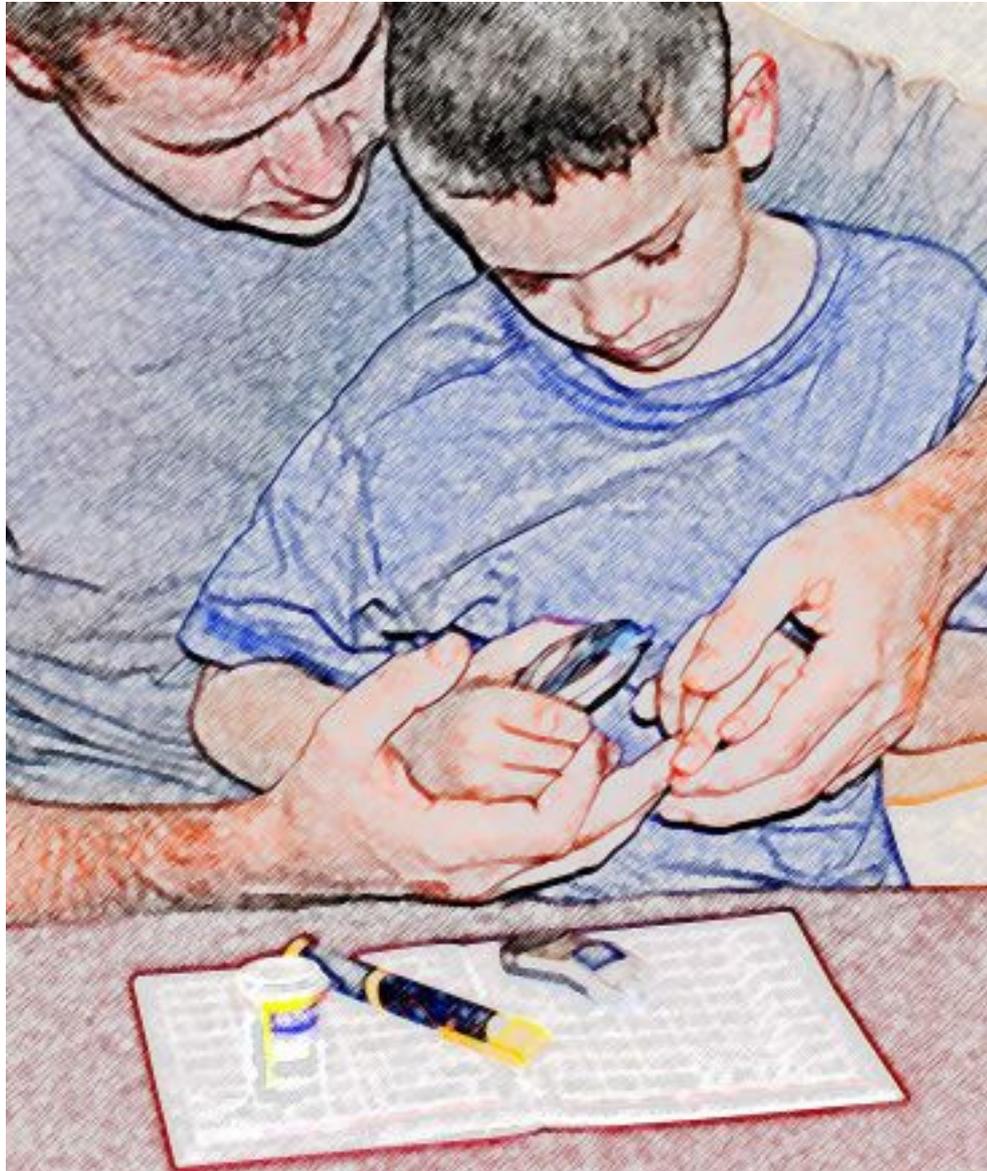


Your guide to **Diabetes in Childhood**



Your guide to diabetes in childhood	Date: 16/6/14
Version: 6a	Date of review May 2015
Owner: George Farmer	

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Dear Parent or Carer

You have been given this folder because your child has been diagnosed as having type 1 diabetes - properly speaking, “diabetes mellitus”. The word diabetes comes from the Greek for “fountain”, and the word mellitus means “sweet”. The term refers to the presence of large amounts of sugar in the urine.

You will probably have been taken by surprise, and be experiencing very mixed emotions just now. If your child has been unwell for some time, you may feel relieved that a diagnosis has been made, and that he/she is beginning to get better. You will probably feel worried about the future, and about how well you and your child will cope with life with diabetes. Many people feel numb, and find themselves living “from day to day” until the information has had time to sink in.

The hospital team is here to help you to adjust. There seems to be a lot to learn. Take it slowly. Ask questions (and feel free to ask the same questions again if need be!). You will find that it all falls gradually in to place.

This folder is yours to keep. We will give you some extra information sheets over the next few days – but the basics are covered in the sheet “AN INTRODUCTION TO DIABETES”. You will also find this sheet helpful for grandparents, aunts and uncles, and babysitters.

The Diabetes Team

The specialist team supports the ward staff during the course of any admission to hospital, and will be your main point of contact when you go home. It consists of two Consultant Paediatricians with an interest in diabetes (Dr Farmer and Dr Franklin), Specialist Nurses, Dietitians, and a psychologist.

Diabetes clinics for children and young people are held at Raigmore, and in Golspie, Caithness, Fort William, Skye, and the Western Isles. There are different Specialist Nurses and Dietitians in each area.

When things are going smoothly, we usually see families every three to four months. Problems sometimes do arise between clinic visits. In most cases they can be sorted out by a telephone call. We will keep your General Practitioner informed about any major changes in treatment, and keep in contact with the school nurse and doctor.

We aim to keep your child healthy, active, and living as full a life as possible. Over time you will learn how best to support your child, how to adjust insulin, and how to cope with special occasions and minor illnesses.

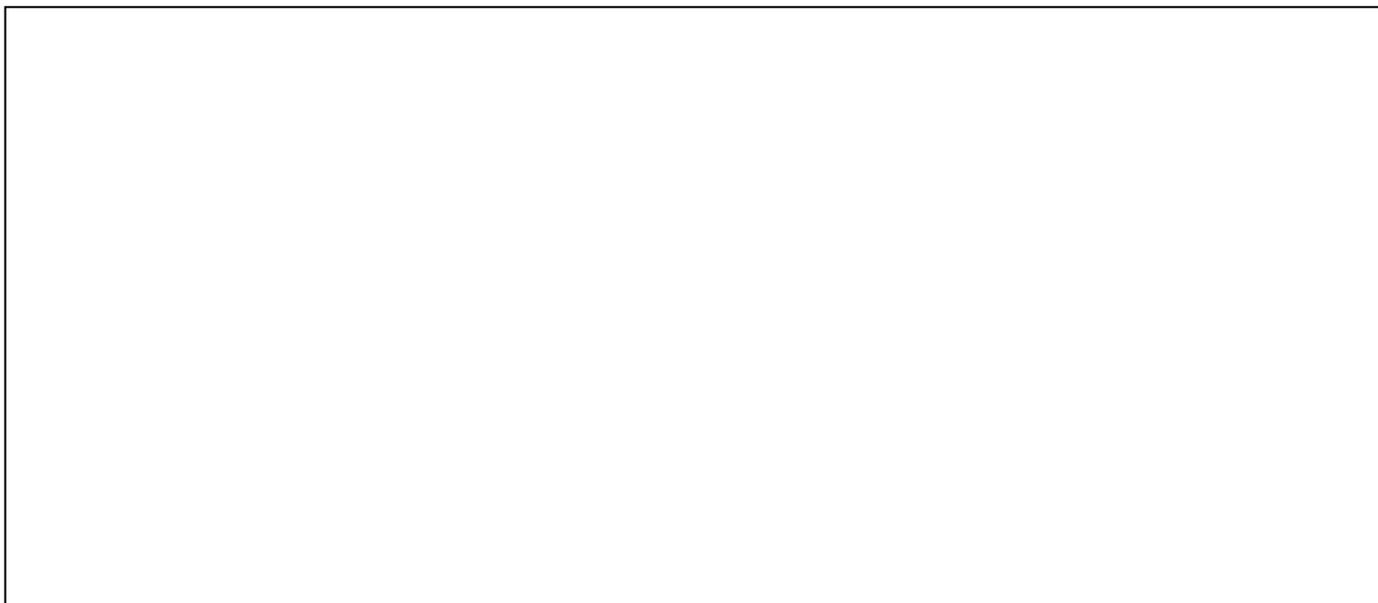
Other people with diabetes

There are two types of diabetes (type 1 and type 2). Most children have type 1 diabetes. You may have heard that there has been an increase in the number of people with diabetes related to the obesity epidemic. This is type 2 diabetes, which is uncommon in children in Scotland. The treatment of type 2 diabetes is quite different.

In Highland region, type 1 diabetes in children seems to be unusually common (about one in every 400 children). You may well find that there are one or two children in your area, or who attend your local school, who have diabetes.

If you would like to make contact with other people who have diabetes, you can join the local branch of Diabetes UK. There is even a club for children and young people – HYwD (Highland Youngsters with Diabetes). A contact number is given at the end of the sheet “CALLING FOR HELP”

We look forward to meeting you soon



You can access extra copies of this booklet and additional resources on the NHS Highland Website:

<http://www.nhshighland.scot.nhs.uk/YourHealth/Diabetes/Pages/DiabetesinChildhood.aspx>

AN INTRODUCTION TO TYPE 1 DIABETES.

What is diabetes?

Diabetes is a condition where the body does not produce enough insulin.

What is insulin?

Insulin is a substance produced by the body to help it to use its food properly. In particular, it helps muscles and bones to take sugar from the blood, and use it for energy and growth. When there is not enough insulin produced, sugar builds up in the blood, you become short of energy, and lose weight.

Where does sugar in the blood come from?

The sugar in the blood comes from food. When we eat starchy foods (potatoes, bread, rice and pasta, for example) this is digested in the gut to sugar, which is then absorbed into the bloodstream. These starchy foods (known as 'carbohydrates') are healthy foods - whether you have diabetes or not!

Sugar is a carbohydrate too. It will increase the blood sugar very quickly. Sugary foods do need to be limited as eating too many upsets the overall balance of the diet.

Why me??

We do not fully understand why some people get diabetes, and not others. We do know that, when children get diabetes, it is not their (or their parents') fault - and probably nothing at all to do with all the sweets and fizzy drinks they may have eaten in their time!

Can it be cured?

Diabetes is a condition that we can treat very effectively, by giving injections of insulin. We do not at present have any treatment which will get the body to start making insulin for itself again, so treatment with insulin has to be lifelong.

What about tablets?

Adults who develop diabetes in later life usually have type 2 diabetes. They often can get by without insulin, just by watching their diet and (sometimes) taking tablets. This form is very uncommon in children in Scotland, and almost all children with diabetes need to take insulin. The only effective way to give insulin is by injection.

Does diabetes make you feel unwell all the time?

Definitely not! At the time of diagnosis, most people will feel listless, moody, and have to run to the toilet a lot. They will also have lost weight. All this will change once the insulin begins to take effect, and they will soon be back on top form.

Will it change my life?

Yes. Living with diabetes is undoubtedly an inconvenience - but it is not a catastrophe. Diabetes need not stand in the way of success at school, sports, most jobs, making friends, marriage, childbirth and the like.

There is more about the kind of changes you can expect on the next page, 'Life with diabetes'.

LIFE WITH DIABETES-AN OUTLINE.

Eating

If you do not have diabetes, your body produces the right amount of insulin exactly when it is needed - it all happens automatically! Most people do not need to think too hard about what they are going to eat, or when. People with diabetes, on the other hand, should have a regular eating routine. It wouldn't do if you took your morning insulin to help you to use your food - and then didn't eat any! The blood sugar would go too low, and you'd feel funny (this is called a "hypo"). It is rare, but if a hypo is left untreated this may result in you passing out. It is usually best to eat three main meals a day, with snacks in the middle of the morning, the middle of the afternoon, and before bed. The dietitian will help you work out an eating plan.

Taking insulin

Insulin is given by injection or by an insulin pump. We often start with twice daily injections, but some children and families opt for more frequent injections. You should never miss a dose of insulin, even when you are unwell. More about that later!

Measuring blood sugar

The normal blood sugar in people who do not have diabetes is between 4 and 7. It is not usually possible for people with diabetes to keep the blood sugar between these limits all the time, and we are usually very pleased if most of the results are between 4 and 8.

The dose of insulin your body needs will not always be the same. We discover what the right dose is by trial and error. Regular measurements of the blood sugar will guide your doctor about when the dose needs to be changed. Families living with diabetes learn how to make these changes themselves after a while.

The most useful times to check the blood sugar are before breakfast, before lunch, before tea, and before the bedtime snack. Blood sugars should be checked four times a day and may be required more often during any illness. Every time a blood sugar is checked, the date, the time, and the result should be written down in the diary provided - this will give you and the team a clear guide as to how things are going, and whether any changes are needed.

'Hypos'

A hypo (hypoglycaemia, to give it its full name) happens when the blood sugar is too low (that is, less than 4mmol/L). It can affect:

how you feel (shaky, tingly fingers or lips; queasy tum; fuzzy head; or just plain hungry!);

how you look (pale, sweating, or trembling); or

how you behave (quiet and vague - or very naughty!).

People with diabetes should always have something sugary close at hand (drinks or dextrose) to take if they feel hypo. You could take a small sugary drink, eg Lucozade or fresh fruit juice, or Dextro-energy tablets, and sit quietly for 10 minutes. You should then recheck your blood sugar to ensure the hypo has been treated. If it is going to be more than an hour until your next meal or snack, you should eat some starchy carbohydrate such as a plain biscuit or a slice of toast. Some kinds of sweets – particularly chocolate – take a long time to digest and are not suitable for treating hypos. Although hunger is a very common symptom of a 'hypo', it is important to limit your intake of sugary drinks or dextrose to that suggested in the hypo treatment guidance (and this is based on your weight), otherwise you are likely to get very high blood sugars later.

Exercise

Most activity will lower the blood sugar, so you are more likely to have a 'hypo' during or after exercise. To prevent this you should take some extra carbohydrate immediately before exercise - something like a cereal bar or a piece of fruit. If the activity is going to last more than 30 minutes, an extra snack should be taken half way through. Test your blood sugars before and after to see how effective this snack has been and whether you need to manage this exercise differently next time. Your blood sugar may fall after exercise so you may need to eat something afterwards.

When you are ill

People with diabetes need a regular supply of carbohydrate - even if they are ill, and even if the blood sugar is high. If you feel sick or can't eat, the carbohydrate is best taken as regular sips of sugary drinks. You will also need to do more blood tests than usual.

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INITIAL DIETARY ADVICE FOR CHILDREN WITH NEWLY DIAGNOSED DIABETES

This is stop-gap advice for you to follow until you can see the dietitian who will plan your personal diet with you.

Eat regularly

You should eat three meals each day, with snacks between meals and at bedtime. Suggestions for snacks include Fresh fruit, plain biscuits (rich tea, digestives or oatcakes), half a sandwich, or diet yoghurt.

Base your meals on “starchy” foods.

- Breakfast cereals - All Bran, porridge, Weetabix, Corn Flakes, and Rice Crispies.
 - Bread - wholemeal or white
- Potatoes - preferably boiled, baked or mashed
 - Rice
 - Pasta

Select one or more of the above to go with the main course and vegetables of your choice

Avoid sugar and sweet foods

- Choose water, low-calorie “no added sugar”, “sugar free”, or “diet” drinks.
- Avoid sweet biscuits, cakes, puddings and chocolate until you see the dietitian.

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Children with diabetes at school

This is initial guidance. A detailed plan for the child in school will be prepared by the diabetes nurse

1) Attitude. DO NOT MAKE AN UNNECESSARY FUSS. One of the biggest problems about living with diabetes is other people! Many children are very knowledgeable about their condition.

2) Hypoglycaemia. People with diabetes may be prone to episodes of low blood sugar (hypoglycaemia) - these episodes are called "HYPOS". They most often occur after exercise, or if a meal or snack is missed. You should KNOW THE SYMPTOMS and be prepared to TREAT PROMPTLY.

SYMPTOMS can include ANY of the following

- Pallor, sweating
- Shaking or unsteadiness
- Funny feelings in the head or abdomen; faintness
- Uncharacteristic behaviour - either quiet (vague), confused, or obstreperous
- Other*

The TREATMENT is with SUGAR, for example

- 3 or 4 Glucose tablets (eg Dextro-Energy, Lucozade)
- Half a glass of Lucozade.
- Other*

Where possible, check a blood sugar to confirm hypoglycaemia (blood sugar less than 4). If you are not sure whether it is a hypo or not you are BEST TO TREAT ANYWAY - no harm will be done. The blood sugar should be checked after 10 minutes to ensure hypo has been treated. Unless there is a snack or meal due within an hour, it is a good idea to follow the sugary snack with longer lasting starchy carbohydrate (for example, a couple of plainish biscuits). Parents are responsible for providing the necessary supplies.

Appropriate treatment can be given in class. Many children will treat a hypo without calling attention to themselves and this is to be encouraged. If the child is feeling unwell they should **NOT LEAVE THE CLASS UNLESS ACCOMPANIED BY A RESPONSIBLE PERSON**. If untreated a hypo can (rarely) cause a child to pass out completely. Should this happen, give nothing by mouth. Lay the child in the recovery position and call an ambulance.

Always let the parents know about hypos occurring in school.

3) Exercise. To prevent hypoglycaemia, parents will provide a SNACK FOR BEFORE PE. Teachers should permit and encourage this to be taken. Ensure the P.E. teacher is aware they have diabetes and how to treat a hypo.

4) Food. MEALS OR SNACKS SHOULD NOT BE DELAYED. Be aware of this if the lunch box/dinner money gets lost, or if the child is detained in class for any reason. Parents will often provide an extra snack for children who stay late for extracurricular activities. The food provided will be at the parents' discretion.

5) Blood testing. Children with diabetes do test their blood, several times each day, and it is necessary for this to be done at school. If assistance is required, one of the diabetes nurses will meet with teachers to provide training. If a child feels unwell or hypo in class, it is important they are supported to check their blood sugar immediately rather than sent away to another room and with minimal fuss.. The parents may wish to negotiate a system so that you can report the results back to them.

6) School trips. These should present no problem if the following rules are followed

- REGULAR MEALS AND BETWEEN - MEAL SNACKS (have some extra food with you in case there is an unforeseen holdup).
- EXTRA SNACKS OR SWEETS FOR VIGOUROUS OR SUSTAINED PHYSICAL ACTIVITY.
- PROMPT TREATMENT OF HYPOGLYCAEMIA should it occur.

Parents should liaise with the clinic doctor or nurse well in advance to discuss any changes in treatment which might be required during the trip. This is particularly important if the trip includes an overnight stay. You should discuss with the parents the degree of supervision which their child is likely to need. The Diabetes Specialist Nurses may arrange to meet with the parents and school before a school trip to provide additional education to the staff going on the trip so that they know how to manage common problems to keep your child safe while they are away.

**Parents may be able to advise you on the particular symptoms which their child experiences with hypoglycaemia, and treatment strategies which they have found particularly suitable.*

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Calling for help

Medical advice

Whereas diabetes is a relatively common condition, diabetes in childhood is much rarer. The paediatric diabetes team obviously look after children with diabetes on a regular basis, and so will be able to give you the best advice. Out of hours, the children's ward at Raigmore can offer advice. Telephone numbers are given overleaf.

Your own GP, health visitor, and school nurse will also be very keen to help, although they will not have so much experience of children with diabetes.

It is not unusual for friends and family, colleagues at work, and people you meet to give well-meaning advice. As you might expect, the quality of this advice will be very variable! Occasionally, you will pick up some good tips. However, a lot of the advice you are given will be out-of-date, inappropriate for your particular needs, or just plain wrong. If you are given advice which differs from what you have been told in Clinic, it is probably best to ignore it, or discuss it with the Clinic staff next time you come.

Medical equipment

Insulin, pen devices and needles, lancets, and blood-testing strips are free on prescription. The Diabetes Specialist Nurses can advise on the maintenance, repair and replacement of blood sugar meters.

Financial assistance

You can apply for "Disability Living Allowance" because your child needs extra supervision. The benefit is not means-tested. Your application is most likely to be successful if your child is young (less than 11 years old) or has additional problems. The form is complicated. You can get help in filling it in from the Specialist Nurse and there is also guidance on filling in the form on the Diabetes UK website (see below for information on Diabetes UK).

If you wish, we can put you in touch with a Social Worker, who can advise about other benefits which you may be entitled to, or help in other ways.

Behavioural difficulties and emotional problems

Sometimes one of the early signs of diabetes will have been a change in your child's behaviour, but this is very short lived and should disappear once treatment commences. However, parents often comment that their child seems different: what has usually changed is not the child's behaviour, but how the parents are reacting to him. In fact, the whole family can become more edgy, and find it more difficult to get along with each other.

Eating problems, sleep problems and temper tantrums are all part of normal childhood. Moodiness and seeing how far you can go are part of normal adolescence. Children with diabetes are just the same as any others when it comes to going through these stages. Most parents can usually work out satisfactory ways of dealing with these stages in children, but if you feel concerned, talk it over with the staff at the clinic and they will be able to advise you.

Carrying ID

It can be helpful for people with diabetes to carry some form of identification, in case they become ill and can't explain their condition. A card for a purse or wallet is available from your diabetic clinic. You may wish to purchase a pendant or wristband. Some of these are expensive, but cheaper versions are available – search on www.amazon.co.uk for 'medic alert wristbands'. Wowbands (www.wowbands.co.uk) are popular too.

Diabetes UK

Diabetes UK is a registered charity, whose members include people with diabetes and their families, and most of the professionals involved in the care of diabetes in this country. It exists to support and advise people with diabetes, and campaign for improvements in quality of life and medical care. There is a lot of information on the website at www.diabetes.org.uk

The Diabetes UK magazine "Balance" is free to members, and is published every two months. It is a "good read" which offers advice about living with diabetes, keeps you up to date with the latest research, and includes features, pen-pals, games and recipe ideas.

The organisation runs and subsidises educational holidays for children with diabetes throughout the UK. There are holidays for different age-groups, covering a wide variety of activities. In addition there are a number of family weekends in Scotland each year. Parents and children (with diabetes and without!) will find these both informative and enjoyable.

You can meet other people with diabetes by joining the local Diabetes UK group. Activities include social meetings, outings, talks, and fundraising. There is a special group for younger children within the Inverness branch (Highland Youngsters with Diabetes). You can contact the organisers (telephone numbers below) to find out when and where they meet, and get a copy of their programme of events.

Useful telephone numbers

DIABETES SPECIALIST NURSES

--

DIETITIANS

--

DR GEORGE FARMER, CONSULTANT PAEDIATRICIAN

--

DR VICTORIA FRANKLIN, CONSULTANT PAEDIATRICIAN

--

DIABETIC CLINIC APPOINTMENTS 01463 255930 (reception)

CHILDREN'S WARD, RAIGMORE HOSPITAL 01463 704335 (when unable to contact diabetes team)

DIABETES UK SCOTLAND

The Venlaw, 349 Bath Street Glasgow
Scotland@diabetes.org.uk

0141 245 6380

HYWD (HIGHLAND YOUNGSTERS WITH DIABETES)

Sheena MacKenzie (Acting Chair): Tel. 07950004017
Email: sheenam1@hotmail.co.uk

The Scottish Study Group for the Care of Diabetes in the Young

The Group is made up of doctors who look after children and young people with diabetes. Our aim is to improve diabetes care. We also provide professional advice and statistical information to the NHS in Scotland.

Since 1985, the Group has kept a register of all children in Scotland who develop diabetes before their 15th birthday. The details recorded are; name, date of birth, date of diagnosis, the hospital at which the diagnosis was made, the name of the consultant responsible for care, whether there are any other members of your immediate family who have diabetes, and the address at onset of diabetes (so that we can identify geographical variations).

The Register is special because almost all young people with diabetes in Scotland are included. It has allowed us to monitor the increase in the number of children who become diabetic each year, and has formed the basis of a number of important research studies. We believe that this kind of information can make a valuable contribution to understanding the causes of diabetes.

As a responsible organisation, we take care to ensure that information on the register can not be misused. We promise that

- 1) The information will only be used for research purposes.
- 2) Every effort will be made to make sure the register is accurate. Where necessary, we will cross check with information routinely collected for NHS use.
- 3) Personal information about you will remain entirely confidential. It will not be released from the register to any other organisation.
- 4) We may be asked from time to time to contribute information to national or international studies. We will only do so where we believe that the study is well-organised, and the results are likely to be useful. Any information we provide will be processed to make sure that individual patients cannot be identified.
- 5) For the purposes of specific research studies, we may ask you for additional information. If this happens, you will be approached either by your consultant or your local clinic, and we will only go ahead if you give your agreement. Any further information you give will be treated with full respect to your privacy.

Consent

Following recent changes to the law, it is only possible to maintain the Scottish Study Group register (and other similar registers) with the explicit consent of the patients. We would be grateful if you would sign overleaf to indicate your consent.

We hope you will join with us in trying to understand diabetes better, and improve the care we offer. If you wish to discuss this further, please speak to your consultant.

The Scottish Study Group Register.

Name
Address
Date of Birth
Hospital Number

I agree that my details be held on the Scottish Study Group Register, and used for the research purposes which have been outlined to me.

Signature of patient (where appropriate)

Signature of parent/guardian

Date

Have we done everything?

After the initial education you should have the following items and information

“Tool kit” document	
Dietary advice (dietitian)	
Insulin delivery device, needles, lancets, glucagon, glucose gel, and blood ketones strips – and instructions for use	
A variable depth blood testing device	
A blood sugar meter and instructions for use	
A blood sugar diary – and instructions for use	
Injection technique – how to do it – and how to rotate sites	
Information about safe disposal of sharps	
A sharps disposal box	
Hypos – when they happen, and how to recognise and deal with them	
Personal hypo action sheet issued.	
Storage of insulin	
How to get supplies	
School health plan/school advice sheet	
DLA (Disability Living Allowance) availability	
Useful organisations Diabetes UK (www.diabetes.org.uk) Juvenile Diabetes Research Foundation (www.jdrf.org.uk)	
Nasty hypos – how and when to use glucose gel and glucagon	
Ketones – what are they, how to test for them (blood ketone meter), when to test for them, and when to use fast acting insulin	
How to cope with illness – and when to call for help.	
Discuss SSG register/ Consent	

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