

# Children with newly diagnosed diabetes

An information guide



# Children with newly diagnosed diabetes

## Introduction

Your child has been diagnosed with Type 1 Diabetes. You will be feeling a mixture of emotions – ‘shock’, ‘upset’, ‘anger’, ‘bewilderment’ and a lot of others.

Over the next days/weeks/months/years you will gain an understanding and become an expert on dealing with your child’s diabetes.

The process of understanding the disease and its treatment will take a certain amount of time, but please be assured that your child, yourself and your family will be supported throughout the whole process and beyond.

**At present there are a few things that you need to understand and think about, these are:**

- Diabetes will not ‘go away’.
- Diabetes can be controlled.
- Your child will need to take insulin injections as treatment (this is currently the only treatment for type 1 diabetes).
- Diabetes will need to be monitored closely to enable good control.
- Diabetes should be given respect and care. Your child can and will lead a normal life and achieve as much as others if the diabetes is respected and controlled.

## **The Diabetes Team**

- You.
- Your child and his/her family.
- Paediatric diabetes consultant.
- Paediatric diabetes nurse.
- Children's community Nursing Team (CNNT).
- Paediatric dietitian.
- Ward link nurses.

These are the main people that will be involved with your child's care during diagnosis and beyond.

The Children's Diabetes Nursing Service will provide constant support and education. They will probably be your first point of contact for any advice or problems.

## **Contact Telephone Numbers:**

Medical support (Registrar):

Diabetes nurse:

Office:

Mobile:

Dietitian:

Ward:

## What happens now?

This leaflet is designed to give you some basic answers to immediate questions and for you to gain a brief insight into diabetes, its treatments and implications.

We hope that it will help you start to develop some basic knowledge about diabetes during your stay on the ward. It is intended to support the information given to you by the ward staff and diabetes team.

The Diabetes Team will guide and support you through the process of education and help you to gain the confidence and knowledge that you will need to deal with the condition.

The members of the diabetes team will be more than willing to discuss and clarify questions, doubts and worries.

**The team want you to ask questions, so ask them again and again.** If you're not sure what is being said, ask again until it makes sense. Your child may also have questions; we/you should encourage them to ask them.

At the back of this leaflet is a 'notes' section for you to list any questions that may pop into your head.

## What is diabetes?

Diabetes occurs when there is a shortage of a hormone called **insulin** in the body. The **pancreas** produces insulin.

The pancreas is a gland in the body and this has become damaged. As a result of this lack of insulin, the amount of glucose in the blood is too high because the body cannot use it properly.

Insulin is a very important hormone as it allows glucose to enter the cell where the body can use it as fuel/energy. Insulin is often described as a key or a bridge that allows access to the cell and enables glucose to enter.

Insulin controls the level of glucose in the bloodstream and therefore lowers the blood sugar level.

**Glucose** is the main fuel used by the body to give you energy and make you feel well.

Glucose comes from the digestion of starchy foods such as bread or potatoes and also sweet foods. Glucose needs to get into the cells of the body to give energy.

In diabetes there is an absence of insulin and glucose cannot get into the cells and is not turned into energy so the glucose accumulates in the blood.

### **Cause**

It is not really understood what causes diabetes.

We do know that some people develop diabetes after having an infection caused by a virus. Sometimes people who develop diabetes have relatives with diabetes.

### **FACTS about Type 1 Diabetes**

- Diabetes is NOT caused by something you have eaten.
- Diabetes is NOT caused by eating too many sweets.
- Diabetes is NOT caused by anything you have said/done/not done.
- Diabetes is NOT like catching a cold.
- You can NOT catch diabetes.

## **Treating Diabetes**

Diabetes is treated by giving injections of insulin. At present injections are the only way to give insulin, it cannot be taken as a tablet as it would be destroyed by the juices in the stomach and would not be able to do its job properly.

Insulin is injected into the fatty layer beneath the skin and is then absorbed into the bloodstream over a period of time.

The number of daily injections depends on a number of factors including age and lifestyle. Most children will have four injections a day.

The thought of having daily injections is understandably daunting however, after adequate learning and support the process is virtually painless. A lot of children get upset over the 'size' of the needle. The usual size for children and normal weight teenagers is 4mm.

Other things that affect blood glucose levels include:

### **Diet**

Your diet is not a special diet; it is a healthy way of eating which is suitable for all of the family. Each meal should include some carbohydrate. You may also need to eat some snacks that include carbohydrate depending on your insulin regime.

### **Exercise/Activity/Play**

Exercise keeps you healthy and is essential for long-term health. It also helps to control your blood sugar. The dietitian will be available for dietary advice and input. Food intake raises blood sugar levels. Physical activity and insulin lower blood glucose levels. **Self-monitoring is the tool which helps manage diabetes.**

## Diabetes Control

The level of glucose in the blood of people who do not have diabetes stays between 4 and 7 mmols/l (measurement of blood glucose). The aim of treating diabetes is to keep your blood glucose levels as near to normal as possible. Balancing insulin, food and exercise does this. Keeping blood glucose 'near normal' relieves the unpleasant symptoms of high and low levels.

Good control means that you will feel well.

We measure your control by testing your blood glucose at regular intervals throughout the day with a blood glucose monitor. Nursing staff will show you how to use the monitor.

We will be aiming (in the long term) to maintain your blood glucose levels between 5 – 10 mmols/l. You will learn how to adjust your insulin to enable good control.

## Hypos and Hypers

Hypoglycaemia is when your blood sugar falls below 4 mmols/l, this is commonly known as a **Hypo**. This needs to be corrected straight away. Nursing staff will teach you more about Hypos and how to recognise and treat them.

Hyperglycaemia is when your blood sugar is consistently above 14 mmols/l this is commonly known as a **Hyper**. It can indicate that diabetes is poorly controlled. The nurse will explain how to recognise and correct this.

## **What happens while in hospital?**

Some children can be quite ill by the time diabetes is detected – the insulin deficiency can creep up on the child.

During this time a lot of fluid may have been lost, and fluid is given through the vein. Insulin may also initially be given through the vein in this sort of situation.

Your child may need to be monitored closely. Once your child is better the drips can be stopped and insulin can be given by injection before meals.

Other children may appear perfectly well and active. These children do not require intravenous fluids and can be managed easily with initiation of insulin treatment.

However well/unwell your child is he/she will still require the same treatment in the long term. This treatment is insulin injections.

Whilst your child is stabilised in hospital there is lots of education and learning to take place about your child's condition. There is also the practical aspect of giving injections and performing the blood glucose monitoring.

We will support you throughout; you will be surprised how quickly you will learn. You will meet various members of the diabetes team. We will be around to explain things and answer doubts and questions.

Once your child is well and you are confident that you can cope at home, its home time!

Once back at home, the Diabetes Team will visit you regularly at first, to make sure you're doing okay. You will then be followed up in the diabetes clinic in hospital.

## **What happens when we go home?**

Life just goes on!

You will feel nervous and anxious about things at first, whatever the age of your child.

In time the checking and injecting will become part of your daily routine. Children aged around 6yrs and above should be encouraged to do their own injections and checking. This is an important part of preparing the youngster to take 'ownership' of his/her diabetes. It is important that children accept, understand and respect their diabetes and accept that it is 'their' diabetes not their parents.

The specialist nurse will visit regularly, and help you throughout. They will be a close contact for you and offer lots of support.

Diabetes control in children is a balancing act in more ways than one. Neglecting or ignoring the diabetes is bad, but also is the situation where the child's diabetes dominates his/her routine – so much so that the normal childhood activity and pleasures are ignored. As parents you have a major role in making sure that everything is well-balanced.

### **Carbohydrate Foods**

- Cereal
- Bread
- Fruit
- Milk
- Pasta
- Pastry / Pies
- Potatoes

## **Protein Foods**

- Cheese
- Eggs
- Fish
- Meat
- Milk

## **Foods Rich in Fat**

- Butter
- Cheese
- Fried Food

**Please write down a list of your child's likes and dislikes of food:**

**Likes**

**Dislikes**

**Please write down a sample menu that your child would eat:**

Breakfast:

Lunch:

Dinner:

Supper:

**Please write below any of your thoughts or any questions that you have for the team to answer:**

## Educational Checklist

The following areas regarding your child's diabetes needs to be learnt and understood by you, before your child is sent home:

<b>Topic</b>	<b>Discussion</b>	<b>Parent Sign</b>	<b>Nurse Sign</b>
<b>Diabetes</b>	Normal insulin production What's gone wrong?		
<b>Injections</b>	Storage Expiry dates Equipment Disposal of Sharps Rotation of sites Injecting Pen device		
<b>Diet</b>	Daily diet Exercise and sport Special products		
<b>Monitoring</b>	Equipment Interpretation Recording of results Disposal Importance		

## **Hypoglycemia** Causes

Signs & Symptoms

Prevention

Treatment

Hypostop

Glucogen

## **Illness**

Never omit insulin

Convert food - fluid

Increase monitoring

## **Ketoacidosis** Causes

Signs & Symptoms

Prevention

Treatment

## **Feet**

Footcare

Footwear

Check ups

## **Other**

Eyes

Identification

Diabetes UK

School

Holidays

Advice

## A GLOSSARY OF TERMS

These are commonly used words when talking about Diabetes. This glossary may help you to understand their meanings.

<b>Term</b>	<b>Description</b>
<b>Diabetes</b>	An absence of insulin from the body.
<b>Insulin</b>	A hormone produced in the pancreas. Acts as a key to let sugar into cells to be used as energy.
<b>Pancreas</b>	An organ in the body that produces insulin.
<b>Ketones</b>	A waste product left behind when the body doesn't have enough insulin to move the sugar into the cells. Ketones indicate not enough insulin in the body.
<b>Mmol/l</b>	Measurement of blood glucose.
<b>HbA1c</b>	A blood test that allows us to see what your long term control is like.
<b>Hypo</b>	A blood glucose measurement less than 4mmol/l. Resulting in a feeling of dizziness, shaking etc. Must be treated immediately.
<b>Hyper</b>	High blood glucose readings resulting in feelings of excess thirst, feeling generally unwell, increase in passing urine.
<b>Carbohydrate</b>	A compound that is made up of different types of sugar.
<b>Honeymoon period</b>	The need for insulin being reduced after the onset of diabetes due to an increase of the residual insulin production of the pancreas.
<b>Ketoacidosis</b>	When the blood turns acidic from a high level of ketones when there is a deficiency of insulin.

<b>Subcutaneous</b>	Fat tissue under the skin.
<b>Type 1 diabetes</b>	Insulin dependant. Caused by the pancreas not producing insulin.
<b>Type 2 diabetes</b>	Caused by an increased resistance to the insulin produced by the pancreas.
<b>Units</b>	The measurement that insulin is measured in.
<b>Glucogel</b>	A glucose replacement used to treat significant hypos.
<b>Glucagon</b>	An injectable glucose replacement for treatment of extreme hypos.
<b>Rotation</b>	Injecting in different areas to avoid insulin gathering underneath the skin.
<b>Diabetes UK</b>	The support charity for people with diabetes. Provide up to date information and support.
<b>DigiBete</b>	A website that has lots of useful information for children and adults.

## What care to expect

Children with diabetes have special needs because of the fact that they are children. It is essential that your child is cared for by a specialist children's diabetes team and seen at a clinic just for children. Specialist clinics give the opportunity to meet other parents and children who are in the same position as you.

Resources throughout the country vary however, the service should include access to:

**Consultant Paediatrician with a special interest in diabetes:** The consultant has overall responsibility for your child's care.

**Paediatric diabetes specialist nurse:** The nurse has expertise in both children and diabetes. She can give support and advice on all issues relating to diabetes. The nurse will be accessible and probably a first point of contact for any problems.

**Paediatric dietitian:** Will give advice and support on family food and diet. This will contribute to control and healthy growth.

**Children's clinical psychologist:** This person can be a valuable resource for emotional issues and behavioural problems.

**GP:** Your GP will attend to non-diabetes problems. He/she will be kept up to date by the diabetes team.

## Care at diagnosis

Your child may be cared for on the children's ward or at home, or a combination of each. However certain things should happen:

- A senior member of the medical team will give an explanation of diabetes.
- You are given the chance to absorb the diagnosis and talk over issues.

- Staff will listen to your worries and provide answers to your questions.
- You will see the dietitian and specialist nurse on numerous occasions.
- You will be given literature to read and think about and will be given information about support groups.
- You should feel supported throughout and be well aware of your next contact with the team, and be made aware of who to contact with any problems.

### **Continuing Care**

Following diagnosis, detailed information and education should be maintained to enable you to manage your child's diabetes:

- You will be given a choice about injecting devices.
- The community diabetes nurse will visit on a very regular basis to provide support etc.
- You will learn more in-depth about diabetes management, insulin, food, exercise, stress etc.
- You will learn how to deal with more severe episodes of hypoglycaemia.

After a time, you will become more confident in managing your child's diabetes. However, the team will always be available when and if you need them.

### **Other Areas:**

**School** – There should be good communication between school and the team. The specialist nurse will visit the school to talk to teachers and staff. The nurse will discuss hypos, mealtimes, snack times, exercise and any other relevant issues.

**Emotional Support** – A diagnosis of diabetes upsets the normal family routine. The specialist nurse should be an avenue of

emotional support however, some emotional and behavioural difficulties may need input from a psychologist/counsellor.

**Clinics** – Your child should be seen at clinic around three to four times per year with other support from the specialist nurse in between. At clinic general health will be reviewed.

### **The Diabetes Clinic**

Your child will be reviewed in clinic on a regular basis.

The diabetes clinics will give you the opportunity to meet other families. You will also see most members of the team, dietitian, specialist nurse and consultant. It is an opportunity to discuss ANY matters relating to diabetes. This may be practical things or emotional aspects of living with diabetes

### **Also at clinic the following will be checked:**

- Height
- Weight
- Blood Pressure
- HbA1c
- Random blood glucose
- Injection sites
- Diet review

### **A few tips, to make the most of your clinic visit:**

- Decide what you want to get out of the consultation
- Make a list of points
- Ask questions
- Make notes
- Ask for clarification if unsure
- Ensure you are happy with the follow-up given, i.e. to see specialist nurse or next clinic appointment.

## **A few rules ...**

- NEVER miss an insulin injection
- Eat regularly
- Don't forget your snacks
- Always carry hypo remedies
- Seek advice when ill
- Ask for advice when unsure

## **Useful Contacts**

[www.diabetes.org.uk](http://www.diabetes.org.uk)

Diabetes UK  
Customer Services  
10 Parkway  
London  
NW1 7AA  
Tel. 02074241010

## **Notes**

**If English is not your first language and you need help, please contact the Interpretation and Translation Service**

Jeśli angielski nie jest twoim pierwszym językiem i potrzebujesz pomocy, skontaktuj się z działem tłumaczeń ustnych i pisemnych

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**For general enquiries please contact the Patient Advice and Liaison Service (PALS) on 0161 604 5897**

**For enquiries regarding clinic appointments, clinical care and treatment please contact 0161 624 0420 and the Switchboard Operator will put you through to the correct department / service**

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