs to treat a hypo, you should also check food and drink labels to see how many carbs they contain. It's important to check often as products and ingredients, like the sugar and carb content, can change. If you're not sure how much to take, speak to your paediatric diabetes team.

## Glucagon injection

Your paediatric diabetes team should give you an injection kit called glucagon for you to use if your child has a severe hypo. The kit includes a syringe of sterile water and a vial of powdered glucagon. You dissolve the powder in the water and inject all, or some of it, usually into your child's leg. Your paediatric diabetes team will tell you how much to inject and show you how to do it.

## Hypos at night

Blood sugars sometimes go low during the night. If your child stays asleep during a mild hypo, their blood sugar levels could go lower still, which could mean the hypo becomes severe. If this still doesn't wake them up, he or she may be very tired when they get up the next morning. They might have a headache. Or they might not have any symptoms.

The best way to find out if your child is having hypos at night is to check their blood sugar levels during the night. Ask your paediatric diabetes team what's the best time – it'll depend on the type of insulin your child takes and when they take it. If the check shows that your child has night-time hypos, your paediatric diabetes team may want to change their insulin dose.

## Avoiding severe hypos

Parents worry that their child might die from a hypo. This is extremely unlikely. Night-time hypos are common in children. They often sleep through them and wake up with few or no ill effects. A bedtime snack or a change in insulin dose may be all that's needed to stop night-time hypos, so speak to your paediatric diabetes team about this.

You may have heard that severe hypos can affect your child's intellectual development. There's some medical evidence to support this. There's also some to support a similar effect from hypes. But, be reassured that if there's any effect at all on a child's intellectual development from hypos or hypes, it's very small. So try not to worry about it too much.

There are a lot of things you can do to help keep your child's sugar levels on target. That includes checking their levels regularly. You should also monitor them closely if they're not eating as well as you'd expect, they're doing a lot of physical activity, or if they're feeling unwell. Keep an eye out for any changes in their daily routine that could affect blood sugar levels.

But, remember, you can't anticipate everything. Children's lives are often unpredictable, and that's fine. You'll develop a sense of the kind of things that could affect your child's blood sugar levels – and you'll become expert at managing it.

## Some questions

### How can I tell if my child is having a hypo?

It can be difficult to recognise a hypo at first. If you're not sure, check their sugar level. If the result is low – under 4mmol/l – it's a hypo and needs to be treated. Over time, you'll start to spot your child's warning signs. They do change, though, so if you've any reason to think their blood sugar levels could be going low, it's best to check.

### Why is my child having regular hypos without any warning signs?

It could be because they're not recognising their warning signs. You can help your child get these back by running their blood sugar levels a little higher for a bit. After two weeks or so, your child will probably be able to recognise them more easily again. But you must talk to your paediatric diabetes team before you try this.

### Why can't I keep my child's blood sugar levels high to avoid hypos?

It's harmful to your child to keep their blood sugar levels high. They may start to feel thirsty, go to the toilet often and feel tired. They could also develop ketones and be at risk of DKA, see page 19. Long-term high blood sugar levels can also lead to complications and damage your child's long-term health, see page 27.

Hypos aren't completely avoidable, but learning what causes them in your child will make you both better at managing them.

### Are my child's hypos my fault?

No, they're not your fault. All children with Type 1 diabetes have mild hypos. They're impossible to avoid. They're a part of life with diabetes, so neither you or your child should feel guilty or like you're failing.

## Need to know

- Make sure everyone who looks after your child knows how to spot and treat a hypo.
- Ask your paediatric diabetes team how much fast-acting carbs your child needs to treat a hypo. As they get older, they'll need more.
- Keep an eye on the product you use to treat your child's hypos as the sugar or carb content might change.
- Check with your paediatric diabetes team if your child also needs a follow-up snack containing slower-acting carbs.
- If your child has a severe hypo – or regularly has mild hypos – speak to your paediatric diabetes team.
- Speak to your paediatric diabetes team if you're worried about doing glucagon injections.
- Get a diabetes identity wristband for your child. Go to [shop.diabetes.org.uk/go/wristbands](https://shop.diabetes.org.uk/go/wristbands)

For more information on hypos, go to [www.diabetes.org.uk/pg-hypos](https://www.diabetes.org.uk/pg-hypos)



## Hypers

Hypers happen when your child's blood sugar levels are too high. It could be because your child:

- missed an insulin dose
- didn't take enough insulin
- has eaten too much sugary or starchy food
- overtreated a hypo
- is stressed
- has an infection.

### Signs of a hyper

They're the same signs your child had before they were diagnosed with Type 1 diabetes:

- weeing more often
- feeling very thirsty
- feeling very tired
- losing weight.

As well as these signs, your child may also have:

- blurred eyesight
- difficulty concentrating
- irritable behaviour.

### Treating a hyper

If your child's blood sugar levels are high for just a short time, you may not need to treat it. But, if your child uses a pump, you need to correct a high level straight away.

- Check your child's blood for ketones, see page 19. Your paediatric diabetes team will explain when you need to do this.
- If there are ketones, it's likely your child doesn't have enough insulin in their body. So, you need to increase their normal dose or give them an extra dose. Talk to your paediatric diabetes team about how to do this.
- Even without ketones, if blood sugar levels are high, your child may need to have extra insulin.

Speak to your paediatric diabetes team about when this might be needed, and how much insulin to take.

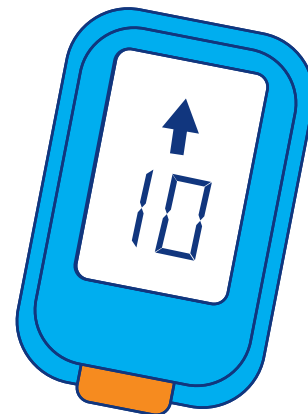
- If your child uses a pump, you may need to change their set. Your paediatric diabetes team will give you specific advice on managing high blood sugar levels in children with pumps.
- Make sure your child drinks plenty of sugar-free fluids.
- If your child has ketones and is unwell – particularly if they're vomiting – contact your paediatric diabetes team immediately.

It's important to make sure blood sugar levels don't stay too high for too long. They could go on to develop DKA – see page 19.

### Need to know

- Make sure everyone who looks after your child knows about hypers and how they're treated.
- Ask your paediatric diabetes team when you need to check for ketones.
- Ask your paediatric diabetes team how much extra insulin your child should take if their blood sugar is high.
- If your child uses a pump, make sure you get written advice from your paediatric diabetes team on how to manage high blood sugar levels.

For more information on hypers, go to [www.diabetes.org.uk/pg-hypers](http://www.diabetes.org.uk/pg-hypers)





# Care



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# Your child's care


**A team of healthcare professionals works with you now to manage your child's diabetes, called a paediatric diabetes team. They're your lifeline: by your side, and by your child's side, every step of the way.**

## Your paediatric diabetes team

First of all, the team will explain what Type 1 diabetes is and how it's treated. They'll then give all of the care and support you need. That includes emotional support.

You and your child live with diabetes every day, so it's vital you're involved in all decisions about their care. You'll probably see your team fairly often in the first months after diagnosis, especially your PDSN. The team will teach you and your child, if appropriate, everything you need to know about diabetes. This may be just with you and your child, or as part of a group. You'll also get a phone number, so you can get in touch between appointments or if you have any problems out of normal hours.

## Your healthcare team



Team member:	What do they do?	Name and contact details:	When do I see them?
<b>Consultant paediatrician or diabetologist with specialist expertise in diabetes</b>	They'll have overall responsibility for your child's care. Your child will still see their GP for things unrelated to diabetes, but anything related to diabetes will usually be handed over to the paediatrician.		
<b>Paediatric diabetes specialist nurse (PDSN)</b>	They're usually your first point of contact.		
<b>Registered dietitian with experience in children with diabetes</b>	They'll help with food choices.		



## Care at the clinic

At least four times a year, you'll have an appointment at the paediatric diabetes clinic. It's probably part of the children's ward of a hospital, part of a diabetes centre or outpatients centre.

The appointment should be with the full team. So, the PDSN, the paediatrician, and the registered dietitian who also specialises in children with diabetes.

Your child should get these checks at every clinic appointment:

- height and weight
- injection sites – to check they're not getting lumpy
- a blood test to check long-term diabetes management, called an HbA1c – see page 25.

And once a year from the age of 12:

- blood and urine tests to check your child's kidneys
- a digital photo of the back of their eyes (their retinas)
- a blood pressure check
- a check of their feet.

**There are 10 essential health checks, care and support that your child should get now that they have diabetes. They're called Type 1 essentials. See page 36 for more on this.**

### Need to know

- Check you have the out-of-hours contact details for your paediatric diabetes team.
- Check that your child is getting all the checks and results they should be.

## Some questions

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

Don't be embarrassed. Your doctor is used to people asking lots of questions and it's essential you ask about anything that's worrying you. Write down a list of questions before you go and make sure you understand the answers before the doctor moves on. You can also write things down when you're there so that you don't forget. Make sure you understand what any test results mean. Never be afraid to ask the doctor – or anyone in your paediatric diabetes team – to explain something again if you don't understand.

**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 may help to take along something to keep them busy or give them a treat – like a favourite meal or movie before or after. Ask your paediatric 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, then don't be afraid to ask to be seen alone.

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

Try to deal with small niggles when they happen and to look carefully at what's made you unhappy. 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. Go to [www.diabetes.org.uk/pg-advocacy-packs](http://www.diabetes.org.uk/pg-advocacy-packs) to find out more.

# Type 1 essentials

**These are the 10 things you should expect from your child's diabetes care. It includes the care, checks and support that your child or family needs to make sure your child's condition is managed well – in hospital, school and wider society.**



## 1 Care from a specialist team

Your child's diabetes team should be able to give you:

- Treatment.
- Advice about food choices.
- Advice about eating healthily and keeping active.
- Support and advice to help with feelings or worries.

Your 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 help you with food choices.
- Someone who can help you and your child get advice about feelings or worries.



## 2 Regular checks

All children should get:

- A blood test to check their diabetes management known as HbA1c four times a year.
- Regular checks of their weight, height and general health.
- Screening for other conditions linked to diabetes. These include coeliac disease when diabetes is diagnosed, and thyroid disease when diabetes is diagnosed and then once a year.
- An opportunity to agree goals.

- An opportunity to talk about emotions or things you might be struggling with.

Children aged 12+ should have these checks once a year:

- 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, carb counting and the most appropriate insulin.
- Blood glucose and ketone meters, testing strips.
- Insulin pumps.
- Continuous glucose monitoring (CGM).



## 4 Support so you can do it yourself

As much as you can, you and your family should be able to manage your child's condition yourselves. To do this, you should get expert advice, education and information that's easy to understand.

This should include:

- High-quality information that your child can understand, in a way that works for them.
- Education so your child can learn how to manage their condition.
- Advice on eating well and keeping active, so you and your child know what needs to be done.
- 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 you with food choices.

Your child may also be able to get Disability Living Allowance. Go to [www.diabetes.org.uk/pg-dla](http://www.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. It may be hard for your child, for you, and for your whole family. You definitely won't be the first family to feel angry, confused or upset by it all. Talk to your paediatric diabetes team who'll be able to help.

As part of diabetes healthcare, your paediatric diabetes team should offer your child and family the chance to talk to a counsellor who is an expert in mental and emotional health, who'll also know about how diabetes can affect emotions and feelings. You can talk to them about particular issues and meet with them regularly, if you want.



## 6 The right care when you are 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 diabetes yourselves if you can. This will help the hospital staff look after your child in the right way.



## 7 A smooth transition to adult diabetes services

Moving from child to adult healthcare services is a big shift. It can be a difficult time for teenagers who are already having to deal with so much change. But it's essential it works well so that they continue to get the care they need. The two 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.



## Meet Simon and Cari

### Simon and Cari learned to control diabetes, not the other way around

“Just after my daughter Cari was diagnosed with Type 1, we were planning our summer holiday. My wife and I had a lot of conversations focusing on diabetes. We finally decided to go on holiday in the UK, where we knew the healthcare system and could speak the language. We ended up letting diabetes drive what we did.

Since then, we've taken the view that diabetes will not stand in the way of our daughter or our family. We decide what we want to do first, then find out how to handle the diabetes side of things second. Yes, it means more planning and research beforehand, but we are in control of the diabetes, not the other way around. After that first year, we've been lucky enough to enjoy several foreign holidays, including some with long-haul flights. As long as you plan carefully, diabetes doesn't need to be an issue.

My advice to any family going through diagnosis is to remember that your child is still the same wonderful, precious person they were before they were diagnosed with Type 1. Don't let them, or you, be defined by what at first seems like an overwhelming condition. It takes a little while, but you do reach a new normal.”



## 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 the diabetes will be treated and managed. You should be able to talk through it and ask any questions.
- 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. This 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. They shouldn't be treated differently because they have diabetes. They should be able to join in with sports, activities, clubs and groups. And, as they grow up, they should be able to learn to drive and do most jobs.

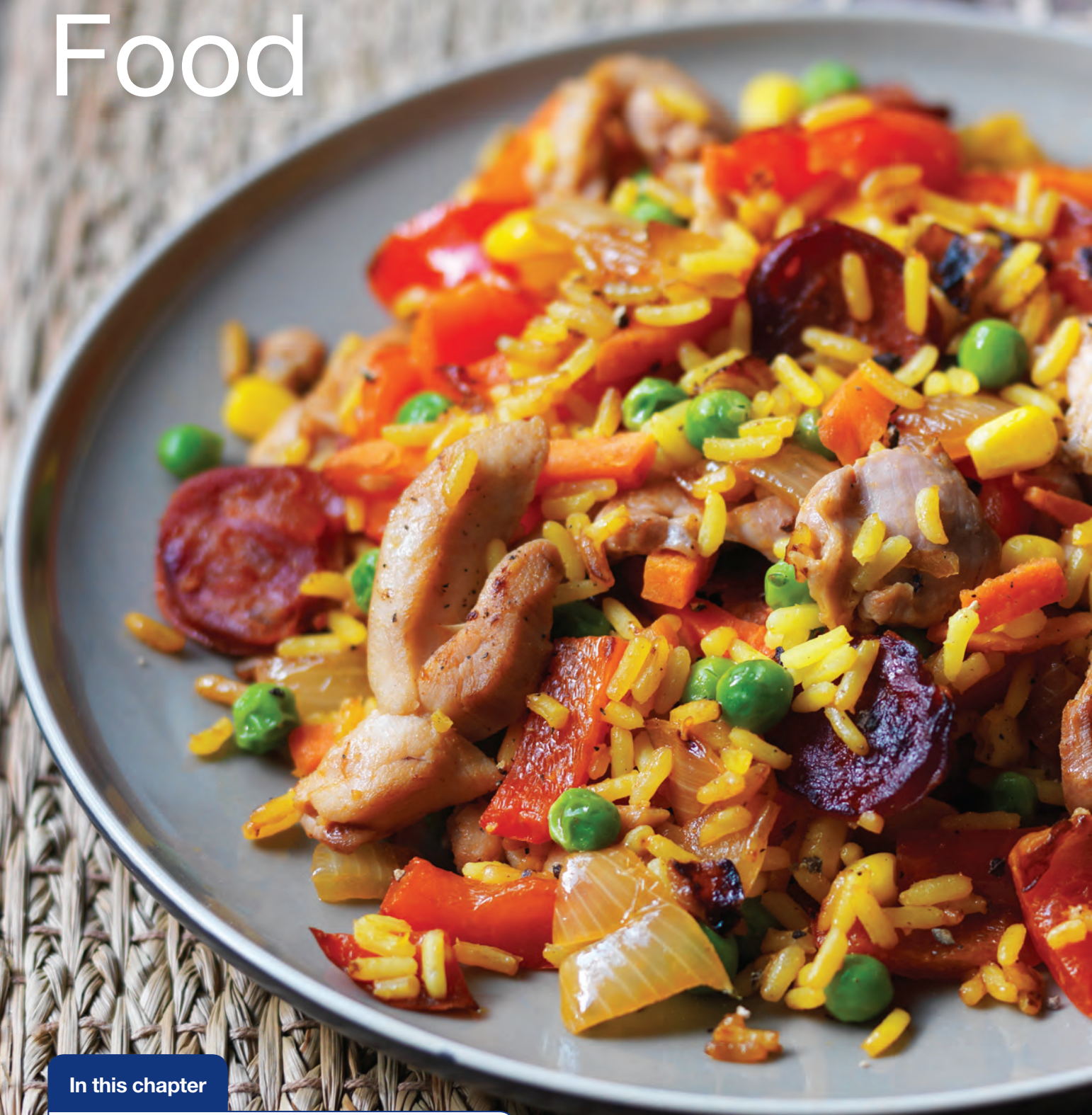
## Some questions

### **We're not getting the right care. What can I do?**

Speak to the people or the service involved. If it's a healthcare issue, talk to your doctor or nurse. If it's a school issue, talk to the teacher, the head of year, head teacher or special educational needs coordinator. If it's a social activity, like a sports or youth club, talk to the organiser or leader. Ask them for a meeting and take a copy of the Type 1 essentials along with you to help get your point across. You can download a copy at [www.diabetes.org.uk/pg-type-1-essentials](http://www.diabetes.org.uk/pg-type-1-essentials)

If you're still not happy, the next step is to make a complaint. Go to [www.diabetes.org.uk/pg-advocacy-packs](http://www.diabetes.org.uk/pg-advocacy-packs) to find out more.

# Food



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# Healthy eating

**Your child doesn't need special food with Type 1 diabetes. They can eat more or less anything they like. But there are a few things it's sensible to avoid. And, it's best for their long-term health if, for most of the time, they follow a healthy diet.**

The aim is to fit your child's diabetes and insulin around the same healthy food choices that's best for all children.

There are a few things to avoid, though. This includes, strangely enough, foods labelled diabetic or suitable for diabetics. There's no need to eat these foods. They don't have any health benefits, are often high in fat and calories, and can give your child an upset stomach. In fact, companies aren't allowed to label their food and drinks diabetic anymore. So, if your son or daughter wants a treat, it's better to have the real thing.

When your child is thirsty, avoid sugary drinks and fruit juices as they can make blood sugar levels go very high in a short space of time. That's why they're recommended for when blood sugar levels have gone too low. When your child is thirsty, it's best for them to they have water or sugar-free drinks that don't affect blood sugar levels.

Making healthier food choices at home should help your child be a healthy weight for their height as they grow up.

## Talk to your dietitian

Either at diagnosis or soon after, both you and your child should see a registered dietitian who understands diabetes – see page 34. You should then meet with them at least once a year. Not only will they advise on the diet and nutrients your child needs, but they'll help make sure your child has a happy and healthy relationship with food.

## Tips for portion control

- Digital scales are great for making sure portion sizes are right. They're also good for working out your child's actual portion size.
- Even if you don't weigh food every time, it's worth doing it again every six months or so, as your child may eat bigger portions as they grow.

It's the carbs in food and drink that make your child's blood sugar level go higher. And, there are different types:



**Starchy:** bread, potatoes, chapatti, rice, pasta, breakfast cereals, couscous, quinoa, yams, cassava and parsnips.



**Natural sugars:** fruit and dairy products.



**Added sugars (also called free sugars):** sweets, chocolate, cakes, biscuits, syrups and non-diet drinks.

Even carbs that don't taste sweet will raise blood sugar. That's because the body digests them and breaks them down into glucose (blood sugar).

Starchy carbs aren't bad even though they raise blood sugar levels. They do a really important job: providing your body with fuel for energy. Foods containing natural sugars usually also contain other useful ingredients.

Foods with free sugars often have fewer nutrients. Although they taste good, we all need to try and reduce how many of these we eat.



## Carb counting

This is a good way of managing Type 1 diabetes, whether your child has injections or uses a pump. By counting carbs you can match your child's insulin to what they eat. So, if they're hungrier and need a bigger portion size, they can have it – as long as they adjust their insulin.

It doesn't mean total food freedom, though. That wouldn't be healthy for a child anyway. Giving insulin for carbs doesn't make their fat and calorie intake disappear, so they still need to make healthy food choices most of the time. But, it does mean that it's easier to manage foods eaten on special occasions or as a treat.

Carb counting means more work at first. It takes effort to work out or weigh foods to calculate the carbs, but it'll get easier and quicker as you get used to it.

### Carb portions

Carbs are measured in grams, in carb portions, or in exchanges. In the UK, each portion or exchange is usually 10g of carbs. In the US and Australia, it's usually 15g, so keep this in mind if you find information on the internet from the US or Australia.

Nutritional information labels on packaged food tell you how many carbs in grams is in 100g, or in a portion. Use the "total carbohydrate" figure when matching insulin, not the "of which sugars" value.

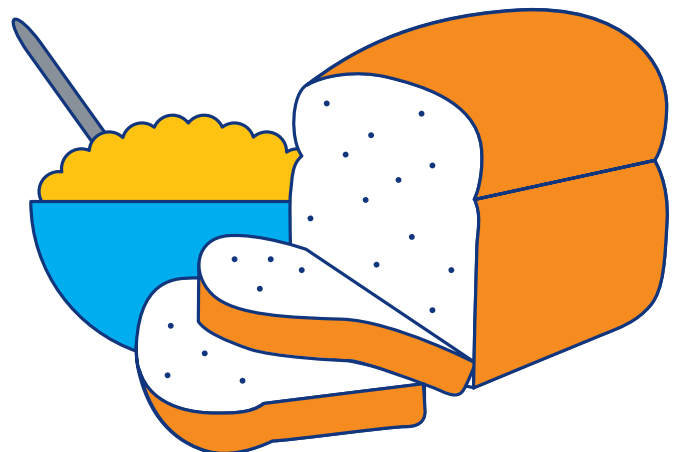
Your paediatric diabetes team works out the amount of insulin your child needs. It depends on their age, weight, how active they are and how long they've had diabetes. If you know how many grams (or portions) of carbs are in a meal, and how much insulin they need per 10g of carbs, then you can work out the number of units of insulin for the meal.

You should really give injections of rapid-action insulin or pump doses before eating. But, if your child's appetite is unpredictable, your child's paediatric

diabetes team might suggest giving the injection immediately after the meal instead. But do talk to them about this. Pump users always need some insulin before eating, and then some extra insulin after the meal if necessary.

### Tips for carb counting

- Your child's dietitian should give you a list of foods and the amount of carbs in them.
- There are books and apps with photos of different portion sizes of carb foods, and smartphone apps. They'll help you with carb counting and recipe calculations.
- Carbs & Cals (Chello Publishing Ltd) has over 1,700 photos of food and drinks, and their carb content. It's also available as an app. Go to [www.carbsandcals.com](http://www.carbsandcals.com)
- Carb Counter: A Clear Guide to Carbohydrates in Everyday Foods (Collins Gem) – is a handy portable guide with clear tables detailing how many carbs there are in everyday foods.
- You could also complete our carb counting module – tailored to parents of children with Type 1 diabetes – on Learning Zone, our free and interactive online platform. Visit [www.diabetes.org.uk/pg-zone](http://www.diabetes.org.uk/pg-zone)





## 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 so much now that insulin treatments are more flexible. In fact, too many snacks when they're not needed can lead to higher blood sugar levels, extra fat and calories.

Even though the healthy schools programme has improved the type of food available in schools, high-fat and high-sugar snacks like crisps, chocolate and sweets are still everywhere – and children of course love them. Type 1 diabetes doesn't stop children having these foods but, as for all children, having too many of them isn't good for their health.

### Young children

All young children need snacks between meals. Their stomachs are too small to fit all the food they need into three meals. Young children with diabetes also need snacks to stop their blood sugar levels dropping between meals when they're playing and being active. All younger children with an insulin pump need insulin with their snacks, but if your child is on multiple daily injections (MDI), check with your paediatric diabetes team because they might not. Children may also need a snack before bed to keep blood sugar levels stable overnight.

### Older children

Older children on MDI, or children with pumps, may not need snacks to maintain their blood sugar levels. They may need extra insulin if they have a snack – or to snack on food with small amounts of carbs instead. But, if they go for a low-carb food, make sure it isn't high in fat instead, because the extra fat and calories aren't good for their general health.

## Some questions

### **My child has quite a sweet tooth and it's hard saying no. What should I do?**

You can't blame children for finding it hard to resist sweet things – particularly if all their friends are having them. It's best not to ban anything as it could lead to them eating secretly, and it'll also make it very hard for your child to come to terms with diabetes. Instead, teach them that no one should have too many sweets and chocolate. And, for them, like everyone else, they should be treats that they don't have too often.

### Need to know

- Some clinics recommend no snacking without insulin, so check with your paediatric diabetes team.







# Dealing with food issues

**It can be really worrying if your child refuses to eat – no matter how old they are. If they're growing well, refusing food isn't likely to cause long-term problems, but you'll still worry about hypos. Keep as calm as you can. Try not to show them how frustrated or anxious you are. Children are good at picking up signals from parents. 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.
- If your child has had insulin and then refuses to finish the meal, make up some of the missing carbs with a drink of milk, yogurt or custard for pudding. There'll be less risk of a hypo.
- It's always 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 bolus dose straight after they do eat instead. Adjust the amount of insulin based on what they've actually eaten.
- Offer small portions 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, etc – 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.

## Teenage food choices

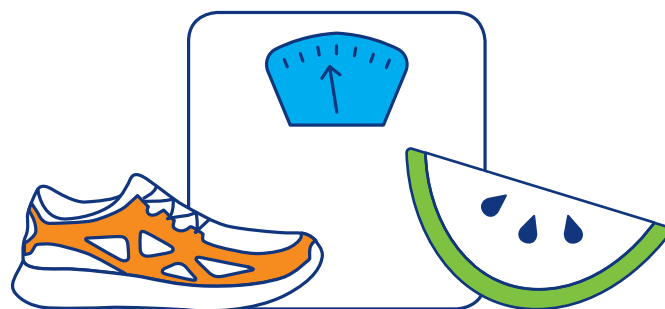
We all know teenagers can be faddy eaters. And, a lot of the time, their choices aren't ideal. But you can't always police food choices. If they take insulin with food, in a safe dose, that might be the best you can hope for a lot of the time. Fast food isn't great, but they're teenagers and they want to have what their friends have. Just try to encourage them to go for smaller portions or healthier options. Many fast-food places have information on their websites about carb content, so it's worth you all checking these.

Always encourage your child to join in regular physical activity – see page 48 – it improves heart health, as well as maintaining weight. Depending on the time of the activity, try reducing the insulin dose at the mealtime before, rather than giving them an extra snack before they start.

## Weight

As your child grows up, they're likely to become more conscious of their weight as their body changes. Just like everyone else. They need to be weighed and measured regularly when they go to the clinic, but it needs to be done sensitively and respecting their privacy.

Unexpected weight gain can be caused by poor thyroid function. It's more common in people with Type 1 diabetes. Your child needs to have their thyroid checked every year – see page 25.



Missing or skipping insulin regularly leads to weight loss. The food isn't absorbed properly, so the body uses fat instead. The raised blood sugar levels means diabetes management slips, which can lead to diabetic ketoacidosis (DKA – see page 19). It can also lead to long-term complications – see page 27.

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 snack on inappropriate foods. If you think your child is regularly missing insulin on purpose to control weight, or is getting an unhealthy obsession with how much they eat, speak to your paediatric diabetes team immediately.

## Treats and sweets

Treats should be just that – something they have now and then, not every day. But, chocolates and sweets are often part of childhood, so they're fine as occasional treats. Just in the same way that they're fine as occasional treats for children without diabetes.

Try having a couple of days a week when the whole family enjoys these things together. For your child with diabetes, 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 increase the dose. Extra insulin is definitely needed when they have sweets or chocolate outside of mealtimes.

### Need to know

- Speak to your PDSN or dietitian for more advice on managing food refusal. You could also speak to a psychologist if it continues.
- Don't bother with sugar-free sweets. The sweeteners still affect blood sugar levels. Sugar-free chewing gum is OK as there's so little sweetener in it.

## Some questions

### Can we still go out for family meals?

Yes, definitely. Once you've got to grips with carb counting, you change your child's insulin dose to fit with what they eat. But, it's trickier with food you haven't cooked yourself, so carb counting books and apps can help. Many chain restaurants list nutritional information on their websites, which can also help.

When eating out, 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 help you.

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?

There's no need for your child to miss out on parties or sleepovers. But sleepovers can make you worry about what they're eating and when, as you won't be there to get things back on track if their blood sugar levels go out of control. It may help to:

- Talk to the other parent beforehand to see what food will be provided and when.
- Remind them that your child can eat the same as everyone else.
- Ask for sugar-free or diet drinks.
- Find out if there's any type of activity that might affect your child's sugar levels.
- Suggest a safe amount of insulin to take if your child can't carb count for themselves, and correct any high levels when they get home. You might feel anxious about letting their sugar levels go higher than usual, but it won't do any damage if it's only once in a while.

- Make sure you swap numbers with the other parent, 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. It's natural to want to fill them up, but maybe it's just too much for them. Talk to your dietitian about the right amount 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.

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. See if you can compromise. Talk to your PDSN or dietitian to see if you can change meal and snack times, so your child can fit in with their friends.

**When my child is at school, they eat regularly and their activity levels don't change much. But school holidays can be tough – there's no routine and we can't get their blood sugar levels right. What am I doing wrong?**

Any change in routine can really upset blood sugar levels. All parents of children with Type 1 diabetes have just the same problems and worries, so don't think it's just you.

You probably think that if you don't get their levels right all the time, it'll affect them later in life. And, it's true that meeting your child's targets most of the time is important. But things go wrong now and again. It's normal and won't cause any long-term damage. Talk to your PDSN, doctor or dietitian about how to manage holidays and other times when there's no routine.



## Meet Amanda and Lily

**Amanda describes how her daughter Lily copes with Type 1 diabetes, which was diagnosed the day before she turned 5**

“Lily has never allowed Type 1 diabetes to stand in the way of her life. She absolutely loves gymnastics, and her pump has never held her back – we just need to check her blood sugar levels before, during and after training. The exercise lowers her blood sugar, so depending on the reading, we might decide she needs a snack, or make a decision about whether we leave her pump on or take it off.

Lily has some amazing friends, who she's known since before she was diagnosed. They show such an amazing interest in her diabetes and sometimes ask to help Lily check her blood sugar levels. Lily decides whether they help – she likes to be in control!

Lily amazes us every day with how she has dealt with her diabetes. We are so proud of her.”



# Physical activity



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Being active

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# Being active

**We all know exercise is good for us. And, now your child is living with Type 1 diabetes, it's even more important they're physically active.**

Like every good childhood, theirs should be full of running around and being out of puff. They can still take part in all sorts of activities and enjoy their favourite sports. It's just that you now need to manage their diabetes treatment around these activities.

All children and young people need to do at least an hour of moderate to vigorous physical activity a day. This includes things like brisk walking, very active play, and most sports and games – skipping, dancing and swimming, etc.

Being active and physically fit keeps the heart healthy, and may help to improve blood sugar levels, as well as keep weight in check.

## The difference between physical activity and exercise

Physical activity is any movement that uses skeletal muscles. Exercise is specific physical activity that involves training and developing sports skills, like team sports, athletics and gymnastics.

## Activity and diabetes

- Activity increases the amount of glucose used by the muscles for energy. This means that being active may sometimes lower blood sugar levels.
- Being active helps the body to use insulin better. Regular exercise can help reduce the amount of insulin your child takes.
- Being active helps your child keep to a healthy weight for their height. This helps their diabetes management.

## Tips for reaching activity goals

- Be as active as possible yourself. Be a role model.
- Encourage your child to try different things. Get them to have a go and see what they like best.
- Remember, just being active is as important as organised exercise. So, encourage walking and active play – games like tag, hide and seek, and hopscotch. Even some jobs around the house can increase activity levels.
- Encourage activity after school and at weekends. Things like walking around the shops or the park cuts down the time spent in front of the TV or computer.
- Split your child's hour into shorter active sessions of 15 to 20 minutes across the day.

## Have an activity plan

Regular activity should be part of your child's routine, and so planning for it will help. Being active may affect blood sugar levels. You may notice changes during or after bouts of activity.

Regularly checking blood sugars will help you understand what activity does to your child's levels. It could cause them to go low or high – or make no difference.

### Activity may cause blood sugar levels to lower if:

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



## Activity may cause blood sugar levels to rise if:

- they don't have enough insulin circulating in their body
- the activity is mostly aerobic or competitive, for example a competition or any activity or sport using bursts of short, sharp, fast movements.

Physical activity can make the body release the hormone 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.



## Tips for physical activity

- Check your child's blood sugar levels before and after activity. You might also need to check during the activity too.
- 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've gone.
- 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 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 be active for at least 24 hours after.
- Aim for blood sugar levels of 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, for example avoid the leg if they're about to play football.
- If you know your child's going to get 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 might well 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. For anything longer, try an isotonic sports drink, pure fruit juice mixing 50/50 with water, or ordinary squash which contains sugar.



## Handling hypos

Tell the person in charge that your child has diabetes and make sure they know how to treat a hypo. Also, make sure your child's friends and teammates know how to spot a hypo.

In case of a hypo, make sure your child keeps something sugary close by, like Lucozade or a non-diet drink, glucose tablets or gel and longer-acting carb foods, if necessary.

## Going for gold

People with diabetes take part in most sports and activities. There's no reason why your child can't enjoy, or even win at, their favourite sport. Worcester Warriors and England rugby player Chris Pennell and the all-diabetes professional cycling team, Team Novo Nordisk, prove the point.

But some sports-governing bodies do have restrictions on people with diabetes. Luckily there aren't 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.

## Some questions

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

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, and it's a matter of 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.

## Need to know

### Planned or unplanned activity

- **For planned activity:** Think about reducing your child's insulin dose if their meal is one or two hours before the activity. Give them a meal with low-fat carbs – things like pasta, baked beans, porridge, milk, yogurt and fruit.
- **For unplanned activity:** Your child will probably need a carb-containing snack to help avoid a hypo. It's important to carry hypo treatments like glucose tablets and cereal bars, 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 before exercising. As a rough guide, if you don't adjust their insulin, during exercise children need up to 1.5g carbs for every kilo that they weigh, depending on their blood sugar level, how long they're exercising for and how strenuous the exercise is.
- **Some time after a meal:** Your child will usually need an extra snack, like a banana, 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, for example a football match:** Blood sugar levels may go lower during the activity, so give your child some quick-acting carbs, like a sports drink, jelly sweets, Jaffa Cakes, etc. Have some hypo treatment to hand throughout the activity.
- **Long activity, for example a long bike ride:** Your child will need a mixture of quick-acting and longer-acting carbs, like fruit juice, sandwiches, fruit bars, crisps and biscuits. They can take these in a small rucksack along with something to treat a hypo, like glucose tablets.

# Everyday life



## In this chapter

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# Illness and infections

**When your child is ill, their blood sugar levels may rise or fall. A high temperature tends to make blood sugar levels rise, whereas illnesses such as diarrhoea and vomiting tend to make them 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 diabetic ketoacidosis (DKA, see page 19). If you're worried and can't get hold of your paediatric diabetes team, take your child to the nearest A&E.

## A&E

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

## Hospital stays

What to do if your child needs to stay in hospital overnight:

- The hospital should provide the insulin your child usually 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. The hospital probably won't be able to supply these.
- Check that the ward staff have spoken to your child's paediatric diabetes team.
- Don't assume that everyone treating your child knows they have diabetes. It's better to be overcautious and keep mentioning it.
- While in hospital your child's blood sugar levels may be higher or lower than normal. Stress and

longer periods of inactivity will affect their levels. So, you or the hospital staff need to check your child more often and adjust their treatment.

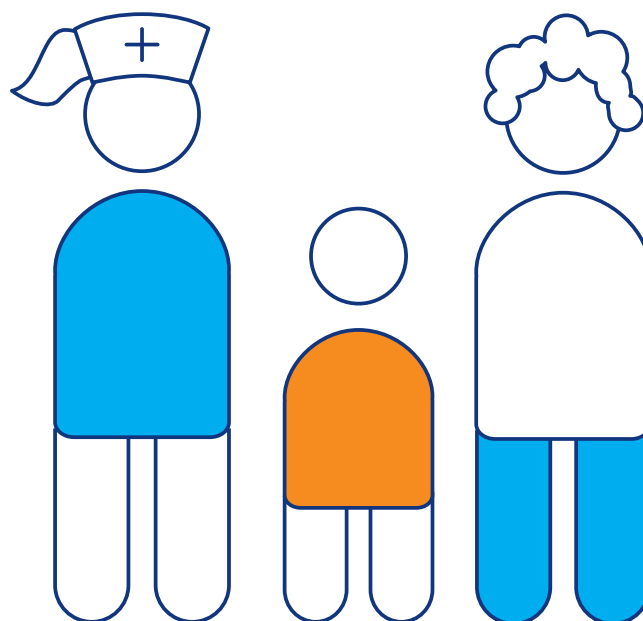
- If you want to manage your child's diabetes care yourself when they're in hospital or if they want to do it themselves, you or your child should be supported in this, unless it's not practical. This includes using an insulin pump.

## Vaccinations

As well as regular childhood vaccinations, your child should be offered an annual flu vaccination from the age of 6 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 2, 4 and 13 months. A child born before 2010 won't have had it but will be eligible for the vaccine because of their diabetes.

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





## Tips for managing illness

- 1** Your child should keep taking insulin, even if they don't feel like eating. In some cases, you may need to change their dose. Your paediatric diabetes team can help you.
- 2** Check your child's blood sugar levels regularly, including through the night. This is the only way you'll know if their levels are too high or too low. You and your paediatric diabetes team will then use these results to decide if their insulin dose needs to be adjusted.
- 3** If your child's blood sugar levels are high, check for ketones. If ketones are present, contact your paediatric diabetes team.
- 4** Encourage your child to have plenty of unsweetened drinks to avoid dehydration, and to eat little and often.
- 5** Encourage small amounts of food or fluids regularly. If your child doesn't feel like eating, is feeling sick or can't keep any snacks or food down, replace meals with snacks or drinks containing carbs, which will give them energy. Try to get them to sip sugary drinks, like Lucozade or non-diet cola, or suck on glucose tablets or have sweets, like jelly beans. Letting fizzy drinks go flat may help your child keep them down. If your child is vomiting, consult your paediatric diabetes team.
- 6** Don't panic. Contact your paediatric diabetes team who will help you.



## Meet Victoria and Benedict

**Victoria's son Benedict was diagnosed at 26 months, and his dad also has Type 1 diabetes**

"It can be frustrating how people think because you're managing Type 1 at the moment that everything's OK. It's a hidden illness and we have to work hard every day to keep Benedict safe. And, even though you learn to manage it as a family, it makes every day more difficult and can be exhausting.

Whereas a child without Type 1 diabetes might get a cold, we have to monitor Benedict's sugar levels carefully, as this will mess up his daily routine. When he goes to school and wants to take part in sports, his blood sugar levels and insulin will have to be adjusted to suit. Travelling in the UK or abroad will have to be planned more carefully to ensure we have enough of his medication and it is stored in the correct way.

We will support him in all the ways we can to make his life as normal as a possible, but we all know growing up is never easy. Type 1 will be an additional challenge that will help define him."

# School



**You can't be there for your child 24 hours a day, every day. You'll need to rely on others to look after them.**

## School

You're bound to worry about your child going to school. A lot of parents worry whether the school staff will look after their child in the way they want them to.

Many schools support children with diabetes very well. But it's fair to say that some parents do have difficulties getting the care their child needs. Be prepared, in case there's a problem. Most schools that are unwilling to look after a child's diabetes aren't being deliberately unhelpful. It's more likely that they're frightened of doing something wrong, or don't understand what's involved. When they're given some information about diabetes and know that there are people to help, they often feel much more able to give a child the support they need.

## Information for you and your school

We've got a lot of information for you and your child's school staff to help make sure your child gets the support they need at school.

There's a pack for you and another for your school to give you the basics about looking after diabetes in school that you can order or download for free.

And, there's much more detailed information about everyone's roles and responsibilities on our website. There you'll also find specific information about trips and exams, videos made by young people themselves about diabetes at school and much more.

You can find all this information, and more, at [www.diabetes.org.uk/pg-schools-info](http://www.diabetes.org.uk/pg-schools-info) or, if you'd like to order a pack by phone, call **0345 123 2399**. If you're in Scotland, call **0141 212 8710**.

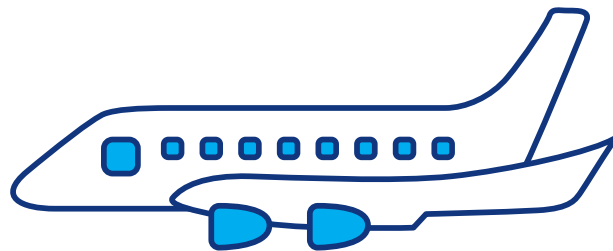
## Tips for school

- 1 Together with your PDSN, give your school as much information as you can about your child's diabetes.
- 2 You, your PDSN and your child's school should work together to create an individual healthcare plan (IHP for short), which details exactly what care your child needs at school, when they need it and who's going to help them. Make sure it's reviewed at least every year and whenever your child's needs change.
- 3 If you've having difficulty getting the support you need for your child, call our helpline on **0345 123 2399**.
- 4 It's difficult to balance this, but try to communicate the importance of looking after diabetes properly, without frightening staff or putting them off. Your PDSN can help with this and so can Diabetes UK's information at [www.diabetes.org.uk/pg-schools-info](http://www.diabetes.org.uk/pg-schools-info)

## Need to know

- Find out who's your main contact at school for your child's diabetes care, and work out the best way of keeping in touch with them.
- Talk to your paediatric diabetes team about training up school staff to look after your child. You will probably be involved with that, too.
- Tell school staff straightaway about any changes to your child's diabetes management.

# Travel



**You and your child can travel all around the world. Diabetes won't stop you, but you need to make the right preparations.**

## Things to check before heading off

- Carry diabetes ID and a letter from your paediatric diabetes team saying your child has diabetes, and what medication they need.
- Take twice 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 there, and is sold under the same name. You can get prescriptions sent by courier.
- Flights might cross time zones. Check with your paediatric diabetes team if you need to make any changes to your insulin regimen.
- Hot or cold climates may affect how your child's insulin and meter work. Check with your paediatric diabetes team.
- Buy travel insurance, ensuring you tell them your child has diabetes when taking out the policy.

## Packing

- Check you have all your child's diabetes medication and equipment packed and make sure you have their diabetes supplies in your hand luggage. Insulin should be kept in hand luggage as it can freeze in the hold.
- Split diabetes equipment between both of your hand luggage bags in case bags get lost.
- Pack snacks in case of delay.
- Take a letter from your doctor or nurse if you have insulin pens with you.

## Travelling with a pump or CGM

If your child treats their diabetes with a pump or uses a continuous glucose monitor (CGM), make sure you contact your 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 will require 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.

There is caution about pumps and CGMs on aircraft due to wireless functionality, which may interfere with communication and navigation systems. If your child's pump or CGM can't work without a wireless signal, 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 your child's pump or CGM through the X-ray machine or full-body scanner at the airport. This is because X-ray waves can cause your pump or CGM to stop working properly.

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 [www.diabetes.org.uk/pg-airport-tech](http://www.diabetes.org.uk/pg-airport-tech)



## Some questions

### What if my child gets sick while 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 your insurance policy, so you know what your insurers will pay 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 – see page 52.

## Need to know

Most travel insurance policies exclude pre-existing medical conditions – medical conditions before the policy was taken out – such as diabetes. It's essential when arranging the policy that you fully disclose your child's medical conditions to the insurance company, including diabetes, even if they don't ask. If you don't, it could lead to them rejecting a claim.

There's more travel advice on our website at [www.diabetes.org.uk/pg-travel](http://www.diabetes.org.uk/pg-travel) to help you make the most out of your trip, including getting insurance, food on the go and managing diabetes in different climates.

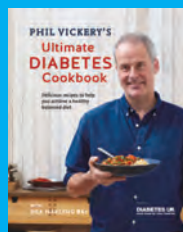
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# Diagnosis in the teenage years

**Being diagnosed with Type 1 diabetes as a teenager can be hard. Just as they're trying to find their own identity and become more independent, a just-diagnosed teenager is forced into being looked after again for a while. The diagnosis also brings new worries. It can be very hard for them. They need to be treated sensitively.**

Your teenager may want to take total management of their diabetes. Or, they may go completely the other way and be so shaken that they need you to look after them. Neither way is right or wrong – you have to do what's right for both of you.

It's important not to push them into too much responsibility too soon. But, also, not to hold them back if they want to handle it themselves. Keep an eye on them and be prepared to step in when they need you. Like all teenagers, they'll want nothing to do with you one day, and be all over you the next.

Even if your son or daughter wants to manage their 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. Diabetes can add another layer of difficulty. You need to know what's going on with your teen's diabetes, even if they want nothing to do with you. These tips may help:**

- 1 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 mood already, try another time.
- 2 Pick your battles.** Complaining about everything they're doing wrong is unlikely to make them change. If you're worried about several things, talk about the big worries first and come back to the others at another time.
- 3 Pick your way.** A face-to-face conversation may make them so uncomfortable that they clam up and aren't honest. Try bringing things up gently, when you're doing something like going for a walk or cooking a meal. It can be easier for them to open up if they don't have to look you in the face.
- 4 Pick your allies.** Don't be hurt by this, but sometimes you're just not the best person to talk to your teenager. They might feel more comfortable with an aunt, uncle or family friend.

If you take this approach, make sure you're all clear about what's shared with who. So you don't feel left out, but also so your teenager doesn't feel there's been any gossiping.

- 5 Pick your info.** Think about whether you want to give your teenager more information and where you're going to get that from.

As your teenager gets used to dealing with Type 1, your paediatric diabetes team may suggest they come to the clinic on their own. You need to talk to them about this, as you may still feel you need to come. Getting the balance right between your teen's independence, and you being there for them when they need it, is different for all families.

These tips can help you and your teenager share responsibility at the clinic:

- Involve them in clinic visits at a level they feel happy with.
- Encourage them to ask and answer questions when they feel ready to.
- 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' lives are completely different from younger children's. They may start experimenting with alcohol, drugs, smoking and sex. All of these things can affect diabetes, so it's important that you both know this.**



## 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 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 switch alcoholic drinks with plenty of water or anything sugar-free to avoid dehydration.
- Alcohol stays in the body for a number of 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

No drug is a safe drug. Alcohol, 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 have different effects. Drugs, legal or not, can be classified into three categories – stimulants, downers/sedatives and hallucinogenics/psychedelics. All can have serious effects on health in general, 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. Talk to FRANK: [www.talktofrank.com](http://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.



## Sex

When you talk about sex with your son or daughter, you also need to mention their diabetes. Make sure they know the following:

- 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.

## Need to know

- Bringing up teenagers is often stressful. Think about who can help and support you through it.
- If you think you need some professional help, talk to your paediatric diabetes team about counselling or psychological support, or call our helpline on **0345 123 2399**. If you're in Scotland, call **0141 212 8710**.

## Notes



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# Glossary

**Basal bolus insulin** (bay-sul bow-lus) A routine of taking insulin, where your child has insulin injections four or more times a day.

**Basal insulin** (bay-sul) The long-lasting insulin your child takes once or sometimes twice a day, which acts over most of the day. Also called background insulin.

**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/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 plastic tube, which sits under the skin, which 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's absorbed.

**Continuous glucose monitoring (CGM)** A sensor worn just under the skin that measures blood sugar levels every few minutes.

**Continuous subcutaneous insulin infusion (CSII)** (sub-cue-tayn-ee-us) Another name for insulin pump therapy.

**Diabetic ketoacidosis (DKA)** (key-toe-ass-ee-doh-sis) Where a build-up of ketones (poisonous chemicals) causes the body 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: these include 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.

**Fructosamine test** (fruc-toe-sa-me-en) A blood test that gives a measurement of diabetes management over the past two to three weeks. It's often done instead of an HbA1c test for people with blood disorders, like sickle cell anaemia or sickle cell trait.

**Glucagon** (gloo-ka-gone) For treating a severe hypo, a kit that includes a syringe of sterile water and a vial of glucagon powder.

**Glucose** The sugar in the blood, which the body uses for energy: the essential fuel for the body.

**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.

**Hyperthyroidism** (hy-per-thigh-royd-ism) Where the body produces too many thyroid hormones.

**Hypoglycaemia (hypo)** (hy-poe-gly-see-me-a) When blood sugar levels drop too low, below 4mmol/l.

**Hypothyroidism** (hy-poe-thigh-royd-ism) Where the body doesn't produce enough thyroid hormones.

**Insulin** The hormone that keeps the levels of glucose in the blood under control.

**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 (a very thin and flexible plastic tube) inserted under the skin, or a patch.

**Ketones** (key-tones) Poisonous chemicals that can develop if there isn't enough insulin in the body to allow enough glucose to enter the cells: 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 of the concentration of a substance in a certain amount of liquid: 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.

**NICE** The National Institute for Health and Care Excellence: decides the criteria for NHS funding, standards and services.

**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.

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

**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.

# Who we are

**We are Diabetes UK. Our vision is a world where diabetes can do no harm.**

Diabetes affects more people than any other serious health condition in the UK. More than dementia and cancer combined. That means we need to take action now.

Because we're the leading UK charity for people affected by diabetes, it's our responsibility to lead the fight against the growing crisis.

And this fight is one that involves all of us – sharing knowledge and taking diabetes on together. Until we achieve our vision.



**A world where  
diabetes can  
do no harm.**



## Get in touch

**Call** 0345 123 2399


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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](mailto:helpline@diabetes.org.uk)** or write to us at: Diabetes UK Helpline, Wells Lawrence House, 126 Back Church Lane, London E1 1FH