

# **Type 1 diabetes in children and young people**

**Understanding NICE guidance – information for young people with type 1 diabetes, their families and carers, and the public**

**Prepared for second consultation**

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## **About this information**

This information describes the guidance that the National Institute for Clinical Excellence (called NICE for short) has issued to the NHS on the diagnosis and management of type 1 diabetes in children and young people in the community and in hospitals. It is based on 'Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults', which is a clinical guideline produced by NICE for doctors, nurses and others working in the NHS in England and Wales.

### ***Clinical guidelines***

Clinical guidelines are recommendations for good practice. The recommendations in NICE guidelines are prepared by groups of health workers, lay representatives with experience or knowledge of the condition being discussed, and scientists. The groups look at the evidence available on the best way of treating or managing a condition and make recommendations based on this evidence.

There is more about NICE and the way that the NICE guidelines are developed on the NICE website ([www.nice.org.uk](http://www.nice.org.uk)). You can download the booklet *The Guideline Development Process – Information for the Public and the NHS* from the website, or you can order a copy by phoning the NHS Response Line on 0870 1555 455 (quote reference number N0038).

### ***What the recommendations cover***

NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or a combination of these. The areas that a guideline covers depend on the topic. They are laid out at the start of the development of the guideline in a document called the scope.

The recommendations in 'Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults', which are also described here, cover the care that should be available from the NHS to

children and young people with type 1 diabetes. They include how the diagnosis should be made and the options that should be offered at different times.

The information that follows tells you about the NICE guideline on type 1 diabetes. It doesn't attempt to explain diabetes or its management in detail. NHS Direct is a starting point to find out more. Phone NHS Direct on 0845 4647 or visit the website at [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk).

If you have questions about the specific options covered, talk to a member of the diabetes care team.

### ***How guidelines are used in the NHS***

In general, health workers in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the recommendations won't be suitable for someone because of his or her specific medical condition, general health, wishes or a combination of these. If you think that the care you or your child receives does not match what's described in the pages that follow, talk to a member of the diabetes care team.

### ***If you want to read the other versions of this guideline***

[The following information will apply once the final guideline has been issued]

There are four versions of this guideline:

- this one
- the NICE guideline, 'Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults'
- the quick reference guide, which is a summary of the main recommendations in the NICE guideline; NICE has sent copies of the quick reference guide to doctors and other healthcare professionals working in the NHS

- the full guideline, which contains all the details of the guideline recommendations, how they were developed and information about the evidence on which they were based.

All versions of the guideline are available from the NICE website ([www.nice.org.uk](http://www.nice.org.uk)). This version and the quick reference guide are also available from the NHS Response Line – phone 0870 1555 455 and give the reference number(s) of the booklets you want (N0xxx for this version, N0xxx for this version in English and Welsh, and N0xxx for the quick reference guide).

### ***Explanation of medical words and terms***

Short explanations of some of the medical words and terms used in this booklet are provided on pages xx to xx.

## **Key recommendations**

The guideline that NICE has issued to the NHS contains many specific recommendations about the sort of care that children and young people with type 1 diabetes should receive in the NHS. These are covered on the following pages. Some of the recommendations in the guideline are known as 'key recommendations'. They are particularly important and should be put in place as a priority.

### ***The healthcare professionals who should be involved***

A team of healthcare professionals with specialist knowledge, training and experience of treating and caring for children and young people with diabetes should look after the health of children and young people with type 1 diabetes. This type of team is called a children's diabetes care team, and the different people in the team should know about:

- what happens when type 1 diabetes develops and the best ways of managing it
- how young people and their parents or carers can best learn to manage the effects of diabetes on everyday activities, such as diet and exercise
- the wider effects of diabetes on the life of a child or young person, so they can advise on how to cope with the day-to-day management of diabetes.

The team should put together a plan of care for the child or young person.

### ***Being able to stay at home rather than go into hospital***

After the diagnosis of type 1 diabetes, children and young people should be able to stay at home rather than go into hospital. The child and their family should be given a contact phone number that can be used at any time of the day or night if advice is needed.

### ***Information and explanations***

The diabetes care team should make sure children, young people and their families or carers have information and explanations at the times when they need them. The information and explanations should be clear and helpful.

People should not be told different things by different team members – information and explanations should be consistent.

### ***Target glyated haemoglobin (HbA<sub>1c</sub>)***

The diabetes care team should discuss a target HbA<sub>1c</sub> to aim for. Normally the aim is to get the HbA<sub>1c</sub> under 7.5%, while at the same time avoiding the child or young person having more periods of hypoglycaemia.

### ***Treating a child or young person with diabetic ketoacidosis***

A child who has diabetic ketoacidosis should be treated following the guidelines published jointly by a patient group and a professional body. These are available from the Diabetes UK website – go to

[www.diabetes.org.uk/dka\\_paed/index.html](http://www.diabetes.org.uk/dka_paed/index.html). You can also call Diabetes UK on 020 7424 1030.

### ***Checking for problems connected with diabetes***

A child or young person should have the following checks (see page 22 for more information):

- coeliac disease when they're diagnosed with diabetes and then at least every 3 years
- thyroid disease at diagnosis and then every year after that

Once a child is 12 years old, they should have the following tests every year:

- an eye check (for retinopathy)
- a urine test for a protein called albumin
- blood pressure measurement.

### ***Help from people working in mental health***

The child or young person and their family should be able to get help and support from health professionals working in mental health when they need it.

## **Type 1 diabetes**

Type 1 diabetes happens when the cells in the pancreas that produce insulin are damaged by the body's own immune system. Insulin is the main

substance that co-ordinates how the body handles glucose (sugar) as it enters the blood from digested food. Without enough insulin, glucose rises in the blood to abnormal levels. A sudden, severe lack of insulin can cause immediate problems, including one kind of coma (ketoacidosis). If blood glucose levels are too high for long periods, it can lead to damage of the blood vessels, heart, nerves, feet, kidneys and eyes.

## Diagnosis

When doctors are deciding on a diagnosis of type 1 diabetes in children and young people, they should follow the advice of the World Health Organization. This is outlined in the next paragraph. The document can be found at [http://whqlibdoc.who.int/hq/1999/WHO\\_NCD\\_NCS\\_99.2.pdf](http://whqlibdoc.who.int/hq/1999/WHO_NCD_NCS_99.2.pdf)

Type 1 diabetes in children and young people is nearly always simple to diagnose. Usually the person is poorly, with high levels of glucose in their blood and urine, together with chemicals known as ketones in their urine (sometimes they are very ill with ketoacidosis – see page 21). Occasionally, symptoms may be very mild: even so blood glucose levels are always higher than they should be. Very rarely, special blood tests may be required to confirm the diagnosis. In most cases, insulin is started quickly in the first day or two of diagnosis.

Sometimes, it's possible that a child or young person may have another type of diabetes. Doctors should think about this if the child or young person:

- has several close relatives with diabetes
- is overweight
- is Black or Asian (or has a Black or Asian background)
- only needs a relatively low amount of insulin in the first year after diagnosis to control blood glucose levels, or doesn't need it at all
- hardly ever has ketones in their urine at the same time as having high levels of glucose in their blood

- has other conditions at the time the diabetes is diagnosed, such as eye problems or deafness.

A child or young person diagnosed with type 1 diabetes should have their details kept on a register so that their diabetes care team knows who they are and can make sure they get the care they need.

## **Straight after diagnosis**

### ***The children's diabetes care team***

A child or young person with type 1 diabetes should be looked after by a team of healthcare professionals with specialist knowledge, training and experience of treating and caring for children and young people. This type of team is called a children's diabetes care team. The different people in the team should know about:

- what happens when type 1 diabetes develops and the best ways of managing it
- how young people and their parents or carers can best learn to manage the effects of diabetes on everyday activities, such as diet and exercise
- the wider effects of diabetes on the life of a child or young person, so they can advise on how to cope with the day-to-day management of diabetes.

The team should put together a care plan for the child or young person.

### ***Staying at home or going into hospital***

When a child or young person has been diagnosed with type 1 diabetes, they should usually be given the choice to stay at home rather than go into hospital for the initial treatment and education programme. Those staying at home, and their parents/carers, should be given a phone number that they can ring at any time of the day or night for advice.

Young children (infants or pre-school age) should be able to start off in hospital. The same applies for children and young people with social or

emotional problems that mean it might be easier if they spent a bit of time in hospital at first.

### ***Starting on insulin***

The doctor should explain that a low dose of insulin may keep blood glucose down at first. However, everybody has an individual need for insulin and some children and young people may need several injections of insulin a day or may need to give their insulin by a special device, an insulin pump.

### ***Dealing with the diagnosis***

Children, young people and their parents or carers should be given the chance to talk about their feelings about the diabetes and any worries about the diagnosis if they want to. They should be offered support that's suited to their individual needs.

### ***Learning about type 1 diabetes and its management***

Soon after the diagnosis, children and young people should be given the chance to learn about:

- type 1 diabetes
- what they have to do to look after themselves
- how others can help.

This should cover:

- the aim of having insulin injections
- how to give injections
- how to check glucose levels
- how glucose levels can be affected by the things they eat and drink, exercise, and being ill
- how to spot if they're becoming low in glucose (hypoglycaemic – a 'hypo'), what to do, and how to avoid it happening (parents or carers should also be told about this).

Education programmes and information about type 1 diabetes should not just be offered straight after the diagnosis. There should be opportunities to ask questions and discuss different things about the diabetes every time the child, young person or parent or carer sees the diabetes care team. Things should be explained in such a way that the information can be understood, so the person feels able take part in the discussions about how the diabetes should be managed. This should be the case whatever the individual circumstances of the child or young person or their family.

Children's diabetes care teams should talk to school staff who come into contact with children and young people with type 1 diabetes, so they can help them understand the condition and its effects.

### ***Information for an emergency***

It's a good idea for children and young people to wear or carry something that tells people that they have type 1 diabetes, just in case they need help while they're out.

## **Using insulin**

Type 1 diabetes means that the body doesn't make the insulin it needs to control the amount of glucose in the blood. So insulin needs to be put into the body to carry out this job. It can be complicated to sort out the best type of insulin and the times to take the insulin during the day that suit an individual child or young person.

Children and young people should be offered advice and support to help them keep or reach a healthy weight while controlling their glucose.

## **Types of insulin**

Different sorts of insulin work for different lengths of time. The main categories are:

- rapid-acting insulin analogues (these act like the insulin that is normally produced to cope with a meal; they act virtually instantly with their effect falling away quickly)
- short-acting insulins (although quick-acting, these work more slowly than rapid-acting insulin analogues, and their effects may last up to 8 hours)
- intermediate-acting insulins (these have an effect that lasts longer, and can even last through the night)
- long-acting insulin analogues (which can last for a longer period, even a whole day).

In people without diabetes, there's normally a low level of insulin in the blood. And then after a meal, this increases to deal with the sudden appearance of high levels of glucose in the blood. By mixing and matching insulins for people with diabetes, it's usually possible to find a pattern that is either similar to this or that gives the same overall control of glucose levels.

It's not possible to have insulin in a tablet form because it is destroyed by the juices in the stomach and intestine. So insulin has to be injected.

## ***Times for the insulin injections***

Children and young people with type 1 diabetes should be offered the types of insulin and pattern for taking them that suit them best. The manufacturers' recommendations should be followed for using them. Pre-school and primary-school-age children should be tried on the type and pattern of insulin most likely to suit the individual child.

A young person (11 or older) should be able to try having more than two insulin injections a day to keep their glucose levels under control. If they try this, they might find that at first they become hypoglycaemic more often, put on a bit of weight, or both. If they find it difficult to remember to take their

insulin, they should have the chance to change to having injections twice a day.

### **Rapid-acting insulin analogues**

If a child or young person is using a rapid-acting insulin analogue with other types of insulin, it should be explained that the rapid-acting insulin analogue is to be used immediately before eating a meal.

For young children who have a rapid-acting insulin analogue, it may be better to use it straight after they've eaten, just in case they don't actually eat their food.

### **Preparations with intermediate-acting insulin**

If the insulin preparation contains an intermediate-acting insulin, the preparation should be mixed before it is used (following the manufacturer's instructions).

### **Systems that deliver insulin continuously**

Sometimes it's impossible to keep an HbA<sub>1c</sub> below 7.5% without there being problems with hypoglycaemia, even with more than two insulin doses a day. In this case, a child or young person should be offered the option of trying a system that puts a continuous amount of insulin into their body (for example, an insulin pump). First, though, the diabetes care team has to decide with the child or young person and their family that they are able, and want, to use the system properly.

If a child or young person is going to try a system, a trained specialist team should be involved in starting them off. The child or young person (and parents or carers) should be able to contact the specialist team if there are any problems. The child or young person should also be trained how to use the system. When they've been using it for a while, the specialist team should see whether it might be a good idea to try switching to insulin doses.

## ***Devices for giving insulin***

Children and young people should be able to choose the devices that they use to give themselves their insulin, though the options will depend on the type of insulin they have. If they use injections, the needles should be the right length for them.

Children and young people shouldn't be prescribed medicines for diabetes with the general (non-brand) names acarbose, glibenclamide, gliclazide, glipizide, tolazamide, or glyburide. They don't improve glucose control but they may cause hypoglycaemia.

## **Coping with diabetes**

Some people find it difficult to use their insulin properly and have the right food and drinks all the time. The diabetes care team should be alert to signs of this in a child or young person. For example, the team should think about whether this could be a problem in someone who has poor glucose control or who has ketoacidosis (see page 21). Young people (11 or older) who keep getting ketoacidosis over quite a short time should see someone to talk to about any possible problems. If they're feeling frustrated and are having problems coping with the routine of diabetes, their diabetes care team should try to help them get through the bad patch.

## **Checking blood glucose**

Keeping blood glucose under control is the most important thing in managing diabetes. The diabetes care team should explain that if the glucose is too high, there's a risk of developing problems with the eyes, kidneys, nerves, feet and heart later in life. But if the glucose gets too low, the child or young person can become hypoglycaemic, and can feel dizzy and faint, and may even black out.

When there's a high amount of glucose in the blood, some of it gets attached to a part of the blood called the haemoglobin. At any particular time, the

amount that's attached shows the amount of glucose that has been in the blood over the last 6 to 12 weeks. The part with the glucose is called HbA<sub>1c</sub>, and this is what should be measured in the clinic's test for blood glucose. The diabetes care team should talk to the child or young person about the level of HbA<sub>1c</sub> to aim for – normally it's a level that's under 7.5%. The child or young person's care package should aim to help the child or young person to reach this while at the same time making sure that they don't become hypoglycaemic too often (see page 10).

A child or young person with a very high HbA<sub>1c</sub> (over 9.5%) should have extra advice to help them improve their glucose control.

### ***At the clinic***

The diabetes care team should test the child or young person's HbA<sub>1c</sub> level two to four times a year. Team members should have the up-to-date results when they see the child or young person.

### ***Self-monitoring***

The diabetes team should explain how and when blood glucose levels should be checked (urine is not checked for glucose as it doesn't give such reliable results). How often to check will depend on the child or young person's individual circumstances. For someone who is trying to sort out the best way to control their blood glucose, it's a good idea to check the levels more than four times a day. If a child or young person is ill, they should also check their blood glucose more than four times a day.

It should also be explained that glucose results need to be thought about in the light of what's going on in the child or young person's world at that time. Different things can affect glucose control.

The diabetes team should explain that using a glucose monitor with a memory to store previous results, together with a diary to write down the results, is the best way to keep a check on glucose levels.

## **What to aim for**

The diabetes care team should explain that the aim of self-monitoring and adjusting the insulin dose is to get a glucose level of 4–8 mmol/litre before a meal, and under 10 mmol/litre after a meal (mmol/litre is pronounced 'milli mole per litre'). They should encourage children and young people who have more than two insulin injections a day to adjust their insulin dose after each glucose measurement (that is, the measurements before meals, at bed-time and occasionally at night-time). Children and young people who have two injections a day should be encouraged to look at the general pattern of their results and adjust their insulin dose if they need to.

## **Food and drink**

In general, children and young people with type 1 diabetes need the same balance of foods as others, and the diabetes care team should talk about this. Very young children (babies and pre-school age children) should have their individual needs worked out by the diabetes team.

The child or young person should be encouraged to learn what different foods give to the body and how they affect glucose levels. If a child or young person has more than two insulin injections a day, they should have the chance to learn how to change the insulin dose and timing according to what they eat. Information and advice should also be available to children and young people to help them cope with their diabetes during special times, such as religious fasts and celebrations.

Together with their parents or carers, children and young people should also have the chance to learn how healthy eating can help to cut the risk of having a heart attack or stroke and how making changes to the food they eat can help them. For example, eating five portions of fruit and vegetables a day can help as part of a healthy lifestyle.

## ***Bed-time snacks***

It's a good idea for children and young people with type 1 diabetes to have a snack at bed time. The team should talk about this with the child or young person, and their parents or carers. They should agree on the best things to have as a snack and exactly when to have them.

## **Exercise**

Exercise is good for all children and young people as it can lower the chance of them having a heart attack or a stroke in later life. It's especially good for people with diabetes who can be more likely to have these problems when they're older because of their diabetes. Reducing this likelihood is a good thing, so the diabetes care team should encourage regular exercise.

Diabetes isn't a barrier to joining in with any sort of sport or exercise, as long as the child or young person makes the right changes in their insulin and food. Their diabetes care team should help with this. For some sports, such as scuba diving, they'll need a lot of advice from their diabetes care team. Information may also be available from local and national diabetes support groups and organisations.

One of the things that's it's important to know about is the effect of exercise on blood glucose. The diabetes care team should advise on checking glucose levels before and after exercising. This is so the child or young person can see how the glucose levels change and can work out how to manage the effects of the exercise. The diabetes team should also advise on how to stop hypoglycaemia from happening during and after exercise or other physical activity – for example:

- to have a carbohydrate-based snack before exercising
- to make sure that there's a carbohydrate-based snack close by during and after exercise
- to be aware that hypoglycaemia can happen several hours after a long period of exercise.

If the blood glucose is under 7 mmol/litre before exercise, the child or young person should eat or drink something containing carbohydrate.

If a child or young person's daily routine changes so that they exercise more or less often (for example, if they start training for an event), their insulin dose, food intake or both may need to be changed.

If blood glucose is above 17 mmol/litre and ketones are present in the urine, the child or young person should be especially careful when exercising. The diabetes care team should discuss this.

## **Drinking, smoking and using drugs**

### ***Alcohol***

Diabetes care teams should talk to young people (11 or older) with type 1 diabetes about the general problems that alcohol can cause, and the particular effects it can have for people with type 1 diabetes (for example, it can cause night-time hypoglycaemia). Young people with type 1 diabetes should be offered the chance to learn more about alcohol on an alcohol education course.

Young people who choose to drink should be advised:

- to eat a carbohydrate-based snack or meal before and after drinking
- to check their blood glucose regularly and try to keep in the right range by eating foods containing carbohydrate.

### ***Smoking, drugs and substance abuse***

Smoking causes all sorts of health problems. In people with diabetes, smoking can increase the already-higher risk of having a heart attack or stroke, so it's a particularly bad idea. The diabetes team should encourage the child or young person not to smoke and, if they already smoke, should help them stop smoking. Children and young people with type 1 diabetes should have the

chance to learn more about the problems with smoking in a smoking education course.

The dangerous effects of illegal drugs and other substances that can be misused should also be explained – both the general effects and the ones that can specially affect someone with diabetes.

## **Problems that can happen because of diabetes**

### ***Hypoglycaemia***

Hypoglycaemia is when the blood glucose dips too low so there's not enough glucose going to the different parts of the body. It can make a person feel dizzy and, if it gets bad, they can black out. These symptoms usually occur in most people when the blood glucose level is under 3 mmol/litre, though for some it may be as low as 2 mmol/litre or as high as 3.5 mmol/litre.

The diabetes care team should explain what to do if there are signs of hypoglycaemia. The child or young person should, for example, always have a carbohydrate-based snack or drink close by, and their glucose monitor should be handy so that their glucose levels can be checked easily. Teachers, parents/carers and friends should also be given the chance to learn about the signs of hypoglycaemia.

If a child or young person is feeling dizzy and weak with hypoglycaemia, the advice is:

- something should be done straight away
- they should eat or drink something that will quickly get sugar into their blood (sometimes it will be easier to drink something than to eat it, or they may have to have several lots of small amounts if they are being sick)
- as they feel better and their blood glucose levels increase, they should eat something that will keep their glucose levels up (unless they're just about to have a meal or they're using a system that delivers a continuous dose of insulin)

- their blood glucose should be checked within 15 minutes of the hypoglycaemia.

If a child or young person has severe hypoglycaemia and becomes unconscious, the advice for the people who treat them is shown in the box below.

#### **Advice when a child or young person has severe hypoglycaemia**

- Glucose (10%) should be injected, if possible
- If it isn't possible to inject glucose, a substance called glucagon should be injected into a muscle (but if alcohol has caused or added to the hypoglycaemia, glucose has to be used as glucagon might not work)
- If the child is over 8 years or weighs more than 25 kg, 1 mg glucagon should be used; younger or lighter children should have half this dose (500 micrograms)
- Blood glucose should start to get back to normal within 10 minutes
- If the child or young person is able to take it, they should be given carbohydrate to eat or drink
- The child or young person may not be properly awake for several hours afterwards; their blood glucose should be checked regularly to see if further treatment is needed
- After 10 minutes, if the child or young person does not seem any better or their blood glucose levels haven't increased, get medical help
- Parents, school nurses and other carers should have glucagon available to use if there's an emergency and should be given the opportunity to learn how to give it

### ***Ketoacidosis***

Diabetic ketoacidosis happens if the body becomes unusually stressed (during an illness, for example) and there's not enough insulin to cope with the effects, plus the person has not been eating or drinking properly and/or may have been sick. The person becomes hyperglycaemic and dehydrated and

what's known as a metabolic acidosis develops (the body's natural acid–base balance becomes disturbed). It's a medical emergency and the person can go into a coma.

A child or young person who has diabetic ketoacidosis should be treated following the guidelines published jointly by a patient group and a professional body. These are available from the Diabetes UK website – go to [www.diabetes.org.uk/dka\\_paed/index.html](http://www.diabetes.org.uk/dka_paed/index.html). The phone number is 020 7424 1030.

At first, a child or young person who has ketoacidosis should go into a high-dependency unit or should be in a high-dependency bed on a children's ward. If they're an infant, they should go into a children's intensive care unit. An older child should be moved to the children's intensive care unit if their condition is getting worse, a problem is suspected or if they are not recovering as expected.

If the child or young person seems well but their acid–base balance is still abnormal, they may be tried on fluids and insulin injections (which should be given frequently). Their blood glucose should be checked regularly.

### ***Checking for other medical problems***

If a child or young person has type 1 diabetes, there's a chance that they could develop other conditions. And there are also problems that can develop as the result of having too much glucose in the blood. Because of these risks, the child or young person should be checked for certain things at regular times.

- When they are first being diagnosed with diabetes, the child or young person should be tested for signs of coeliac disease, a condition that affects the digestive system; this test should be repeated at least every 3 years.
- They should be tested for signs of thyroid disease when they're diagnosed and then every year after that. The thyroid is a gland in the

neck. It produces hormones that are important for several things in the body, including the regulation of metabolism (the balance of chemical reactions in the body).

- Once a child gets to 12 years, they should be tested every year for:
  - signs of eye disease linked to diabetes, known as retinopathy
  - the presence of a protein, called albumin, in their urine (this can be a sign of kidney problems)
  - high blood pressure.

Children and young people with type 1 diabetes should also be offered a foot check every year. At every clinic visit, the diabetes care team should ask if they can look at the injection sites to check they're OK.

Regular dental check-ups and eye tests are recommended as for other children and young people (that is, every 6 months for a dental check-up and every 2 years for the eye test).

There is no reason presently for a child or young person with type 1 diabetes to have their blood lipid levels checked regularly (lipids are fat-like substances, and the amount in the blood can be linked with the risk of heart disease and stroke), or a check of their nerve function (older people with diabetes can develop problems with their nerves and their ability to feel things).

Juvenile cataract (where the lens in the eye becomes cloudy), necrobiosis lipoidica (which is skin changes, usually on the legs), and Addison's disease (where the body produces only very low amounts of steroid hormones) are some conditions that can be linked with type 1 diabetes, but they are rare. The diabetes care team should bear them in mind, though, when they see a child or young person with type 1 diabetes.

Finally, the child or young person's height and weight should be measured and put on a growth chart that plots these measurements over time every time they go to the clinic.

## ***Anxiety and depression***

People, including children, with a long-term medical condition can get anxious, depressed or both. This may happen in a child or young person if, for example, they can't seem to get their glucose levels under control. If a child or young person has problems sorting out their blood glucose, their team should discuss anxiety and depression with them. If the child or young person, or their team, thinks that they may be going through a bad patch, they should see a specialist who can help.

## ***Eating disorders***

Children and young people with type 1 diabetes are more likely to develop an eating disorder than others. If a child or young person does have an eating disorder, they may also have problems with hyperglycaemia, repeated spells of hypoglycaemia, and symptoms linked with gastric paresis, which is where the stomach doesn't empty the food into the intestine properly. If the diabetes care team thinks a child or young person has an eating disorder, they should arrange for them to see a specialist who will then work with the team to provide help.

## ***Problems with memory and thoughts***

Young (pre-school) children who have very frequent severe hypoglycaemia have a chance of developing problems with their memory and thought processes later in life. This risk is small, but is especially linked to children who have hypoglycaemia that causes seizures. The diabetes care team should discuss this with parents. They may recommend having an assessment of the child's ability to think clearly and remember things (this ability is called cognitive function).

Teachers should be aware of a link between type 1 diabetes and possible problems with cognitive function.

## **Advice if a child or young person is ill**

The diabetes care team should explain what to do about insulin and food and drink if the child or young person is poorly, for instance with diarrhoea and vomiting. This advice is sometimes called 'sick day rules'. They should talk about using short-acting insulin or rapid-acting insulin analogues to help control blood glucose during the illness. These should be available to the child or young person, as should test strips for ketones in the blood, urine or both.

## **Immunisations**

The Department of Health recommends that children (over 6 months) and young people with diabetes should have a yearly flu jab. Immunisation against pneumococcal infection is recommended for those over 2 years.

## **Having an operation**

If a child or young person needs an operation for some reason, it should be done only at a hospital that has special facilities for children and young people with diabetes. The surgeon and anaesthetist should talk to the diabetes care team before the child or young person goes into hospital or, if they've gone in for an emergency operation, as soon as possible afterwards.

All medical centres and hospitals that look after children and young people with diabetes should have sets of written rules about the care of children and young people with diabetes who are having an operation.

## **Long-distance travel**

Children, young people and their parents should have information about problem that might occur during long-distance travel for a person with type 1 diabetes. They should have the chance to learn more about what might happen and what to do during this type of travel.

## **Help and support**

Children and young people should be given the chance to learn some ways of coping with their feelings and the consequences of having diabetes. Young people should also be able to have some other guidance, such as from a mentor, to help them feel more in control and able to cope. If behaviour is a problem, the child or young person and their family or carers should be offered help from a specialist in this area. This help should be available when it's needed.

The family of a child or young person with diabetes will also be affected from time to time, and problems may occur. Families should have the chance to learn some ways of dealing with these and keeping them to a minimum.

The diabetes care team should be able to get advice and help from professionals who work in mental health if they need it.

## **Diabetes support groups**

The diabetes care team should be able to tell a child or young person, and their parents or carers, about the local and national groups for people with diabetes and what they have to offer.

## **Moving to an adult diabetes clinic**

As the teenager becomes more responsible for managing their diabetes they should continue to attend a diabetes clinic on a regular basis (three to four times a year).

The diabetes care team should make arrangements for special clinics for older teenagers. They should be able to settle into the change in their own time so they get used to the adult clinic and any changes in their care. The specific arrangements for moving to the adult clinic will depend on what's done in the area, though the timing of the change depends on the individual.

For example, it shouldn't be done at a time when other things are changing in the teenager's life.

## **Where you can find more information**

If you need further information about any aspects of type 1 diabetes or the care that you or your child is receiving, please ask a member of the diabetes care team. You can discuss this information with them if you wish, especially if you aren't sure about anything. They will be able to explain things to you. NHS Direct may also be helpful – phone 0845 4647 or visit the NHS Direct website at [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk).

For further information about the National Institute for Clinical Excellence (NICE), the Clinical Guidelines Programme or other versions of this guideline (including the sources of evidence used to inform the recommendations for care), you can visit the NICE website at [www.nice.org.uk](http://www.nice.org.uk). At the NICE website you can also find information for the public about other guidance in the following areas. These can also be ordered from the NHS Response Line (phone 0870 1555 455):

- the use of long-acting insulin analogues for the treatment of diabetes – insulin glargine, reference number N0181 (based on NICE Technology Appraisal Guidance No. 53)
- the use of continuous subcutaneous insulin infusion for diabetes, reference number N0196 (based on NICE Technology Appraisal Guidance No. 57)
- patient education models in diabetes, reference number N0251 (based on NICE Technology Appraisal Guidance No. 60).

## Explanation of medical words and terms

- Albumin:** a protein that can leak into the urine – if it's there persistently, it can be a sign of kidney problems
- Child:** in this booklet, a child is under 11
- Diabetes care team:** see multidisciplinary team; for children and young people, the team members should have particular skills and training in looking after children and young people with diabetes
- Gastric paresis:** where the stomach doesn't empty properly into the intestine
- HbA<sub>1c</sub>:** the short-hand abbreviation for glycosylated haemoglobin: this is a measure of the average level of blood glucose over 6–12 weeks. The range for children without diabetes is under 6%. The recommended target for children and young people with type 1 diabetes is under 7.5%.
- Heart attack:** where part of the heart dies because the heart artery is blocked and blood has been unable to get through to the heart muscle
- Hyperglycaemia:** where there is too much glucose in the blood
- Hypoglycaemia:** where there is too little glucose in the blood
- Insulin analogue:** a synthetic form of insulin manufactured to be similar to human insulin, but with new characteristics that can make it last longer in the body
- Ketoacidosis:** a condition where the person is hyperglycaemic and dehydrated and what's known as a metabolic acidosis

develops (where the body's natural acid–base balance becomes disturbed)

**Ketones:** substances that occur in the body under certain conditions of low blood insulin levels

**Multidisciplinary team:** a team of different types of health professional who work together to make sure that people have the care they need, at the time they need it; for children with diabetes, these are known as children's (paediatric) diabetes care teams

**Retinopathy:** disease involving the blood vessels of the inside back wall of the eye (the retina)

**Stroke:** where the blood stops getting through to an area of the brain

**Young person:** in this booklet, a young person is 11 or over, but under 18