



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Information Booklet for Children and Young People with Type 1 Diabetes

Information for patients, relatives and carers

Paediatric Diabetes Team

① For more information, please contact:
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What is this booklet for?

This booklet is aimed at helping young people to understand and control their Type 1 diabetes. It is intended for you to read and to refer to, as you manage your condition. Some of the content can be a little technical and may be difficult to fully understand; don't worry. The Diabetes Team are always on hand to explain it and help you.

You may find it easier to understand the booklet if you read it through with your Mum or Dad.

The Children and Young Peoples Diabetes Team

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What is Diabetes?

Type 1 diabetes is a condition that occurs when the cells in the pancreas (organ in your body) which normally produce insulin are damaged. Insulin is a hormone which acts as a 'key' that opens the door from the blood stream to the muscles and cells, to be used and stored as energy.

Without insulin the blood glucose cannot be used by the body as fuel, resulting in high levels of glucose in the blood.

No one knows what causes Type 1 diabetes, and developing it is no one's fault. Scientists believe that genetics, environment and autoimmune factors may be involved.

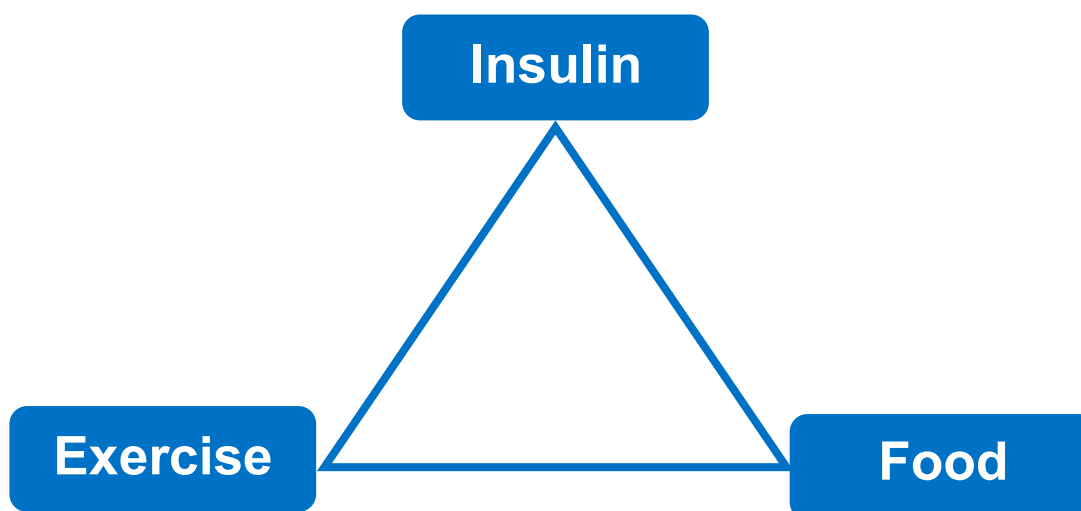
Life does change on diagnosis, but it doesn't mean you have to give anything up. Please discuss any concerns with your diabetes team.

The warning signs when a child or young person develops Type 1 diabetes are:

- ❖ Passing urine frequently – caused by increased sugar in the urine
- ❖ Extreme thirst
- ❖ Weight loss – which may be dramatic
- ❖ Drowsiness & lethargy
- ❖ Sudden changes in vision
- ❖ Increased appetite.

Treatment of Type 1 Diabetes

Type 1 diabetes is controlled with insulin, given via injections or a pump, carbohydrate counting and exercise. The amount of insulin injected needs to be balanced against the amount of food eaten, the current blood glucose level and the amount of exercise or activity.



The amount of insulin you need alters regularly. You may need more insulin if you are ill and less insulin if you are doing lots of exercise. Doing blood glucose tests at home will help you decide how much insulin to take and also help you decide whether the amounts of insulin you are taking is right for you.

Starting your Insulin

On diagnosis, the doctor will prescribe a starting dose of insulin. This will alter over time according to your blood glucose levels and lifestyle.

Insulin is measured in units and you will take two types of insulin each day. A long acting/slow release insulin, called Degludec (Tresiba). This is usually taken once a day, usually at night. This is the basal insulin, often called the background insulin. You will also take rapid acting insulin with each meal and some snacks, called NovoRapid. These are known as bolus injections. The amount of this insulin will vary according to your pre-meal blood glucose test and how many carbohydrates you eat at mealtimes. This should be injected 15-20 minutes before meals.

Initially the diabetes team will be able to advise you on how and when to adjust your insulin doses, but as time goes by you will become expert in this yourselves. **but**, remember the diabetes team is always here for advice.

Never Miss Your Insulin Injections

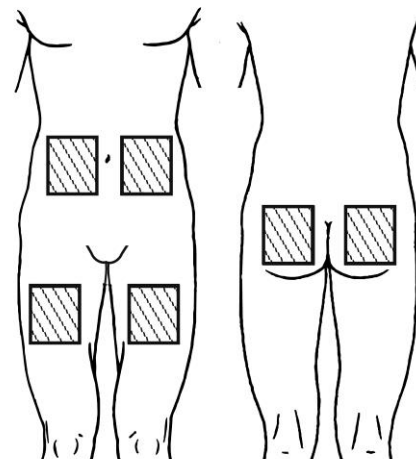
Insulin Injections

The nurses and doctors will show you and your parents how to give your insulin injections. The insulin is injected into the fat just under the skin and as long as your skin is not dirty, there is no need to wash the area you are injecting into. It is not advisable to inject through clothes.

The sites recommended for injections are:

- The top and side of the legs
- Abdomen
- Buttocks
- Upper arms (in older teens and adults only)

It is important to make sure that you use a different area each time you inject. If you use the same site too often, the area will become lumpy and thick, preventing the absorption of insulin.



Insulin pen devices

There are two types of insulin pen devices available – pre-filled pens that are disposable and reusable pens that you put disposable cartridges/penfills into.

The nurses will show you how to assemble and prepare your insulin pen for injection. Remember to do an “air shot” of 2 units to prime the needle before you administer your injection. You must make sure that the dial has returned to ‘0’. You must remove the needle after each injection, and use a fresh one each time.



Administering the injection

Your nurse will show you how to hold the area that is to be injected. Once you have dialled up your dose of insulin you push the needle into the skin at 90 degrees (right angle) and press the plunger as far as it will go, ensuring the dial has again returned to ‘0’. Once the insulin has been delivered it is advisable to keep the insulin pen in position for the count of 10, so that the full amount of insulin has been delivered. This also reduces any leakage.

Storage of insulin

Store the insulin you are not using in the fridge in its original packaging.

The insulin **in use** can be kept at room temperature but should be discarded after **four** weeks for NovoRapid and **eight** weeks for Tresiba.

Blood Glucose Tests

This is a very important way of monitoring your diabetes which is carried out using a blood glucose meter, flash blood glucose monitoring or CGM. These levels are measured in mmol/litre. The normal blood glucose levels are between 4 and 7mmol/l for a person without Type 1 diabetes. A Child or Young Person with Type 1 diabetes we aim to achieve between 4mmol/mol – 7mmol/mol pre-meal and 4mmol/mol – 9mmol/mol after a meal.

We expect your blood glucose levels to be higher when you are first diagnosed with diabetes. Your diabetes team will guide you on this. Checking your blood glucose level and keeping a diary of the results allows you, together with the diabetes team, to see how effective and balanced your activity, insulin doses and diet are.

During your stay on the children's ward, you will be shown how to perform and record your results.

The purpose of checking your blood glucose is also used to know when to adjust your insulin doses and to determine hypoglycaemia (low blood glucose) and/or hyperglycaemia (high blood glucose).

Technology to monitor your/your child's blood glucose level has improved over the years, moving onto other system will be discussed with your consultant and diabetes nurse.

Tips for successful testing:

1. Wash your hands in warm water and dry thoroughly. This will remove any substance that may interfere with the test. If you expect that you are not going to be able to access hand washing facilities, pack a wet flannel in a plastic bag to wipe your fingers.

We do not recommend that you use wet wipes or alcohol rub as these can alter your blood glucose result.

2. Prepare your meter ready for a test.
3. Prick the side of your finger with your finger pricker.
4. Don't immediately squeeze your finger but hold your hand down below your waist for about five seconds.
5. 'Milk' the finger so that a small amount of blood appears.
6. Apply the blood to the test strip and wait for the result.



There are lots of different meters available; the diabetes team will help you choose one that suits you best.

When to test

The best time to test your blood is before your main meals and before bed. It is also useful to test your blood two hours after your food and insulin to assess the effectiveness of your insulin dose and to understand how different foods affect your blood glucose level.

You will also need to do more tests during times of illness as insulin doses will need to be adjusted.

To avoid hypoglycaemia (low blood sugar) it is also important to test at times of exercise.

Your diabetes team will advise you about your particular testing needs. We usually want you to test your blood glucose six to eight times per day, to help you gain good control of your glucose levels.

Downloading your glucose meter

We will ask you for an email address which can be used for contact purposes, but also to invite you to Diasend/Glooko. This is a web-based management system where your blood glucose levels are saved and reviewed, we would advise you to download your meter every two weeks and prior to any clinic appointments.

By regularly downloading your glucose meter, you can work with your diabetes team to make any required adjustments to your insulin regime.

Being aware of your glucose levels and how to manage them, will improve your diabetes control, helping to keep you fit and healthy.

Hypoglycaemia (hypos)

Hypoglycaemia is when your blood glucose is less than 4mmols/l. In a person without diabetes, the body detects when the blood glucose has fallen below normal and switches off the production of insulin and this stops the blood glucose falling any lower.

But when someone has diabetes the insulin that has been injected will go on working even when the blood glucose is low. Therefore, it is necessary to eat or drink some fast-acting sugar to counteract the effect of the ongoing action of the insulin and this will stop the glucose level falling lower.

It is difficult to avoid hypoglycaemia completely when your diabetes is controlled with insulin and if your everyday blood glucose is low. Symptoms of a hypoglycaemia can vary between people or you may not have any symptoms. Hypoglycaemia are classed as mild, moderate, and severe.

Hypoglycaemia can occur if:

- ❖ You have injected too much insulin
- ❖ You haven't eaten enough food
- ❖ You do more exercise than usual
- ❖ You have skipped a meal/snack or had it later than usual
- ❖ You are unwell with sickness/diarrhoea.

Signs and symptoms of hypoglycaemia:

- ❖ Sweating
- ❖ Tingling lips
- ❖ Hunger
- ❖ Paleness
- ❖ Lack of concentration
- ❖ Difficulty in waking
- ❖ Headache
- ❖ Personality change
- ❖ Irritability
- ❖ Shaking/wobbly legs/dizzy
- ❖ Dilated pupils



Treatment of a hypoglycaemic episode

You should always treat a hypo as soon as it happens rather than waiting to see what happens. It is also important not to be left alone when you have a hypo. You should not do any activity until your blood glucose level is in a normal range; this would reduce your blood glucose further.

Mild

This is when there are no symptoms, or you have symptoms but are still able to treat it yourself. It is always important to tell an adult when this happens.

Take dextrose in the form of three to four dextrose tablets, full sugar coke (100-150mls) or fresh orange/apple juice (100-150mls).

It is important to recheck your blood glucose after 15 minutes, if your blood glucose is not above 4mmols then repeat the dextrose as above. When it has come back into a normal range, it is a good idea to do another blood test within an hour.

You should think about having a carbohydrate snack, for example, if the hypoglycaemia happened a few hours before your next meal, before bedtime or if you are going to do some exercise. Here are a few ideas for a carbohydrate snack:

- One to two slices of bread (toast/sandwich)
- 200mls milk
- Three to four rich tea biscuits
- One to two digestives
- One small banana
- One large piece of fruit

Moderate

This is when you are drowsy but still able to swallow. The child will need extra help to treat this type of hypoglycaemia, due to being disorientated and/or confused.

Use GlucoGel/Dextragel: This is a sugary gel that can be rubbed into your lips, gums and the inside of your cheeks; you will probably use a whole tube.

Test your blood sugar as with the mild episode and remember to think about a carbohydrate snack.

Severe

In severe hypos, it is possible that you may have a fit (seizure) or become unconscious. This can be very worrying for your parents but we wouldn't expect you to remember it. If this happens, if the GlucoGel is not effective or you are unconscious, you may need an injection of Glucagen. Glucagen is a hormone that releases stored glucose from your liver. Again, follow the above processes after your injection. The Glucagen injection may make you feel or be sick. Your parents will be shown how to give this injection by the diabetes team. **It is important that nobody gives you anything to drink if you are unconscious.**

You may be completely fine after a hypo or you may feel unwell, tired and have a headache for a number of hours afterwards.

Hyperglycaemia

A **hyperglycaemia** is when your blood glucose is **high**. It may be caused by:

- ❖ Too little or no insulin
- ❖ Eaten more carbohydrates than your insulin allows
- ❖ Infection, fever
- ❖ Emotional stress
- ❖ Less exercise taken than usual

What to look out for:

- ❖ Increased thirst and passing urine
- ❖ Weakness and lethargy
- ❖ Tummy ache
- ❖ Loss of appetite
- ❖ Mood changes
- ❖ Loss of concentration



If your blood glucose level stays in the high range, it could mean that you need more insulin. The diabetes team will teach you how to adjust your insulin dose in response to high blood glucose levels.

Seek advice if:

- ❖ Your blood glucose levels stay high despite extra insulin
- ❖ Your blood glucose levels are high and you feel ill

REMEMBER
Never miss your insulin
and contact your diabetes team for advice

What happens when I am ill?

When you are ill, particularly if you have a fever, your body needs more energy, and therefore more glucose to fight the infection. Normally extra insulin is produced to cope with the rise in blood glucose, but when you have diabetes, the body cannot meet the extra demands. Many people with diabetes make the mistake of thinking that because they eat very little or nothing at all they should cut down or omit their insulin. This is not the case and contact with your diabetes team is important so adjustments and advice can be made to your treatment.



Drink regular amounts of fluid and if your blood glucose levels are on the low side drink a sugary drink to maintain your levels.

- ❖ Measure and monitor your blood glucose and ketones levels more often
- ❖ Adjust your insulin requirements according to your results
- ❖ Monitoring your ketone levels will tell you if you are at risk of diabetic ketoacidosis (DKA).

It is a good idea to drink extra non-sugary fluids if your levels are high and you may need to do more blood tests.

Hyperglycaemia and ketones

Ketones show up in your blood when your body is short of insulin. They appear because your body starts to burn fat for energy. Your body does this when it cannot use the glucose in your blood due to a shortage of insulin.

If there are too many ketones, this can make your blood acidic and lead to a serious condition called diabetic ketoacidosis.

This can happen when you are unwell, as your body needs more glucose and so more insulin when you are ill.

You will be given a blood meter to test your ketones if needed. Your parents will also be given some guidelines called “**sick day rules**” to follow along with help from the diabetes team.

Ketones are produced in the body when:

- ❖ There is not enough insulin in the body
- ❖ Muscles use the body's fats for energy
- ❖ You are not getting enough carbohydrates to eat.

What to look out for:

- ❖ Weeing a lot
- ❖ Thirsty
- ❖ High blood glucose levels
- ❖ Levels of ketones on testing greater than 0.6mmol/L
- ❖ Tummy ache
- ❖ Feeling or being sick
- ❖ Difficulty breathing
- ❖ Acid (pear drop) smell on the breath.

With guidance from the diabetes team or hospital you will need to:

- ❖ Adjust your insulin dose according to your results
- ❖ Test your blood glucose more often
- ❖ Test your blood ketones
- ❖ Drink fluids such as water or non sugary drinks

Blood ketone levels:

- ❖ Below 0.6mmol/L
Readings below 0.6 mmol/L are in the normal range.
Follow your healthcare professional's advice before making any changes to your diabetes medication.
- ❖ Between 0.6 and 1.5 mmol/L
Readings in this range, with blood glucose level higher than 13.9 mmol/L, may mean the development of a problem. Follow your health care instructions.
- ❖ More than 1.5 mmol/L
Readings above 1.5 mmol/L, with blood glucose level higher than 13.9 mmol/L, suggest you may be at risk of developing diabetic ketoacidosis (DKA)

Contact your diabetes team, GP, children's ward or A&E department for advice.

What can I eat?

A healthy diet is a very important part of your treatment. It is not a special diet, but a healthy eating plan, which the whole family can follow. You will see a dietitian during your stay on the ward, or an appointment will be sent to you.

The dietitian will also speak to you about carbohydrate counting. Carbohydrate in the food that you eat is measured in grams and is an accurate way of matching your food to your insulin requirements. Working with your diabetes team to balance your insulin with what and how much you eat, along with your activity, will help to get your blood glucose levels within target range.



Exercise

Why do exercise and Diabetes go well together?

- ❖ It improves the body's ability to use glucose
- ❖ It can make the action of insulin on fat and muscle cells more efficient
- ❖ It lowers blood pressure
- ❖ It helps with weight control



What should you do before and after exercise?

- ❖ Monitor your blood glucose and record your result, making a note of anything that may affect them
- ❖ Eat enough carbohydrate to compensate for using extra energy OR reduce your insulin if you know you are going to perform exercise
- ❖ Carry a fast-acting glucose and carbohydrate with you
- ❖ Avoid injecting into an arm or leg as this sometimes increases the action of the insulin when you are exercising

You may like some extra advice on exercise from the diabetes team, please don't hesitate to contact the team.

Follow-up

We expect to see you in clinic every three months. Initially we will see you more often than this, within the first two to four weeks and six weeks after diagnosis. It is important to attend these appointments as things are often changing as you grow, and this will allow the diabetes team to advise you on changes more frequently.

When you are in clinic we will weigh and measure you and take your blood pressure. We also ask for a finger prick blood sample to test your HbA1c (see below).

HbA1c – what is it?

Another way of looking at your overall blood glucose control is by monitoring and performing a HbA1c blood test. It is performed by a finger prick blood test, and shows the average blood glucose over a two to three month period. The HbA1c level is a long-term average of blood glucose control and can help the diabetes team recommend changes to your insulin regime.

School, Nursery and Playschool

After you have been diagnosed with diabetes it is important you are able to go back to school, nursery and playschool as soon as possible. However, it is important that your teacher/assistants understand your condition.

Your specialist nurse will make an appointment to go into school and discuss your regime. Points discussed are:

- ❖ What diabetes is?
- ❖ What to do if your blood glucose level is low or high
- ❖ How to manage your injections and blood test
- ❖ When you should have meals and snacks
- ❖ School trips
- ❖ To be aware of different signs about your daily routine



It is important that you take your 'hypo' supplies into school and keep them stocked up. These include:

- ❖ Dextrose/Lucozade tablets or sugary drink
- ❖ A tube of Glucogel
- ❖ Some biscuits or cereal bar

School Meals and Packed lunches

It is always advisable to choose the healthier options if you have a school meal. Both school meals and packed lunches should consist of carbohydrate; this will keep your energy levels up.

The dietician will give you ideas for your packed lunches.



Feeling a bit fed up?

Your health care team understands that from time to time you may feel a bit fed up about having diabetes, testing your blood glucose levels and injecting insulin. It helps to share your feelings with someone else. You may need to talk to your parents, doctor, our team psychologist, or diabetes nurses. We hope that you feel you are able to talk to a member of the diabetes team - we can arrange for you to be seen by one of our teams who are used to helping people find ways of coping with their diagnosis.



Long Term Complications of Diabetes

Diabetes affects all parts of your body; if your blood glucose levels remain raised over long period of time, then these organs can become damaged. By monitoring your blood glucose levels and taking control, the risk is reduced.

It is important to understand that these complications will not occur for some years after, so it is very important that you visit and attend your clinic appointments. The main areas that can be affected are your:

- ❖ Eyes
- ❖ Feet
- ❖ Kidneys
- ❖ Blood pressure

You will also have a blood check every year and provide a sample of urine for testing.

What else can you do to avoid the complications associated with diabetes?

- ❖ Do not smoke
- ❖ Reduce the amount of fatty foods you eat
- ❖ Exercise regularly
- ❖ Try to maintain a healthy weight and BMI

Diabetes supplies and equipment

When leaving the hospital you will be given enough supplies to last a few days - this will give you time to see your GP and request a repeat prescription. You should allow your GP 48 hours when requesting your supplies, so don't let your supplies get too low before you do this.

Meters and finger pickers' are available from the diabetes team. Should you have a problem with your meter you can ring the help line printed on the instruction booklet or contact the diabetes team.

It is also a good idea to register your meter with the manufacturers as they will send you free batteries.

Sharps bins for safe disposal of needles can be obtained on prescription from your GP. You will need to contact the council to arrange safe disposal of these.

Council Contact numbers: York: 01904 551551
Selby: 01757 705101
East Riding: 01482 393939

Storage of equipment

All equipment should be stored in a safe place at room temperature apart from insulin supplies not in use, which should be kept in the fridge.

NB. Some blood glucose meters will not work if they are too cold.

Disability Living Allowance

Although we do not class diabetes as a physical disability, Parents/Carers are entitled to claim an allowance because of the extra care required to look after a child with diabetes. This allowance helps to make life a little easier. The allowance is paid at varying rates - higher, medium and lower and is available to everyone independent of any other allowances you may receive.

The diabetes team will inform the Department of Works and Pensions (DWP) of your diagnosis. The DWP will forward you the necessary forms to complete and the diabetes nurses are available to help you with these forms. You are not eligible for payment until three months after diagnosis, so there is plenty of time to fill them in. The allowance is reassessed from every 1-3 years, when you need to complete another form.

Should your application be refused, we can always appeal against the decision. It is helpful to make a copy of your completed application form to refer to if you need to appeal or for when you need to re-apply. It is usual to receive this payment until the age of 16 is reached. At the age of 16 years you will need to apply for Personal Independence Payments through the department of work and pensions.

Suggested Reading

- ❖ Type 1 Diabetes in children, adolescents and young adults.
Author: Dr. Ragnar Hana.
- ❖ Diabetes – Through the looking glass.
Author: Dr. Rachel Besser.
- ❖ No Added Sugar – growing up with type 1 diabetes.
Author: Fibi Ward.
- ❖ Carbs & Cals.
Author: Chris Cheyette and Yello Balolia.
- ❖ www.childrenwithdiabetesuk.org
- ❖ www.jdrf.org.uk
- ❖ www.diabetes.org.uk
- ❖ www.runsweet.com
- ❖ www.digibete.org

Our ultimate objective is to be trusted to deliver safe, effective and sustainable healthcare within our communities.

If you found this information useful and have any comments or queries please contact a member of the Paediatric diabetes team on 01904 721317.

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

Paediatric Diabetes Team, The York Hospital, Wigginton Road, York, YO31 8HE or telephone 01904 721317.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Leaflets in alternative languages or formats

Please telephone or email if you require this information in a different language or format, for example Braille, large print or audio.

如果你要求本資 不同的 或 式提供 , 電或發電

Jeżeli niniejsze informacje potrzebne są w innym języku lub formacie, należy zadzwonić lub wysłać wiadomość e-mail

Bu bilgileri değişik bir lisanda ya da formatta istiyorsanız lütfen telefon ediniz ya da e-posta gönderiniz

Telephone: 01904 725566

Email: access@york.nhs.uk

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