

Emergency contact information

Diabetes nurses Tel: 07880 794616

This number is for emergency contact only and will be answered Monday to Friday, 8:00am to 5:00pm.

Outside of these hours, please contact the Paediatric Assessment Unit.

Paediatric Assessment Unit Tel: 0300 422 8305 (open 24hrs)

Reference No. GHPI1331_06_24 Department Diabetes

Review due

June 2027



Contact information

Paediatric Diabetes Specialist Nurses Tel: 0300 422 8473 Monday to Friday, 8:00am to 5:00pm Email: <u>ghn-tr.paediatricdiabetesnurses@nhs.net</u>

Dietitian Tel: 0300 422 8473 Email: <u>ghn-tr.paediatricdiabetesdietitians@nhs.net</u>

Download Clinic These are held weekly. To book a slot, please contact the team. Tel: 0300 422 8473

Children's Centre Tel: 0300 422 8307 or Tel: 0300 422 8308

Your consultant is:

Your Paediatric Diabetes Specialist Nurse is:

Your dietitian is:



Introduction

This booklet covers some of the most important things that have been discussed with you during admission. The information in this booklet aims to help you through the first few weeks following diagnosis and also gives you advice and guidance to help you to make the safe transition from hospital to home.

At first, the diagnosis of diabetes and learning the things you need to know about diabetes may seem overwhelming. Please talk to a member of the diabetes team, they have years of experience and during that time they have spoken to many families in similar situations. Do not be afraid to ask about something again if you do not understand it the first, second or third time.

Please remember there will always be ongoing support and guidance. Our strongest recommendation is for you to contact the Paediatric Diabetes Team (see contact numbers) if there is anything you need help with, regardless of how small or silly you think it is.

Coping with the diagnosis

Diabetes may be a major shock to the young person diagnosed with the condition. It may take some time for you and your family to come to terms with this. The period just after you find out the young person has diabetes is likely to be a very unsettling time for the whole family. There may be a variety of feelings, including shock, denial, anger, sadness, fear and guilt which can put pressure on relationships.

It helps to keep in mind that each of us reacts differently to stressful events. Although these feelings can be distressing, remind yourself that they are a normal response to a challenging situation.

You will be the best individual to support the young person diagnosed with diabetes through this difficult time because you know them so well. Sharing your own feelings about what has happened can encourage the young person to do the same.

The Diabetes team's Clinical Psychologist is specially trained to help you and the young person to understand reactions to their diagnosis and make sense of the experience.

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Asking for help is one way of coping. It also helps to be mindful of your own needs. This can mean putting aside some time just for you.

We recommend that you join either **The Families with Diabetes National Network**, **Diabetes UK** or the **Juvenile Diabetes Research Foundation** (the details are available at the end of this booklet).

Open access

The Children's Ward operates an open access arrangement for all young people with Type 1 Diabetes. This means that if you have any serious concerns regarding diabetes and wish for a review, you can contact the ward. A doctor will give you advice on what to do. The contact details are at the beginning of this booklet. The young person with diabetes may be asked to attend the ward or they may be able to be managed at home.

Insulin

The liver produces glucose (sugar) naturally throughout the day and night. Glucose levels in the blood rise sharply after food containing carbohydrates are eaten; therefore 2 types of insulin are required. A long-acting (basal) insulin to deal with the natural glucose produced and a short-acting (bolus) insulin to deal with the sharp rises in glucose levels after a meal.

Basal insulin should be given once a day, at the same time every day. Bolus insulin should ideally be given 15 minutes before a meal. Additional short-acting insulin can be given to correct high blood glucose levels; this is known as a correction dose.

Injection technique guidance

It is recommended that both short acting and long-acting insulins should be given in different sites. The usual injection sites are:

 Abdomen/tummy – we suggest this area is used for shortacting insulin when the person with diabetes is older or has more fat in this area.



- Front of thigh/lateral thigh we suggest this area is used for short acting insulin.
- Buttocks we suggest this area is used for long-acting insulin.
- Lateral aspect of arm this area can be used for short-acting insulin but this is not often taught to younger children due to the possibility of injecting in to the muscle.



Avoid using injection sites that show signs of

inflammation, oedema or infection until the skin has had time to heal. You should also avoid areas showing signs of lipohypertrophy for a period of 3 months. Lipohypertrophy is where fatty lumps appear at the injection site causing problems with insulin absorption.

Injection technique

- Remove the insulin pen cap and check that you have the right insulin for the time of day.
- Screw on a new pen needle.
- Prime the needle with 2 units of insulin, to check if the needle and pen are working correctly. When a drop of insulin has been seen, the pen is ready to use.
- Dial up the number of units calculated for the injection.
- Choose the injection site.
- Inject into the chosen site at a 90-degree angle, pressing down on the pen device button/plunger as far as it will go and making sure to count to 10 before taking the needle out of the skin.
- Once the needle has been injected, it will automatically reset back to zero indicating the dose has been administered.
- Following the injection, take the outer needle cover (do not try to replace the small inner cover) and use it to discard the needle safely into a sharps container. Replace the cap on the insulin pen.



Adjusting insulin doses

Over time you and the young person with diabetes will learn to adjust insulin doses yourselves. The advice we give about when to change insulin, is based on blood glucose readings. For example, if blood glucose levels are high or low on waking and remain similar throughout the day this shows that the longacting insulin needs to be increased or decreased.

If there is a specific time of the day that the blood glucose always reads high or low then this may show that the carbohydrate ratio needs to be changed to deliver more or less insulin before food.

You will be supported in adjusting insulin doses both in your Multi-disciplinary Team (MDT) outpatient appointments and in the Download Clinics.

Blood glucose testing

Blood glucose levels should be checked often, especially in the early stages following diagnosis of diabetes in order to make the necessary adjustments to insulin doses.

It is recommended to check levels:

- Immediately before all food.
- 2 hours after all food.
- Before bedtime.
- Before and after exercise.
- If the young person with diabetes is unwell or feels unwell.
- We expect a minimum of 6 to 8 blood glucose tests a day to begin with.

Normal and abnormal blood test results

Blood Test Result (mmol/L)	Status	Intervention
3.9 or under	Too low (hypoglycemia)	Treat with fast-acting glucose immediately (see hypo treatment).
4.0 - 6.9	Normal	Follow advice on 'bolus advisor'.
More than 7.0	Above target	Follow advice on 'bolus advisor' as a correction dose may be needed.
More than 14	Above target (hyperglycemia)	Follow advice on 'bolus advisor' as a correction dose may be required. Also check for ketones and use the traffic light sheet.

Remission phase

In a person who has Type 1 diabetes, the insulin-producing beta cells in the pancreas are destroyed. Therefore, it is typical for individuals to need larger amounts of insulin because the body is not as sensitive to insulin as it should be.

However, once treatment starts, most people go through a 'remission phase' in which their existing beta cells still function, producing some insulin. Their body is likely to regain its sensitivity and the amount of insulin needed may be greatly reduced. The time this phase lasts varies from person to person.

Dietitian

During your hospital stay, you and the young person with diabetes will see a dietitian to learn about carbohydrate counting. You will also be setup with a bolus advice app.

You will be shown how to use a photo guide called 'Carbs and Cals' where you match your portion of food to a photo.







You will then be able to put the amount of carbohydrates the young person is going to eat, with their blood glucose reading, into the bolus advisor app. This will tell you how much insulin to give.

The dietitian will also show you how to read food labels and discuss exercise and a healthy diet to help the young person with diabetes to grow and develop appropriately. This is not a sugar-free diet but a healthy eating plan, which is what would be advised to all young people regardless of having diabetes or not.

Dietitians are usually present at each of the young person's consultant clinic appointments. You will also be offered an additional dietetic appointment each year.

Take home medication

Before the young person is discharged from hospital you will be given a supply of their take-home medication (TTOs). You will get future supplies of medication from the young person's GP. The GP will have received a list of the prescribed items from the doctors on the Children's ward.

Below is a description of some of the medication and equipment you may be given on discharge.

ltem	Purpose
Bolus insulin This is shown with a cartridge injection pen (Store unopened cartridges in fridge)	Bolus or short-acting insulin is given with meals. It is used to treat the glucose in food eaten. You can also give extra with a meal or between meals to correct a high blood glucose level, known as a correction dose.
Basal insulin This is shown with a cartridge injection pen (Store unopened cartridges in fridge)	Basal or long-acting insulin is usually given once a day in the evening. It is used to treat the continuous and naturally occurring glucose that the liver produces and is not connected to glucose produced from eating food. Each dose lasts for about 24 hours.



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4mm needles	The injection needles are for single use only and should always be discarded in a sharps box after use. If there is bruising or discomfort, please discuss this with your diabetes team.
	A 4mm pen tip needle is usually appropriate regardless of age or size.
Glucose Tablets	Glucose tablets are one of the standard treatments used for hypos. They can be chewed and have a chalky-like texture.
	Glucose tablets must never be given to a person who is unconscious, as this may lead choking.
Glucose Juice	Glucose Juice is another standard treatment used for hypos. It is a thin liquid that comes in a variety of flavours. Glucose juice must never be given to a person who is unconscious, as this may lead choking.



Patient		
Information	Glucogel[®] Glucose gel in tubes	Glucose gel is used to treat hypos when it is not possible to give normal hypo treatment such as glucose tablets or glucose juice. This may be because the young person's blood glucose level is so low that they are resisting normal hypo treatment and you cannot persuade them to eat or drink anything. Or it may be because the low blood glucose level means that chewing or swallowing glucose is difficult.
		Glucose gel can be rubbed into the gums and cheek where it is then absorbed into the blood system without the need of swallowing or chewing.
		Glucose gel must never be given to a person who is unconscious as this may lead to gel getting into the lungs or you may have your fingers badly bitten if the young person begins to fit from severely low blood glucose levels.
	GlucaGen® 1 mg injection kit	GlucaGen [®] is for hypos when the young person is unconscious or fitting. It is very rarely required.
		The injection kit contains a white solution of glucagon hormone which when injected encourages a store of glucose in the liver to start working, bringing the young person back to consciousness.
		They will almost certainly feel nauseous (sick) after having this injection but it is important to get the young person to drink and eat some form of carbohydrate to replenish the emergency store of glucose in the liver. Inside the cover is a picture sequence describing how to use the injection kit.
		Severe hypoglycaemia is very rare but if it ever happens you must call 999 for an ambulance so that the young person can be reviewed in hospital.
	Blood glucose meter and blood glucose/ketone test strips	Each patient will be provided with a blood glucose meter which can be used for testing blood glucose and blood ketone levels.



Bolus Advisor App	All patients will be setup with a bolus advisor app, when they are diagnosed, which is programmed to advise you on how much insulin to give with all food. It can also be used to calculate how much insulin you need to correct a high blood glucose level.
Lancets for finger pricking	Lancets are used to test blood glucose levels with a finger pricking device.
Sharps bin	The sharps bin is used for the safe disposal of all needles, such as those from the insulin pen, the finger pricker lancets and used test strips. Only close the lid when the bin is full as you will not be able to open it again. The GP will provide you with new sharps bins on prescription.
	Some surgeries dispose of sharps bins or you can hand over sealed bins to your local pharmacy - you will need to check with your surgery for the local arrangement.

Follow up after discharge

After the young person is discharged from hospital, we encourage you to keep in regular contact with the Paediatric Diabetes Team via phone and/or email for support with reviewing their blood glucose levels. We will advise you on how often to contact us before the young person is discharged from hospital.

Children's Diabetes Clinics

Following discharge, you will be given clinic appointments for the young person to attend once a week for the next 6 weeks. One of these appointments will be held virtually with a dietitian/nurse, the others will be face-to-face in the clinics staffed by the Consultant, a Paediatric Diabetes Specialist Nurse and Dietitian and sometimes a Clinical Psychologist.



Any young person under paediatric care must be offered at least 4 clinic appointments per year as set out in government guidelines. If you are unable to attend a clinic appointment, please try and give at least 24 hours' notice and where possible we will try to fit you into the next available clinic slot. If that is not possible, we may be able to arrange a personal appointment outside of the normal clinic hours to make sure that the young person does not go too long before being seen by a member of the team. Repeated non-attendance at clinic is viewed as a serious concern.

At every clinic:

- The clinic nurse will measure and record the young person's height and weight. This is to make sure of normal physical growth. Significant weight loss or failure to grow may be a sign of high blood glucose levels or insufficient insulin.
- An HbA1c finger prick sample will also be taken (see the "What is glycated haemoglobin, HbA1c' section).
- The young person's blood pressure will be measured and recorded.
- Blood glucose levels will be reviewed.
- Clinics are also an opportunity for you to ask questions and raise any concerns you may have.

Once per year:

- Every young person will have an annual blood screen, which will include an investigation into thyroid function and coeliac status. This is because there is a higher risk of developing thyroid problems and coeliac disease for people who have Type 1 Diabetes.
- When the young person is 12 years of age or older, they will have their cholesterol level reviewed as part of the annual blood screen.
 - They will be asked to give urine samples so that their kidney function can be checked.
 - They will be invited to a retinopathy screen (photographs of the back of the eye) to check for any risks to their eyesight.
 - They will have a foot check to review their foot health.



What is glycated haemoglobin (HbA1c)?

HbA1c stands for glycated haemoglobin and is an average measure of how much glucose is 'sticking' to the red cells in the blood. A finger prick blood sample will be taken at every clinic appointment to measure the HbA1c. This is important as it tells us how stable blood glucose levels have been over the last 3 months, the higher the HbA1c, the higher blood glucose levels have been.

Young people will naturally have a high HbA1c on their first clinic visit because their blood glucose levels would have been very high for some time before they were diagnosed with Type 1 Diabetes. The first HbA1c result received at clinic is not something to be concerned about but we hope to see it reducing over future visits.

A HbA1c of **48mmol/mol or lower** is the target for good health.

Immunisations

The Department of Health recommends that all children (over the age of 6 months) and young people with Type 1 diabetes have annual immunisations against influenza. It also recommends immunisation against pneumococcal infection for children and young people with diabetes who need insulin or oral hypoglycaemic medicine.

Dental and optician

All children and young people are advised to have regular dental and eye examinations. It is important to inform the dentist and optician about the young person's diabetes diagnosis at their next visit.

Back to school

It is important that you inform the school of the young person's diagnosis of Type 1 Diabetes. The Paediatric Diabetes Specialist Nurses will provide education and a health care plan to school staff. You will be invited to attend this education meeting.

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When the young person returns to school, you will need to supply a School Emergency Kit. This can be a food container holding spare test strips, lancets, batteries, hypo treatments and contact details. This will be kept on the school premises in case of a hypo emergency.

Basic rules for school:

- Ideally young people should keep their hypo treatment close by. They should not be made to move to fetch their hypo treatment from another part of the school.
- Young people must be supervised at all times during their treatment of a hypo and should be allowed to treat their hypo in the classroom or have a responsible friend or adult accompany them if they have to go to another room. This is because removing them from the watchful eyes of others puts the young person at greater risk and isolates them from assistance if they should need it.
- Young people must have privacy and access to a purposebuilt medical room or area with running water, to perform their blood glucose tests and injections. However, the young person might choose to have their health care needs attended elsewhere.
- Young people should not be excluded from any school activity, including excursions, based on their diabetes as this represents disability discrimination, which is in breach of the Equality Act 2010.

Low blood glucose levels (hypoglycaemia)

Low blood glucose levels can happen for many different reasons but will always need prompt treatment.

Warning signs

- Shakiness or dizziness
- Tiredness
- Sweating or feeling clammy
- Headache
- Feeling hungry



Or you might notice

- A change to complexion
- Dark tired looking eyes
- A change in behaviour such as a bad mood
- Disorientation
- Lack of concentration

Possible causes

- Planned or unplanned activity/exercise
- Hot weather or extremely cold weather
- Too much insulin at a meal time for example, your child did not eat the anticipated meal
- Excitement

Treatment of low blood glucose

A low blood glucose is a level of 3.9mmol/L and below

Step 1

Give a fast-acting carbohydrate, for example:

- Glucose tabs
- Lift Juice
- Glucogel

The Paediatric Diabetes team will help to calculate the amount of fast-acting carbohydrate required to treat a hypo. This will vary depending on age, weight and activity levels. The amount needed for the young person will change as they get older.

Step 2

Retest blood glucose level 10 to15 minutes later.

If the blood glucose is still below 4mmol/L repeat Step 1 until blood glucose is above 4mmol/L.

If the blood glucose is above 4mmol/L continue as normal.

Patient



High blood glucose levels

Information

Blood glucose levels may drop and rise at times. If blood glucose levels stay high for a long period of time this can lead to symptoms such as:

- Hyperactivity
- Personality change
- Loss of appetite
- Feeling generally unwell
- Increased thirst and tiredness
- Frequent passing of urine
- Feeling nauseous or vomiting
- High blood ketones

High blood glucose levels can happen for many different reasons including; illness, fever, too little or no insulin, eating more carbohydrates than calculated for, stress or less activity than usual.

Treatment for high blood glucose levels

A high blood glucose is a level above 14mmol/L.

Step 1

Check blood ketones, if they are above 0.6 mmol/L follow the advice on the blood ketone management sheet. We will provide you with a copy of the blood ketone management sheet before the young person is discharged from hospital. If the blood ketones are below 0.6 mmol/L then follow the advice below.

Step 2

Type the young person's blood glucose level into the bolus calculator app and give the advised correction dose. This can be given with mealtime insulin or as a separate dose.

Step 3

Encourage the young person to have a sugar-free fluid to drink.

Step 4

Check the young person's blood glucose level 2 hours after the correction dose has been given to determine if the blood glucose level is decreasing.

If blood glucose levels are coming back down into range, then continue to monitor more frequently throughout the day or night.



If blood glucose levels are getting higher and symptoms are worsening then call the diabetes nurses for advice Monday to Friday, 8:00am to 5:00pm or outside of these hours contact the Gloucestershire Hospital Paediatric Assessment Unit on Tel: 0300 422 8305.

Advice about blood ketone testing

Blood ketones can be tested using the ketone meter and blood ketone test strips. Blood ketone testing is more accurate than urine tests.

What causes blood ketones?

Blood ketones are caused when the body does not receive enough insulin. This will cause the breakdown of fat in the body which will produce acids called ketones.

Are ketones dangerous?

At low levels, ketones can be managed by giving extra shortacting insulin. If ketones are allowed to build up too high in the blood, they may lead to a condition called ketoacidosis, which cannot be reversed without hospital admission.

The young person will feel very unwell and have symptoms of nausea and/or vomiting.

Signs and symptoms of ketones

- Nausea and/or vomiting early sign, test for ketones immediately.
- **High blood glucose levels** early sign of possible ketone build up.
- Fruity smelling breath serious sign of advanced ketone build up.
- Stomach pain very serious sign of advanced ketone.
- **Difficulty breathing** ketoacidotic, emergency help is required immediately, telephone 999 for an ambulance.
- Confusion and/or disorientation ketoacidotic, emergency help required immediately, telephone 999 for an ambulance.



How do I prevent ketones being produced?

Never stop giving long-acting insulin. Missing any insulin is not good for a person with diabetes, but missing the long-acting insulin will lead to ketones being produced more quickly.

If you realise that the young person has missed a dose of longacting insulin, for whatever reason, then give half the normal dose immediately and test the blood ketones and blood glucose. You must then call the diabetes nurse or the Children's Ward for further advice. Tell them what the blood ketone and blood glucose levels are.

When should I test for blood ketones?

We only expect you to test for blood ketones in the following circumstances:

- If the young person is unwell and their blood glucose level is above 14 mmol/L, especially with a high temperature, flu symptoms or signs of infection.
- If you think you have forgotten to give or the young person has missed a dose of long-acting insulin. This will be noticeable by rising blood glucose levels.
- If the young person wears an insulin pump and insulin doses for meals and correction do not appear to be having any effect or there is a steady rise in blood glucose levels, despite insulin being given. This might indicate that the pump set is faulty and the pump set and insulin will need to be changed quickly.



What should I do if I discover blood ketones?

A blood ketone level is measured in mmol/L just like blood glucose levels. The grid below explains what to look out for and what to do in the event of high blood ketones and blood glucose levels.

Make sure to leave a gap of 2 hours between correction doses.

Blood Ketone level	Risk of developing ketoacidosis	Action
0.5 mmol/L or under	None	No action – this is a natural level of blood ketones.
0.6 – 1.0 mmol/L	Slight	Give usual correction dose and test ketones and blood glucose again in 2 hours.
1.1 – 1.9 mmol/L	Moderate	Give usual correction dose + 25% extra and test ketones and glucose again in 2 hours. If the blood ketone level has dropped, repeat correction dose using the new blood ketone and blood glucose readings. Contact the diabetes nurses or on-call tier 2 doctor in the Paediatric Assessment Unit (PAU) for further assistance if the young person's blood ketone level is not dropping.
2.0 – 2.9 mmol/L	Moderate to High	Give usual correction dose + 50% extra and test ketones and glucose again in 2 hours. If the blood ketone level has dropped, repeat the correction dose using the new blood ketone and blood glucose readings. Contact the diabetes nurses or on-call tier 2 doctor in PAU for further assistance if the blood ketone level is not dropping.

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3.0 mmol/L High	Give double the usual correction dose. Seek medical advice from the diabetes nurses or the on-call tier 2 doctor (see telephone number below) immediately. Prepare for admission to hospital.
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Further information

Patient Advice and Liaison Service (PALS) Contact the PALS team if you have any concerns about your care. Tel: 0800 019 3282 (Freephone) Email: ghn-tr.pals.gloshospitals@nhs.net

Benefits advice

Type 1 Diabetes is considered a disability under English law. The Disability Living Allowance (DLA) is therefore payable for all children and young people with Type 1 Diabetes, until the age of 16. To request a claim form, please contact the Department of Work and Pensions. These benefits are to help you with the extra costs of caring for a young person with diabetes.

Department of Work and Pensions

Tel: 0800 882 200

Medical alert bracelets

Wearing a medical alert bracelet is advised for children and young people with Type 1 Diabetes so that in the event of an emergency, people can be alerted to the condition and help.

Medical alert bracelets are available to order online through many websites as listed below:

Website: <u>www.medicalalert.org.uk</u> Website: <u>www.medi-tag.co.uk</u> Patient



There are many websites and books about Type 1 Diabetes:

Information Websites

Diabetes UK Tel: 020 7713 1000 Website: <u>www.diabetes.org.uk</u>

Juvenile Diabetes Research Foundation Tel: 020 7713 2030 Website: www.jdrf.org.uk

Digibete

Website and app provide a basic overview of diabetes management. The 'Clinic Code' for the app is HIMPQ. Website: <u>www.digibete.org/</u>

Facebook

Facebook also has forums for people with Type 1 Diabetes. Website: <u>www.facebook.com</u>

We are not in a position to support or disagree with the comments on Facebook forums but we appreciate that a number of parents use it as a useful way of exchanging information and support.

Books

Paediatric Diabetes Teams across the UK approve the following books as guides for families and carers with a child or young person with Type 1 Diabetes.



Type 1 Diabetes in children, adolescents and young adults

How to be an expert on your own diabetes by Dr Ragnar Hanas Published by: Class Health (Please note that the cover colour changes with each new edition published)





Carbs and Cals

A visual guide Carbohydrate Counting and Calorie Counting for people with diabetes. By Chris Cheyette and Yello Balolia Published by: Chello Publishing Limited Carbs and Cals is also available as a Downloadable application for smartphones.

Content reviewed: June 2024

Making a choice

Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.

Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

- 1. What are my options?
- 2. What are the pros and cons of each option for me?
- 3. How do I get support to help me make a decision that is right for me?

oted with kind permission from the MAGIC Progra ne, supported by the H Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of info Patient Education and Counselling, 2011;84: 379-85



AQUA References Interview Interview Action A