

Paediatrics

Patient Information Leaflet (PL)

Paediatric Diabetes Clinic Brochure



You have just been told your child has type 1 diabetes 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 and managed. Insulin must be given several times a day to keep the diabetes under control. With the proper management and treatment your child will soon be back to good health and will be able to return to school and all their usual activities.

How will we manage?

We aim to support you through these difficult early days, both in hospital and at home. 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 to grow in a healthy way through childhood and adolescence. This will be good preparation for your child in managing their diabetes as an adult. 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 admitted to the children's ward in hospital. The length of stay in hospital will be kept as short as possible. You will be introduced to the Diabetes team, who will teach you about diabetes, help you to care for your child and discuss how long the stay in hospital will be.

It is very important that you let your child know that having diabetes has not made them a different person; they 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 the lack of a hormone called insulin in the body. Insulin is produced by a large gland called the pancreas which lies between the stomach and the backbone. When food is digested the carbohydrate element is converted to glucose and enters the blood stream. Insulin helps to move the glucose out of the blood and into the cells where it is used to produce the energy the body needs to function properly. This process will keep the blood glucose level between 4-7mmol/l (amount of glucose in a litre of blood).

When someone has diabetes, there is not enough insulin about to let the glucose out of the bloodstream, so the levels get higher and higher. The body will try to remove the high level of glucose through the passing of urine. This leads to thirst and is why you may have noticed that your child has been drinking a lot and going to the toilet more frequently.

When the body's cells don't have enough energy the body starts to make other substances called ketones for fuel, by breaking down fat. When ketone levels are high they become poisonous to the body and cause nausea and vomiting.

Without insulin, the body becomes low on energy and there will be too much glucose in the blood, which can cause tiredness.

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

What causes diabetes?

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

We know that something triggers the immune system to start destroying the insulin and 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. We do not know yet what the triggers may be. No one can catch diabetes from you nor is it caused by eating too many sweets!

The symptoms of type 1 diabetes include: 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.

The treatment

Diabetes cannot yet be cured, but it can be controlled by giving insulin by injection to allow the body to run normally again. 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 in the gut before it has a chance to enter the bloodstream.

As your child’s body is not making insulin we will teach you and your child how to give insulin.

Treatment will start immediately and will involve:

- Regular blood glucose tests
- Meals and snacks containing carbohydrate foods
- At least four injections of insulin a day

The Insulins

Lantus/ Levemir/Degludec

This is the **basal insulin**. This will provide the background insulin over a 24 hour period. It is given once a day (usually in the evening) at a time convenient to your child depending on their bedtime or evening activities. It is recommended that it is then given at the same time each evening.

NovoRapid

This is the **bolus insulin** that is to be given at meal times. It is a fast acting insulin given immediately before any meal. There may be occasions when it would be more appropriate to give this insulin straight after a meal but the Paediatric Diabetes Specialist Nurse will discuss this with you. NovoRapid begins working within 20 minutes of the injection and lasts for 2-3 hours.

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

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

It will not be possible for you to master the whole of diabetes in a few days, but always ask if there is something that you don't understand.

There are some things which you need to know straight away but some things can be learnt gradually once your child is home.

Your GP will be informed of the diagnosis before you leave the hospital. You will be given all the equipment you require and we will arrange for your GP to prescribe further supplies.

Food and diabetes

The Paediatric Dietician will see you and your child as soon as possible after diagnosis and will arrange further reviews with you.

On admission: your child may have very little appetite until treatment with insulin has begun and they start to feel better.

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. The most important part of a healthy diet for children with diabetes is the carbohydrates foods which include bread, cereals, fruit, milk, potatoes, rice and pasta.
- The first thing you need to establish is a regular meal pattern which is made up of breakfast, lunch and dinner. Other snacks between meals may be necessary if your child is very hungry.

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

All drinks must be sugar free and can include water, fruit squashes i.e. Robinsons Special R Reduced Sugar Squash or diet fizzy drinks, e.g. Diet Coke and diet lemonade. Fresh fruit juice must not be taken as it has a high sugar content. Milk should be taken with meals or snacks but not in-between.

A question about food often asked at diagnosis is:

Can my child still eat sweet foods, particularly chocolate?

Answer: Sweet foods including chocolate are not banned from the diet of children with diabetes, and the dietician will discuss this in detail with you when she gives you the other dietary advice. 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.

Paediatric Diabetes Specialist Nurses on 01908 996 522, or Ward 4 on 01908 996 367 (pdsn@mkuh.nhs.uk)

The Paediatric Diabetes Specialist Nurse will visit you on the ward, and for the first few days at home close contact will be kept. She will visit you several times over the initial diagnosis period and we would urge that regular contact is maintained. A school or nursery education package will be offered.

The Paediatric Diabetes Specialist Nurse will be responsible for coordinating the care of your child in hospital, when you go home and in the clinic. She will be involved in the ongoing 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 a later date following a structured education programme e.g. times of illness, low and high blood glucose levels, holidays, exercise, parties and school trips.

We will keep in close contact with you over the first few months, both at home and in the clinic.

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.

Children's and young people's diabetes outpatient clinic

Regular clinic visits are essential to ensure your child's continuing good health. The diabetes team includes: consultants, diabetes specialist nurses, a dietician, a psychologist and the clinic nurses. Together they are responsible for helping you to 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 the various team members.

We look forward to seeing you in clinic. Please tell us exactly how things have been and not what you think you ought to say. We can be of more help that way!

Where?

The outpatient department, Luing Cowley, Milton Keynes University Hospital

How often?

Every three months

What to bring?

Bring blood glucose diary/record book and blood glucose meter to every clinic visit.

What happens?

- Book in at reception
- Blood test (finger prick) will be taken HbA1c
- Child will be weighed and measured
- Information from your child's blood glucose meter will be downloaded
- You may see a combination of doctor, nurse, dietician and psychologist, who will discuss your child's diabetes, general health, growth and any problems you may have
- Teenagers are offered the opportunity to be seen on their own at the start of the consultation. However, parents will always be included in any decision or changes that are made.

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

Other people you may see at clinic:

The dietician and psychologist are core members of the diabetes team. You will be offered the opportunity to meet with them.

Student doctors and nurses sometimes attend clinic to learn about diabetes. You may be asked if one can accompany you or sit in the clinic room, but you may refuse if you wish.

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

- Measuring blood glucose levels
- Giving insulin injections and adjusting insulin doses
- Knowing how to recognise and treat low and high blood glucose levels
- Knowing how and when to test for blood ketones
- Eating well for diabetes
- And how to deal with:
 - Infections such as illness, 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 and YOUR CHILD to look after THEIR diabetes. Please bring the blood glucose monitoring diary and blood glucose meter to every visit.

Most minor illnesses can be managed at home. However, if your child is unwell please contact a PDSN or use your red box access.

Glossary

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

Glucagon Kit – a box containing a syringe of fluid and 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

Glycosylated – see HbA1c

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

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 blood and urine) and acids as by-products

Ketones – fat is broken down to fatty acids when the body cells are “starving” due to the lack of glucose. The fatty acids are transformed into ketones by the liver, and the ketones then appear in the blood and urine. This can occur when there is a lack of insulin (with high blood glucose) or when there is a lack of food (with low blood glucose)

Pancreas – a gland situated near the stomach which produces digestive enzymes, insulin and other hormones

Subcutaneous – under the skin

We ask for information about you so that you can receive proper care and treatment. This information remains confidential and is stored securely by the Trust in accordance with the provisions of the Data Protection Act 2018/GDPR. Further guidance can be found within our privacy notice found on our Trust website: www.mkuh.nhs.uk

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