

**Patient
Information**

Managing Type 1 Diabetes at home



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

General contact information

Paediatric Diabetes Specialist Nurses

Tel: 0300 422 8473

Monday to Friday, 8:00am to 5:00pm

Email: ghn-tr.paediatricdiabetesnurses@nhs.net

Dietitian

Tel: 0300 422 5506

Monday to Friday, 8:30am to 4:30pm

Email: ghn-tr.paediatricdiabetesdietitians@nhs.net

Download Clinic

Monday to Friday, 9:30am to 11:30am

Email: download.clinic@nhs.net

Reference No.

GHP11331_02_21

Department

Diabetes

Review due

February 2024

**Patient
Information****Psychologist**

Tel: 0300 422 8523

Children's Centre

Tel: 0300 422 8307/8

Your Consultant is:**Your Paediatric Diabetes Specialist Nurses is:****Your Dietitian is:****Introduction**

This booklet covers some of the most important things that have been discussed with you during your child's 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 and your child 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. Remember there will always be ongoing support and guidance and 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.

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Coping with the diagnosis

A diagnosis of diabetes may be a major shock to you, your child and the family, and it may take some time to come to terms with this. The period just after you find out your child has diabetes is likely to be a very unsettled time for the whole family.

All family members may have a variety of feelings, including shock, denial, anger, sadness, fear and guilt which can put pressure on family relationships. It helps to keep in mind that each of us reacts in our own ways to stressful events. Although these feelings can be distressing, remind yourself they are a normal response to a challenging situation. You are the best person to help your child through this difficult time because you know them so well. Sharing your own feelings about what has happened can encourage your child to do the same. The diabetes team's psychologist is specially trained to help you understand your reactions and make sense of your family's experience. 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 children with Type 1 Diabetes. This means that if you have any serious concerns regarding your child's diabetes and wish for your child to be reviewed you can contact the ward and a doctor will give you advice on what to do. The contact details are at the beginning of this booklet. You may be asked to attend the ward or you may be able to be managed at home.

**Patient
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On discharge from hospital you will have been advised as to how much insulin your child needs. They are as follows:

Basal insulin

Levemir®, Lantus®, Abasaglar® or Tresiba®: _____ units

Bolus insulin

NovoRapid®, Humalog®, Fiasp® or Apidra®:

Breakfast

1 unit of insulin to ____ grams of carbohydrate

Mid-Morning

1 unit of insulin to _____ grams of carbohydrate

Lunch

1 unit of insulin to ____ grams of carbohydrate

Mid-Afternoon

1 unit of insulin to _____ grams of carbohydrate

Evening meal

1 unit of insulin to ____ grams of carbohydrate

Correction dose

1 unit of fast-acting insulin will reduce your child's blood glucose by ____ mmol/L.

Correction doses may vary depending on time of day.

Insulin

Your child's 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 insulin to deal with the natural sugar produced and a fast-acting insulin to deal with the sharp rises in sugar levels after a meal.

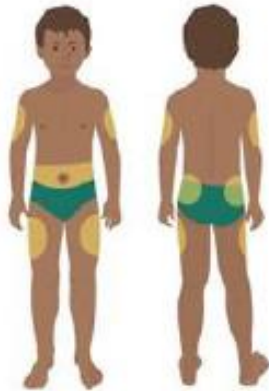
Basal insulin should be given once a day, at the same time every day. Bolus insulin should ideally be given 15 minutes before a meal. Additional fast-acting insulin can be given to correct high blood glucose levels; this is known as a correction dose.

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Injection technique guidance

It is recommended that both fast 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 fast acting insulin
- Front of thigh/lateral thigh – we suggest this area is used for fast 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 a sign of lipohypertrophy, inflammation, oedema or infection until the skin has had time to heal. Lipohypertrophy is where fatty lumps appear at the site of injection 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
- Chose the injection site

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- Inject into the chosen site at a 90 degree angle, pressing down on the pen device button/plunger as far as it will go, it will then automatically reset back to zero indicating the dose has been administered
- Count to 10 before taking the needle out of the skin
- 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 in to a sharps container. Replace the insulin pen cap.

Adjusting insulin doses

Over time you will learn to adjust insulin yourself. The advice we give on 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 would show that the background long acting 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 would show that the carbohydrate ratio needs to be changed to deliver more or less insulin.

You will be supported in adjusting insulin doses both in your MDT outpatient appointments and in the Download Clinics.

Blood glucose testing

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

Recommended testing times are:

- Immediately before all main meals
- 2 hours after a main meal
- Before bedtime

We expect a minimum of 6 to 8 tests a day to begin with.

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Normal and abnormal blood test results

Blood Test Result (mmol/L)	Status	Intervention
3.9 or under	Too low (Hypo)	Treat with fast-acting sugar immediately (see low treatment).
4.0 – 6.9	Normal	Follow advice on 'bolus advisor'.
More than 7.0	Above target	Follow advice on 'bolus advisor'.

Remission (honeymoon) phase

Most people with type 1 go through a 'honeymoon phase' in the period after diagnosis. In a person who has type 1 diabetes, the insulin-producing beta cells in the pancreas are destroyed. However, during the period immediately following diagnosis most people go through a 'honeymoon phase' in which their existing beta cells still function, producing some insulin.

At diagnosis your child is likely to need larger amounts of insulin because the body is not as sensitive to insulin as it should be. Once treatment starts, the 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 your child will see a dietitian to learn about carbohydrate counting. You will also be provided with a bolus advice meter.



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You will be shown how to use a photo guide called 'Carbs and Cals' and match your portion of food to a photo book. This can be then inputted to the bolus meter following a test and the meter will tell you how much insulin to give.






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



Dietitians are usually present at each of your child's consultant clinic appointments. You will also be offered an additional dietetic appointment yearly.





Take home medication

Before your child is discharged from hospital you will be given a supply of take home medication (TTOs). You will get future supplies of medication from your GP who will have been sent a list of the prescribed items by the doctors on the Children's ward.

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

Item	Description	Purpose
	<p>NovoRapid® insulin cartridge, shown with injection pen (Store unopened cartridges in fridge)</p>	<p>NovoRapid® is a fast-acting insulin given with meals. It is used to treat the sugar in food eaten. You can also give extra NovoRapid® with a meal to correct a high blood glucose level, known as a correction dose. (See 'Treatment plan' section on doses of insulin' to remind you of what these doses are).</p> <p>This is referred to as bolus insulin.</p> <p>If you do not have NovoRapid®, your fast-acting insulin will be Humalog®, Fiasp® or Apidra®. These insulins act in exactly the same way.</p>
	<p>Levemir® insulin cartridge, shown with injection pen (Store unopened cartridges in fridge)</p>	<p>Levemir® is the long-acting insulin given once a day, usually in the evening. It is used to treat the continuous and naturally occurring sugar that the liver produces, and is not connected to sugar produced from eating food. Each dose lasts for about 24 hours.</p> <p>This is referred to as basal insulin.</p> <p>If you do not have Levemir®, your long-acting insulin will be Lantus®, Abasaglar® or Tresiba®. These insulins act in the same way.</p>
	<p>4mm BD pen tip needles</p>	<p>The injection needles are for single use only and should always be discarded in a sharps box after use.</p> <p>If your child has bruising or discomfort, please discuss this with your diabetes team.</p> <p>A 4mm pen tip needle is usually appropriate regardless of your child's age or size.</p>

Item	Description	Purpose
	<p>Glucogel® Glucose gel in tubes</p>	<p>Glucose gel is used to treat lows, when it is not possible to give normal low treatment such as Lucozade, glucose tablets or sweets. This may be because your child's blood glucose level is so low that they are resisting normal low treatment and cannot persuade them to eat or drink anything. Or it may be because the low blood glucose level means that chewing or swallowing sugar in some form is difficult.</p> <p>Glucose gel can be squirted into the mouth where it is then absorbed into the blood system without the need of swallowing or chewing. You can rub it into the gums or inside of the cheek for greater effect.</p> <p>Glucose gel must never be given to a child who is unconscious though, as this may lead to gel getting into the lungs or you may have your fingers badly bitten if your child begins to fit from severely low blood glucose levels.</p>
	<p>GlucaGen® 1 mg injection kit</p>	<p>GlucaGen® is for serious lows and is very rarely required.</p> <p>The injection kit contains a white solution of Glucagon hormone which when injected encourages a store of sugar in the liver to start working, bringing the child back to consciousness. They will almost certainly feel nauseous after having this injection but it is important to get the child to drink and eat some forms of carbohydrate afterwards to replenish the emergency store of sugar in the liver. Inside the cover is a picture sequence describing how to use the injection kit.</p> <p>Severe hypoglycaemia is very rare but if it ever happens you must call 999 for an ambulance so that your child can be reviewed in hospital.</p>

Item	Description	Purpose
	<p>Blood glucose meter and blood glucose test strips</p>	<p>The Accu-chek Expert® is a bolus advisor meter which is programmed to advise you how much insulin to give with meals and snacks.</p> <p>Everyone will be offered a bolus advisor meter at diagnosis.</p>
	<p>Blood ketone meter and blood ketone test strips</p>	<p>You will also receive a ketone testing meter. It is only necessary to measure blood ketones if your child's blood glucose levels are very high without an obvious reason or if your child is unwell.</p> <p>Missing long-acting insulin (Levemir®, Lantus®, Abasaglar® or Tresiba®) can also result in blood ketones being produced.</p> <p>A high number of ketones can become a life threatening problem requiring immediate admission to hospital. Prompt testing and seeking advice may enable you to manage blood ketones at home. See section on blood ketone testing for more information.</p>
	<p>Lancets for finger pricking device</p>	<p>The correct lancets must be used for specific finger pricking devices. The Fastclix drum fits the AccuChek Fastclix finger pricking device.</p>
	<p>Sharps Bin</p>	<p>The sharps bin is used for the safe disposal of all needles, such as those from the insulin pen and 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.</p> <p>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.</p>

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Follow up after discharge

After your child is discharged from hospital, we encourage you to keep in regular contact with the Paediatric Diabetes Team via phone and/or email.

Children's Diabetes Clinics

Following discharge, your child will be given clinic appointments, 1 a week for the next 6 weeks. One of these appointments will be with a dietitian/nurse in the clinic.

Clinics are staffed by the consultant, a paediatric diabetes specialist nurse, a dietitian and sometimes a psychologist. Any child 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 beforehand, where possible, we will try to fit your child into the next available clinic slot. If that is not possible we can arrange a personal appointment outside of the normal clinic hours to make sure that your child 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 your child's height and weight. This is to make sure of normal physical growth. Significant weight loss or failure to grow is a sign of poor diabetes control. Signs of obesity are also looked for
- An HbA1c finger prick sample is also taken (see what is 'HbA1c')
- Your child's blood pressure will be measured.

Annual Review Clinic – once per year:

- Your child 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

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What is glycated haemoglobin (HbA1c)?

HbA1c stands for glycated haemoglobin and is an average measure of how much sugar is 'sticking' to the red cells in the blood.

A finger prick blood sample will be taken at every clinic to measure the HbA1c. This is important as it tells us how stable your child's blood glucose levels have been over the last 3 months, the higher the HbA1c, the poorer the control.

Your child 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.

An HbA1c of **48mmol/mol or lower** is the target for very 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.

Back to school

It is important that you inform the school of your child's diagnosis of Type 1 Diabetes. The paediatric diabetes specialist nurses will provide education to school staff and provide them with a health care plan. You will be invited to attend this meeting.

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On their return to school, you will need to supply a School Emergency Kit. This can be a food container holding spare test strips, lancets, batteries, low treatments and contact details. This will be kept on the school premises in case of a low emergency. Your child should also carry fast-acting carbohydrates with them at all times.

If dextrose tablets, which are meant as medicines, are likely to be taken by your child or by their friends as a tasty snack, it might be useful to give your child the Glucogel® to keep in their pocket as their immediate treatment for a low. This does not have a pleasant taste and will not be a temptation.

Basic rules for school:

- Children must not be removed from the classroom to treat a low or to test for a suspected low. Removing the child from the watchful eyes of others puts your child at greater risk and isolates them from assistance if they should need it
- Children 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
- Children must never be sent alone to fetch low treatment from another part of the school. They must be allowed to treat their low in the classroom or have a responsible friend or adult accompany them if they have to leave the classroom
- Children must be supervised at all times during their treatment of a low
- Children must have privacy and access to a purpose built medical room or area, with running water, to perform their blood glucose tests and injections. However, the child might choose to have their health care needs attended elsewhere.

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Low blood glucose levels

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

Possible causes

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

Treatment of low blood glucose

Blood glucose 4.0mmol/L or **below**

Step 1

Give a fast acting carbohydrate for example:

- 3 glucose tabs
- 150mls of Lucozade

The paediatric diabetes team will work with you to calculate the 'Low Treatment' amount as this will vary depending on your child's age, weight and activity levels. The amount they need will change as they get older.

**Patient
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Retest blood glucose level 10 minutes later.

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

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

High blood glucose levels

Blood glucose levels may drop and rise at times, but if your child's blood glucose level stays high for a long period of time this can lead to feeling generally unwell, increased thirst and tiredness.

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

Signs of a high blood glucose level include:

- Hyperactivity
- Personality change
- Loss of appetite
- High blood glucose
- High blood ketones/urine ketones

Higher blood glucose levels will lead to increased thirst, frequent passing of urine and feelings of nausea or vomiting.

Treatment for high blood glucose levels

Blood glucose level above 14mmol/L

Step 1

Check blood ketones, if blood ketones are above 0.6 mmol/L follow the advice on blood ketone management. If the blood ketones are below 0.6 mmol/L then follow the advice below.

Step 2

Give advised correction dose from the meter, this can be given with mealtime insulin or calculated by meter based on the high blood glucose level read by the meter.

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Step 3

Encourage sugar free fluid to drink.

Step 4

Check the blood glucose level 2 hours after a correction dose has been given, to determine if the level is decreasing.

Blood glucose levels coming back down into range

Continue to monitor more frequently throughout the day or night.

Blood glucose levels getting higher and symptoms worsening?

Call the diabetes nurses for advice Monday to Friday, 8:00am to 5:00pm or out of these hours contact the Gloucestershire Hospital Paediatric Assessment Unit on Tel: 0300 422 8305.

Advice on blood ketone testing

Blood ketones can be tested in exactly the same way as blood glucose but you will need the Optium Neo® meter and special blood ketone test strips (see below) to perform a blood ketone test. Blood ketone testing is more accurate than urine tests.



Optium Neo® blood ketone meter



Blood ketone test strips

What causes blood ketones?

Blood ketones are caused when the body does not receive enough insulin, especially long-acting insulin such as Levemir®, Lantus®, Abasaglar® or Tresiba®. The body starts to break down fat in the body and this process produces acids called ketones.

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Are ketones dangerous?

At low levels ketones can be managed by giving extra fast-acting insulin such as NovoRapid®, Humalog®, Fiasp® or Apidra®. 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.

Your child will feel very unwell and symptoms of nausea and/or vomiting should firstly be treated as a likely sign of ketones and not necessarily a bug or ordinary illness, especially if the child felt well the day before.

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 required immediately Tel: 999
- **Confusion and/or disorientation** - ketoacidotic – emergency help required immediately Tel: 999

How do I prevent ketones being produced?

Never stop giving long acting (basal) insulin. Missing any insulin will not be good for your child but missing the long acting insulin will lead to ketones being produced.

If you realise your child has missed a dose of their long acting insulin, for whatever reason, then give half the normal dose immediately and test the blood ketones and blood glucose. Then call the diabetes nurse or the Children's Ward for further advice. Tell them what the blood ketone and blood glucose levels are.

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When should I test for blood ketones?

Blood ketone test strips are very expensive compared to the urine ketone strips so we only want you to test for blood ketones in certain circumstances. They are:

- If your child 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 or missed a dose of long acting insulin. This will be noticeable by rising blood glucose levels
- If your child wears an insulin pump and insulin doses for meals and correction do not appear to be having any effect. A steady rise in blood glucose levels despite insulin being given suggests that the pump may not be working.

A positive test for blood ketones will almost certainly confirm that it has malfunctioned 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 above explains what to look out for and what to do in the event of blood ketones and high blood glucose levels.

Never give a correction dose within 2 hours of giving a previous correction dose.

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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 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 blood ketone level has dropped repeat correction dose using new blood ketone and blood glucose readings. Contact diabetes nurses or on-call registrar (see telephone number below) for further assistance if blood ketone level 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 blood ketone level has dropped repeat correction dose using new blood ketone and blood glucose readings. Contact diabetes nurses or on-call registrar (see telephone number below) for further assistance if blood ketone level not dropping.
3.0 mmol/L	High	Give double the usual correction dose. Seek medical advice from the diabetes nurses or on-call registrar (see telephone number below) immediately. Prepare for admission to hospital.

**Patient
Information****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 with Type 1 Diabetes. 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 your child.

Department of Work and Pensions

Tel: 0800 882 200

Medical alert bracelets

Wearing a medical alert bracelet is advised for children 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: www.medicalalert.org.uk

Website: www.theidband.com

Website: www.mediband.co.uk

Website: www.medi-tag.co.uk

There are many websites and books about Type 1 Diabetes:

Diabetes UK

Tel: 020 7713 1000

Website: www.diabetes.org.uk

Juvenile Diabetes Research Foundation

Tel: 020 7713 2030

Website: www.jdrf.org.uk

Digibete

Website and app provides a basic overview of diabetes management. The 'Clinic Code' for the app is HIMPQ.

Website: www.digibete.org/

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Facebook

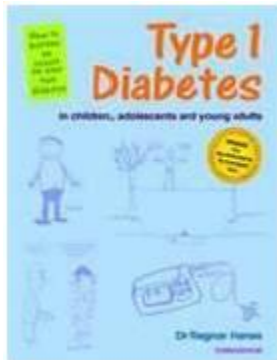
Facebook also has forums for people with Type 1 Diabetes.

Website: www.facebook.com

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 with a child with Type 1 Diabetes.

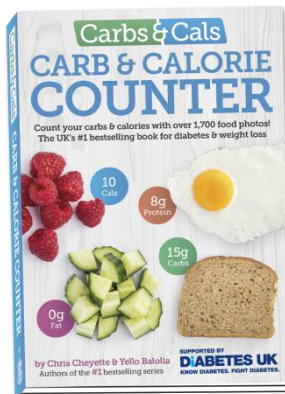


Type 1 Diabetes in children, adolescents and young adults: How to be an expert on your own diabetes

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: February 2021