

Type 1 diabetes in children and young people

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

Update, June 2009

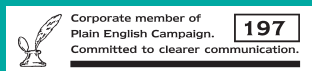
We have updated our guidance on screening for other conditions in children and young people with type 1 diabetes (page 43); we have removed the recommendation to re-test for coeliac disease at least every 3 years after diagnosis.

This update follows the development of 'Coeliac disease: recognition and assessment of coeliac disease' (NICE clinical guideline 86, 2009).

The changes are shown in this document as greyed out text.



July 2004



Type 1 diabetes in children and young people

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

Issue date: July 2004

To order copies

Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0623.

A version in English and Welsh is also available, reference number N0560. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0560. The NICE clinical guideline on which this information is based, *Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults*, is available from the NICE website (www.nice.org.uk/CG015NICEguideline). A quick reference guide for healthcare professionals is also available from the website (www.nice.org.uk/CG015childrenquickrefguide), and the NHS Response Line, reference number N0622).

National Institute for Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk

ISBN: 1-84257-689-5

Published by the National Institute for Clinical Excellence
July 2004

Artwork by LIMA Graphics Ltd, Frimley, Surrey
Printed by Oaktree Press Ltd, London

© National Institute for Clinical Excellence, July 2004. All rights reserved. This material may be freely reproduced for educational and not-for-profit purposes within the NHS. No reproduction by or for commercial organisations is allowed without the express written permission of the National Institute for Clinical Excellence.

Contents

About this information	4
Clinical guidelines	4
What the recommendations cover	5
How guidelines are used in the NHS	6
If you want to read the other versions of this guideline	7
Explanation of medical words and terms	8
Type 1 diabetes	8
Diagnosis	9
Straight after diagnosis	11
The children's diabetes care team	11
Staying at home or going into hospital	13
Diabetic ketoacidosis	14
Dealing with the diagnosis	14
24-hour advice	15
Learning about type 1 diabetes and how to manage it	15
Starting insulin	16
Ongoing care	16
Education about type 1 diabetes	16
Information for an emergency	18
Using insulin	18
Insulin timings	22
Insulin delivery systems	26

Other medicines for diabetes	27
Checking blood glucose	28
At the clinic	29
Self-monitoring of blood glucose	29
Diet	32
Bedtime snacks	34
Exercise	34
Drinking, smoking and using recreational drugs	36
Alcohol	36
Smoking	37
Recreational drugs and substance abuse	37
Problems that can happen because of diabetes	38
Hypoglycaemia	38
Diabetic ketoacidosis	41
Checking for other medical problems	43
Emotional problems and difficult behaviour	46
Anxiety and depression	46
Eating disorders	47
Problems with memory and thoughts	48
Advice if a child or young person is unwell	49
Immunisations	49
Having an operation	50

Long-distance travel	51
Coping with diabetes	51
Help and support	52
Diabetes support groups	54
Moving to an adult diabetes clinic	54
Where you can find more information	55
Explanation of medical words and terms	57

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. NICE has also issued information describing the guidance on the diagnosis and management of type 1 diabetes in adults.

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). You can download the booklet *The Guideline Development Process – An Overview for Stakeholders, 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 N0472).

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.

The recommendations in *Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults* (NICE Clinical Guideline No. 15), which are also described here, cover the care that should be available from the NHS to children and young people with type 1 diabetes. In this information, a child is someone younger than 11 years of age, a young person is 11 or older and younger than 18, and an adult is 18 or older. The recommendations 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 46 47 or visit the website at www.nhsdirect.nhs.uk

If you have questions about the specific options covered, talk to a member of your 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

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* (NICE Clinical Guideline No. 15)
- 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 health 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). 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 (N0623 for this version,

N0560 for this version in English and Welsh, and N0622 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 57 to 60.

Type 1 diabetes

Type 1 diabetes happens when the cells in the pancreas that produce insulin are damaged by the body's immune system. Insulin is the main substance that coordinates how the body handles glucose (sugar) after it enters the blood from digested food. Without enough insulin, the amount of glucose in the blood becomes higher than normal.

There are two groups of problems that can happen as a result of type 1 diabetes. First, a sudden, severe lack of insulin can cause immediate problems, including one kind of coma. Second, having blood glucose levels that are too high for long periods can damage the blood vessels, heart, nerves, feet, kidneys and eyes.

Type 1 diabetes is managed by putting insulin into the body – this is sometimes called ‘insulin replacement’ because you are replacing the insulin that would normally be made in the body. There are different types of insulin, and insulin is usually given by injection or using what’s known as an insulin pump (see pages 18 to 27).

Diagnosis

Doctors should follow the advice of the World Health Organization when they are deciding on a diagnosis of type 1 diabetes in children and young people (the document with this advice can be found on the Internet at http://whqlibdoc.who.int/hq/1999/WHO_NCD_NCS_99.2.pdf). The advice is outlined in the next paragraph.

Type 1 diabetes in children and young people is nearly always simple to diagnose. Usually the person has high levels of glucose in their blood and urine, and chemicals known as ketones in their urine (sometimes they are very ill with ketoacidosis – see page 14). Occasionally, symptoms may be very mild: even so, blood glucose levels are always higher than they should be.

If it's thought that a child or young person may have type 1 diabetes, they should be able to see a children's diabetes care team that same day. The health professionals in this team should be able to confirm whether it is type 1 diabetes and to start to look after the child or young person if it is. There is more information on children's diabetes care teams on pages 11 to 13.

Sometimes, it's possible that a child or young person may have another type of diabetes (different types of diabetes need different treatments). 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)
- needs quite a small amount of insulin to control their blood glucose levels, even when they're not in a partial remission phase (this is an initial period when a person's body is still able to make some insulin so they don't need to have the full pattern of insulin replacement straight away)

- does not need insulin at all
- hardly ever or never has ketones in their urine when they have high levels of glucose in their blood
- has signs that their body doesn't use insulin normally (for example, they may have brown markings on their skin – this is known as acanthosis nigricans)
- has other conditions at the time the diabetes is diagnosed, such as eye problems or deafness.

Children and young people diagnosed with type 1 diabetes should have their details kept on a register, for example at their clinic or doctor's practice, 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 team of health professionals called a children's (paediatric) diabetes care team should be involved in confirming the diagnosis of type 1 diabetes in a child or young person.

From that time onwards, it's this team that the child or young person should see for treatment and care.

A children's diabetes care team is what's known as a multidisciplinary team: it's made up of different types of health professional with specialist knowledge and up-to-date training of, in this case, treating and caring for children and young people with diabetes. Between them, the team members should know about:

- teaching people about or giving information on diabetes, or both
- nutrition for children and young people with diabetes
- how diabetes affects a child or young person's life and how the effects can be managed
- mental health problems (such as anxiety) that may affect a child or young person with diabetes
- looking after the feet of a child or young person with diabetes

The team should offer the child or young person a 'package' of care that brings all these things together. And this should continue to be on offer as the child or young person gets older. The child or young person and their family should be involved in the decisions made about the package of care.

Staying at home or going into hospital

At the time of diagnosis, a child or young person should be offered care at home or in hospital, depending on:

- how likely they are to need medical help quickly (for example, if they are poorly at diagnosis they are likely to need to be in hospital)
- their family's circumstances and wishes
- how far they live from the hospital.

Normally, being cared for at home is as good as being cared for in hospital, as long as the diabetes care team is involved and the person or their family can get advice when they need it. But a short time in hospital should be offered for:

- young children (under 2 years)
- children and young people with social or emotional problems
- children and young people who live a long way from the hospital.

Diabetic ketoacidosis

If the first sign of type 1 diabetes is that the child or young person has diabetic ketoacidosis, they should be treated in hospital (see page 41).

Dealing with the diagnosis

After the diagnosis, children, young people and their families should be given the chance to talk about their feelings and any worries. They should be offered support that's suited to their individual needs (for example, it should be suited to their age, how upset they feel, their background and their culture). They should also be told about support groups for people with diabetes (see page 54).

24-hour advice

Children and young people with type 1 diabetes and their families should be able to get advice from their diabetes care team 24 hours a day.

Learning about type 1 diabetes and how to manage it

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

- the aims of insulin therapy
- how insulin is given
- how and when to check their blood glucose levels
- how glucose levels are affected by food and drink, exercise, and being unwell
- the signs of a hypoglycaemic episode and what to do if this happens (this is known as having a 'hypo', where blood glucose drops to a low level).

These things should be covered in a structured education programme rather than being discussed informally.

Starting insulin

In most cases, insulin is started straight away in the first day or two of diagnosis (see page 18 for more information about insulin).

Ongoing care

The following sections describe the ongoing care you should receive, including the information you should be offered, day-to-day management of diabetes and dealing with problems that can happen because of diabetes.

Education about type 1 diabetes

Children and young people with type 1 diabetes, and their families, should be offered information about the development, management and effects of type 1 diabetes as and when they need it. Things should be explained in such a way that the information can be understood, so each person feels able to take part in the discussions and decisions about how the diabetes should be managed. It's also important that children, young people and their families aren't told different things by different members of the

care team, and that the information they are given is right. There should be an opportunity to ask questions and to discuss different issues about diabetes at every clinic visit.

The way in which a child or young person is given information should be matched to their age and maturity, culture, and their wishes and those of their family. How much the family already knows about type 1 diabetes should also be taken into account. Health professionals should be particularly careful that useful information is available for children, young people and parents with special needs. These include people with disabilities and people who find it difficult to speak or read English.

Children's diabetes care teams should be in regular contact with school staff who look after children and young people with type 1 diabetes. They should offer staff education and practical information about diabetes and its management.

Children and young people with type 1 diabetes and their families should be told how to find out about government disability benefits that they may be able to claim.

Information for an emergency

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

Using insulin

Type 1 diabetes happens when 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 do this. At first, a person may only need a low dose of insulin to control their blood glucose because their body is still making some insulin itself – this period is called a partial remission phase (or 'honeymoon period'). This period does not last, and it can't be made to last longer by having more than two daily insulin injections or by using an insulin pump.

If the balance of insulin and food is not quite right, the person can become hypoglycaemic – too much insulin means that the blood glucose level becomes so low that there isn't enough to supply the body. Children, young people and their families should be told how to reduce the likelihood of a hypo and what to do if it happens.

The main types of insulin are described in the box on the next page.

Types of insulin

In people without diabetes, there's normally a low level of insulin in the blood. After a meal, the level of insulin increases to deal with the sudden increase of glucose in the blood that comes from the food or drink.

Different types of insulin are available for people with type 1 diabetes. They work for different lengths of time. By matching the type of insulin to a person's needs, it's usually possible to get a pattern of glucose control that is either similar to the normal pattern or that gives the same overall control of glucose levels. The main categories of insulin are:

- **rapid-acting insulin analogues:** (an insulin analogue is a synthetic form of insulin made to be similar to human insulin, but with characteristics that affect how long it lasts in the body) rapid-acting insulin analogues aim to work like the insulin normally produced to cope with a meal; their effect falls away quickly
- **short-acting insulins:** these work more slowly than rapid-acting insulin analogues, and their effect 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:** these have an effect that can last for a longer period, even a whole day.

A **biphasic insulin** is a mixture of rapid-acting insulin analogue or short-acting insulin together with intermediate-acting insulin.

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 put into the body in a way that bypasses these, using injections or a pump.

Children and young people with type 1 diabetes should be offered the insulins that are likely to suit them best. The choice depends on the child or young person's individual needs and what's appropriate for them according to the instructions in the patient information leaflet supplied with the insulin.

Insulins containing intermediate-acting insulin

Insulin products that contain intermediate-acting insulin should be mixed before being used (following the instructions in the patient information leaflet supplied with the insulin).

Insulin timings

There are different patterns for taking insulin. The number of times each day and the exact times of the day that the person has to take insulin will depend on the types of insulin being taken. The more common daily patterns for taking insulin are shown in the box on the next page.

Insulin timings

One, two or three insulin injections per day: these are usually injections of short-acting insulin or rapid-acting insulin analogue mixed with intermediate-acting insulin.

Multiple daily injection regimen: the person has injections of short-acting insulin or rapid-acting insulin analogue before meals, together with one or more separate daily injections of intermediate-acting insulin or long-acting insulin analogue.

Insulin pump therapy: a pump worn on the body gives a regular or continuous feed of insulin into the skin (see page 25) – the medical name is continuous subcutaneous insulin infusion.

Pre-school and primary school children

For a pre-school or primary school child, the insulin pattern should be individually designed to suit the specific needs of the child.

Multiple daily injection regimens

A young person or child who is using a multiple daily injection regimen should be warned that, at first, they may find that they become hypoglycaemic more often, put on a bit of weight, or both.

Young people (11 or older) should be able to try a multiple daily injection regimen (see box on page 23) to keep their glucose levels under control. But they should only try this as part of a 'package' of care, because having the whole package improves glucose control. This package should include:

- continuing education about diabetes
- help with diet
- being taught how to use insulin delivery systems and how to monitor their own blood glucose levels (known as 'self-monitoring')
- support for emotional problems or to overcome difficult behaviour patterns
- help from doctors, nurses and dietitians with expert knowledge about diabetes in young people.

If a young person finds it hard to keep their blood glucose levels under control with a multiple daily injection regimen, they should be offered extra help from the diabetes care team and, if it is appropriate, they should be offered a different insulin regimen (one, two or three times a day or insulin pump therapy).

If a young person finds it difficult to keep to the multiple injection regimen, they should be able to change to two insulin injections a day.

Using rapid-acting analogues

For children and young people using multiple daily insulin injections, injecting a rapid-acting insulin analogue before eating helps with glucose control. For pre-school children, it may be better to inject it shortly after they've eaten, just in case they don't actually eat their food.

Insulin pumps

Sometimes it's impossible to keep to the target HbA_{1c} without having problems with hypoglycaemia, even with multiple daily injections (see 'Checking blood glucose')

on page 28 for more information on HbA_{1c}). In this case, a child or young person should be offered the option of trying an insulin pump (a system that puts a regular or continuous amount of insulin into the body), if the diabetes care team and the child or young person and their family feel that that they are able, and want, to use the system.

If a child or young person is going to try a pump, they should be trained how to use it. A trained specialist team should be involved in starting them off with the pump, and should provide advice if it's needed once the pump is being used. After a person has been using a pump for a while, the specialist team should see whether it might be a good idea to try a switch to multiple daily injections that include insulin glargine (a long-acting insulin analogue).

Insulin delivery systems

Children and young people should be able to choose the insulin delivery system they want to use to give themselves their insulin, although the options (for example, syringes or pens) will depend on the type of insulin they have and what's suitable for them.

If needles are used for injections, the needles should be the right length for the child or young person (short needles for children and young people with less body fat and longer needles for children and young people with more body fat).

Other medicines for diabetes

Children and young people with type 1 diabetes should not be prescribed acarbose, glibenclamide, gliclazide, glipizide, tolazamide, or glyburide to help with their diabetes (these are not brand names, they are the general or generic names). These medicines wouldn't be expected to improve glucose control and they may increase the risk of hypoglycaemia.

Another medicine, metformin, should be prescribed for a child or young person with type 1 diabetes only as part of a research study. Not enough is currently known about its effect on blood glucose for it to be used routinely.

Checking blood glucose

It is important to keep blood glucose levels under control. The diabetes care team should explain that if the glucose level is too high, there's a risk of developing problems with the eyes, kidneys, nerves, feet and heart later in life. But if their glucose level gets too low, a child or young person can become hypoglycaemic – feeling dizzy and faint, and even possibly blacking 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_{1c}, 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_{1c} to aim for – normally the aim is 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 target, while at the same time making sure that they don't have problems with hypoglycaemia too often. The person shouldn't be having repeated hypos that put them in the position of needing help from

someone else – not only is this unpleasant but it can make the person worry about the next time it's going to happen.

Children and young people who continue to have a very high HbA_{1c} (over 9.5%) should be offered extra help to improve their glucose control.

At the clinic

At the clinic, the diabetes team should check how a child's or young person's blood glucose control has been over the previous few months. This is best done using a test that measures a substance in the blood called HbA_{1c}. Tests for HbA_{1c} should be carried out two to four times a year, and team members should have the up-to-date results when they see the child or young person in the clinic, so that they can decide whether any immediate changes are needed to the person's insulin or diet.

Self-monitoring of blood glucose

When a person checks their own blood glucose, it's known as 'self-monitoring' – the test is different from the HbA_{1c} test that's done in the clinic because it measures the amount of

glucose in the blood at that moment. People who self-monitor their blood glucose control properly are more likely to get to and keep to their target HbA_{1c} because their overall awareness of their blood glucose is better. The diabetes team should explain how and when to self-monitor (blood is used, not urine, because urine doesn't give such reliable results).

Children and their families, and young people should be able to choose the type of equipment for self-monitoring that suits them best. The diabetes team should explain that the best way to keep a check on glucose levels is to use a glucose monitor with a memory that stores results, together with a diary to write down the results as well as other things that happen (such as, food eaten and hypos) as this helps reduce the frequency of hypoglycaemia.

Children and young people should be offered a system that monitors their glucose levels all the time if either or both of the following continues to happen.

- They don't realise when they are becoming hypoglycaemic.
- Their blood glucose often becomes too low (hypoglycaemia) or too high (hyperglycaemia).

Regular self-monitoring should be part of children and young people's care packages, together with diet management, and having continuing opportunities to learn about diabetes and regular contact with members of the diabetes care team.

What to aim for

Self-monitoring of blood glucose measures the amount of glucose in the blood as 'mmol/litre' (mmol/litre is pronounced 'milli mole per litre'). The diabetes care team should explain that the aim of self-monitoring is to get a blood glucose level of 4–8 mmol/litre before a meal, and less than 10 mmol/litre after a meal. Remember, this is different from the HbA_{1c} test – self-monitoring of blood glucose is a measure of how much glucose there is in the blood at the moment, whereas HbA_{1c} is a measure of how well blood glucose has been controlled in the last few months.

To try to keep to the targets, children and young people should be taught how to adjust their insulin and diet. How often someone should check their blood glucose depends on their individual circumstances.

Diabetes care teams should encourage children and young people who have multiple daily insulin injections to check their blood glucose

before meals, at bedtime and occasionally at night-time and to adjust their insulin if they need to. Children and young people who have two insulin injections a day should be encouraged to take measurements before meals, at bedtime and occasionally at night-time and to look at the general pattern ('trend') and adjust their insulin dose if they need to.

For someone who is trying to work 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 unwell, they should also check their blood glucose more than four times a day.

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, and diabetes care teams should explain this. Many different things can affect glucose control – for example, stress because of exams or moving schools can have an effect.

Diet

In general, children and young people with type 1 diabetes need the same balance of foods as other people of their age, and diabetes care teams should talk about this. Very young

children (newborns, infants and pre-school children) should have their individual dietary needs worked out by their diabetes team.

Sometimes, using insulin can make a person put on weight. Children and young people should be offered advice and support with their diet so that they can keep to or reach a healthy weight while, at the same time, they achieve good glucose control.

Children and young people should be encouraged to learn what different foods provide to the body and how they affect glucose levels. As part of their package of care, a child or young person who has multiple daily insulin injections should have the chance to learn in depth how to change their 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 the practicalities of managing their diabetes during special times like religious fasts and feasts.

Together with their families, children and young people with type 1 diabetes should have the chance to learn about healthy eating and how they can reduce the risk of having problems such as heart disease or stroke when they're older. For example, they should be encouraged to eat five portions of fruit and

vegetables a day as part of a healthy lifestyle. They should also have help to make changes in their diet after type 1 diabetes is diagnosed and at different times from then on if changes are needed.

Bedtime snacks

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

Exercise

Regular exercise at any level is good for all children and young people because it can lower the chance of having problems such as heart disease or stroke in later life.

Diabetes isn't a barrier to taking part in any sort of sport or exercise, as long as the child or young person makes the right changes in their insulin and diet. Their diabetes care team should help with this. For some sports, such as scuba diving, a lot of advice will be needed from the team. Information

may also be available from local and national diabetes support groups and organisations.

One of the things 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 that the child or young person can see how the glucose levels change and can work out how to manage their insulin and diet to allow for the effects of the exercise. The diabetes team should also explain how exercise can cause hypoglycaemia during or after exercise – a long period of exercise can result in hypoglycaemia several hours later. They should advise on how to reduce the chance of a hypo; this should include advice to:

- have an extra carbohydrate-based snack before exercise, as needed (for example, if blood glucose is under 7 mmol/litre before exercise)
- make sure that there's a carbohydrate-based snack close by during and after exercise.

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, carbohydrate intake or both may need to be changed.

If blood glucose is above 17 mmol/litre and there are signs of ketosis, the child or young person should be especially careful when exercising. Ketosis is the medical name for a build-up of ketones – the signs are a feeling of, or actual, sickness and stomach pain. The diabetes care team should discuss this.

Drinking, smoking and using recreational drugs

Alcohol

The particular problems that alcohol can cause people with type 1 diabetes (for example, night-time hypoglycaemia) should be explained to young people (11 years or older) with type 1 diabetes. They should also be offered an alcohol education programme to help them learn more.

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 to try to keep their glucose levels in the right range by eating foods containing carbohydrate.

Smoking

Smoking causes all sorts of health problems. For example, it increases the risk of problems such as heart disease and stroke. Diabetes care teams should talk about this with children, young people and their families. Children and young people should be encouraged not to smoke. If they smoke, they should be helped to stop and should be offered a programme designed to stop people smoking (this is called a smoking cessation programme).

Recreational drugs and substance abuse

The dangerous effects of recreational drugs and other substances that can be misused should be explained – both the general problems and the ones that can specifically 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.

Diabetes care teams should explain what to do if there are signs of hypoglycaemia. Children and young people 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. Parents, other carers and schoolteachers should also be given the chance to learn about the signs of hypoglycaemia and what to do if the child or young person becomes hypoglycaemic.

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

- do something straight away (don't wait to see how it goes)

- the child or young person should eat or drink something containing sugary carbohydrate that will quickly get sugar into the bloodstream (sometimes it will be easier to drink something than to eat it; if the person is being sick they may have to have several lots of small amounts) – blood glucose should start to rise in 5 to 15 minutes
- once they feel better or their blood glucose returns to the usual level, they should eat starchy carbohydrate foods that will keep the glucose levels up (unless they are just about to have a meal or are using an insulin pump)
- re-check blood glucose within 15 minutes.

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 on the next page.

Advice when a child or young person has severe hypoglycaemia

- If in hospital, medical staff should inject glucose (10%) into a blood vessel (vein) if this is possible.
- If not in hospital or if it isn't possible to inject into a blood vessel, inject glucagon (a hormone that raises blood sugar levels) into a muscle or get the person to swallow a concentrated dose of glucose. If alcohol has caused or added to the hypoglycaemia, glucagon is unlikely to work, and intravenous glucose will have to be used.
- If the child is over 8 years old or weighs more than 25 kg, use 1 mg glucagon (all the injection); use 500 micrograms (half the injection) for younger or lighter children.
- Blood glucose should start to get back to usual levels within 10 minutes.
- Providing they are awake, give starchy carbohydrate food to eat as they start to get better or their blood glucose gets back to the usual level.

- The child or young person may not be properly awake for several hours afterwards. If this is the case, their blood glucose should be checked regularly to see if further glucose is needed.
- Get medical help if the child or young person does not seem any better or their blood glucose levels haven't increased after 10 minutes.

Parents, school nurses and other carers should have glucagon available to use if there's an emergency, especially if severe hypoglycaemia is quite likely. They should also be given the opportunity to learn how to give glucagon.

Diabetic 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; for example, if the person has not been eating or drinking properly and perhaps has been sick as well. The body starts to break down fat for energy, and ketones build up in the blood and

urine. Blood glucose levels are very high (hyperglycaemia) and the person is dehydrated. What's known as a metabolic acidosis develops (the body's natural acid levels become disturbed). Diabetic ketoacidosis is a medical emergency. The person may go into a coma if they aren't treated.

A child or young person who has diabetic ketoacidosis should be treated following the guidelines published by a professional body (the British Society for Paediatric Endocrinology and Diabetes).

At first, a child or young person who has ketoacidosis should go into a hospital high-dependency unit or should be in a high-dependency bed on a children's ward. If they're under 2, 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 level is still abnormal (pH less than 7.3), they may be given fluids and insulin injections (which should be given frequently). Their blood glucose should be checked regularly.

Checking for other medical problems

There's a chance that children and young people with type 1 diabetes can develop other conditions linked with type 1 diabetes. There are also problems that can develop as a result of having too much glucose in the blood over a long period of time. Because of these risks, children and young people 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 until the person moves to an adult clinic.**
- They should be tested for signs of thyroid disease when they're diagnosed and then every year after that until they move to an adult clinic. The thyroid is a gland in the neck that produces hormones. The important effects of these hormones include metabolic regulation (the metabolism is the balance of chemical reactions in the body).

- Once a child is 12 years old, 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.
- They should be offered a foot check every year.
- At every clinic visit, a member of 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.

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 children and young people with type 1 diabetes.

Finally, every time a child or young person goes to the clinic, their height and weight should be measured in a private room. The readings should be put on a growth chart. This will show how their weight and height are changing as they get older, so it's easy to see whether they are growing normally and have a normal weight. Unexpected changes in a person's height or weight can be a sign of problems with their glucose control. The child or young person's body mass index should also be worked out at every clinic visit. Body mass index (or BMI for short) is a standard way of working out a person's weight in relation to their height.

It is **not** recommended that children or young people with type 1 diabetes have regular checks of:

- their blood lipid levels (lipids are fat-like substances, and the amount in the blood can be linked with the risk of heart disease and stroke), or
- their nerve function (older people with diabetes can develop problems with their nerves and their ability to feel things).

When a young person transfers to an adult diabetes clinic, they should be offered regular checks for blood lipid levels and nerve function.

Emotional problems and difficult behaviour

Having type 1 diabetes can make a child or young person more likely to have an emotional problem or to behave in a way that's difficult to manage than others of their age. The diabetes care team should be aware of this and should look out for signs that problems might be developing.

If a child or young person has a disorder that's making them behave in a difficult way, they and their families should be able to see mental health professionals who can help them.

Anxiety and depression

Children and young people with type 1 diabetes can suffer from anxiety, depression or both. This may happen if, for example, they've had type 1 diabetes for a while but suddenly seem to have problems keeping their glucose levels

under control. The diabetes care team should know the signs of anxiety and depression and should watch out for them in the children and young people they look after. Also, if a child or young person has problems keeping their blood glucose levels under control, their team should discuss anxiety and depression with them and should offer them the chance to be checked for signs of these.

If the diabetes team thinks a child or young person may have anxiety or depression, they should arrange without delay for them to see one or more health professionals who specialise in helping children and young people with mental health problems.

Eating disorders

Children and young people with type 1 diabetes, especially young women, 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 a condition called gastric paresis, which is where the stomach doesn't empty food into the intestine properly. The diabetes care team should be aware of these things. If they think

a child or young person has an eating disorder, they should arrange for them to see one or more health professionals who specialise in helping children and young people with mental health problems. These health professionals should then work with the diabetes care team to help the child or young person.

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. 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 to remember things (this ability is called cognitive function).

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

Advice if a child or young person is unwell

Children, young people and their families should be told what changes to make to their insulin and their diet if they're unwell. This advice is sometimes called 'sick-day rules'. The diabetes care team 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 checking ketones in the blood, urine or both.

A child or young person who is unwell should try to check their blood glucose more than four times a day (see page 29).

Immunisations

Children and young people with type 1 diabetes and their families should be told about the Department of Health recommendations that apply to people with diabetes.

- 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 months. Pneumococcal infection is a bacterial infection that can cause pneumonia, meningitis and septicaemia (infection in the blood).

Having an operation

If a child or young person needs an operation, it should only be done 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 instructions about the care of children and young people with diabetes who are having an operation.

Long-distance travel

Children, young people and their families should have education about when to take their insulin and when to eat when travelling across time zones during long-distance travel. They should have the chance to learn about any problems that might happen during the journey and while they are away, and how to deal with them.

Coping with diabetes

Some people find it particularly difficult to use their insulin properly and to have the right food and drinks all the time. Teenagers, in particular, may want to rebel against their therapy. The diabetes care team should be alert to signs of this. For example, the team should think about whether this could be a problem if someone is having trouble keeping their glucose levels under control or if someone who has had type 1 diabetes for a while suddenly has one or more episodes of diabetic ketoacidosis (see page 41). If they suspect there could be a problem, they should raise it sensitively with the child, young person or their family.

If a young person (11 or older) keeps having episodes of ketoacidosis over quite a short time, they should have a check to make sure that they are feeling OK emotionally and that they aren't having problems with their behaviour.

If a young person is feeling frustrated and is having problems coping with the routine of diabetes, their diabetes care team should try to help them get through the bad patch. Diabetes care teams should be aware that children and young people with type 1 diabetes are more likely to have emotional and behavioural problems than other youngsters.

Help and support

Children and young people should be given the chance to learn ways of coping with their feelings and the consequences of having diabetes. This is especially important for those who have multiple daily insulin injections. Young people should also be able to have some other specific help so they can feel more in control and able to cope. For example, they may have a mentor to talk to (a mentor is someone other than a parent or carer who gets to know the child or young person and gives guidance and advice). Or they may be taught how to use self-monitoring so they can

make changes to their diet or insulin to help themselves to control their glucose better.

Children and young people with type 1 diabetes, and their families, should be able to get help from health professionals who specialise in mental health as and when they need it. This is because problems with mental health (such as anxiety and depression, and problems in the family) can affect how well a person manages their diabetes.

Diabetes care teams should understand how important it is to encourage families to help children and young people deal with the day-to-day practicalities of diabetes and with the wider effects on their lives. Family life may also be affected by the child or young person's diabetes, and family members should have the chance to learn some specific ways of dealing with and preventing these effects so problems can be avoided.

A diabetes care team should be able to get advice and help from professionals who work in mental health if they need it to help them care for a child or young person with type 1 diabetes.

Diabetes support groups

The diabetes care team should tell a child or young person, and their parents or carers, about local and national groups for people with diabetes. They should have the contact details for the groups and should know what they have to offer and how people can join and become involved with the groups. This information should be given to the child, young person or parents soon after the diagnosis has been made, and then the team should discuss support groups with them again from time to time.

Moving to an adult diabetes clinic

Young people should be encouraged to carry on going to the diabetes clinic regularly (three or four times a year). Children's and adults' diabetes care teams should make arrangements for special joint clinics for older teenagers and young adults.

When the time comes to move to an adult clinic, the young person should have time to get used to the idea of the move and any changes in their care. They should be told that

some things will change – for example, the self-monitoring targets and the routine checks they have for medical problems.

The specific arrangements for moving to the adult clinic will depend on what's done in the local area, although the timing of the change depends on the individual. For example, the move shouldn't be made 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 46 47 or visit the NHS Direct website at 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. On 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):

- type 1 diabetes in adults, reference number N0559 (based on *NICE Clinical Guideline No. 15*)
- 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 blood protein that can leak into the urine – if it's there persistently, it can be a sign of kidney problems.

Body mass index (BMI): a measure of a person's weight in relation to their height, showing if they are overweight or underweight.

Child: in this booklet, a child means someone younger than 11 years.

Diabetes care team: see also '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. In particular, the team should have members who have specific training in:

- the treatment and care of children and young people with diabetes
- teaching people about or giving information on diabetes, or both
- nutrition for children and young people with diabetes
- how diabetes affects a child or young person's life and how the effects can be managed

- mental health problems (such as anxiety) that may affect a child or young person with diabetes
- looking after the feet of a child or young person with diabetes.

Gastric paresis: where the stomach doesn't empty properly into the intestine.

HbA_{1c}: the abbreviation for glycated haemoglobin: this is a measure of the average level of blood glucose over 6–12 weeks. Children without diabetes have an HbA_{1c} less than 6%. The recommended target for children and young people with type 1 diabetes is less than 7.5%.

Heart attack: where part of the heart is damaged because the heart artery is blocked and blood has been unable to get through to the heart muscle.

High-dependency bed or unit: places in a hospital for children who need to be watched and checked more closely than children on an ordinary children's ward.

Hyperglycaemia: where there is too much glucose in the blood.

Hypoglycaemia: where there is too little glucose in the blood.

Infant: in this booklet, an infant means a baby older than 4 weeks but younger than 1 year.

Insulin analogue: a synthetic form of insulin manufactured to be similar to human insulin, but with new characteristics that can make it shorter-acting (for meal-time use) or longer-acting (as a background insulin).

Ketoacidosis: a condition where the person has raised blood glucose levels and is dehydrated so that 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.

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.

Multiple daily injection regimen: this is a pattern of taking insulin where the person has injections of short-acting insulin or rapid-acting insulin analogue before meals, together with one or more separate daily injections of intermediate-acting insulin or long-acting insulin analogue.

Newborn baby: in this booklet, a newborn baby (neonate) is a baby up to 4 weeks old.

Pre-school child: in this booklet, a pre-school child is 1 year or older, but younger than 5 years.

Primary school child: in this booklet, a primary school child is 5 years or older, but younger than 11 years.

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 years or older, but younger than 18.



*National Institute for
Clinical Excellence*

**National Institute for
Clinical Excellence**

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk