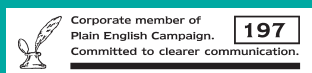


Type 1 diabetes in adults

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

July 2004



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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 N0559.

A version in English and Welsh is also available, reference number N0624. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0624. 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/CG015adultsquickrefguide), and the NHS Response Line, reference number N0558).

National Institute for Clinical Excellence

MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk

ISBN: 1-84257-623-2

Published by the National Institute for Clinical Excellence
July 2004

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

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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 adults 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 for the families and carers of children with type 1 diabetes, young people with diabetes, and the public.

Although the information in the present booklet has been written chiefly for adults with type 1 diabetes, it may also be useful for family members, those who care for adults with type 1 diabetes and anyone interested in diabetes or in healthcare in general.

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 adults with type 1 diabetes. They include how the diagnosis should be made and the options that should be offered at different times. They don't cover the additional care that is needed during pregnancy, or for women who develop diabetes during pregnancy. NICE is planning to produce a guideline on these aspects in 2006.

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 receive does not match what's described in the pages that follow, you should talk to your 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*
- 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). 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 (N0559 for this version, N0624 for this version in English and Welsh, and N0558 for the quick reference guide).

Explanation of medical words and terms

Brief explanations of some of the medical words and terms used in this booklet are provided on pages 61 to 64.

Type 1 diabetes

Type 1 diabetes happens when the cells in the body that produce insulin are destroyed by the body's own immune system. Insulin is the substance that regulates how the body deals with glucose (sugar) as it enters the blood from digested food and, at night, from the liver. Without enough insulin, high levels of glucose stay in the blood. Lack of insulin can cause immediate problems, including one kind of

coma. Having glucose levels that are too high for long periods can damage the blood vessels, heart, nerves, feet, kidneys and eyes. Type 1 diabetes is the standard medical name for the condition, but in the past it has been known as juvenile onset diabetes or insulin-dependent diabetes mellitus (IDDM).

The other common form of diabetes is type 2 diabetes (in the past, this was known as adult onset diabetes or non-insulin-dependent diabetes). In this type of diabetes, either the body isn't making enough insulin to deal with the glucose from the diet, or the body isn't able to use insulin properly. Type 2 diabetes appears most often in middle-aged and older adults, although it can develop in young people too. Type 2 diabetes is usually treated differently from type 1 diabetes – usually other medicines are prescribed before insulin. NICE has issued guidance on the management of type 2 diabetes – see the website (www.nice.org.uk) for details.

Diagnosis

In adults, type 1 diabetes usually comes on quite suddenly, giving a characteristic pattern of symptoms. If there is nothing to suggest that a person has type 2 diabetes or another illness, the diagnosis of type 1 diabetes should be confirmed by doctors. This is achieved by measuring the amount of glucose (sugar) in the blood, which is done in a laboratory. Special tests for type 1 diabetes (such as a test for antibodies that attack your own body or a test to check for a substance known as C-peptide) aren't usually needed, although they may sometimes be used if it's hard to tell whether a person has type 1 or type 2 diabetes.

If a doctor has diagnosed or is considering a diagnosis of type 2 diabetes, and either there are substances called ketones in the person's urine, the person has lost a lot of weight, or there are no signs of what's known as the metabolic syndrome (which is linked to type 2 diabetes, see Box, page 40), then the doctor should consider whether the person actually has type 1 diabetes. Similarly, if a younger person has signs of diabetes and a doctor has diagnosed or is considering a diagnosis of type 1 diabetes, and if the person is overweight or has a close relative with diabetes, then the doctor should consider whether they actually have type 2 diabetes.

After you've been diagnosed

If you've just been diagnosed with type 1 diabetes, you should see a team of health professionals (the diabetes care team) who will plan with you what will happen in the first few weeks and months. You should be involved in the decisions about your care and if you don't understand something, it should be explained to you. To find out more about your individual condition and needs, your health should be checked. This should include checks:

- to make sure your symptoms are not being caused by another condition
- to see if you have any other medical conditions or are taking any other medicines that might affect your treatment or the results of any tests
- for any other things that might make you at risk of having problems with your blood vessels (such as smoking)
- on the health of parts of your body (eyes, heart, feet and kidneys) that could be affected by diabetes later.

You should also be asked about:

- your home and work life, and the things you do in your spare time
- the sort of food you eat and prefer and the exercise you take
- your feelings about diabetes and your role in managing it
- any other things that might affect the way your diabetes is managed.

An individual plan should be put together on the basis of these checks and your views. It should include details of the sessions that you can attend to learn about diabetes (where they are held and how long it's recommended that you go for). It should also include details of the management of your diabetes and how you are going to check your own blood glucose levels ('self-monitor' – see 'Checking your own blood glucose' on page 13). It should say how you can contact members of the diabetes care team, and how often you should see someone (including your yearly check-up, see 'Yearly review' on page 13). Finally, it should say what has been agreed about managing your risk of problems linked with diabetes (known as complications).

Over the following weeks, you should have the opportunity to feed back your thoughts about the plan and how well it seems to be working. Some parts of the plan may need changing as a result. In any case, it should be reviewed with you every year. The annual review will include assessment of complications and vascular risk.

Learning about type 1 diabetes

If you have been diagnosed as having type 1 diabetes it's important that you understand what's happening in your body, how to deal with it, and how and when to seek help. In the months after you've had the diagnosis, you should be offered the chance to learn about these things. The way of doing this should be designed to suit your individual needs, so you can understand the things you are being told. You should be told who you can contact for help and advice when you need it.

Yearly review

You should have a special review with your diabetes team every year to see how well you are coping with your diabetes and whether you might benefit from learning more about diabetes and how to deal with it. If you feel that it would be helpful to know more about it or that you need to refresh your knowledge, you should say so at this time or at one of your more frequent check-ups.

Checking your own blood glucose

Soon after you are told you have diabetes, you should be taught how to check your own blood glucose levels (this is known as 'self-monitoring'). Your diabetes care team should tell you about the different ways of doing this and you should be able to choose what suits you most. A test strip and measuring device is usually the best. In general, the most practical types need small amounts of blood, give you the result quickly and are able to store previous results. You should use blood from your fingertips – in the future, it may be possible to use blood from other places, but it is not yet known whether this will give reliable results.

When talking to you about how often to check your blood glucose, your doctor should discuss your individual pattern of glucose control, the type of insulin you use, and your own preferences and lifestyle. You and your doctor should discuss a target blood glucose level, which will usually be in the range 4.0–7.0 mmol/litre for levels before food, and under 9.0 mmol/litre after food (mmol/litre is pronounced 'milli mole per litre'). It should be explained to you that major things happening in your life can affect your blood glucose results and that you need to bear this in mind.

Every year, your diabetes care team should check the equipment you're using, and how well your self-monitoring is going. There may also be times outside of the annual review when self-monitoring is discussed – for example, if you are finding it difficult to reach your target HbA_{1c} (see page 18).

Eating and diabetes

From the time that you have the diagnosis, you should start to be told about the effects of food and drink on your blood glucose levels, and how these relate to the type of insulin you use. Some of the information should be given

as part of the information sessions described on page 12 ('Learning about type 1 diabetes'), but your doctor, nurse or dietitian should also help you. The information and advice you get should be right for you. It should take into account things like your individual needs and beliefs. It should be adapted if you are overweight or underweight, have high blood pressure, have an eating disorder such as bulimia, or have a kidney problem. Again, if you need more information or think it would be helpful to go to some refresher sessions at any stage, say so.

The aim is that you can judge for yourself what you should eat or drink. It's also important that you know when and how to change your insulin dose if you eat more or less of your normal foods.

Another area that should be discussed is snacking. You should be told about the effects of different types of snack on your blood glucose and the types of insulin that are available to match your preferred snacks. After this, you and your doctor, nurse or dietitian should agree a plan for the type, amount and timing of snacks.

If you choose to drink alcohol, eat foods that are high in calories and/or sugar, or eat foods that have a high glycaemic index (which means that sugar is released into the blood quickly), the effects of doing this should be explained to you and you should be told how to use insulin to help.

You should also be given advice about how you can eat healthily to help to reduce the risk of getting arterial disease, because having type 1 diabetes puts you at higher risk of this in the long run. (Arterial disease is the medical name for problems involving your blood vessels, heart, or both; it can result in angina, which is chest pain caused by heart problems, heart attack and stroke.) If you need some help to try to change your eating habits, this should be available after diagnosis and at all times afterwards.

Activity and exercise

Your diabetes care team should discuss how exercise can help to reduce your risk of arterial disease. If you are trying to have a healthier lifestyle and want to include some exercise, you should be offered advice on:

- the intensity of exercise that's best for you and how often you should take it

- how you might need to change your diet and/or insulin in general and also during and after periods of exercise, and how you should check the effects on blood glucose by self-monitoring
- the dangers of exercising if you have high blood glucose levels
- the effects of alcohol in the 24 hours after exercise.

You should also be given details of other sources of information and contacts regarding physical activity and exercise.

Having your blood glucose checked

Your blood glucose levels should be checked every 2–6 months using a test that measures HbA_{1c} (A1c for short). HbA_{1c} is blood haemoglobin that has sugar attached to it – the amount of HbA_{1c} in the blood relates to the amount of glucose that has been in the blood in the previous 6–12 weeks. So if your blood glucose has been high during this time, your HbA_{1c} result will be relatively high, too. If your blood has some particular

abnormalities this test might not work reliably, and your diabetes care team will suggest using another test. This will give the same sort of information but is less useful. Your doctor should not regularly measure another substance – fructosamine – in place of HbA_{1c}.

If your blood glucose levels are stable, you're at your target blood glucose level, and/or you've been on the same type of insulin for a while, you'll probably have your HbA_{1c} checked every 6 months or so. But if you're having problems with your glucose levels or have recently changed insulin (either the type of insulin or the pattern of taking it), then you should have the test more often. Your blood test should be carried out at a time that means your doctor can discuss the result with you (so it should be carried out either while you're at the clinic or just before your appointment). Every time your HbA_{1c} is measured, you should be told the result.

If you have a lot of problems with your glucose levels, your doctor may discuss using a continuous glucose-monitoring system. The sort of problems where this type of system might be helpful include: if you often become hypoglycaemic (have low blood sugar) or hyperglycaemic (have high blood sugar) at the same time of day; if you become

hypoglycaemic without noticing the symptoms; or if your glucose levels don't seem to change as they would be expected to with insulin.

Setting a target HbA_{1c}

Having prolonged periods with higher-than-normal glucose levels in the blood can eventually cause problems in the eyes, kidneys, nerves and heart. Keeping your HbA_{1c} to below 7.5% is believed to reduce the risk of getting these problems. And even if you don't reach your target, any reduction in your HbA_{1c} helps.

If you decide to try to keep your HbA_{1c} below 7.5%, your diabetes care team should give you the help and support you need. If there are signs that you might be at a higher risk of getting arterial disease, then your doctor should discuss whether it would be good for you to aim for a lower HbA_{1c} (6.5% or lower). Again, if you want to go for the lower level, you should be given the support and help you need.

If your HbA_{1c} result is low (that is, at a normal or nearly normal level) or it is lower than expected going by the results of your self-monitoring, your doctor should think

about whether you could be having spells of hypoglycaemia or you are at risk of hypoglycaemic coma. Whoever discusses your target HbA_{1c} with you should also discuss your experiences and thoughts about hypoglycaemic episodes. If you are worried about becoming hypoglycaemic, you and your doctor may decide to go for a higher HbA_{1c} target. This should also be the case if you would have to make so many sacrifices to get to an HbA_{1c} of less than 7.5% that your enjoyment of life would be markedly affected.

Insulin

People with type 1 diabetes have to take insulin every day to control their glucose levels. A key part of managing your diabetes is finding a type of insulin and pattern of taking it that gives you the best glucose control with the fewest problems, and that suits you best. If there are any cultural reasons why some insulins are not acceptable to you, you should be able to discuss these and your wishes should be respected. See pages 21 and 22 for information on types of insulin.

In general, people with type 1 diabetes do not benefit from medicines other than insulin to reduce their blood glucose.

Types of insulin

People who don't have type 1 diabetes have a background ('basal') amount of insulin in their blood. After a meal, the amount increases to deal with the sudden appearance of high levels of glucose in the blood. By mixing and matching insulins for people with type 1 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.

Insulin can be prepared in several different ways. It can be prepared from pigs' ('porcine') pancreases, and also from cows' ('bovine'), although bovine insulin is not used much nowadays; these are known as animal insulins. Human insulin (unmodified insulin) can be manufactured using DNA methods in bacteria or yeast. The same methods are also used to make new types of insulin, known as insulin analogues.

Different preparations of insulin work for different lengths of time in the body. Broadly speaking, an insulin is one of the following, depending on the length of time it has an effect on blood glucose levels:

- **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, 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 insulins:** these have an effect that can last for a longer period, even a whole day.

A **biphasic insulin** is a mixture of meal-time (rapid- or short-acting) and intermediate-acting insulins.

It's not possible to have insulin in a tablet form because it would be digested in the body before it could get into the blood system, so insulin has to be injected.

If you are just starting on insulin, your body may still be able to make some insulin so you may not need to have the full pattern of insulin replacement straight away.

If your diet and/or pattern of activity change quite widely from day to day, your doctor should pay particular attention to your self-monitoring results and work with you to find the pattern of insulin that works best.

Meal-time injections

If you and your doctor decide on a pattern of insulin that includes injections before meal times (which is usual), these injections should be of unmodified insulin or a rapid-acting insulin analogue. If you get periods of hypoglycaemia at night or when it's nearing the time for your next meal, you should be offered one of the rapid-acting insulin analogues to use before main meals as an alternative to meal-time injections of unmodified insulin. You should also be offered one of the rapid-acting analogues if they work well enough that you don't need to have a snack between meals, and these snacks are something that you should or would like to avoid.

Background insulin

Your body's background level of insulin (including that at night time) should be provided by NPH insulin (intermediate-acting insulin) or a long-acting insulin analogue (such as insulin glargine). NPH insulin is normally used at bed time. If you use rapid-acting insulin analogues at meal times or if you have a small dose or no insulin at midday, you may need to take NPH insulin twice a day (or more often).

A long-acting insulin analogue, such as insulin glargine, should be used if you're having night-time hypoglycaemia despite using NPH insulin, or if you are hyperglycaemic in the morning on NPH insulin and this makes it difficult to control your glucose levels during the day. You may also choose to use a long-acting insulin analogue if you use a rapid-acting insulin analogue at meal times.

Minimising injections

If it's important to you not to have too many injections, you should be offered the chance to try having your insulin injections twice a day. In this case, you have a mixture of insulins that work for different lengths of time, with the aim of supplying insulin to cover both the meal-time and the background levels of glucose.

Changes to your routine

If there are times when you fast or sleep straight after eating (for example, for religious reasons or because you work shifts), you should discuss this with your doctor. You may need to take a rapid-acting insulin analogue before your last meal (as long as the meal itself doesn't last a long time).

It should be explained to you what to do with your insulin doses if you are ill (this advice is sometimes called 'sick-day rules'). You should also be given a phone number for urgent advice from someone who knows about diabetes.

If glucose levels become uncontrolled

If your blood glucose levels have been controlled but suddenly start to go up and down in a way that can't be predicted, a member of your diabetes team should think about and talk to you about:

- how you are doing the injections
- what sites you are using for your injections
- how you are monitoring your blood glucose levels
- any lifestyle changes you've had
- any problems that might be affecting the way you handle your diabetes
- any medical conditions or treatments that might be causing the change.

Insulin delivery systems

You should be able to have the injection device that suits you best – often, this means using one or more types of injection pens. If you have particular needs because of a disability, you should have a system that gives

you accurate doses and that you can use on your own.

A member of your diabetes care team should discuss how and in what part of your skin to inject yourself. When you inject yourself, the needle should go into the fatty layer that lies under the skin. You should be supplied with needles of the right length for this.

You should be recommended to use the same area of your body for injections at the same time of day, but to inject into different spots within that area. If you need to have meal-time injections, you should, ideally, inject into the abdominal area.

The effects of some types of insulin designed to last for longer periods, such as NPH insulin, may last for longer if they're injected into the thigh rather than the arm or abdominal area. For this reason, you may be advised to use this site.

You should never share needles with others. You should be given a special bin to collect your used needles in, and be told the arrangements for disposing of the bins when they're full.

Your injection sites should be looked at by a member of your diabetes care team every year, or if you start having problems with your glucose levels.

Oral medicines to lower blood glucose

In general, people with type 1 diabetes shouldn't be prescribed glucose-lowering medicines that have to be swallowed. These are more commonly used for type 2 diabetes.

Preventing and managing hypoglycaemia

Most people with type 1 diabetes who use insulin to control their glucose levels are likely to have hypoglycaemia at some time or other. Your doctor should help you to try to keep this to a minimum while you try to manage your glucose levels. If you have severe problems with hypoglycaemia, your doctor may discuss using an insulin pump, which is worn on the body and gives a continuous feed of insulin into the skin.

If you are becoming hypoglycaemic

If you need to take something sugary because you think you are becoming hypoglycaemic, any sugary (glucose or sucrose) drink is suitable if you can swallow it. Tablets and gels containing glucose can also be used. If a quick effect is needed, fluids containing pure glucose give a more immediate effect. The recommendations for adults dealing with someone who is severely hypoglycaemic are shown in the box on the next page.

If someone is hypoglycaemic and is drowsy or unconscious (so they can't swallow a sugary substance)

- A trained person should inject glucagon* into a muscle (health professionals may prefer to inject glucose into a blood vessel – this is an 'intravenous injection').
- The person's response to the glucagon injection should be monitored for 10 minutes – if there's no improvement, glucose should be given by intravenous injection.
- When the person starts to come around, they should be given suitable food when it's safe for them to take it; they should have someone with them, and this person should know about the risk of the problem happening again within a few hours.

*Glucagon is a hormone that raises blood sugar levels.

If hypoglycaemia is a problem

If your self-monitoring shows that you are sometimes hypoglycaemic without realising it, your doctor should assume that you're also having some periods of hypoglycaemia at times that can not be detected by self-monitoring. They should try to check whether this is the case. If it is, they should work with you to try to stop it from happening. You should also be given some information specifically on this subject.

Where periods of hypoglycaemia are causing problems, your doctor should think about and talk to you about:

- whether the type and timings of your insulin injections are right for you
- your usual patterns of meals, drinks and activity
- the way you give yourself the injections and the injection sites you use
- any medical conditions that might be causing the problems

- any other things that might be affecting your body (such as other medicines you might be taking or the physical activity you have taken in the past 24 hours) or the way you are dealing with your diabetes.

If you become hypoglycaemic during the night, your doctor should discuss with you the pattern and type of insulin that you're using, any exercise you have taken, and the times and types of meal you have in the evening. Your doctor should offer you a change to your insulin prescription, and discuss possible changes to the pattern in which you take your insulin, with the aim of finding a pattern less likely to cause blood glucose to drop during the night. This could be NPH insulin at bedtime, a rapid-acting insulin analogue with your evening meal, insulin glargine or, if these don't work, using an insulin pump.

If you become hypoglycaemic late after your last meal, your doctor should discuss whether having a snack might help, or whether you should use a rapid-acting insulin analogue before meals.

One of the factors that may be affecting a person's ability to notice when they're hypoglycaemic is damage in the nervous system (such as following a stroke), and doctors should take this into consideration when trying to work out what's happening.

Possible effects on memory and thoughts

If a person who has taken insulin for a long time starts to notice problems with their memory and thoughts, the doctor should look into whether the person may have been having hypoglycaemic spells, as well as doing the normal investigations for these symptoms. If they have been having periods of hypoglycaemia, steps should be taken to help prevent this.

Diabetic ketoacidosis

Diabetic ketoacidosis happens if the body is 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 vomiting. The person has high blood glucose levels and becomes dehydrated. What's known as a metabolic acidosis develops; this is a medical emergency because the person can go into a dangerous coma. The recommendations made for health professionals treating a person with diabetic ketoacidosis are shown in the box on the next page.

If someone has diabetic ketoacidosis

- The person's fluids should be replaced using isotonic saline, which shouldn't be given too quickly.
- Bicarbonate (alkali) will probably not be needed.
- Insulin to go directly into the vein should be given by infusion.
- Once the person's plasma glucose concentration has fallen to 10–15 mmol/litre, fluids containing glucose should be given, together with a higher amount of insulin than might normally be used.
- Potassium should be replaced soon, and the patient should be checked regularly for hypokalaemia (when the body becomes low in potassium).
- The patient's condition should be continuously monitored and their situation reviewed at very frequent intervals.

Medical conditions linked to diabetes

Arterial disease

Arterial disease is much more common among people with type 1 diabetes than among the general population. Arterial disease can cause angina, heart attack and stroke (where the blood stops getting through to an area of the brain), and problems in the legs. The end result of having too much glucose in your blood over a prolonged period is that your blood vessels can become narrow, your blood pressure can increase and your blood can become more likely to form small clots. All these are factors in arterial disease. You should be given information on this and how to reduce your risk of getting arterial disease.

Every year you should be offered checks for things connected with an increased risk of arterial disease; these are:

- the amount of a protein called albumin that is being passed in your urine (your 'albumin excretion rate' should be measured, which gives an indication of how well your kidneys are working, see page 45)

- whether you smoke and if you do, how much
- your blood glucose control
- your blood pressure
- the lipid profile of your blood (lipids are fatty substances – cholesterol is one type of lipid)
- your age
- whether you have or had close relatives with arterial disease
- the amount of fat around your abdomen (the pattern of having fat around the centre of your body, rather than all over, is linked with arterial disease).

Identifying adults at high risk of arterial disease

Adults with a raised albumin excretion rate or two or more of the signs of metabolic syndrome (see page 40) should be thought of as being at the highest risk of developing problems. Adults who aren't in this group but who have other characteristics that make them more likely to get arterial disease should be thought of as being at moderately high risk. Your doctor shouldn't use risk tables, equations

or other ways of showing you your calculated risk of arterial disease because these will be inaccurate for adults with type 1 diabetes.

Medicines to help reduce the risk

Your doctor should offer you treatment to reduce the risk of developing arterial problems. If you are in either the high- or moderately-high-risk group, you should be recommended to take 75 mg of aspirin per day. Standard doses of cholesterol-lowering medicines known as statins should also be recommended if you are in these groups. If you can't take some of the statins, your doctor should think about prescribing other medicines to help lower your blood lipids.

Your doctor may recommend that you take the lipid-lowering medicine known as a fibrate or other lipid-lowering medicines, depending on your risk of developing arterial disease and the pattern of fatty substances in your blood.

If you take a medicine to help to reduce the amount of fatty substances in your blood, the effects of the medicines should be monitored by blood tests. If the medicines aren't having the effect expected, your doctor should think about whether the treatment could be changed to make it more effective.

If you have had a heart attack or stroke, your doctor should offer you treatment to reduce the risk of further problems. They should follow relevant guidelines for treatment for people who don't have type 1 diabetes.

Advice about smoking

If you smoke and have type 1 diabetes, you should be advised and helped to stop. Your doctor should take every opportunity to help you to stop smoking.

If you're a young person who doesn't smoke, you should be advised never to start smoking.

Managing high blood pressure

Reducing high blood pressure can help to reduce the risk of stroke and of eye or kidney damage caused by diabetes. You should be given information on how to improve your blood pressure and support if you want to make some changes to your lifestyle to help with this.

If your blood pressure is above 135/85 mmHg, your doctor should take steps to help reduce your blood pressure. If you have a raised albumin excretion rate or two or more of the signs of metabolic syndrome (see page 40), action should be taken if your blood pressure is above 130/80 mmHg. You should be involved in the decisions about which steps to try. To help with this, you should be told about:

- why your doctor thinks you might need a certain level of help with your blood pressure
- what the benefits of reducing your blood pressure would be
- the possible downsides of treatment.

Signs of the metabolic syndrome that show that a person might be more likely to develop arterial disease

- Average blood pressure over 135/80 mmHg (men and women).
- Waist measurement more than 90 cm (women) or 100 cm (men); in people with a South Asian background, these measurements are 80 cm (women) and 90 cm (men).
- Serum HDL cholesterol ('good cholesterol') less than 1.2 mmol/litre (women) or less than 1.0 mmol/litre (men).
- Serum triglycerides more than 1.8 mmol/litre (men and women).

Medicines to help with blood pressure

The first medicine you will be offered should normally be a low dose of what's known as a thiazide diuretic (the exception is if you have signs of kidney damage, see page 45), but you may well have to take more than one medicine to help. Doctors may be concerned about the risk of side effects with certain types of medicine. These concerns shouldn't lead them to avoid discussing or prescribing effective medicines, but they should make sure you are alert to possible side effects. Specific recommendations for doctors are shown in the box below.

Recommendations about medicines for blood pressure in adults with type 1 diabetes

- A trial of a low-dose thiazide diuretic should be started as first-line therapy for raised blood pressure, unless the person with type 1 diabetes is already taking a renin-angiotensin system blocking drug for raised albumin excretion rate.
- Selective beta-adrenergic blockers should not be avoided just because a person is on insulin.

- A person can take a low dose of a thiazide diuretic together with a beta-blocker.
- If a calcium channel antagonist is prescribed, it should be one of the long-acting ones.
- When checking for side effects, people should be asked about problems with erections (erectile dysfunction), tiredness and loss of energy, and feeling dizzy when they stand up.
- Care should be taken that the person is not put at risk of feeling dizzy when they get up because of low blood pressure caused by a combination of the effects of a blood pressure medicine and nerve problems.

Retinopathy (an eye problem)

Retinopathy is an eye condition that happens because there has been too much glucose in the blood over a long period of time. The small blood vessels in the eye become damaged, leaky and clogged so the blood can't pass through them. The body eventually makes new blood vessels to try to compensate for this, but these are not very strong and bleed ('haemorrhage') easily. At the same time, scar tissue can form which can lead to more damage in the eye. If retinopathy isn't treated early, a person can go blind.

Adults with type 1 diabetes should have their eyes checked regularly (at least every year) and specifically for signs of diabetes-related eye damage. Your doctor should explain to you how important it is that eye problems are spotted early and treated. Depending on the results of your check, you should be checked again a year later, or sooner, or you should have an appointment with an eye specialist (ophthalmologist).

When you go for your check, the person doing it should tell you that they plan to use drops to make your pupils get bigger (the drops are called tropicamide and the medical word for the effect is mydriasis). This can have short-lived effects on your eyesight, and these should be explained to you before you agree to have it done. The check should also include a test of how clearly you can see things, as in a normal eye test (this is done before the drops are put in). The back of your eyes should then be photographed with a special electronic eye camera and the pictures discussed with you.

Seeing the ophthalmologist

If you lose your sight suddenly, or you are told that you have a condition called rubeosis iridis (where new blood vessels grow on the front of the iris), pre-retinal or vitreous haemorrhage (bleeding into the eyeball) or retinal detachment (when the layer on the inside back wall of the eyeball starts to come away), you should be offered an emergency appointment with an ophthalmologist.

If you don't have these but there are signs that new blood vessels are growing in your eye, you should be given an appointment to see an ophthalmologist urgently.

You should see an ophthalmologist soon if there is damage in the macula, which is the area of the inside back wall of the eyeball that is particularly important for seeing things clearly that are directly in front of you. The recommendations on this are quite detailed and won't be described here, although they can be found in the NICE guideline (see page 3). You should also see an ophthalmologist if there are signs that new blood vessels may be about to start to grow or if your eyesight worsens without explanation over a few months.

Nephropathy (kidney problems)

If the blood vessels in the kidneys become damaged, the kidneys can gradually stop working. One sign that this may be starting is if a protein called albumin starts to appear in your urine – if the kidneys are working well, albumin shouldn't be able to pass into your urine.

Every year, a specimen of your urine should be checked for the ratio of albumin to another substance called creatinine. (Creatinine is normally found in urine – its measurement helps doctors to understand the albumin measurement better.) At the same time, you should be asked if a sample of your blood can be taken, and this sample tested for creatinine itself.

If the results show that there may be a problem (and you don't have an infection that would explain it), you should have the same test every time you go to the clinic or at least every 3–4 months. If another test gives the same result, your doctor should discuss this with you and tell you what it means, and you should be started on a medicine called an ACE inhibitor. If there's a reason why an ACE inhibitor may not be suitable for you, you should be started on a different medicine, called an angiotensin 2 receptor antagonist. You should also be given some advice about foods to avoid if you normally eat a lot of high-protein foods, such as meat. You should then also be offered help to keep your blood pressure under very tight control (See 'Managing high blood pressure', page 39).

There should be agreements in your local area between the diabetes specialists and kidney specialists that will help your doctor arrange for you to see a kidney specialist if they feel it is necessary.

Foot problems

A person with diabetes can get problems with their feet because the nerves to the feet can stop working properly. As a result, the person can't feel sensations or pain that would normally tell them that something was wrong (shoes were rubbing, for example). This means that problems can develop which aren't noticed until they are really quite bad.

Your doctor should explain to you how important it is that foot problems are spotted early and treated. You should have your feet checked once a year. This should include looking at:

- sensation in the feet
- blood supply to the feet
- the condition of the skin on the feet
- the shape of the feet
- your shoes.

The sensation in your feet should also be checked (using suitable equipment that won't damage your skin), as should the blood vessels there.

If you are at risk of getting foot ulcers

If you are at risk of getting foot ulcers (open sores) because you've had foot ulcers before, the following should happen.

- The other things that might increase your risk should be checked, such as whether or not you smoke.
- You should be offered regular foot care aimed specifically at stopping foot ulcers developing.
- You should be offered opportunities to learn how to look after your feet.

You may be offered special shoes if your feet have become misshapen or you have areas of very hard skin caused by rubbing against shoes.

If you have foot ulcers

If you have ulcers on your foot, an appointment should be made so that you can see a member of the local specialist diabetes foot care team within a few days. If there are signs of an infection, you should get an emergency appointment and you should be given antibiotics. You may have to take these for a long time if the infection keeps coming back. The ulcers should be dressed and the dressings should be changed often. Your foot should be examined often to check that the ulcer is healing. More specific recommendations for podiatrists (chiropodists) and doctors are shown in the box on the next page.

Recommendations about treating foot ulcers

- Dead tissue should be removed from the ulcers.
- The podiatrist or doctor should think about making a cast of the person's foot to show where the contact with a shoe occurs if there are problems with sensation.
- In general, cultured human skin (dermis), hyperbaric oxygen therapy, topical ketanserin and growth factors should not be used.
- If there are signs of damage in the blood vessels, the person should see a member of a specialist team.

Charcot osteoarthropathy

If you have a condition affecting your foot joints known as Charcot osteoarthropathy, or there are signs that you may have this, you should be given an appointment to see a member of a specialist 'high-risk' foot care team quickly.

Neuropathy (problems with the nerves and sensation)

Having too much glucose in the blood can cause imbalances in the body that eventually damage the nerves. Because the nerves run throughout the body, the damage can cause problems in different parts.

Erectile dysfunction (impotence)

Possible difficulties with erections should be discussed at a man's yearly check. If there's a problem, the doctor should offer to prescribe a medicine called a phosphodiesterase-type-5 inhibitor to help. If this doesn't help, your doctor should discuss having an appointment with someone to discuss other options that might help.

Problems with the digestive and urine systems

If you're on insulin and are having problems with your blood glucose levels or have bloating or vomiting with no obvious cause, your doctor should think about whether you might have gastroparesis. This is where the stomach has stopped emptying properly. If you are thought to have gastroparesis, you should be offered a medicine to help to get the system working properly again.

If you have unexplained diarrhoea, it's possible that it might be because of problems with the nerves in your intestine. Similarly, if you have problems urinating fully, it may be because of problems with the nerves to your bladder. Your doctor should think about these possibilities and offer you appropriate treatment.

If your nervous system has become damaged

If you are due to have a general anaesthetic and there are signs of problems with your nervous system, your anaesthetist should be aware that you may also have problems with the nerves to your heart.

If you are given a medicine to help reduce your blood pressure, your doctor needs to be careful that the effects don't combine with the effects of damage to your nervous system. If this is the case, the overall effect could be that you feel dizzy when you stand up, or even that you fall over or black out.

Helping with the pain

If you are in pain because of problems with your nerves, you should try paracetamol or aspirin as a first step and use other things such as bed cradles (which keep the covers off your legs and feet) to help to avoid triggering the pain or making it worse. If these things don't work, you shouldn't have to carry on with them. The next step is to try a tricyclic medicine, taking the tablet regularly to coincide with the time of day when the pain is at its worst. If this doesn't help, you should be prescribed a medicine called gabapentin. You should stay on this unless the maximum dose you can take (probably around 1800 mg a day) is still not helping. If this is the case, your doctor may suggest trying another medicine – carbamazepine or phenytoin. Strong painkillers (opiate analgesics) may be an option if you are in a lot of pain; in this case, your doctor should liaise with a local team that specialises in helping people with long-term pain. If the pain is bad or nothing seems to be working, your doctor should take the time to explain the reasons for this, what's likely to happen in the future, and how improving your blood glucose levels might help.

If a medicine helps, after 6 months your doctor should think about offering to reduce your dose or stopping treatment to see how you get on without it.

Other autoimmune diseases

Type 1 diabetes is an autoimmune disease, meaning that it is a person's own immune system that causes the problem. In type 1 diabetes, it is the cells that normally produce insulin that are destroyed. Your doctor should watch out for signs of other diseases where your immune system attacks your own body, because these are more likely in people with type 1 diabetes.

Coeliac disease

If you have a low body mass index (which is a measure of your body weight in relation to your height) or if you suddenly lose weight without any obvious reason, your doctor should check for signs of coeliac disease, which is an autoimmune disease affecting the digestive system.

Depression and anxiety

People with a long-term medical condition such as diabetes can get depressed, anxious or both. Doctors who advise or care for people with diabetes should watch out for signs of depression or anxiety, especially in people who are having difficulty managing their diabetes. Health professionals working in diabetes care teams should be able to spot and manage the less severe problems such as depression and anxiety. A person should be offered help from a specialist psychologist if the problem interferes with their well-being or affects the way they manage their diabetes. In general, the same approach should be used to help with these problems as would be used in someone who didn't have diabetes. The exception is where a person has heart or blood-pressure problems – in this case, if the person is taking medicines for these, they may have to avoid some of the usual medicines for depression or anxiety because they may cause harmful effects.

Eating disorders

Doctors should watch out for signs of an eating disorder (for example, anorexia nervosa, bulimia nervosa or manipulation of insulin doses) in a person with type 1 diabetes if:

- they have a view of their body size that doesn't match reality, or
- they are very thin for their height, or
- their glucose control is poor overall.

Because of the risk of problems in the body, a person with type 1 diabetes who has signs of having an eating disorder might need to get specialist help sooner than they would do if they didn't have diabetes.

If you are in hospital

If you need to go into hospital for something other than your diabetes, your hospital doctors should be able to liaise with colleagues with specialist knowledge of diabetes. While you are in hospital, your knowledge and experience of managing your own diabetes (for example, monitoring and timing of insulin)

should be respected and followed. Similarly, your knowledge and experience of different foods should guide the foods you are offered, except when your health or an operation changes your food needs.

The hospital should have a set of rules that are followed so that your blood glucose levels are managed without putting your body at risk of becoming stressed. Usually this should involve regular testing of your blood glucose levels and adjustment of your insulin based on the results.

If you are in hospital because you have had a heart attack or stroke or there's a suspicion of one, your glucose levels should be tightly controlled using insulin and glucose. Critical care and emergency departments should have sets of rules for doing this.

The organisation of healthcare services

The people who advise you about the different aspects of your diabetes should have specialist skills in caring for adults with type 1 diabetes. They should work in teams so that there is a coordinated approach to your care.

If you need help or advice, you should be able to walk into or phone a diabetes service during normal working hours. You should also be given the number for a 24-hour helpline where you can speak to someone who knows about diabetes. You should be given the details of all these services.

Support groups

After you've been diagnosed, you should be offered information (including the contact details) on local and national support groups for people with diabetes and what the advantages of joining might be. Every now and then your diabetes care team should discuss these with you again.

The clinics and other places that you go to for your diabetes appointments should also keep information on support groups.

Where you can find more information

If you need further information about any aspects of type 1 diabetes or the care that you are receiving, please ask your doctor, nurse or other health professional. 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. 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):

- type 1 diabetes in children and young people, reference number N0623 (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.

Angina: a condition caused by problems with the arteries carrying blood to the heart muscle; the person has short periods of chest pain and a feeling of constriction or tightening.

Arterial disease: problems involving the blood vessels, heart, or both; it can result in angina, heart attack and stroke.

Basal insulin: the background insulin needed to control the normal levels of glucose in the blood between meals and at night.

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

Chiropodist: a podiatrist – a healthcare professional who looks after people's feet.

Diabetologist: a doctor who has specialist knowledge about diabetes and its management.

Dietitian: a healthcare professional who has specialist knowledge about eating and the effects of different foods and drinks on the body.

Erectile dysfunction (impotence): where a man cannot get or keep a full erection.

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

Glycaemic index: a measure of how quickly a food is broken down into sugar that enters the blood.

HbA_{1c}: haemoglobin in the blood that has had sugar chains attached to it; A1c is a simple term for this.

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 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.

Meal-time insulin: insulin that is given to cope with the high levels of glucose that happen after a meal.

Metabolic syndrome: this is a set of abnormalities that are found together in many people who later develop arterial disease. The abnormalities include high blood pressure, disturbed blood fat levels, and insulin resistance (where the body don't respond normally to 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 diabetes, these are known as diabetes care teams.

Nephrologist: a doctor who has specialised in diagnosing and treating kidney conditions.

Nephropathy: kidney disease.

Ophthalmologist: a doctor who has specialised in diagnosing and treating eye conditions.

Podiatrist: see chiropodist.

Retinopathy: disease involving the inside back wall of the eye (the retina).

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

Ulcer: an open sore or crater that becomes red and painful (inflamed); in diabetes, one of the aims is to stop ulcers from developing on the feet.



*National Institute for
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MidCity Place
71 High Holborn
London
WC1V 6NA

www.nice.org.uk