A PARENT’S GUIDE TO TYPE 1 DIAGNOSIS

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A parent’s guide to Type 1 diabetes is one of a series of companion guides for people with diabetes. This guide has been written by a Paediatric Diabetes Specialist Nurse and Clinical Advisor at Diabetes UK, and the content has been taken from current NICE guidelines, up-to-date medical research and advice from paediatric diabetes healthcare professionals and parents.

Diabetes UK’s companion guides are available in printed and digital forms (from Apple, Android and Kindle Fire app stores).

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Diabetes UK is the leading UK charity for people affected by and at risk of diabetes. We're here with all of the information, advice and support you might need to manage your condition well. We're here to put you in touch with others with diabetes, and campaign tirelessly for better care and improved healthcare services. Our world-class research changes lives and is bringing us closer to a future without diabetes.

For more information, go to www.diabetes.org.uk

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When your child is diagnosed with Type 1 diabetes, you’re likely to find yourself dealing with a lot of new things at once. The fact that your child has diabetes may have come as a complete shock – possibly the last thing you’d have thought would be behind their illness. With this diagnosis come the practical realities that you now have to face of treating and managing the condition (injections, blood tests and clinic visits), as well as the emotional issues of reassuring your child, while – at the same time – feeling naturally anxious and concerned about their wellbeing and future health.

This new way of life, following diagnosis, can be difficult for you and your child to cope with – as can the fact that family life has also changed. Around this time, it’s not unusual for your child to be anxious and upset, whatever their age. These reactions and the feeling that life has become more difficult are all perfectly normal. It’s also important to know that you’re not alone – your paediatric diabetes team can help and support you and your child as you learn to manage the condition as part of your everyday lives. Diabetes UK can help, too.

In this guide, we give you all the essential information you need to manage your child’s Type 1 diabetes – including treatment, testing, eating, exercise and wellbeing. We also let you know where you can get more detailed information and more practical support for your family, including Diabetes UK Care Events for children, young people, adults (18–30) and families. These events are an opportunity to meet others going through similar situations, and to get a better understanding of your child’s condition, so that you can all feel more confident when it comes to managing it well (see pages 12 and 49).

This guide has been written by a Paediatric Diabetes Specialist Nurse and Clinical Advisor at Diabetes UK, following advice from parents of children with diabetes. With the professional care your child can expect for their diabetes, both now and in the future, as well as support from Diabetes UK, you can help them to enjoy a full and healthy life.
ABOUT TYPE 1 DIABETES

Following your child’s diagnosis of Type 1 diabetes, you may want to know a bit more about their condition. Here, we explain what Type 1 diabetes is, detail some of the symptoms you may have noticed and give you a quick treatment overview.

Diabetes is a condition where the body can’t make insulin properly: either it doesn’t make enough, or the insulin doesn’t work properly. Without the right amount of insulin, or if the insulin isn’t doing its job properly, a person can become very ill.

Insulin is a hormone that helps the body use the glucose in the blood to produce energy. Insulin is made by the pancreas, which is just behind the stomach. It acts as the key that unlocks the body’s cells to let in glucose, where it’s then converted into energy.

Glucose enters the bloodstream when carbohydrate is digested from various kinds of food and drink. Carbohydrate is found in starchy foods (such as bread, rice, potatoes), fruit, some dairy products, sugar and other sweet foods. The liver also produces glucose. In people without diabetes, insulin carefully controls the amount of glucose in the blood.

Type 1 diabetes develops when the pancreas doesn’t produce any (or very little) insulin, and glucose is unable to enter the cells to be converted into energy (this is why it can cause tiredness). As glucose can’t provide energy, the body tries to get it from elsewhere and instead starts to break down stores of fat and protein, which can cause weight loss.

Glucose can then build up in the blood, which the body tries to flush out in the urine. This causes frequent urination and dehydration, which then causes extreme thirst. High levels of glucose in the blood, if not treated, can lead to serious health problems, called complications (see page 20).
CAUSES

If your child’s Type 1 diagnosis has felt like a bolt out of the blue, you’re not alone – for many parents, it’s a complete shock to the system. As you try to come to terms with the diagnosis, it’s natural to start wondering why it was your child who developed Type 1 diabetes and want to find out more about its causes. But, in your search for answers, you’ll discover that there is still a lot that we don’t know about the condition and why some children go on to develop it, yet others don’t.

What we do know is that Type 1 diabetes is an autoimmune condition, which means that the body has damaged its own cells – the cells that make insulin – so that they stop working. It’s thought that a viral illness can trigger this. Once the cells stop working they can’t make insulin again, so the result is Type 1 diabetes.

What we don’t know is why this happens to some children and not to others. Although genes play a small part – Type 1 diabetes is slightly more common when a child’s parent or sibling has it – there are many other unknown factors involved.

Many parents blame themselves when their child gets Type 1 diabetes and feel they should have been able to prevent it. Please remember that there’s nothing you (or anyone else) did or didn’t do to cause your child’s Type 1 diabetes – nor is there currently any known way to prevent it developing.

“Like a baby, it wakes us up in the middle of the night, interrupts mealtimes, and forces us to carry special equipment around with us whenever we leave the house. It demands a lot of us all, regularly draws blood, and there’s currently no prospect of getting rid of it.”

Olly, whose sons, Joe and Tom, have Type 1 diabetes
SYMPTOMS
The main symptoms of untreated Type 1 diabetes, sometimes known as the 4 Ts, are:

- **Toilet** – going to the toilet a lot, bed wetting by a previously dry child or heavier nappies in babies.
- **Thirsty** – being really thirsty and being unable to quench this thirst.
- **Tired** – feeling more tired than usual.
- **Thinner** – losing weight or looking thinner than usual.

Q&A

Are there other types of diabetes?

There are two main types of diabetes – Type 1 and Type 2. There are 3.3 million people with diabetes in the UK, overall. About 10 per cent of these people have Type 1, and about 90 per cent have Type 2. However, when it comes to children, the vast majority have Type 1 (95.1 per cent).

Type 1 and Type 2 diabetes are different conditions, with different causes and different treatments. But both types are serious, lifelong conditions. There are also other forms of diabetes, such as MODY (Maturity Onset Diabetes of the Young), but these are much rarer than Type 1 and Type 2 diabetes.

How common is Type 1 diabetes in children?

In the UK, about 31,500 children and young people under the age of 19 have Type 1 diabetes.

Are there risks with Type 1 diabetes?

Having Type 1 diabetes can mean a higher chance of developing health problems (complications) later on as an adult. Potential complications include damage to the kidneys, eyes and nerves, and heart disease. However, you can greatly reduce your child’s risk of these by helping them to manage their blood glucose levels (also called blood sugar levels), encouraging them to eat healthily and helping them to be physically active on a regular basis.
TREATMENT
Although Type 1 diabetes can’t be cured, it can be successfully managed. Your child will need to take insulin several times a day to control their blood glucose levels (also called blood sugar levels), and you’ll need to test these regularly with a blood glucose meter. You’ll also learn how to control your child’s blood sugar levels, and balance the amount of insulin they take with the food they eat and the activity they do. Your paediatric diabetes team (see page 28) will work with you to plan the best treatment for your child. You can find out more about insulin on page 10.

Looking after diabetes needs planning and attention, which may feel overwhelming, particularly when your child is first diagnosed. Many parents describe trying to manage Type 1 diabetes as a bit like a roller-coaster ride – sometimes your child’s blood sugar levels are too high, sometimes too low, and sometimes just right. As well as being frustrating, this can also be scary, as you feel you’re solely responsible for your child’s health and are terrified of what might happen if you get it wrong.

Remember that there are healthcare professionals – the doctors, nurses and dietitians who make up your diabetes team – to help and support you every step of the way. And there’s Diabetes UK, too. With the right help and support, there’s no reason for Type 1 diabetes to stop your child living a long and healthy life.
Taking insulin is essential to treat Type 1 diabetes and manage your child’s condition successfully. Here, we remind you how and where to inject, and how to best store your child’s insulin. There’s also advice on how to inject your baby or toddler, on helping your child do their own injections and on what to do if your child refuses injections. You’ll also learn about the advantages and disadvantages of insulin pumps.

Insulin is a type of hormone that’s made by the pancreas, but with Type 1 diabetes the body has stopped making insulin. So, to treat diabetes many different types of insulin have been created to replace the natural hormone.

Most children use a synthetic type of insulin. This is genetically engineered to be almost identical to natural insulin.

INSULIN INJECTIONS
Children will usually inject insulin four (or more) times a day. This is sometimes called basal bolus insulin or multiple daily injections (MDI).

Your child will take a rapid-acting insulin (bolus insulin) before meals and a long-lasting insulin (basal insulin) once (or sometimes twice) a day.

This means that your child can be flexible with mealtimes and the amounts of food they eat – plus you can learn to adjust the amount of insulin your child takes depending on how much they eat (see page 36).

Coping with injections
After diagnosis, you (and maybe your child, depending on their age and confidence) will have been shown how to inject insulin. You and your paediatric diabetes team (see page 28) will also have worked out which type of insulin is best for your child and when to inject.

You’ve probably been given a pen injector device. Pens are fairly easy to use and there’s a whole range to suit different types of insulin. Insulin needs to be injected under the skin – not into a muscle or a vein. Once injected, the insulin is taken into the bloodstream where it gets to work. Your child will probably find the first few injections a bit uncomfortable or painful, as you’ll both be tense and anxious, but as your confidence grows injecting will become easier.

Where to inject
There are four main injection sites:

- stomach
- bottom
- thighs
- arms.
Injecting into the arm isn’t suitable for everyone, though, so your diabetes team will advise whether this is appropriate for your child.

It’s vital that you rotate or change injection sites. If you keep injecting the same site, small lumps can build up under your child’s skin. These make it harder for the body to absorb and use the insulin properly – and they don’t look or feel very nice.

It’s also important not to inject the same spot within each site. By rotating injection sites and spots, you can prevent lumps from developing. Any lumps that do develop will slowly disappear over time.

**How to inject**

1. Make sure your hands and the area you’re injecting are clean.
2. Eject a tiny amount of insulin into the air to make sure the tip of the needle is filled with insulin (this is called an ‘air shot’).
3. Choose somewhere on your child’s body that has lots of fatty tissue, such as the tops of their thighs or their bottom.
4. If you’ve been advised to, lift a fold of skin and insert the needle at a 90° angle. Make sure you lift a skin fold rather than pinch the skin – this helps get the insulin into the right place. With some short needles you don’t need to pinch up: check with your diabetes team if you’re unsure.
5. Put the needle in.
6. Inject the insulin and count to 10 before removing the needle.
7. Release the lifted skin fold (if using this method).
8. Dispose of the used needle safely.

**TOP TIPS**

**Storing insulin**

1. Store insulin that’s not in use in the fridge at 2–8°C.
2. Keep the insulin you’re using at room temperature (under 25°C) as this makes it more comfortable to inject.
3. Don’t let insulin get too hot – avoid keeping it near a radiator, in direct sunlight or close to electrical devices.
4. Don’t let insulin freeze.
5. Keep an eye on the expiry date and don’t use the insulin if it’s past this date.
6. If you need to transport insulin, keep it in a cool bag or flask.

**Q&A**

**Why can’t insulin be taken as a tablet?**

Insulin is a protein, so if it’s taken by mouth it’s destroyed by the acids in the stomach before it has the chance to work. Insulin has to be injected just under the skin, where it’s absorbed very easily.

**Does insulin go off?**

Yes, it does. Clear insulin goes cloudy, and cloudy insulin sometimes goes lumpy and sticks to the container. Always check the expiry date and don’t use the insulin if it’s past this date.
Insulin absorption
Avoid injecting into an area that your child will use immediately for activity because this makes the insulin act quicker and makes a hypo (see page 22) more likely. For example, don’t inject your child’s leg just before they play football – instead, inject somewhere like the tummy.

TAKING RESPONSIBILITY
There’s no right age for your child to take responsibility for their injections. Some children prefer to do it themselves straightaway; others may want to get used to having injections given to them before injecting themselves. Your child needs to make the decision in their own time. When they’re ready, you can gently help them take on the responsibility themselves.

Many children gain confidence with their injections when around other children with diabetes. Consider attending events run by your child’s clinic or Diabetes UK (qualified medical staff are always on hand to help and advise), where they can see other children injecting.

Go to www.diabetes.org.uk/care-events for more information on Diabetes UK Care Events for children, young people, adults (18–30) and families.

INJECTING A BABY
It can be scary injecting your baby for the first time, but the more you do it, the easier it gets. Your diabetes team will show you how to do this. Some insulin pens give half units of insulin, which can be helpful when injecting a baby-sized dose. Alternatively, your baby may be given an insulin pump (see page 13).

If it’s difficult to hold your baby still, hold them securely over your knee and inject into their bottom. Remember, though, that it’s important to rotate injection sites, even if you find injecting into one place easier than another.

TOP TIPS

### Helping your child to inject

1. Don’t pressure your child to do their own injections – wait until they’re ready.

2. Don’t insist on doing injections yourself if they want to take responsibility.

3. Remember that even when your child does their own injections, they may not want to do them all the time. Be prepared to do their injections yourself if and when they want you to.

4. Don’t assume that your child will always do their injections perfectly as they’ve been taught – keep an eye on their injection technique.
If you’re unsure about your – or your child’s – injection technique, ask your diabetes team for help.

If your child isn’t rotating the injection site and spot, make a progress/reward chart to keep track.

For resources to help you talk about diabetes with your child, go to https://shop.diabetes.org.uk

**INSULIN PUMPS**

Some children use an insulin pump rather than having injections. Insulin pump therapy is also known as continuous subcutaneous insulin infusion (CSII).

An insulin pump is about the size of a small mobile phone and delivers a steady flow of rapid-acting insulin around the clock. The pump has a reservoir, which usually holds about two to three days’ supply of insulin. This insulin is generally delivered through an infusion set – a very fine tube that runs from the pump to a cannula (a very thin and flexible plastic tube), which is inserted under the skin. However, patch pumps that sit directly on the skin are also available. The cannula or patch pump can usually be left in for two to three days before it needs to be repositioned and replaced – your diabetes team will show you how to do this. The pump is battery powered and will tell you when power is low.

The pump delivers a varied dose of rapid-acting insulin throughout the day and night, at a rate that’s pre-set according to your child’s needs (known as a basal rate). When your child has something to eat, you or your child 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 content in meals and snacks, so you can give the right bolus dose (see page 36). A bolus dose can also be given if your child’s blood glucose levels (also called blood sugar levels) rise too high.

**Q&A**

**What should I do when my 6-year-old daughter refuses her injections?**

Reasoning with a young child can be difficult, but make sure you explain so that your daughter knows she has no choice about having the injection. You can, though, give her a choice in other ways: let her help choose the injection site and spot, who does the injection (if possible) and where she sits. You can also ask her to choose a favourite book to look at or TV programme to watch while she has her injection. She may also like to help with the injection, for example by lifting the skin or pushing the plunger.

Although it’s reasonable to let your daughter protest and express her feelings, don’t let it go on for too long. Ask your diabetes team for advice, as they can suggest techniques to help. Diabetes UK also produces tailored information for children and young people – go to www.diabetes.org.uk/mylife

**How can I stop my child getting bruises from their injections?**

If the needle punctures a capillary (small blood vessel), there may be bleeding under the skin that shows as a bruise the next day. There may also be some bleeding straight after you’ve injected. Lightly pressing on the site – with a finger or tissue – after injecting helps avoid bruising and stops any bleeding. If it’s happening a lot, check with your diabetes team about your injection technique.

**How can I make my son’s injections hurt less?**

Injections are more likely to hurt when the needle enters the skin slowly, so try pushing the needle through his skin quickly. Holding an ice cube against the skin for a few seconds first can also help.

**ACTION POINTS**

- If you’re unsure about your – or your child’s – injection technique, ask your diabetes team for help.
- If your child isn’t rotating the injection site and spot, make a progress/reward chart to keep track.
  - For resources to help you talk about diabetes with your child, go to https://shop.diabetes.org.uk
Advantages

- You can make very tiny adjustments to the amount of insulin you give in both the basal rates and bolus doses.
- The continuous supply of basal insulin means that it’s not so important for your child to eat at regular intervals.
- It can be easier to manage physical activity.
- Medical research suggests that severe hypos (see pages 23–24) are less likely on a pump.
- Pumps reduce the chance of high blood sugar levels when your child wakes up (sometimes known as the dawn phenomenon).
- Your child always has their insulin with them.
- If your child doesn’t like injecting in public, a pump is less obvious.

Disadvantages

- Your child will need their blood sugar levels testing frequently. This is because the insulin is rapid-acting, which means that if the supply fails for any reason their blood sugar levels will rise very quickly.
- The pump needs to be attached to your child all the time, so it can be more obvious – especially in hot weather or during exercise – which they might not like.
- If you’re having difficulties managing your child’s diabetes, you may need to change the cannula more often than every two to three days – and you may have to change it at short notice.

SUPPORT FOR YOUR CHILD

Children:

Teenagers:
- [www.diabetes.org.uk/teens-testing](http://www.diabetes.org.uk/teens-testing)
- [www.diabetes.org.uk/teens-insulin](http://www.diabetes.org.uk/teens-insulin)
**Q&A**

**Can my child use a pump?**
In England and Wales, the National Institute for Health and Clinical Excellence (NICE) has published criteria that people should meet in order to use a pump. Talk to your diabetes team about the criteria and whether or not pump treatment is suitable for your child (to read the criteria go to [www.nice.org.uk](http://www.nice.org.uk)).

The NICE criteria on pumps for children are also followed in Northern Ireland.

In Scotland, the decision is made individually between the child and their diabetes team.

**How will we know how to use a pump?**
You and your child should be given training from your diabetes team when your child starts to use a pump, and you’ll receive ongoing support. Although many diabetes teams have experience using pumps, in some cases you may need to see another team for your child’s pump care.

You can also get support from the manufacturer – most have helplines and a representative may even be there when your child starts to use a pump. There are also support groups, including INPUT ([www.input.me.uk](http://www.input.me.uk)) and Insulin Pumps ([www.insulin-pumpers.org.uk](http://www.insulin-pumpers.org.uk)).

For more information on insulin – including different types – injections and insulin pumps, go to [www.diabetes.org.uk](http://www.diabetes.org.uk).

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**CASE STUDY**

“How did we cope? Honestly, the truth is not very well. It felt like grieving for the healthy child you had. As her mum, I was supposed to be good at looking after her, and I kept getting it wrong. I’d forget to give her insulin at mealtimes and keeping records was hard work. It just seemed like a huge task in lives that were really, really busy. Now we handle it better. Mia is a true star about it – as many young kids are – she takes it all in her stride. She’s on a pump now, and it makes handling it a bit easier.”

Sara, whose daughter, Mia, has Type 1 diabetes
An essential part of managing your child’s diabetes is frequently testing their blood sugar levels to help avoid highs and lows – and knowing when to test for ketones. At times, this testing may be difficult – both for you and your child, especially if they’re very young. So, follow our advice to make testing as painless as possible.

BLOOD SUGAR TESTING
Good diabetes management is important both for your child’s day-to-day health and to help prevent any diabetes-related problems in later life. Regular blood glucose testing (also called blood sugar testing) is a key part of this – but what exactly does this testing involve?

Your paediatric diabetes team (see page 28) will give you a blood glucose meter, used to check your child’s blood glucose levels (also called blood sugar levels). Normally, there are a few to choose from and your diabetes team will help you and your child make the right choice. Your meter comes with a finger-pricking device and an initial supply of lancets (to take a drop of blood from the finger) and testing strips (to apply a drop of blood to, in order to get the result). Your diabetes team will also explain to you how to get further free supplies of these on prescription from your GP.

Many parents worry or are anxious about testing their child’s blood sugar levels. Pricking their fingers can be painful, especially at first, and no parent wants to hurt their child. Then there’s the anxiety about what the levels will be. You’ll be told your child’s target levels to aim for, and it can be frustrating and even scary if you’re not meeting these. Blood sugar levels are measured in millimoles per litre, which are written as mmol/l.

Many things affect blood sugar levels – food, exercise, illness, stress, even just the natural growth spurts that all children have. Sometimes, you’ll know why their levels are higher or lower than you’d like, but, at other times, there’s just no reason. Do try not to blame yourself – everybody goes through this to some extent, it’s not just you. Talk to your diabetes team if this keeps happening, and if you’re worried.

How to test
1. Wash your child’s hands.
2. Prick the side of your child’s finger rather than the tip, as this keeps pain to a minimum. Don’t prick too near the nail and don’t prick the index finger or thumb.
3. Other devices are now available that allow you to take blood from different parts of the body, such as the base of the thumb or the arm. Talk to your diabetes team about the suitability of alternative site meters.
4. Insert a test strip into the blood glucose meter – this will turn on most meters automatically.
5. Apply a drop of blood to the test strip, and the meter will automatically read the test results. All meters and strips are tested to ensure they’re accurate, but be aware that extreme temperatures can affect meter readings.
6. Make a note of all the test results – this will help you and your diabetes team to establish your child’s pattern of blood sugar levels.
7. Depending on the type of meter, you may need to calibrate it when you first use a new packet of test strips. Talk to your diabetes team about how to do this.
8. You may also need to quality-check your meter from time to time. Again, talk to your diabetes team about this.
When to test
A test gives you an immediate picture of how much sugar is in your child’s blood. It’s often recommended to test:
- before a main meal
- before bed
- if they feel unwell (see pages 50–51)
- before and after physical activity (see pages 40–42)
- if they feel any hypo warning signs (see pages 22–24)
- any time you or your child feels their blood sugar levels are too high or too low.

Your diabetes team may also ask you to test at other times as well or instead (eg during the night), in order to get an overall view of your child’s diabetes control. If your child has recently been diagnosed, it’s particularly important to test often to get a good idea of what’s happening with their blood sugar levels.

“\textit{When your child cries in pain or against having an injection, it’s really hard. I feel terrible for hurting them and I just wish I could take it away from them. Trying to control their levels when they’re poorly, growing or simply being active is always a challenge.}”

Luke, whose twins, Amelie and Albie, have Type 1 diabetes

Testing your baby
With babies, you need to prick their heels, instead of their fingers. Your diabetes team will show you how to do this.

Because your baby can’t tell you how they feel (other than by crying), you’ll probably need to check their levels frequently. Again, your diabetes team will guide you on this.

Testing your toddler
Getting a drop of blood from a toddler can be difficult. Try to get your child to cooperate as much as possible: explain what you’re going to do and reassure them that even though it may hurt, it’ll be over very quickly. Try pricking teddy’s finger or encourage your child to help if they want to. If you’re finding it difficult, talk to your diabetes team, who’ll have lots of tips.
Q&A

What blood sugar targets should I aim for?
The general target ranges for blood sugar levels are 4–7mmol/l on waking, 4–7mmol/l before meals at other times of the day, and 5–9mmol/l two hours after meals, but your diabetes team may suggest individual targets for your child. Although you shouldn’t expect to achieve these targets all the time, aiming for them will help your child to keep good control of their diabetes.

How important is it to keep a record of my child’s test results?
This is really important, as it helps you and your diabetes team see how well your child’s diabetes control is working. It will also help you and your child make decisions and adjustments between clinic visits. It doesn’t matter if you write the results in a blood sugar diary or record them electronically – the important thing is to have a record of your child’s blood sugar levels that both you and your diabetes team can use.

I’ve heard of continuous glucose monitoring systems (CGM). What are they?
With CGM a small sensor is inserted just under the skin and measures blood sugar levels continuously. Every few minutes, the sensor transmits the blood sugar level to a receiver or an insulin pump. You still need to do finger-prick blood tests, though, to calibrate the sensor and check it for accuracy. CGM aren’t available for everyone, but if you think your child would prefer one, speak to your diabetes team.

TESTING FOR KETONES
Ketones are poisonous chemicals that can develop if there isn’t enough insulin in the body to allow enough glucose to enter the cells. If ketones are left untreated they can cause the body to become acidic – this is called diabetic ketoacidosis (DKA).

You should check for ketones if your child’s blood sugar level is high – your diabetes team will tell you at what level – or if they are ill. Most children will check their blood for ketones in a similar way to checking blood glucose levels.

Diabetic ketoacidosis (DKA)
DKA can develop:
- when your child is first diagnosed with Type 1 diabetes (some children aren’t diagnosed until they develop DKA)
- when your child is ill
- during a growth spurt/puberty
- if your child hasn’t taken their insulin dose(s).

DKA takes time to develop, so if your child has high blood sugar levels you generally have time to take steps to prevent it. Sometimes, though, it can develop more quickly, particularly in young children and pump users. It has to be treated in hospital, as your child will need a drip and an insulin infusion.

SIGNS OF DKA
Watch out for the following symptoms:
- ketones in the blood/urine
- abdominal 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 diabetes team immediately. If DKA is picked up early it’s easily treated with extra insulin and fluids, but, left untreated, it could cause your child to become seriously ill.
TESTS FOR LONG-TERM MANAGEMENT

Diabetes does carry a risk of potential complications later in life, so your child will also have other tests, both to monitor their diabetes management and to check for other conditions. These tests should be done at least every year, to help ensure your child stays as healthy as possible in the long term.

HbA1c TEST

As well as day-to-day blood sugar testing, there’s another test that monitors your child’s diabetes management. This is called the HbA1c test and it’s usually done either at the clinic or before your child’s appointment. This blood test measures diabetes control over a period of two to three months. It is measured in millimoles per mol (mmol/mol).

The recommended level for children is generally 48mmol/mol, but targets are individual and your diabetes team may suggest a different target for your child.

For some people, the HbA1c test may not be accurate, for example if your child has a blood disorder, such as sickle cell anaemia or sickle cell trait. In this case, a fructosamine test is often done, which gives a measurement of diabetes management over the past two to three weeks.

ACTION POINTS

Ask your diabetes team what the target is for your child’s HbA1c or fructosamine test.

Check with them how often, and where, the test will take place.

If you know that your child has a blood disorder, tell your diabetes team in case it affects the accuracy of the HbA1c test.

OTHER TESTS

As it’s an autoimmune condition (caused by the body destroying its own cells), Type 1 diabetes is also linked to other autoimmune conditions, such as thyroid problems and coeliac disease. Because this link is well known, your child will also be tested for these conditions.

Thyroid tests

The thyroid is a gland in the neck, just below the Adam’s apple, which produces hormones to 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 – just as the body’s cells attack the pancreas in the case of Type 1 diabetes. For this reason, thyroid problems are more common in people who have Type 1 diabetes.

There are two types of thyroid disorder:

Hypothyroidism

This is where the body doesn’t produce enough thyroid hormones: it’s particularly common in people with Type 1 diabetes. Symptoms include:

- tiredness
- feeling cold all the time
- constipation
- more frequent hypos (see page 22).

Hyperthyroidism

This is where the body produces too many thyroid hormones. Symptoms include:

- weight loss
- feeling warm all the time
- diarrhoea.
Often, though, there are no symptoms of thyroid problems, so your child should have a blood test to check that their thyroid is working properly when they’re first diagnosed with diabetes – and then tested every year.

There’s no cure for either type of thyroid condition, but both can be treated with tablets.

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

Your child should have a blood test to check for coeliac disease at diagnosis and again if they show any symptoms. Some hospitals test more regularly than this, when annual blood tests are taken. If the blood test is positive, the diagnosis will be confirmed by a gut biopsy under general anaesthetic. The only treatment for coeliac disease is a permanent change in diet to avoid gluten, and it’s vital that you see a dietitian who can advise on both diabetes and coeliac disease.

If you suspect your child might have coeliac disease, don’t start them on a gluten-free diet until you have a definite diagnosis. Following a gluten-free diet before a test for coeliac disease may give an inaccurate result.

For more information, go to www.coeliac.org.uk

COMPLICATIONS
Type 1 diabetes does carry a risk of potential complications in the long term, such as heart disease or damage to the kidneys, eyes or nerves. It’s natural after diagnosis for parents to fear that their child will develop severe health problems, especially if they know someone with diabetes this has happened to.

However, medical research has shown that these potential complications are much less likely in people who keep their blood sugar levels as close to their target as possible.

This doesn’t mean that you should get anxious or feel guilty if your child’s blood sugar levels aren’t perfect all the time. Nobody with diabetes can always get it right, and short periods of high levels aren’t a problem long-term. Diabetes aside, as a parent, you’ll encourage your child to follow a healthy lifestyle to ensure they get the best start in life. Managing your child’s diabetes is another part of this.

You can find out more about diabetes complications and how they’re treated at www.diabetes.org.uk/complications

ACTION POINTS
Check that your child has had their thyroid hormone levels tested. If they haven’t, talk to your diabetes team.

Make sure that this thyroid check then happens every year.

Check that your child has had a test for coeliac disease, and if they show any symptoms contact your diabetes team.

SUPPORT FOR YOUR CHILD
Children:
- www.diabetes.org.uk/mylife-glucose-right
- www.diabetes.org.uk/kids-coeliac

Teenagers:
- www.diabetes.org.uk/teens-coeliac
AN ORIGINAL DIARY DESIGNED FOR CHILDREN WITH TYPE 1 DIABETES

My Diabetic Diary is an A4 annual diary and is suitable from any age of diagnosis up to early teens. It can be started at any point during the year and provides a significant tool for children with diabetes and their family. The diary is designed to act as an interactive book and includes tables and charts with enough space for young children to write in, or parents, if children are too young to do so.

The basic information and ‘tips’ offered throughout the book are written in a simple and child friendly way so that children and adults can learn together and the colourful illustrations have been individually created to add amusement and interest but also to highlight key information in a fun way.

**Aims**
- To engage children in recording information at a young age and encourage independence
- To improve understanding and the importance of good diabetes management
- To enable brothers, sisters and family to comment and be involved
- To share essential information with other adults about a child’s requirements when they are away from home i.e. during sleepovers, school trips etc.
- To support health professionals when providing care and advice
- To achieve good day to day management resulting in less long term side effects

**Features**
- Separated into 7 sections for quick and easy retrieval of information
- Organised by specific subjects
- Relevant information and appointments can be kept in one place
- Wire bound spine allows the diary to be laid flat so children can easily write down their information
- The diary can be started at any point during the year.

To preview or buy a Diary, visit our website at [www.mydiabeticdiary.co.uk](http://www.mydiabeticdiary.co.uk)

£1 donated to Diabetes UK for every book sold.
Hypos & Hypers

Low and High Blood Sugar Levels

Balancing your child's blood sugar levels isn't always easy, and sometimes they may go too high or too low. If this happens, you and your child need to take quick action, so make sure you know what symptoms to look out for and what to do.

However careful you are, there'll be times when your child's blood glucose levels (also called blood sugar levels) drop too low (hypoglycaemia or hypo) or rise too high (hyperglycaemia or hyper).

**HYPOGLYCAEMIA (HYPOS)**

Hypoglycaemia is when your child’s blood sugar levels drop too low, usually below 4mmol/l. In people without diabetes, low blood sugar levels trigger the body to stop producing insulin and release some of the stored glucose to bring levels back to normal and keep the body going. But, with Type 1 diabetes the insulin your child injects can’t be switched off, and it will keep working even when your child’s blood sugar levels are too low.

Why do hypos happen?

We don’t always know why hypos happen, but they become more likely if your child:

- takes too much insulin
- misses or delays a meal or snack
- doesn’t have enough carbohydrate
- is more active than normal.

It’s important to treat a hypo as soon as you recognise the symptoms or discover your child’s blood sugar levels are low. Act quickly or the hypo may become more severe – see box on severe hypos, far right.

**Glucagon injection**

Your paediatric diabetes team should give you an injection called glucagon to use if your child has a severe hypo. Glucagon comes as a kit, which includes a syringe of sterile water and a vial of powdered glucagon. To use it, dissolve the powder in the water and inject all or part of it, usually into your child’s leg. Your diabetes team will show you how to do this and tell you how much to inject.

**SIGNS OF A HYPO**

Everyone has different hypo symptoms, but the most common ones include:

- trembling and dizziness
- feeling hot or having cold sweats
- becoming anxious or irritable
- becoming pale
- palpitations and fast pulse
- drowsiness
- blurred vision
- lack of concentration
- confusion
- feeling hungry or sick.
Hypos at night
Blood sugar levels sometimes become low during the night. If your child stays asleep during a mild hypo, their blood sugar levels may drop further and the hypo become more severe. If the hypo doesn’t wake them your child may feel very tired the next morning, and may also have a headache (similar to a hangover) – or they may have no ill effects. The best way to confirm if your child is having hypos at night is to do a blood test during the night. Ask your diabetes team when the best time to test is, as this depends on the type of insulin your child takes. If the night-time blood test appears to show that your child has night-time hypos, talk to your diabetes team, as his or her insulin dose may need to be adjusted.

1. Get your child to stop what they’re doing – ignoring a hypo will make it worse.
2. If you have time, test their blood sugar levels. If not, get them to eat first and test them later.
3. Make sure they eat or drink something sugary, such as glucose tablets, Jelly Babies or a non-diet drink. This quick-acting carbohydrate will quickly raise their blood sugar levels: the amount needed will vary from child to child.
4. Don’t give them chocolate, as the high-fat content slows down the absorption of the sugar.
5. Sit them down until they feel better.
6. After 10–15 minutes, check their blood sugar levels again. If their levels are still low, give them more quick-acting carbohydrate.
7. Retest your child’s blood sugar levels in a further 10–15 minutes to confirm that they’re back up to target. If not, give them some more sugary food or drink.
8. Some children need a longer-acting carbohydrate, as well, such as fruit, biscuits, a small sandwich or their next meal, if it’s due. This helps prevent their blood sugar levels from dropping again. Ask your diabetes team if your child needs this type of follow-on snack.

SEVERE HYPOS
If a hypo isn’t treated, there’s a risk that your child will become unconscious or have a convulsion. This doesn’t happen often, but it’s important to know what to do if it does:

- Never give them food or drink by mouth as this will cause them to choke.
- If possible, place them in the recovery position (on their side with their head tilted back).
- If you have a glucagon injection and know how to use it, inject it as you were shown. If not, or if your child hasn’t recovered within 10 minutes of being given the injection, call an ambulance.
- Always tell your diabetes team if your child has a severe hypo, as their treatment may need to be changed.
Avoiding severe hypos

Some parents worry that their child could die from a hypo, but this is extremely unlikely. Studies have shown that night-time hypos are common in children, and they often sleep through them and wake up with few or no ill effects. One way to try to prevent hypos during the night is to give your child a suitable bedtime snack. Talk to your diabetes team about this.

The effect of severe hypos on a child’s intellectual development, particularly if they’re a young child, may be something you’ve heard about. Dealing with severe hypos can be daunting at the best of times, but concerns that they might affect your child’s development can, quite rightly, make you feel very anxious. However, taking a look at the effect of severe hypos in perspective – although there is some medical evidence to support this, as well as some research suggesting that high blood sugar levels can have a similar effect, it’s thought any adverse effect on a child’s development is minimal.

There’s also a lot you can do to help keep your child’s sugar levels on target, like checking their blood sugar levels regularly, and monitoring them closely if they don’t eat as well as expected, do a lot of physical activity or are feeling unwell. Changes in your child’s daily routine can upset how they manage their diabetes, so it’s worth keeping an eye out for anything unexpected that may crop up. Although you can’t always plan for the unexpected, as children’s lives can be unpredictable, over time you’ll get a feel for the changes in routine that have an impact on their diabetes management.

Q&A

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

At first, it can be difficult to recognise a hypo. If you’re unsure, do a blood test. If the result is low (under 4mmol/l), it’s a hypo that needs to be treated. Over time, you’ll start to recognise your child’s hypo warning signs. These can change, though, so it’s worth testing your child if they show any signs of a hypo, even if they’re not their usual ones.

It can be particularly difficult to recognise a hypo in a baby – sometimes the only warning signs are that they look floppy, pale or go very quiet. Check your baby’s blood sugar levels if you see these signs or anything else that worries you. Ask to see a paediatric dietitian to discuss your baby’s feeding and ways to reduce the risk of your baby having a hypo.

Why is my 8-year-old son having regular hypos without any warning signs?

If your son is having regular hypos, he may not recognise his hypo symptoms. You can help him regain his hypo warning signs by running his blood sugar levels a little higher for a while, but talk to your diabetes team about how best to do this, as you don’t want them to run too high for too long. After two weeks or so, he’s likely to be able to recognise hypos more easily.

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

Keeping your child’s blood sugar levels high is harmful. They may start to feel thirsty, go to the toilet frequently and feel tired. They may also develop ketones and be at risk of DKA (see page 18) – and long-term high blood sugar levels can lead to complications (see page 20). Although hypos aren’t completely avoidable, learning what causes them will help you and your child to manage them better.

Are my child’s hypos my fault?

No, definitely not. All children with Type 1 diabetes experience mild hypos – they’re almost impossible to avoid. No matter how careful you are with tests and injections, your child will have some hypos. They’re a part of life with diabetes, so neither you nor your child should feel guilty when they happen.
“Diabetes is a game-changer in life – no question. A mixture of snakes and ladders with the highs and lows of hypoglycaemia and hyperglycaemic attacks; Cluedo, when you are completely baffled as to why blood sugars are too high; Scrabble, when you’re trying to understand all the medical jargon for the condition, not to mention scrabbling around for a Jelly Baby or two… and chess, when you’re trying to decide the best move. We’ll continue to learn the rules of diabetes and manage the condition, rather than allowing it to manage us.”

Linda, whose son, Freddie, has Type 1 diabetes

**ACTION POINTS**

- Make sure that anyone who looks after your child knows how to spot a hypo and how to treat it.
- Ask your diabetes team how much quick-acting carbohydrate your child needs to treat a hypo. Remember that as your child gets older, they need more.
- Check with your diabetes team if your child needs a follow-on snack of slower-acting carbohydrate.
- If your child has had a severe hypo or regularly has mild hypos, discuss this with your diabetes team.
- If you need more confidence in using glucagon injections, talk to your diabetes team.
- Get a diabetes identity wristband for your child – go to https://shop.diabetes.org.uk/go/wristbands
**HYPERGLYCAEMIA (HYPERS)**

Hypers happen when your child’s blood sugar levels are too high. A hyper can happen because of:

- a missed insulin dose
- not enough insulin being given
- eating too much sugary or starchy food
- overtreating a hypo
- stress
- being unwell with an infection.

**Treating a hyper**

If your child’s blood sugar levels are high for just a short time, treatment may not be necessary. But, if your child uses a pump you need to correct a high level straightaway:

- Check your child’s blood for ketones (see page 18). Your diabetes team will advise you on when you need to do this.
- If ketones are present, 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 of insulin. Talk to your diabetes team about how to do this.
- Even if there are no ketones, your child may need to take some extra insulin. Your diabetes team will advise you on how much they should take and when.
- If your child uses a pump, you may need to change their set. Your diabetes team will give you specific advice on managing high blood sugar levels for 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 diabetes team immediately.

It’s important to make sure your child’s blood sugar levels don’t stay too high for too long as they could go on to develop diabetic ketoacidosis (DKA, see page 18).

**SUPPORT FOR YOUR CHILD**

**Children:**
- [www.diabetes.org.uk/kids-hyper](http://www.diabetes.org.uk/kids-hyper)

**Teenagers:**

**ACTION POINTS**

Make sure anyone who looks after your child knows about hypers and how they’re treated.

Ask your diabetes team at what blood sugar levels you should check for ketones.

Ask your diabetes team how much extra insulin your child should take if their blood sugar is high – with and without ketones.

If your child uses a pump, make sure your diabetes team gives you written advice on managing high blood sugar levels.

**SIGNS OF A HYPER**

These are the same as the signs your child had before they were diagnosed with Type 1 diabetes:

- passing urine more frequently
- feeling very thirsty
- feeling very tired
- losing weight.

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

- blurred eyesight
- difficulty in concentrating
- irritable behaviour.
Medical ID Jewellery with a distinct difference

Our beautiful jewellery ranges have your child’s urgent medical details engraved on the reverse, so that in an emergency, you know they will receive the correct treatment - quickly. Further information such as your child’s emergency contacts, GP/Hospital details and current medicines or treatments can be accessed 24/7 from the emergency phone number on their disc.

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YOUR CHILD’S CARE

Following your child’s diagnosis, you’ll naturally want to know what kind of care they’ll receive to help manage their condition, who exactly will be looking after them and who to contact if you have any concerns. Here, we introduce the various healthcare professionals who’ll be working with you and your child – your paediatric diabetes team.

YOUR PAEDIATRIC DIABETES TEAM

Your diabetes team will help explain what diabetes is and how it’s treated. They will also help you look after your child’s diabetes and provide emotional support to help you cope. You should meet a member of your diabetes team the next working day after your child’s diagnosis.

Paediatrics is the branch of medicine that deals with children, so your diabetes team will be specialists in treating and looking after both diabetes and children, and will include:

● A consultant paediatrician (or diabetologist) with specialist expertise in diabetes who’ll take overall responsibility for your child’s diabetes care. You’ll still see your GP for your child’s non-diabetes health needs, but anything diabetes-related is usually referred to your paediatrician.

● A Paediatric Diabetes Specialist Nurse (PDSN), who is usually your first contact for diabetes advice.

● A registered dietitian with experience in children with diabetes, who will advise on your family’s food choices.

You and your child are the ones who live with diabetes every day, so it’s vital that you’re involved in all decisions about your child’s care. You’ll probably see your diabetes team frequently in the first months after diagnosis, particularly your PDSN. Your diabetes team will teach you (and your child, if appropriate) everything you need to know about diabetes. This may be as part of a group or on an individual basis. You’ll also be given a contact number, so you can get in touch if you have any questions between appointments or problems out of hours.

CARE AT THE CLINIC

You and your child should have an appointment at the paediatric diabetes clinic at least four times a year. The clinic is often attached to the children’s ward of a hospital or is part of a diabetes centre.

Your appointment should be with a multidisciplinary diabetes team, as discussed left: a PDSN, a doctor with training in paediatric diabetes and a registered dietitian with training/experience in children with diabetes.

Your child should get the following checks:

● height and weight
● injection sites – to check they’re not getting lumpy
● blood tests – to check long-term diabetes management (HbA1c – see page 19).

There are 10 essential health checks, help and support your child should receive now they have diabetes, called the Type 1 essentials – see pages 30–31.

For more information on the Type 1 essentials, including what to do if you’re not receiving one or more of them, go to www.diabetes.org.uk/what-are-Type-1-essentials
Q&A

Sometimes, I don’t understand what the doctor tells me and I’m too embarrassed to ask them to repeat things. What can I do?

Try not to feel embarrassed – your doctor’s used to people asking lots of questions, and it’s really important to ask about anything relating to your child’s diabetes that’s worrying you. Write down a list of questions before you go and make sure you understand the answers – and what any test results mean. Never be afraid to ask the doctor, or anyone else in your diabetes team, to explain something again if you don’t understand it.

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

Most children’s clinics do their best to make children feel comfortable, but if your child is nervous, take along something to keep them occupied or give them a treat – such as a favourite meal or movie – before or after the visit. If your child is refusing tests, ask your diabetes team for suggestions to help.

Some consultations include other people, such as medical students, which can make the experience scarier for your child. If you’d both prefer to see the doctor alone, don’t be afraid to ask.

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

Try to deal with minor irritations as they arise, and look carefully and honestly at what’s happened. Persistent problems are best discussed 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 in each nation within the UK – go to www.diabetes.org.uk/teens-complaining to find out more.

ACTION POINTS

Check that you have the out-of-hours contact details for your diabetes team.

Check that your child is getting all the tests and results they should be.

SUPPORT FOR YOUR CHILD

Children:
- www.diabetes.org.uk/kids-healthcare

Teenagers:
- www.diabetes.org.uk/teens-healthcare
1 CARE FROM A SPECIALIST TEAM
Your children’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 diabetes care for children
- a children’s nurse with experience in diabetes
- a dietitian with experience in children’s diabetes, who can advise you about 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 measure their diabetes management (known as HbA1c) – four times a year
- regular checks of their weight, height and general health
- screening for other conditions that are 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 also get:
- blood and urine tests to check kidneys – once a year
- digital photo of retinas (eyes) – once a year
- blood pressure check – once a year
- foot examination and footcare review – once a year.

3 THE RIGHT TREATMENTS
You should be told about all the available treatments, including new ones. And you should be able to get the treatments that are right for your child. These might include:
- multiple daily injections, carbohydrate counting and the most appropriate insulin
- blood glucose and ketone meters, and testing strips
- insulin pumps
- continuous blood glucose monitoring.

4 SUPPORT SO YOU CAN DO IT YOURSELF
As much as possible, you and your family should be able to manage your child’s condition yourselves. To help you do this, you should be able to get expert advice, education and information that is easy to understand.

This should include:
- consistent, high-quality information that your child can understand, in a format that suits you and your child
- 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 for you in your diabetes team
- the chance to regularly see a dietitian, who can advise you about food choices.

Your child may also be able to get Disability Living Allowance.
5 HELP WITH FEELINGS OR WORRIES
Coping with diabetes can sometimes be really difficult – both for the child, and for the rest of the family. It is perfectly normal to feel upset, angry, confused or worried. Make sure you talk to your diabetes team about this.

As part of your diabetes healthcare, your diabetes team should offer your child and your family the chance to talk to a psychologist – an expert in mental and emotional health. They should have experience in diabetes and how it affects children and their families. You should be able to talk to them about particular issues if you need to, and have regular meetings just to see how things are going.

6 THE RIGHT CARE WHEN YOU ARE IN HOSPITAL
If your child has to go into hospital for any reason, you should have contact with a children’s diabetes team. You and your child should also be allowed to carry on managing their condition yourselves if possible. This will help the hospital staff to 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 change. It can be a difficult time for teenagers, who are already dealing with other changes in their lives. But it is important that the move works well, so children keep on getting the care they need. The two diabetes services should work together to make sure the move goes as smoothly as possible for your child, at an age that is right for them, and in a way that suits them.

8 A SAY IN THE CARE YOU GET
You and your child should be involved in making decisions about the care you get, and have a say in how your child’s diabetes is managed.

For example, you should:
- be able to work with your doctor or diabetes team to create a plan for how your child’s diabetes will be treated and managed, talk through the plan, and ask any questions
- get copies of letters that say what everyone has agreed to
- help design services that are right for you.

You should also be invited 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. He or she should be able to take part in all areas of school life, including classroom work, trips, sports and after-school clubs. Your diabetes team should work with your school to make sure that happens.

For example, they should:
- agree a healthcare plan with you and your child
- work out who will make sure your child gets the diabetes care they need at school
- keep plans up to date and make sure everyone knows what is happening.

10 EQUAL OPPORTUNITIES
Your child should be given the same opportunities as everyone else, and not be treated differently simply because they have diabetes. They should be able to join in with sports, activities, clubs and groups. And they should be able to learn to drive and do most jobs.
“a change for the better”

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*Search OneTouch® on LloydsPharmacy.com for full eligibility criteria. Whilst stocks last. The low and high range limits you set in the OneTouch Verio® and OneTouch Select® Plus meters apply to all glucose test results. This includes tests taken before or after mealtimes, medications, and around any other activities that may affect your blood glucose. Be sure to talk to your healthcare professional about the low and high limits that are right for you. Available from 1/11/15.

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HEALTHY, BALANCED EATING

If you think your child’s diagnosis means they now have to eat special food, think again. With Type 1 diabetes, they can eat more or less anything they like. Here, we run through foods to eat – and the few to avoid – and explain carbohydrate counting. There’s also advice on eating out, sleepovers, snacks and dealing with food issues.

That being said, there are some foods that are best avoided. These include foods labelled ‘diabetic’ or ‘suitable for diabetics’. Often, people think that these foods are healthier, but they actually contain the same amount of calories and fat as the regular versions of these types of food, and they can still affect blood glucose levels (also called blood sugar levels). They’re also more expensive and can cause diarrhoea, especially in children. So, if your child wants a treat, it’s better to give them the regular versions.

Before their diagnosis, your child probably had an unquenchable thirst. Try to avoid sugary drinks and fruit juice as a way of quenching thirst, as these tend to raise blood sugar levels very high, very quickly – which is why they’re really good for treating low blood sugar levels. Instead, give your child water or sugar-free drinks.

Providing a healthy, balanced diet at home most of the time will hopefully help your child achieve a healthy weight for their height as they grow up.
**TALK TO YOUR DIETITIAN**

You and your child should meet with a paediatric dietitian (see page 28) who understands about diabetes, either at diagnosis or soon after. You should then have at least one appointment with them every year. The dietitian will not only advise you on foods and a diet to provide all the nutrients your child needs, but also help your child to build a positive relationship with food.

**TOP TIPS**

1. Digital scales are very useful to weigh portion sizes, helping you to work out portion sizes accurately, and then what your child’s own portion size contains.

2. Even if you don’t weigh food every time, it’s worth reweighing every six months or so, as your child may eat a bigger portion as they grow.

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**CARBOHYDRATES**

Managing your child’s day-to-day blood sugar levels involves thinking about carbohydrate foods. There are different types of carbohydrates (carbs):

- Starchy: bread, potatoes, chapatti, rice, pasta, breakfast cereals, couscous, quinoa, yams, cassava and parsnips.
- Natural sugars: fruit and dairy products.
- Added sugars: sweets, chocolate, cakes, biscuits, syrups and non-diet drinks.

All carbohydrates increase blood sugar levels – even those that don’t taste sweet, as the body digests them and breaks them down into glucose.

Starchy carbs shouldn’t be seen as ‘bad’ – even though they raise blood sugar levels – as they do a really important job, acting as fuel for the body to provide energy. Foods containing natural sugars usually contain other useful nutrients.

Foods with added sugars, though, often have fewer nutrients, and although these foods taste nice we all need to try and reduce how many of them we eat.
Q&A

Can we still go out for family meals?
Yes, definitely. Once you’re confident carb counting, you can change the amount of insulin your child has to fit in with what they eat. But, as it’s more difficult to estimate the amount of carbs in food you haven’t cooked yourself, this is where carb counting books and apps can help. Many chain restaurants and takeaways provide nutritional information on their websites, which can also help.

When eating out, your child may choose foods that are higher in fat than you normally cook for them at home. You’ll probably eat over a longer period of time, too. As fat slows down the absorption of carbohydrate into the bloodstream, foods like pizza, curry, and fish and chips may take hours to affect your child’s blood sugar levels. An injection or standard pump bolus dose may have finished working before all the carbs have been absorbed, so you may need to give your child more than one injection or an extended or dual wave pump bolus dose. Your Paediatric Diabetes Specialist Nurse (PDSN) or dietitian can advise you about this.

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

What about parties and sleepovers?
There’s no need for your child to miss out on parties and sleepovers. As a parent, though, sleepovers can make you anxious because you don’t know what your child will be eating or when – and 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 host 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 going to be 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 – although you may feel anxious about letting your child’s sugar levels go higher than usual, this won’t cause any problems if it happens once in a while
- make sure you and the host parent swap phone numbers, so you can be in touch if there are any worries
- 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 give them. What should I do?
First of all, make sure you don’t give your child too much food. It’s natural to want to fill them up so they don’t have a hypo, but maybe you’re giving them too much. Talk to your dietitian about appropriate amounts 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 quantity isn’t the issue, perhaps your child just doesn’t like the food you give them or wants to eat the same food as friends. Maybe you can compromise as to what you give your child to eat. Teenagers also may not want to eat snacks if their friends don’t. Talk to your PDSN or dietitian to see if you can change meal and snack times, so your child doesn’t feel different to their friends.

When my child’s at school they eat regularly and their activity levels don’t change too much. But, holidays are a nightmare as there’s no routine and I just can’t get their blood sugars right. I feel so guilty – what am I doing wrong?
Any change in routine can really upset blood sugar levels. Nearly all parents of a child with Type 1 diabetes have the same problems and worries, so it’s not just you.

You may fear that if you don’t get your child’s blood sugar levels just right all the time, they’ll have problems later on in life. But, although it’s true that you do need to meet your child’s targets most of the time, remember that if things go wrong now and again, this won’t cause any long-term damage. Talk to your PDSN, doctor or dietitian about how best to manage these out-of-routine times.
CARBOHYDRATE COUNTING

Carbohydrate counting (carb counting) is a good way of managing Type 1 diabetes, whether your child uses injections or a pump. By counting carbs you can individually match your child’s insulin to what they choose to eat. Portion sizes can then reflect their appetite, rather than your child eating a fixed amount of carbohydrate for a fixed amount of insulin.

Although this doesn’t mean total food freedom – this would be unhealthy for any child – it does mean that food eaten at special occasions or as a treat can be more easily managed. Giving insulin for carbs doesn’t mean that their fat and calorie content disappear, though, so making healthy food choices is still important.

Carb counting means more work at first – assessing or weighing foods to calculate the amount of carbohydrate – but it gets easier as you become more skilled and used to it. If your child is older, or as they grow up, you’ll need to share these skills with them, too.

How much?

Carbohydrate can be counted in grams, carbohydrate portions or exchanges. In the UK, each portion or exchange is usually 10g of carbohydrate, while in the US and Australia it’s 15g (so, if you read diabetes information on the internet from these countries, remember that it’s counted differently).

Nutritional information labels on packaged food tells you how much carbohydrate (in grams) is in 100g or in a portion. Use the ‘total carbohydrate’ figure when matching insulin, not the ‘of which sugars’ value.
Your child’s dietitian will give you a list of carbohydrate foods and the amount of carbs they contain. There are also books with photos of different portion sizes of carbohydrate foods, and smartphone apps to help with carb counting and recipe calculations.

The amount of insulin your child needs is worked out by your diabetes team, and depends on their age, weight, activity levels and how long they’ve had diabetes. If you know how many grams (or portions) of carbohydrate are in a meal, and how much insulin they need per 10g of carbohydrate, then you can work out the number of units of insulin for the meal.

Wherever possible, give injections of rapid-acting insulin or pump doses before eating. If your child’s appetite is unpredictable, then you could give the injection immediately after the meal, but talk to your diabetes team about this. Pump users should always have some insulin before eating, and then some extra insulin after the meal, if necessary.

**SNACKS**

In the past, snacks played a big part in managing blood sugar levels in Type 1 diabetes, but now insulin treatments are more flexible this is not so much the case. Indeed, too many unnecessary snacks can lead to higher sugar levels, extra fat and unwanted calories.

Even though the healthy schools programme has improved the types of food available in schools, high-fat and high-sugar snacks such as crisps, chocolate and sweets are still very accessible – and very tempting. Although Type 1 diabetes doesn’t stop a child enjoying these foods, for general good health, nobody – with or without diabetes – should have too many of them.

But, it’s hard for children to resist sweets and chocolates, especially if all their friends are having them. So, don’t cut them out completely – your child may then eat them secretly. And, don’t let your child think that they can’t eat sweets because of their diabetes, as this won’t help them come to terms with it. Instead, explain that nobody should have too many sweets and chocolates.

“Joe and Tom often celebrate getting home from school with a massive bowl of cereal. The problem is that it’s hard for their insulin to keep up with their appetite, and they don’t always remember to test their blood sugar before they chow down.”

Olly, whose sons, Joe and Tom, have Type 1 diabetes

**Young children:**

All young children need snacks between meals, as their stomachs are too small to fit all the food they need into three main meals. Young children with diabetes also need snacks to maintain their blood sugar levels between meals if 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 diabetes team in case they don’t. Children may also need a snack before bed to maintain blood sugar levels overnight.

**Older children:**

Older children on MDI, or children with pumps, may not need snacks to maintain their blood sugar levels. If they want snacks they may need additional insulin – or they may be able to have snacks containing small amounts of carbohydrate without extra insulin.

Some clinics do not recommend any snacking without insulin, so it’s always important to check with your diabetes team.
DEALING WITH FOOD ISSUES

Children of any age who refuse to eat can cause parents a lot of anxiety. If your child is growing well, then refusing food is not likely to cause any significant long-term problems, but it’s understandable for you to worry about hypos. Keep as calm as you can if your child refuses to eat. Even though it’s frustrating, try not to let it show. Children are good at picking up signals from parents and showing your anxiety can make things worse.

Try the following:

● Offer regular carbohydrate-containing meals and snacks. If your child isn’t eating big meals, then they’ll need small snacks. Try not to provide a constant supply of snacks, though, as this reduces their appetite for meals.

● Limit mealtimes to 30 minutes. After this time, clear the meal away without offering alternatives.

● If you give your child insulin and they then refuse to finish their meal, make up some of the missing carbohydrate with a drink of milk or a yogurt/
custard for pudding, to reduce the risk of a hypo.

● Although it’s best to inject or give a pump bolus dose before a meal, if your child refuses to eat, you may instead need to inject or give a bolus dose straight after they eat, adjusting the amount of insulin based on what they’ve actually eaten.

● Offer small portions so as not to overwhelm them, and praise good eating behaviour.

● Try not to let your child drink 30–45 minutes before their meal’s due, so they don’t fill up on fluid.

● Be consistent. Everyone who feeds your child should manage any refusal to eat in the same way – parents, grandparents, nursery staff, etc. Hopefully, your child will then receive the same positive message about eating.

● Encourage your child to eat with other children who are good eaters. Children love to copy.

Speak to your PDSN or dietitian for further advice on managing food refusal, as you may wish to seek advice from a psychologist if the problem persists.
TEENAGE FOOD CHOICES

When teenagers choose their own food, their choices may not always be ideal. They know it, and you know it, but you can’t always police their food when they eat away from home. Encouraging them to always take their insulin with food, in a safe dose, may be the best you can achieve. Fast foods aren’t ideal, but teenagers with diabetes will usually choose the same food as their friends, despite your requests to make ‘healthy’ choices. Try suggesting smaller portions, or any of the healthier options. Many fast-food outlets have information on their websites about carbohydrate content, so it’s worth checking these.

Always encourage children to participate in regular physical activity (see pages 40–42), as this improves heart health, as well as maintaining weight. Depending on the time of the activity, rather than giving an extra snack to prevent a hypo during it, try reducing the insulin dose at the mealtime before, instead.

Teenagers may become more conscious of their weight as their bodies change. As they should be weighed and measured regularly when attending clinic, this needs to be done sensitively and in a private place.

Unexpected weight gain can be caused by poor thyroid function, which is more common in people with Type 1 diabetes. Your child should have their thyroid function checked every year (see pages 19–20).

Missing or skipping insulin on a regular basis can lead to weight loss – food eaten without insulin is not absorbed properly and fat is then used as an alternative energy source. When blood sugar levels rise and long-term control slips, this can lead to diabetic ketoacidosis (DKA, see page 18) and long-term complications (see page 20).

Young people may also miss meals or over-restrict their food to control their weight. Discourage your child from missing meals to lose weight – children are more likely to snack on inappropriate foods if they’ve missed a meal and feel hungry. If you suspect your child is regularly missing insulin on purpose to control their weight – or is developing an unhealthy obsession about their weight or how much they eat – speak to your diabetes team immediately.

TREATS AND SWEETS

Treats should be exactly that – an occasional treat, not an everyday occurrence. Chocolate and sweets are part of a normal childhood, so make sure you treat your child in the same way you would treat your other children.

Choose a couple of days a week when all the family can enjoy these things together. For your child with diabetes, it may be better to eat sweeter foods (sweets, chocolate, sticky puddings) as part of a meal, as they’ll be taking insulin then anyway, although you may need to increase the dose. Extra insulin should definitely be taken if sweets or chocolate are eaten outside mealtimes.

Don’t bother buying ‘diabetic’ or ‘sugar-free’ sweets – the sweetener they contain can still affect blood sugar levels. Sugar-free chewing gum is acceptable in small quantities due to the small amount of sweetener in each piece.

SUPPORT FOR YOUR CHILD

Children:
- www.diabetes.org.uk/Good-to-eat

Teenagers:
OF COURSE, YOU KNOW THAT BEING ACTIVE IS GOOD FOR EVERYONE'S HEALTH – BOTH PHYSICAL AND EMOTIONAL – AND THE MORE ACTIVE YOUR CHILD IS THE BETTER. ALTHOUGH IT'S IMPORTANT TO PLAN AND MANAGE YOUR CHILD'S EXERCISE, THEY CAN STILL TAKE PART IN TEAM GAMES, JOIN IN ALL KINDS OF ACTIVITIES AND ENJOY ALL THEIR FAVOURITE SPORTS.

PHYSICAL ACTIVITY IS AN IMPORTANT PART OF A HEALTHY LIFESTYLE AND ALL CHILDREN AND YOUNG PEOPLE SHOULD 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 (EG SKIPPING, DANCING AND SWIMMING).

BEING ACTIVE AND PHYSICALLY FIT REDUCES BLOOD PRESSURE, LOWERS THE LEVELS OF FATS IN THE BLOOD, KEEPS THE HEART HEALTHY, AND MAY HELP TO IMPROVE BLOOD GLUCOSE LEVELS (ALSO CALLED BLOOD SUGAR LEVELS) AND PREVENT EXCESS WEIGHT GAIN.

THE DIFFERENCE BETWEEN PHYSICAL ACTIVITY AND EXERCISE

Physical activity is any movement that uses skeletal muscles, while exercise is specific structured physical activity that involves training and developing sports skills, eg 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 more efficiently, and regular activity can help reduce the amount of insulin your child takes.
● Being active helps your child maintain a healthy weight for their height, which in turn will help their diabetes control.

REACHING ACTIVITY GOALS

● Be as active as possible yourself – be a role model.
● Encourage your child to try lots of different activities – get them to have a go and see what they like best.
● Remember that being active is as important as formal exercise, so encourage more walking and active play (eg games like tag, hide-and-seek and hopscotch). Even some jobs around the house will increase activity levels.
● Encourage activity after school and at the weekends. Walking around the shops or the park are also good, even just to cut down the time spent in front of the TV or playing computer games.
● Split your child’s hour into shorter active sessions of 15–20 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 in blood sugar levels during and after any bouts of activity. Regular blood glucose testing (also called blood sugar
testing) helps you to understand what being active
does to your child’s blood sugar levels.

Being active may cause low blood sugar levels or
high blood sugar levels – or have no effect at all.

Activity may cause blood sugar levels to drop, if:

● there’s too much insulin working in your
child’s body
● the activity lasts longer than one hour
● the activity is very strenuous.

Activity will cause your child’s blood sugar levels
to rise, if:

● they don’t have enough insulin circulating in
their body
● the activity is mostly anaerobic or competitive,
eg a sports competition or any sport using lots of
bursts of short, sharp, fast movements.

Physical activity can make the body release the
hormone adrenaline, which also 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 that’s stored in their muscles and liver. They
need to replace these stores 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 much carbohydrate.

After exercise your child’s insulin will be more
effective, so they may have low blood sugar levels.
You may need to adjust their insulin or food intake
to prevent delayed hypoglycaemia (hypo), so talk to
your paediatric diabetes team about this.

CASE STUDY

“Months after diagnosis, we attended a
Diabetes UK Family Event. We felt less alone
and I was reassured to hear another mum
describe how I’d felt about grieving for the
boy I had, pre-diagnosis. The toughest thing
for Allen is remembering what it’s like not to
be diabetic and being able to play football
without stopping to test and inject – I miss
the carefree days of parenting.”

Helen, whose son, Allen, has Type 1 diabetes

TOP TIPS

Planning physical activity
These are general guidelines, so discuss
them first with your child’s diabetes team.

1 Check your child’s blood sugar levels
before and after activity.

2 If their blood sugar levels are above
14mmol/l, check for ketones. If there
are ketones, don’t allow any activity
until they’ve gone.

3 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.

4 Aim for blood sugar levels of 5mmol/l
or more before starting any planned
activity, to reduce the chance of a hypo.

5 Always try to choose an injection or
cannula site away from the muscles
that your child is about to use (eg avoid
the leg if your child’s going to play
football). During exercise the blood flow
to the muscles increases, speeding up
the action of the insulin.

6 If your child gets active within one to
two hours of an injection or pump bolus
dose, you may need to reduce their
insulin dose with a meal to help prevent a
hypo. If you don’t reduce the insulin, they
may need an extra snack before exercise.
Talk to your diabetes team about this.

7 If your child exercises for 60 minutes or
longer, make sure they have some extra
carbohydrate during the activity.

8 All children should drink when they
exercise. For activity lasting less than
an hour, water or sugar-free squash is
fine. But, for activity that lasts longer
than an hour try an isotonic sports drink,
pure fruit juice (mix 50/50 with water) or
ordinary sugar-containing squash.

PHYSICAL ACTIVITY
HANDLING HYPOS WHILE ACTIVE

Tell the person in charge of the activity 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 recognise the signs of a hypo.

In case of a hypo, make sure your child keeps something sugary close by, such as Lucozade or a non-diet drink, glucose tablets or gel (plus a longer-acting carbohydrate food, if necessary).

GOING FOR GOLD

Having diabetes doesn’t stop your child from enjoying – and succeeding in – their favourite sport. Rower Sir Steve Redgrave – five-times Olympic gold medallist – and the all-diabetes professional cycling team, Team Novo Nordisk, prove this point. People with Type 1 diabetes can (and do) take part in most sports and activities.

Although some sports-governing bodies do have restrictions on people with diabetes, luckily there aren’t many. Certain sports like scuba diving have strict guidelines, but they have been put in place for safety reasons as much as anything else. Contact the relevant sporting body or a local sports group for more information.

BE CONFIDENT

Remember that everyone’s different – what might work for one child might not work for another. Balancing food, insulin and physical activity levels isn’t easy, and at first it’s a matter of trial and error. Have the confidence to experiment, and check your child’s blood sugar levels to see how they’re getting on. Your child’s diabetes team is also there to help.

And finally...

Active parents are more likely to have active children – remember that they’ll follow the example you set.

GETTING ACTIVE CHECKLIST

Is the activity planned or unplanned?

☐ Planned
Think about reducing your child’s insulin dose if their meal is one to two hours before the activity. Give them a meal or snack containing low-fat carbohydrate, including things like pasta, baked beans, porridge, milk, yogurt and fruit.

☐ Unplanned
Your child will probably need a carbohydrate-containing snack to help avoid a hypo. Carrying hypo treatments like glucose tablets and cereal bars is important, in case your child does an activity that isn’t planned.

How soon after a meal is the activity?

☐ Within one to two hours after a meal
Think about reducing your child’s insulin dose with the meal before exercise or give them a carbohydrate-containing snack before exercising. As a rough guide, if you don’t adjust their insulin, during exercise children need at least 1g carbohydrate for every kilo they weigh.

☐ Some time after a meal
Your child will usually need an extra snack, eg 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.

How demanding is the activity?

☐ Strenuous (eg a football match)
Blood sugar levels may fall during activity, so give your child some quick-acting carbohydrate, eg sports drink, jelly sweets, jaffa cakes, and have some hypo treatment available throughout the activity.

☐ Long (eg a long bike ride)
Your child will need a mixture of quick-acting and longer-acting carbohydrate, such as fruit juice, sandwiches, fruit bars, crisps and biscuits. They can carry these in a small rucksack along with something to treat a hypo, such as glucose tablets.

SUPPORT FOR YOUR CHILD

Children:
- www.diabetes.org.uk/mylife-active

Teenagers:
- www.diabetes.org.uk/teens-sport
Do you need help getting the right diabetes care for your child at school?

The Care in School Helpline provides information and support to make sure that children with diabetes are happy and healthy at school.

Many parents find it difficult to get their voice heard about decisions or issues that affect their child’s health and education. Having someone at the other end of the phone or email to help is vital at a time like this.

Go to www.diabetes.org.uk/care-in-school
Tel 0345 123 2399*

“...The Care in School Helpline is fantastic! Ollie’s school refused to allow him to attend the after school club. The service wrote to the head teacher for us and now they’ve employed two trained members of staff so he can attend. It’s an invaluable service for parents.”
– Ollie’s mum
“With small children, you have to watch everything they do and always be there with them. You need to be super organised, ever prepared and ever mindful. I can’t just leave them for a couple of hours like other parents.”

Jude, whose twins, Amelie and Albie, have Type 1 diabetes

A diagnosis of Type 1 diabetes can affect the whole family. It’s important to listen to, and communicate with, all members of your family – especially any other children – and get help and support if you or anyone else needs it. Here, we explore the reactions of a child and a parent to diagnosis, and emphasise the importance of allowing your child – and yourself – to grieve for what’s been lost. Remember that there’s a lot of support available for you and your family, so please don’t be afraid to ask for help.

FAMILY RELATIONSHIPS

While you’re getting to grips with your child having diabetes, it’s easy to forget about the needs of other children you may have. But, they, too, will be affected by their sibling’s diagnosis. They may feel that their brother or sister is getting special treatment, and may also worry that their sibling will get really sick – or be scared that they’ll develop diabetes themselves.

Rivalry and jealousy are common in most families, and one child with diabetes can cause upset between siblings. In the early days, after diagnosis, it’s only natural for you to be anxious and focus your attention and care on your child with diabetes. But, regular hospital visits, attention to diet and everything else that goes with diabetes has a longer-term impact on all the family.

Brothers and sisters will always squabble, but there’s plenty you can do to calm them down.

- Try to listen to both sides equally and be sensitive to their 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.
- It’s not easy, but try not to put family life on hold.
SEPARATED PARENTS
When parents are separated, it can be a challenge to manage a child’s diabetes when they go from one home to another. Whatever your feelings about your ex-partner, the two of you need to work together to make sure your child’s diabetes is well managed, whoever they stay with.

Think about:
- making sure both of you learn about managing your child’s diabetes from your paediatric diabetes team – second-hand information can be confusing or inaccurate
- how you’ll let each other know about any changes to your child’s treatment or routine and make sure you always keep each other updated
- how you’ll involve new partners.

LONE PARENTS
As a lone parent, you may have particular difficulties because all the pressures fall on you alone.

Think about:
- who you can 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 some time off
- involving siblings in your child’s care, being careful not to give them too much responsibility.

EXTENDED FAMILY
When your child is diagnosed with Type 1 diabetes, it’s natural for grandparents, aunts and uncles, etc to be as upset and worried as you are. They may be in constant contact, asking for updates or how they can help – or they may leave you alone to concentrate on your child and what you need to learn. However they react, you may prefer them to do things differently.

Some of the following are worth considering:
- Keep one person up to date. If lots of people want to know what’s going on, this person can then update everyone else: group texts and emails work well for this.
- Ask for the help you need. Perhaps you’d like someone to look after your other children, do a bit of shopping for you or walk the dog? People often want to help, but don’t know what to do – so tell them.
- Think about the future. Your family will be living with Type 1 diabetes from now on, so how can your extended family best support you? If your child is used to staying over with relatives, it’s important that they can still do so. If grandparents and other family members are worried about looking after them, try involving them in your child’s diabetes care. You could also bring them to clinic appointments to help them learn more about diabetes and ask questions for themselves. Most of all, be honest with them, tell them how you feel and ask them to help you keep your child’s life as normal as possible.
GETTING HELP
If you’re struggling:

- ask your diabetes team for advice
- contact Diabetes UK Careline, which is run by trained counsellors who can give support. Call 0345 123 2399 (Monday–Friday, 9am–7pm) or email careline@diabetes.org.uk or carelincollection@diabetes.org.uk
- connect with other parents of children with diabetes for support and to share experiences – go to the Diabetes UK Facebook page (/diabetesuk), or the Diabetes Support Forum – go to www.diabetesuk.org.uk/
- join a Diabetes UK group – go to www.diabetes.org.uk/groups for further information
- contact Diabetes UK’s Peer Support service to talk to specially trained volunteers – including parents – with first-hand experience of living with diabetes. Call 0843 353 8600 (Sunday–Friday, 6pm–9pm) or take a look at the peer profiles at www.diabetes.org.uk/peer-support

ACTION POINTS
Take a few minutes to think about how each member of your immediate family is dealing with your child’s diabetes.

If you’re worried that diabetes is upsetting your family in any way, get help.

Look after yourself – you’ll then be in a better position to look after your family.

Be honest with your extended family and let them know how they can help you and your child.

Q&A
Will my other children get diabetes?
Medical research has shown that Type 1 diabetes is caused by a combination of genetic and environmental factors. If one family member has Type 1 diabetes, there’s a slightly increased risk of another family member developing it, too. But, many people diagnosed have no family history of Type 1 diabetes. It’s natural to worry that your other children will also develop Type 1 diabetes, but try not to let this worry affect you too much. Talk to your diabetes team or contact Diabetes UK Careline on 0345 123 2399 for support.

DIAGNOSIS: A CHILD’S/YOUNG PERSON’S REACTION
For the child or young adult, the actual time of their diagnosis is often a confusing or frightening blur. They have a memory of feeling ill, being suddenly taken to hospital and waking up on a drip, surrounded by various medical staff and anxious parents. It may all seem like a nightmare, best forgotten.

Diabetes, though, can’t be forgotten. Unlike the usual illnesses of childhood, Type 1 diabetes won’t ever go away. When the child slowly realises this they’re naturally both frightened and upset. They may long for it to be yesterday, or last week – to return to the way things were before.

All people – and families – have different ways of coping with things, and children are likely to copy the way that their parents cope. After such a huge shock, both physical and emotional, expecting a child to deal with things quickly and practically isn’t helpful. This shock and the way their life has changed need to be acknowledged and talked about, allowing them to express their feelings, however difficult.

No one knows precisely what the child has gone through, and they may not be able or have the words to explain it. They may blame themselves, or see their diabetes as a punishment for something. It’s a good idea to let them express their fears and emotions now, as these won’t simply disappear – and even if they lie buried they may re-emerge at a later date, maybe in their teens or 20s, say.
Some children may choose to minimise their difficulties, preferring not to mention it, ignore it or play it down. Everyone finds their own way of coping, and some children may cope better than others. Be aware, though, that a child who seems to be coping very well may be hiding their true feelings.

After a loss – and this is a loss – people naturally go through a period of grief and mourning. This process takes time, but is necessary for recovery and for getting used to a new and difficult way of life. How long it takes depends on the individual and how much support, both emotional and physical, is available. Allow children to grieve in their own way, and don’t try to hurry them.

One way to help a child through this difficult time is to let them talk openly to someone who’ll listen and understand. Having Type 1 diabetes is often a lonely business, and having the support and understanding of family and friends can be a great source of strength.

Many children (especially older children) find it difficult to talk about their diabetes – as indeed do many adults. They may find it easier to talk to someone outside their immediate family – like a grandparent or best friend. It can also help an older child to keep a daily journal to say how the day was, what was especially difficult and what was good.

Young children need comfort, cuddles and calm handling. If your child is diagnosed when they’re very young, be aware that problems may emerge when they’re older – often when school starts and your child realises that their life is different to those of other children.

There’s no need for Type 1 to stop a child doing anything their friends do. But, there can be difficulties on the way and these need to be acknowledged.

If you want to talk through any concerns or get more information on any aspect of diabetes, call Diabetes UK Careline on 0345 123 2399 (Monday–Friday, 9am–7pm).

“Nobody could have prepared me for the shock and powerful roller-coaster of emotions that began five minutes after getting into the doctor’s waiting room. I remember sneaking to the toilet and bursting into floods of tears. It was like a bereavement. My son was the bravest anyone could be in the situation and I kept strong in front of him, but inside my heart broke. We came out of hospital three days later armed with insulin and a boat-load of information. We’ve been there for each other from day one and I’ve told him many times how proud I am of him. We go onto the pump soon, so it’s all the nervous anxiety of the unknown, but I know we’ll do a fab job because we do it together. It’s been several months of no sleep and fighting hypers at night and hypos during the day, but we’ll get there in the end – I know we will.”

Kerry, whose son, Ben, has Type 1 diabetes

DIAGNOSIS: A PARENT’S REACTION

For the parent, as for the child, the diagnosis of Type 1 diabetes is likely to come as a huge and often sudden shock. One moment your child or teenager is well, then suddenly they have an unquenchable thirst and run to the loo every few minutes. Or your baby drenches their nappies. Then, just as suddenly, they become alarmingly ill.

You hurry them to the doctor. By now you’re really worried: Is it some infection? What’s going on? And when your GP either calls an ambulance or tells you to go to A&E immediately, normal life as you know it suddenly changes forever.

Events now move so quickly that you barely have time to think. But, then you’re given a diagnosis: “It’s diabetes”. It’s a huge shock to learn that your child has a medical condition. And diabetes? Most people have no idea what ‘diabetes’, in all its complexity, means.

At the same time, you’re trying to stay calm, and comfort your distressed and frightened child, whatever their age. It’s also upsetting for you to hear your child
Sign up today as a mobile member to get expert advice on diabetes sent straight to your phone.

For just £3 a month, you'll receive tailored, expert advice to your phone and you'll be supporting our vital research into diabetes care, cure and prevention.

As a mobile member, you’ll get:

- Monthly text messages tailored to your needs whether you have Type 1 diabetes, Type 2 diabetes or are a parent of a child with diabetes.
- Access to Diabetes Balance magazine on your smartphone.
- Full access to our other informative companion guides.

It take seconds to sign up, there is no long form to fill out and your £3 monthly donation will be deducted directly from your phone bill.

Are you a parent of a child with diabetes? Become a family mobile member today.

Text FAMILY to 70002 to give £3 a month and get monthly expert advice about your child's diabetes.

If you have Type 1 diabetes, text MANAGE to 70002
If you have Type 2 diabetes, text MEMBER to 70002

For further details please go to www.diabetes.org.uk/mobile-member or call 0345 123 2399*

*Calls may be recorded for quality and training purposes
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say things like: “I don’t want any more needles”, or even: “Am I going to die?”. There’s no easy way to deal with this situation. Use your own knowledge of your child and the relationship between you – and common sense. Even if you don’t know much about diabetes yet, you do know your own child.

A diagnosis of diabetes can bring with it a great sense of loss. Allow yourself to go slowly through the process of mourning, which involves acknowledging grief, anger, fear. Don’t be tempted to overlook or hurry this mourning process, even if you think you should be positive and calm for the sake of your child. Ignore well-meaning people who tell you: “Be positive! There’s no other choice!”. After all, ‘being positive’ can be hard and isn’t something you can choose to do as and when you please.

It may help to separate the physical, practical and immediate demands of managing diabetes from the emotional acceptance of the condition, which is likely to take much longer to come to terms with. You also need to recognise that although both you and your child are grieving, you’re both feeling different things and expressing your grief in different ways.

As a parent, you need to be able to allow and manage your child’s confusion and distress. This doesn’t mean taking a deep breath, ignoring all your difficult emotions, acting calm and pretending to cope. It does mean getting proper adult support for yourself. If you do get support, you’ll find it easier to allow your child the time and freedom to come to terms with their new way of life.

If you’re lucky, you’ll have support from your family and friends. If you’re not so lucky, you still have the support of your Paediatric Diabetes Specialist Nurse (PDSN) and diabetes team – and Diabetes UK. If you’d like to talk to other parents, your PDSN may be able to help; or you may want to attend a Diabetes UK Care Event, which run throughout the year, across the UK, and are aimed at children, young people, adults (18–30) and families living with diabetes. Go to www.diabetes.org.uk/care-events for further information.

For help and support, call Diabetes UK Careline on 0345 123 2399 (Monday–Friday, 9am–7pm).

### DEALING WITH DIABETES

Some older children may want to think about these points:

- **Diabetes – and those who live with it**
  - deserved respect. Give it, and expect it.
- **Try to acknowledge privately and publicly that it’s difficult, but also that you have the strength to handle it.**
- **Try to work out a relationship with diabetes that isn’t destructive.** It can’t be the enemy if it’s part of you, if you live with it.
- **Think of diabetes as a difficult relative who you care for – sometimes it’s easy, sometimes it’s frustrating and sometimes it’s infuriating.** At times, you’ll cope really well; at others, you won’t. Be kind to yourself – you’re only human.

### SUPPORT FOR YOUR CHILD

Diabetes UK offers a range of support for children of all ages with diabetes.

**Children:**
- [www.diabetes.org.uk/mylife](http://www.diabetes.org.uk/mylife)
  - Problem page – answers to a wide range of questions, from bruising to bullying.
  - Ask Libby – where children can email their questions and concerns.
  - Fed up? – suggestions on how to beat the blues.
  - Fun stuff – pictures and stories.
  - My Life – a magazine for primary school children.

**Teenagers:**
  - Problem page – for information on teenage issues, including periods, pumps and problems at home.
  - Email for confidential help and advice.
  - Fun stuff – where they can share pictures and stories of life with diabetes.

**Young adults (16–30):**
- [www.diabetes.org.uk/type1uncut](http://www.diabetes.org.uk/type1uncut)
  - #Type1Uncut – factsheets and videos.
LIVING WITH DIABETES

Once life’s relatively back to normal you may still have further concerns about your child’s diabetes. Here, we discuss what happens if your child becomes ill, what information to give your child’s carers and what can happen at school. There’s also a quick guide to teenage issues, covering alcohol, drugs, smoking and sex.

ILLNESS AND INFECTIONS

When your child is ill, their blood glucose levels (also called 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 also a common reason for developing diabetic ketoacidosis (DKA, see page 18). If you’re worried and have trouble contacting your paediatric diabetes team, take your child to the nearest hospital Accident & Emergency (A&E) department.

A&E

If your child needs medical attention for something other than their diabetes, such as an accident or injury, this may involve a long wait. Make sure you tell the staff as soon as you arrive that your child has diabetes, and that they may need to eat to avoid a hypo – usually people are advised not to eat or drink while in A&E in case they need surgery. If you feel your child does need to eat or drink, check with the staff first.

Hospital stays

If your child has to stay overnight in hospital, it’s a good idea to consider the following:

- The hospital should provide the insulin your child normally uses – but this may take some time, so take some with you to avoid delays.
- Take your own supplies of diabetes equipment, such as a blood-testing kit or pump supplies (which the hospital probably won’t be able to provide).
- Check that the ward staff have spoken to your child’s diabetes team.
- Don’t assume that everyone treating your child knows they have diabetes – it’s better to be over-cautious 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 may need to test your child more often and adjust their treatment.
- If you want to manage your child’s diabetes care yourself while they’re in hospital (or if they want to look after their own diabetes), you/they should be supported to do so, unless this is impractical. This includes using an insulin pump.

For more information on hospital stays, go to www.diabetes.org.uk/young-people-hospital

Vaccinations

As well as their 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.

All children are offered a pneumococcal vaccination as part of their routine childhood vaccinations. This vaccine is given as three doses at 2, 4 and 13 months. Be aware that some children’s blood sugar levels go up following a vaccination because the body is making antibodies.
**TOP TIPS**

**Managing illness**

1. Your child should keep taking insulin even if they don’t feel like eating. In some cases, you may need to alter their dose – your diabetes team will be able to advise on this.

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 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 their ketones. If ketones are present, contact your 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/fluids regularly. If your child doesn’t feel like eating, is feeling sick or can’t keep any food down, replace meals with snacks or drinks containing carbohydrates, which will give energy. Try to get them to sip sugary drinks (such as Lucozade or non-diet cola) or suck on glucose tablets or sweets, such as jelly beans. Letting fizzy drinks go flat may help your child keep them down. If your child is vomiting, consult your diabetes team.

6. Don’t panic – contact your diabetes team who’ll help you if you have any queries.

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**CHILDCARE**

No matter how much you want to protect and care for your child, it’s impossible to do so 24 hours a day. For some of the time, you’ll have to rely on others to look after them.

Nobody knows your child better than you, and learning to trust others to care for them can be difficult. But, if you refuse to allow anyone else to look after your child, two problems can arise:

- Your child may become too dependent on you, making it difficult when they eventually need to take responsibility for their own diabetes.
- You’ll be neglecting your own needs. Caring for any child is tiring enough, but when they have diabetes it can be doubly exhausting. By giving yourself a break, even if it’s only the odd hour now and then, you’ll be in a fitter state (both emotionally and physically) to look after your child when they’re in your care.
Is your child going to do any type of physical activity with their carer? Make sure they know how to manage this.

Give your child’s carer all the equipment they need to look after your child, plus spares in case of accidents.

Have you given your child’s carer your contact number in case of any problems? Make sure you also give them someone else’s contact number in case they can’t get hold of you.

Talk to your diabetes team for more individual advice about leaving your child with a carer. Your Paediatric Diabetes Specialist Nurse (PDSN) may be able to help teach your child’s carer about diabetes and how to manage it.

If you’re going to leave your child with a carer regularly for a long period of time, you may find it useful to give them the written healthcare plan that’s recommended for use at school (see page 53). Go to www.diabetes.org.uk/child-IHP

For more information on registered childminders, go to www.ofsted.gov.uk

**CARERS CHECKLIST**

You may need a carer for a variety of reasons – perhaps you need a regular childminder to take care of your child while you’re at work, or maybe you just fancy an evening out. You may opt for a professional childminder or go for a more informal babysitting arrangement with a friend. Whichever you choose, the following checklist will help you plan what you need to do so that you can leave your child safely with somebody else.

- How much does your child’s carer know about diabetes and what are they prepared to do for your child?
- Give the carer as much information as they need about your child’s diabetes, and back it up with written information.
- Is your child’s carer going to give your child insulin or do their blood sugar test? If so, do they know how to do this correctly? Allow plenty of time for teaching and practising.
- Do they know what the blood sugar tests mean and how to respond? Make sure they know what your child’s blood sugar targets are and what to do if their results are outside this range.
- Is your child going to eat with the carer? If so, tell the carer which foods to give your child and when. Make sure they know whether they need to give your child insulin with any snacks or meals, and how much.
- Does your child’s carer know how to recognise and treat a hypo? Give them a written list of your child’s usual hypo symptoms, as well as their usual hypo treatments.
- Is your child going to do any type of physical activity with their carer? Make sure they know how to manage this.
- Give your child’s carer all the equipment they need to look after your child, plus spares in case of accidents.
- Have you given your child’s carer your contact number in case of any problems? Make sure you also give them someone else’s contact number in case they can’t get hold of you.
- Talk to your diabetes team for more individual advice about leaving your child with a carer. Your Paediatric Diabetes Specialist Nurse (PDSN) may be able to help teach your child’s carer about diabetes and how to manage it.
- If you’re going to leave your child with a carer regularly for a long period of time, you may find it useful to give them the written healthcare plan that’s recommended for use at school (see page 53). Go to www.diabetes.org.uk/child-IHP
- For more information on registered childminders, go to www.ofsted.gov.uk

**CASE STUDY**

“While Josh has had great care and support over the years, I didn’t feel comfortable with him going round to his friends’ houses or going on school trips. Sometimes, I made up different excuses as to why he couldn’t go somewhere – I was so worried he’d go hypo and no one would know what to do. I’ve started to realise that this isn’t good for Josh. I just need to make sure that anyone looking after him in my absence knows what to do.”

Janine, whose son, Josh, has Type 1 diabetes

**ACTION POINTS**

Discuss your child’s needs around their diabetes with their childminder. Your PDSN should be able to provide training.

Think about how long you need a childminder for and how often. This will help you decide whether a professional childminder or a friend/relative is more appropriate.

Check if your childminder needs to be registered with Ofsted – see Carers checklist, above.
TOP TIPS

1. Together with your PDSN, give your school as much information as you can about your child’s diabetes.

2. If you’re having difficulty getting the support you need for your child, contact Diabetes UK’s Care in School helpline – go to www.diabetes.org.uk/Care-in-School for details.

3. It’s difficult to balance this, but try to communicate the importance of looking after diabetes properly at school, without frightening staff and putting them off. Your PDSN should be able to help with this.

Diabetes UK also has many practical resources that can help you and your school support your child. As part of its Type 1 diabetes: Make the grade campaign, Diabetes UK has produced:

- Information packs – one for parents and one for schools. These packs include information about diabetes, what care to expect, practical and useful tools and templates.

- Detailed online information. An extension of the packs, this gives more detail about looking after diabetes in school, including information on testing, injecting, food, telling friends and staff about diabetes, and how to manage trips. There’s also information about the roles and responsibilities of all involved, nation-specific laws and guidance, and information specifically for children and teenagers.

You can find all this information, and more, at www.diabetes.org.uk/schools. Or, if you’d like to order a pack by phone, call 0345 123 2399.

SCHOOL

Many parents worry about their child going to school – and it’s common to have concerns about whether school staff are willing and able to look after your child the way you 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 at school they need for their child – so just be prepared in case you do have 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 they don’t understand what’s involved. When they’re given some information about diabetes and know that there are people to help them, they often feel much more able to give your child the support they need.

There are a number of things that can help you and your school to look after your child properly. To start with, recent legislation in England puts a legal duty on schools to provide appropriate care for children with medical conditions, which includes Type 1 diabetes. In Scotland, Wales and Northern Ireland there are similar strong guidelines in place.

ACTION POINTS

- Find out your main contact at school for your child’s diabetes care.
- Talk to your diabetes team about how they can support the school in looking after your child’s diabetes.
- Tell school staff straightaway about any changes to your child’s diabetes management.

Have a look at Diabetes UK’s information about looking after Type 1 diabetes at school – go to www.diabetes.org.uk/schools

SUPPORT FOR YOUR CHILD

Children:  
- www.diabetes.org.uk/mylife-schools

Teenagers:  
- www.diabetes.org.uk/Teens-School-college
DIAGNOSIS IN THE TEENAGE YEARS

Being diagnosed with Type 1 diabetes as a teenager can raise specific issues. Teenagers are often trying to find their own identity and starting to become more independent. You’re probably well aware of the difficulties that the teenage years can bring, and a diagnosis of Type 1 diabetes needs sensitive handling.

Your teenager may want to take total control of their diabetes – or they may be shaken by the diagnosis, worried about dealing with it and want you to look after them. There’s no right or wrong way to manage this – just do what’s right for you and your child.

The important thing is not to push them into taking too much responsibility too soon, and not to hold them back when they want to take on more. Also, be prepared to take control if and when you want you to – it’s common for young people to want to be their own boss one day, but not the next.

Even if your teenager wants to take total control of their diabetes, it’s still important that you’re involved. Talk to them about how it’s going to work and make a plan between you. Explain that you trust them, and discuss any worries you have and how they can reassure you that they’re doing OK.

TOP TIPS

Talking to your teenager

There’s no doubt that the teenage years can be a real challenge for families, and diabetes can add another layer of difficulty. But, as you’ll still want to know what’s going on with your teen’s diabetes, these tips may help:

1. **Pick your time** – there’s no point trying to have a conversation with your teenager 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 to stop and start the conversation again.

2. **Pick your moods** – trying to talk to your teen when you’re cross with them won’t work. Likewise, don’t try to approach your teenager when they’re in a mood – they won’t be open to discussion.

3. **Pick your arguments** – complaining about everything your teenager is doing ‘wrong’ is unlikely to make them change. If you’re worried about a number of things, talk about the ones you’re most concerned about first, and come back to the others at a different time.

4. **Pick your approach** – sitting your teenager down for a face-to-face conversation may make them so uncomfortable that they clam up and don’t answer you honestly. Try bringing things up gently when you’re doing something together, such as going for a walk or cooking a meal. It can be easier for your teen to open up when they don’t have to look you in the face.

5. **Pick your allies** – it might feel hurtful, but sometimes you aren’t the best person to talk to your teenager. They might feel more comfortable with a favourite aunt, uncle or family friend. If you take this approach, make sure you’re all clear on what’s shared with whom – not only so you don’t feel left out of the discussion, but also so your teenager doesn’t feel there’s been any tale-telling.

6. **Pick your resources** – think about if you want to give your teenager some more information.
As your teenager gets more familiar with their diabetes, your diabetes team may give them the choice to come to the clinic on their own. Again, this is something you need to talk to them about, as you may still want to come, too. Achieving a balance – between letting them be independent and being there when they need you – works in different ways for different families.

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

- Involve your child in clinic visits at the level they feel comfortable with.
- Encourage them to ask and answer questions themselves when they feel ready to.
- Involve them in any decisions about their care and treatment.
- Give them opportunities to discuss their fears and worries. Encourage your child to think of their own solutions to problems, which you can then all discuss with the doctor, PDSN or paediatric dietitian.

As well as having more independence, a teenager’s lifestyle is usually quite different from that of younger children. In particular, it’s the time when they may start experimenting with alcohol, drugs, smoking or sex. All these things can affect diabetes, so it’s important that you and your teenager are aware of this.

**Alcohol**

People with diabetes can still drink alcohol, but too much isn’t good for anyone’s health. It’s recommended that the maximum intake is no more than three units per day for men and two units per day for women. Remember that these recommendations are for adults.

**Alcohol makes a hypo more likely, so make sure that your teen knows the following:**

- Not to drink on an empty stomach and to have a meal before drinking. If this isn’t possible, they need to eat some carbohydrate-containing snacks, such as a sandwich or crisps, while drinking.
- To tell their friends about their diabetes and how to treat a hypo.
- To carry diabetes identification with them because a hypo may be mistaken for drunkenness.
- After a few drinks, they may be less aware of hypo warning signs – so they should try to drink in moderation.
- To alternate alcoholic drinks with plenty of water (or anything that’s sugar-free) to avoid dehydration.
- Alcohol stays in the system for a number of hours, which means that a hypo may happen some time 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 best way to avoid any problems is obviously to avoid drugs.

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

- Different drugs have different effects. Drugs, legal or not, can be classified into three categories – stimulants, downers (or sedatives) and hallucinogenics (or 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 to take – they can still make you seriously ill and even cause death.
- Possessing illegal drugs can lead to a fine or imprisonment, as well as a criminal record that could affect future job prospects.
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 discuss sex with your teenager, 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 their diabetes under control can help avoid thrush, and they need to visit their GP if they have genital itching and discharge.

● Girls with diabetes can still take the contraceptive pill.

● It’s important for both teenage girls and boys to use some form of contraception, unless they’re ready to start a family.

ACTION POINTS
Are there any aspects of your teen’s behaviour or diabetes management that you’re concerned about? If so, plan a time when you can both talk about these issues.

Bringing up teenagers can be difficult and stressful. Think about who can help and support you through it.

Do you think you need some professional help? Talk to your diabetes team about counselling or psychological support.

SUPPORT FOR YOUR CHILD
Teenagers:

● www.diabetes.org.uk/teen-living
● www.diabetes.org.uk/teen-help-support
GET INVOLVED

BECOME A MEMBER
0800 138 5605
Join our 300,000 supporters who help us care for, connect with and campaign on behalf of all people affected by and at risk of diabetes.

RAISE YOUR VOICE
www.diabetes.org.uk/ diabetesvoices
Join Diabetes Voices and make a difference to services and care by working alongside us to campaign and influence for change.

VOLUNTEER
www.diabetes.org.uk/ volunteer
Whether you can spare an hour a month or a day a week, there are many ways that you can make a difference at Diabetes UK.

RAISE FUNDS
www.diabetes.org.uk/ fundraising
There are many ways you can raise funds or give to Diabetes UK. Visit our website to find out how you can help us to improve the lives of people with diabetes.

CALL OUR CARELINE
0345 123 2399*
A free and confidential service offering information on diabetes and the opportunity to talk things over.
*Calls may be recorded for quality and training purposes.

TALK TO SOMEONE WITH DIABETES
0843 353 8600**
A helpline and email service delivered by specially trained volunteers who have first-hand experience in living with diabetes.
**Calls to 0843 numbers may be free depending your phone package but will cost a maximum of 7p per minute to call plus your network providers access charges.

JOIN A LOCAL GROUP
volunteering@diabetes.org.uk
Our local support groups offer the chance to share experiences with others in your area and keep up to date with our work.

GO ONLINE
www.diabetes.org.uk
Our website offers information on all aspects of diabetes and access to our activities and services. Our Facebook and Twitter communities provide support and a chance to talk to others.
A&E
A hospital Accident & Emergency department.

Basal bolus insulin (bay-sul bow-lus)
Describes 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 reads your child’s blood testing strips and stores the results of their blood glucose 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), 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, inserted under the skin, through which insulin is delivered from an insulin pump.

Carbohydrate
The body’s preferred 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 choose to eat.

Coeliac disease (see-lee-ack)
A common autoimmune disease where the body reacts to gluten (a protein found in wheat, barley and rye), which damages the gut lining and affects how food is absorbed.

Complications
Health problems those with Type 1 diabetes are at risk of developing in later life: these include damage to the kidneys, eyes and nerves, and heart disease.

Continuous glucose monitoring (CGM)
Where a sensor is 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.

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-meen)
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 those with blood disorders such as 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
An alternative to 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.

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 test blood sugar levels.

Millimoles per litre (mmol/l)
A measurement of the concentration of a substance in a given amount of liquid: expresses the amount of glucose in the blood.

Multiple daily injections (MDI)
Describes 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: this body decides the criteria for NHS funding, standards and services.

Paediatric
(pee-dee-at-rick)
Paediatrics is 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 will provide 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, eg 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 who have Type 1 diabetes.
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