

Information for Parents with a Child Newly Diagnosed with Diabetes

Paediatric Diabetes Team Brochure

If you require a translation or alternative format of this leaflet please call Patient Advice & Liaisons Service (PALS) on 01296 316042

Safe & compassionate care,

every time

Members of the Children's Diabetes Team

Wycombe Hospital Team 01494 425353

Dr Michelle Russell Taylor-Consultant Paediatrician
Kausar Hassan –Paediatric Diabetes Specialist Nurse
Janice Furneaux-Paediatric Diabetes Specialist Nurse
Frances Taylor- Dietician 01494 425776

Stoke Mandeville Hospital Team 01296 315159

Dr Atanu Dutta- Consultant Paediatrician
Michelle Parker-Paediatric Diabetes Specialist Nurse
Flavia Marcus-Paediatric Diabetes Specialist Nurse
Andrea Young-Dietician 01296 315775

Dr Shelagh Watts-Consultant Clinical Psychologist (Both Sites)

buc-tr.paedsdiabetes@nhs.net

EMERGENCIES- For advice regarding an unwell child or if recently diagnosed with diabetes

From 7am- 10pm call:-

Wycombe Patients 07876790954

Stoke Mandeville Patients 07876578515

After 10pm call 01296 315145/6 (Stoke Mandeville Hospital -Ward 3 the Children's ward) to explain your concerns and then they will speak to the Paediatric Registrar on call who will call back to advise you.

Or If unable to contact anyone go to your nearest A&E (Stoke Mandeville Hospital if travelling from home or local area). **There is no A&E at Wycombe Hospital**

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Introduction and Diagnosis

You have just been told your child has diabetes, this is most likely to be type 1, and we all understand that this is a particularly difficult time for you.

It is important to realise that no one is to blame when a child develops diabetes, and although it is a permanent condition, it is one that can be treated. Insulin injections must be given several times a day to keep the diabetes under control.

Your child will very soon be back to good health and will return to school and all their usual activities.

Taking it in

We aim to support you through these difficult early days, both in hospital and once you are home, and to give you continuing support to manage your child's diabetes. We will teach you how to keep your child's blood glucose levels as normal as possible, allowing them to enjoy life to the full and grow in a healthy way through childhood and adolescence. This will be a good preparation for your child in managing their diabetes as adults.

In these early stages it seems that there is much to learn - try not to let it overwhelm you. There is plenty of time and there are lots of people to help you and your family.

What happens at Diagnosis?

Children are usually referred to the paediatric team who will see them at the hospital. Whether your child is admitted or not depends on how well they are when seen by the team.

If admitted to the hospital, your time as an inpatient will be kept as short as possible, and you may attend as a day patient.

You will be introduced to the diabetes team, who will begin to explain & teach you about diabetes, and help you to care for your child. They will plan with you the frequency of contact in the early weeks after diagnosis.

Diabetes has not made your child a different person- your child will still be able to do all the same things at school, and with their friends.

What is Diabetes?

Diabetes is a condition caused by lack of the hormone INSULIN in the body. Insulin is produced by a large gland called the pancreas which lies between the stomach and the backbone, next to the liver.

**The pancreas produces INSULIN.
Type 1 Diabetes occurs when the pancreas stops making insulin.**

When we eat food, the starchy carbohydrate foods are broken down into glucose which gets absorbed into the blood stream.

Insulin is needed for this glucose to be let out of the blood and into the cells of the tissues of the body where it is stored to be used for energy by our bodies.

**Our bodies use the food we eat to make glucose and then energy.
The glucose goes from our digestive tract into our blood.
It now needs to move from our blood into our body cells ready for use.
Or it is converted to fat for energy storage.**

This energy is needed for our muscles, brain, heart etc to work, allowing us to move and think. Normally this process is so well controlled that the level of blood glucose is always kept between 4 and 5.5mmol/litre (an amount of glucose in 1 litre of blood).

When someone has diabetes, there is not enough insulin about to let the glucose out of the bloodstream, so the levels of blood glucose get higher and higher. This glucose will then start to leak out of the kidneys into the urine, and because it is very concentrated, it takes water out of the body in the urine. This makes your child dehydrated and they feel very thirsty. This is why your child has probably been drinking and going to the toilet a lot.

In addition cells don't have enough energy so the body starts to make other substances called ketones for fuel, by breaking down stores of fat in the body. When ketone levels are very high they become poisonous to the body and cause nausea and vomiting. We will teach you how this is treated.

Without insulin, your child's body has been short of energy and they will have had too much glucose in their blood, making them feel very tired.

With insulin treatment, all these problems will quickly settle down and your child will begin to feel much better. The other part of the pancreas, which produces intestinal juices, is working perfectly normally.

What causes Diabetes?

No one really knows what causes diabetes. We do know that some people are more at risk because of the genes that they are born with.

Something triggers the immune system to start destroying the insulin producing cells in the pancreas. This is called auto immunity. This process may have been going on for several months, even years, without any symptoms.

No-one can catch diabetes from your child, nor is it caused by eating too many sweets

The symptoms of undiagnosed Type 1 diabetes are:

- passing large amounts of urine,
- excessive thirst,
- tiredness and
- possibly some weight loss.

The good news is that although diabetes and insulin is for life, research is going on and it is hoped that there will be an alternative to injections at some time in the future.

If your child keeps good blood glucose levels and looks after themselves during teenage years and adulthood, there is no reason why they should not lead a normal healthy life doing what everyone else can do.

The Treatment

Diabetes cannot yet be cured, but it can be controlled by giving insulin by regular subcutaneous injection to allow the body to run normally again.

Your child will feel well and will grow and mature normally. Your child will have insulin injections every day, and you will be taught how to give these. Unfortunately insulin cannot be taken as tablets because it is destroyed within the stomach before it has a chance to enter the blood stream.

As your child's body is not making insulin we will teach you how to inject their insulin.

Treatment will start immediately and will involve:

- A minimum of four injections of insulin a day.
- Regular meals and sometimes snacks containing carbohydrate foods.
- At least 4 blood glucose blood tests (finger pricks) each day.

The Paediatric Diabetes Dietician will discuss ways of eating with diabetes and will contact you within the first few days and again during the following weeks.

Once your child is feeling better, the whole family can start to learn:

- What diabetes is.
- How to give insulin injections.
- How to measure blood glucose levels.
- How to recognise and treat low and high blood glucose.
- How to test for ketones.
- The best type of eating pattern.
- Where and when to phone for advice.
- Current thoughts on how it occurs.

It will not be possible for you to master the whole of diabetes in a few days or even weeks but always ask if there is something that you do not understand.

There are some things which you need to know soon but others which can be learned gradually once your child is home.

Your G.P. will be informed of the diagnosis before you leave hospital and may like to see you soon after discharge. You will be given all the equipment and medication required on leaving the ward and we will inform your doctor of this list for repeat prescriptions.

Food and Diabetes

The Paediatric Dietician will see you and your child as soon as possible after diagnosis to teach you about the dietary aspects of diabetes.

On Admission:

Your child may have very little appetite until treatment with insulin has begun and they start to feel better. This can often increase their appetite hugely temporarily.

Once your child is able to start eating again the following guidelines will apply:

- Eating with diabetes is based on healthy eating principles that apply to all children and young people.
- It is Important to eat carbohydrate food at each meal.
- You will be taught how to count the carbohydrate in meals and snacks if they are eaten, so that you will give the right dose of insulin on each eating occasion.

As treatment with insulin starts to make them feel better, your child's appetite may be larger than normal. This is what we would expect to happen and you should allow your child to eat to their appetite.

Your child should have enough to eat at each meal or snack to last them until the next meal or snack so they are not eating more than six times a day.

If remaining in hospital Main meals can be chosen from the hospital menu and puddings should be limited to fruit, yoghurt or ice cream while an inpatient.

All drinks must be "Sugar Free"/"No Added Sugar" and can include water, fruit squashes such as Robinson's Special R reduced sugar squash or diet fizzy drinks e.g. diet coke, diet lemonade etc. Fresh fruit juice has a high sugar content, so should be taken only with a main meal. Milk should be taken with meals or snacks but not in-between so the milk sugars can be counted to assess the insulin dose needed.

A question about food often asked at diagnosis:

CAN MY CHILD STILL EAT SWEET FOODS, PARTICULARLY CHOCOLATE?

Sweet foods including chocolate are not 'banned' from the diet of children with diabetes and the dietician will discuss this in detail with you. However, it is best to avoid them at the beginning to give the blood glucose levels a better chance of returning to normal as quickly as possible.

Children's Diabetes Nurse Specialists (PDNS)

The children's diabetes specialist nurse will visit you on the ward and teach you how to do blood glucose tests and insulin injections and help you to feel confident to manage on your own at home. She will visit you at home and keep in regular contact by phone for the first few weeks. Training & information about diabetes will be given to the staff at your Child's school. A school diabetes management plan will be developed in partnership with you, PDNS & school.

The Diabetes Specialist Nurse will be responsible for co-ordinating the care of your child in hospital, when you go home and in the clinic. She will be involved in the on-going education of your family and your child regarding the management of your child's diabetes.

Some issues that may be of concern to you will be discussed at home and during clinic visits: e.g. Blood testing, sick days & illness, low and high blood glucose, holidays, exercise, parties, School trips, identity bracelet, careers, general health issues etc.

We will keep in close contact with you over the next few months, both at home and in the clinic. Members of the clinic team are usually available for telephone advice.

Children will often be able to take on some aspects of their own diabetes care depending on their age and maturity, however, even children and teenagers who are proficient in some practical aspects of diabetes need the continuing help and support of their parents and family.

Clinical Psychologist

The Clinical Psychologist aims to support you and your family with adjusting to having diabetes in your lives. They can work with you to find ways of coping in the short and long term.

The Clinical Psychologist is trained in child development, how children and young people think and learn and how families operate. Hence they have an understanding about what issues and obstacles that can add to stress levels during difficult times. They can advise & support you and your family whilst you begin to deal with the daily demands of treatment.

Being able to talk about diabetes and how it affects the family's lifestyle and feelings is something that the Clinical Psychologist aims to support you with so that the demands of the care can be met with a positive approach. We recognise that your family are an integral member of the team caring for your child.

As your children grow their knowledge, understanding, coping mechanisms, the ability to manage their diabetes more independently can improve. All children are individuals and some find it easier than others to manage the challenges at different stages of their life. The aim of the clinical psychologist is to be able to support you & your family through these various transitions as necessary.

Children's Diabetes Clinic

Regular clinic visits are essential to ensure your child's continuing good health. The diabetes team includes: doctors, children's diabetes nurses, diabetes dieticians, clinical psychology and the clinic nurses.

Together they are responsible for helping you learn to manage the many different aspects of your child's condition.

The diabetes team meets after every clinic to exchange information, and to keep all members well informed. It is important for your child to see and interact with the various team members.

**We look forward to seeing you in clinic.
Please tell us exactly how things have been, we can be of more help that way!**

Where is my appointment?

The Outpatient Departments are in Amersham, Wycombe or Stoke Mandeville Hospital

When will it be?

Clinics usually take place on Tuesdays or Wednesdays.

How often will we be seen?

Initially we will see you monthly in out-patients, as well as having regular contact with your diabetes nurse, dietician, or psychologist.

Once you have learnt the basics of managing the condition we will see you 3 monthly or more often when there are problems with blood glucose levels.

What do I bring to clinic?

Blood Glucose record book and meter and insulin pens to every clinic visit please.

•Hypo supplies/ snacks

What happens at clinic?

- Book in at reception desk.
- Children will be weighed , measured , an HbA1c taken , their meters downloaded & may have their blood pressure checked.(usually annual review clinic)
- You may see a combination of doctor, nurse, dietician and clinical psychologist who will discuss your child's diabetes, general health, growth and any problems.
- Teenagers may wish to have a consultation without their parents. However, parents will always be included in any decisions or changes that are made.

Write down any questions you have so you remember to ask them at your visit

Other People in the Clinic

Junior doctors, Student nurses, Student dieticians , and research nurses sometimes attend clinic to learn about diabetes.

You may be asked if one can accompany you or sit in in the clinic room, but you may refuse if you wish.

By the end of the first year we hope that you will feel confident in coping with:

- Giving injections and adjusting your doses
- Eating well for diabetes
- Measuring blood glucose levels
- Knowing how and when to test for ketones
- Knowing how to recognise and treat low and high blood glucose levels.

And how to deal with:

- Infections such as diarrhoea, flu etc
- Exercise
- Parties
- Holidays

We will discuss these and other aspects of diabetes with you as they occur or become relevant.

In addition we hope that you will have an understanding of the philosophy of diabetes care, and why we are interested in your blood glucose and HbA1c results.

Remember, keeping a diary of home blood glucose results is to help you to look after your child's diabetes.

Do please bring your child's blood glucose monitoring diary and your meter at every visit

The Annual Review Clinic

This is an annual review to check that your child is keeping well and that there is no evidence of poor blood glucose control, diabetes-related complications or conditions which are more common in people with diabetes.

The first of these will be one year after diagnosis and then annually. You will receive a letter in advance of your appointment outlining the need for any tests .

The Annual Review Clinic will take longer than usual as there will also be:

- A blood test is needed for the clinic – and if you can have this done with the forms that you are sent in the post about one week prior to the appointment you will have the results at the appointment. The blood test is taken through a vein (with anesthetic cream or spray if wanted). This checks for other conditions which may be present with diabetes, particularly thyroid problems and coeliac disease. Even if your child is young they will require a blood test from a vein. You may need to come for your blood test the week before your appointment so the doctor will have the results to discuss with you at the clinic appointment

- A physical examination, including a check of the feet in children especially if over 12 years of age.
- If over the age of 11 years or they have had their diabetes for more than 5 years , your child will need to bring three early morning urine samples, to check for protein in the urine. This is an early indicator of diabetic kidney disease). (The bottles are sent in the post.)
- If over 12 years, your child will be required to have an eyesight check and a photograph of the back of the eye to check for diabetic retinopathy (diabetic eye disease). This will be done in a separate appointment at the eye clinic . If this is not done locally the team will ask you for a copy of the letter sent to you stating the result . Please bring this to your next appointment with the team

Hospital Admissions

Related to Diabetes:

Are rare and most minor illnesses can be managed at home, however, if your child does need to be admitted to hospital please let us know especially if this occurs while away on holiday or at another local hospital ie Wexham Park . It will usually be Ward 3 at Stoke Mandeville Hospital.

For another reason:

Your child may require to be admitted to a surgical ward. If a general anesthetic is needed for any reason e.g. for an operation, either as an emergency or as a planned procedure, admission to hospital will be necessary. This is because your child will be unable to eat before an operation and so may require fluids and glucose intravenously via a “drip”.

Aims of The Children’s Diabetes Team

We work together as a team to provide a service to children, young people and their families. We agreed that the following were the aims of the team. If you do not feel we are meeting these aims, please let us know. We will be asking for your opinion in regular patient/parent satisfaction surveys.

- To enable the child or young person with diabetes to lead a full active and healthy life.
- To educate the child and family about diabetes and its management so that they have the knowledge, skills and confidence for optimal self-management.
- To monitor and optimise glycaemic control.
- To actively support those involved with the child at school to ensure that the child is cared for appropriately and can participate in school life to the full.
- To be aware of and offer help for any psychological problems.

- To be available to families for discussion of problems, and to offer a consistent approach.
- To facilitate peer support for young people with diabetes and their families
- To communicate within the team about management plans for individual children.
- To educate hospital staff regularly to ensure they are aware of Trust and paediatric diabetes related policies.
- To keep up to date with current best practice and to have an active involvement in Paediatric diabetes related audit and research.
- To facilitate a smooth transition to Adult Services.

Glossary

PDNS- Paediatric Diabetes Nurse Specialist

Blood Glucose -The level or concentration of glucose in the blood.

Carbohydrate - One of the three main energy-giving nutrients in foods, composed mainly of sugars and starches.

GlucaGen Kit - A box containing a syringe of fluid & a vial of glucagon powder to be injected to correct a severe “hypo”.

Glucagon - A chemical messenger which increases glucose levels in the blood.

Glucose - A sugar which is the chief source of energy for the body.

Glycosuria - The presence of glucose in the urine.

Glycosolated - See HbA1c

Haemoglobin HbA1c - A blood test that measures how much glucose is attached to red blood cells. It gives a measure of the average blood glucose level during the previous 6 to 12 weeks.

Honeymoon Period - The length of time during which the pancreas of someone who has recently been diagnosed with Type 1 diabetes continues to make some insulin.

Hormone - A chemical substance produced in one of the glands in the body and carried by the blood to have a specific effect on the functioning of other cells in the body.

Hyperglycaemia - High blood glucose level.

Hypoglycaemia - Too low a level of blood glucose.(or “Hypo”)

Hypothyroidism - A low level of thyroid hormone in the blood.

Incidence - The number of diagnosed cases per year of a particular disease.

Insulin - A hormone produced by the beta cells of the pancreas which lowers the blood glucose by enabling transport of glucose from the blood into the body cells. This allows the cells to use glucose for energy.

Ketoacidosis - A serious condition caused by a deficiency of insulin which results in body fat being used for energy and producing ketones (which can be detected in the urine) and acids as by products.

Ketones - Fat is broken down to fatty acids when the body cells are starving due to lack of glucose. The fatty acids are transformed into ketones by the liver, and ketones then appear in the blood and the urine. This can occur when there is a lack of insulin (with a HIGH BLOOD GLUCOSE) or when there is a lack of food (with a LOW BLOOD GLUCOSE)

Microalbuminuria - Very small amounts of protein in the urine.

Pancreas - A large gland situated near the stomach which produces digestive enzymes, insulin and other hormones.

Subcutaneous - Under the skin.

How can I help reduce healthcare associated infections?

Infection control is important to the well-being of our patients and for that reason we have infection control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to or after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser. Staff will let you know if this is the case.

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