



PATIENT INFORMATION

Type 1 Diabetes Education for Families

We will teach you how to manage your child's diabetes allowing them to enjoy life to the full and grow in a healthy way



Produced by the Torbay Paediatric Diabetes Team

Adapted from material originally produced by the Paediatric Diabetes Team at The Royal United Hospital Bath NHS Trust

Contents

<u>TOPIC</u>	<u>PAGE</u>
<u>Introduction</u>	3
<u>Paediatric Team Diabetes Contact Details</u>	4
<u>Team Aims</u>	5
<u>Tips for dealing with Feelings</u>	6
<u>What is Type 1 Diabetes</u>	7
<u>How is Type 1 Diabetes Treated</u>	8
<u>What Causes Type 1</u>	8
<u>Insulin</u>	9
<u>Learning To Give Injections</u>	10
<u>Sharps Disposal</u>	11
<u>Eating with Type 1 Diabetes</u>	12
<u>Carbohydrate Counting</u>	13
<u>Glycaemic Index</u>	14
<u>How to Count Carbohydrate in Food</u>	14
<u>Monitoring Treatment</u>	16
<u>Hypoglycaemia (Low blood glucose)</u>	17
<u>Hypoglycaemia Treatment Flow Chart</u>	19
<u>Hyperglycaemia (High Blood glucose)</u>	20
<u>Hyperglycaemia Treatment Flow Chart</u>	21
<u>Sick Day Rules</u>	22
<u>Going Home</u>	23
<u>Supplies & equipment</u>	23
<u>Follow-up</u>	23
<u>Returning to School</u>	23
<u>Prescription Items</u>	24
<u>Disability Living Allowance</u>	25
<u>Identification – Medical I.D.</u>	25
<u>The Honeymoon Period</u>	26
<u>Technology</u>	26
<u>Other Useful Sources of Information</u>	26
<u>Glossary</u>	28

Introduction

We understand that finding out that your child has Type 1 Diabetes can be a huge shock, and that it is a difficult time for you. The Paediatric (Children's) Diabetes Team are here to provide you with education and support to enable you to manage the condition, both here in hospital and when you go home. We will continue to offer support until they reach adulthood.

There is an awful lot that you need to learn about diabetes in a short space of time, and this can feel a bit overwhelming, however the team are here to support you every step of the way and would encourage you to ask lots of questions and to tell us if there is anything you are at all unsure about or you don't understand.

We would like your child to be able to enjoy life to the full and to be as healthy as possible. By having a sound understanding of diabetes and good care routines, the chances of developing future health problems related to diabetes can be reduced.

When a child develops Type 1 Diabetes, it is very important to remember that no-one is to blame; there is nothing that you have done, or not done to cause it neither has it been caused by eating too much sugar..

It should not take long for your child to feel well again. They should be able to return to all their usual activities soon, although a little extra planning may be needed for some things. There may also be a bit of 'trial and error' to find out what works best for you.

Everyone is different and it can take time to adjust to having diabetes and there will good days and some not so good days. The Diabetes Team will support you and your child wherever they can and if needed, signpost you to other services. Our psychologists are also available to support you with the emotional aspects of living with a long term medical condition.

This booklet has been written to help you understand some of the essentials of managing Type 1 Diabetes. You will learn more as time goes by as we add to this information. We may do this on an individual basis and sometimes we will ask you to attend group education sessions.

There is a lot of information available, particularly on the internet about diabetes, but some of it will be outdated, inaccurate or even dangerous. If in doubt, please check with a member of the team, as we aim to keep up to date about developments in the management of diabetes, and show you where to find appropriate sources of information and support.

The Paediatric Diabetes Team

Paediatric Consultants	<i>Dr Phillip Reilly Dr Ravi Lehal</i>	<i>01803 656192 (Secretary)</i>
Diabetes Team Administrator	<i>Laura Coley</i>	<i>01803 655784</i>
Paediatric Dietitians	<i>Liz Wardle Emma Prestidge Keri Davies</i>	<i>01803 654723 01803 654384 01803 654384</i>
Paediatric Diabetes Team Clinical Psychologists	<i>Dr Bhaveena Studley Dr Katie Stuart</i>	<i>01803 654573</i>
Paediatric Diabetes Specialist Nurses (PDSNs)	<i>Alison White (Mon – Fri)</i> <i>Louise Cameron (Mon, Tues, Thurs, Fri)</i> <i>Annie Diamond (Mon, Tues, Weds)</i> <i>Becky Hudson (Tues, Weds, Thurs)</i> <i>General Team Number</i>	<i>07796 194460</i> <i>07775 518334</i> <i>07825 572390</i> <i>07825 572400</i> <i>07788 416019</i>
Out of Hours or Emergency Contact <i>After 6pm , weekends or bank holidays or if unable to contact one of the PDSNs</i>	<i>Louisa Cary Children’s Ward (24 hours a day)</i> <i>Ask to speak to on-call paediatric registrar</i>	<i>01803 655526 or 01803 655531</i>
<i>In an emergency dial 999 and ask for an ambulance. If you have time, contact the paediatric registrar to tell them you are on your way in.</i>		

Your Key worker is:

The Paediatric Diabetes Team aims to:

- Provide you and your child, or young person with initial and on-going education about Type 1 Diabetes, so that in the future they will be able to self-manage the condition. This will be tailored to individual needs.
- Enable your child to lead an active and healthy life, with the knowledge and confidence to successfully manage their diabetes
- Encourage your child, with support from you and as far as they are able, to be involved in all aspects of their diabetes management
- Teach your child about diabetes in a way that they can understand
- Teach you about diabetes, so that you are able to feel confident in caring for your child
- Discuss with you and your child the best choices with regard to diabetes management and for your child to be actively involved in making decisions about this
- Offer support and advice with the aim of preventing the long term health problems that can be associated with diabetes, such as problems with the heart, kidneys, eyes or feet
- Offer education and support to the staff at your child's school, nursery or college, to enable them to look after your child safely during the school day.
- Ensure that your child is made aware of the diabetes services for young people as they move into adulthood and preparing them for a smooth transition to adult services. Where possible we would aim to introduce them to members of the adult team prior to moving across.

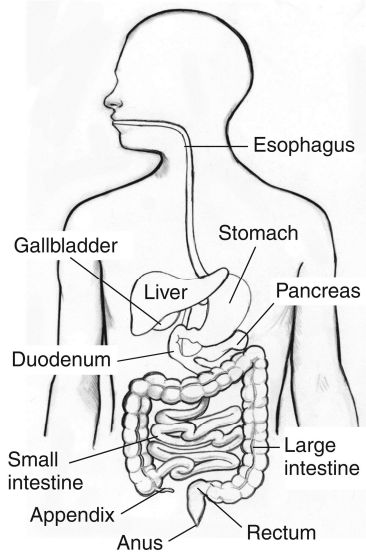
Tips for dealing with difficult thoughts and feelings about Diabetes

Being diagnosed with diabetes can be quite emotional and you may experience a range of feelings. Everyone is different and there are no rules as to how you should feel.

- ✓ It is natural to feel worried, down or angry at times. Don't give yourself a hard time about this
- ✓ Try to keep routines and boundaries as much as possible. You may want to reduce some less urgent life commitments to give yourself time and space to take everything in
- ✓ Keep talking - Communicating honestly with your family and your family and Diabetes Team can be helpful
- ✓ Find ways of letting your feelings out – it is important. Things to try could include exercise, playing music, or writing a diary
- ✓ Relax – spending just a couple of minutes doing deep breathing can really help to relax your body
- ✓ Plan things to look forward to – go to see a friend, watch a favourite film etc.

If you need support to deal with your feelings, talk to any member of the Team. They may suggest that you may find it helpful to meet with the Clinical psychologist. Please do ask for more information.

What is Type 1 Diabetes?



Type 1 Diabetes is a condition where the body is unable to control blood glucose levels as it is no longer able to produce the hormone **insulin**. Without insulin, the level of glucose in the blood becomes very high.

Insulin is normally produced by special cells called **Islets of Langerhans**. These are found in a gland called the **Pancreas** which is tucked in behind the stomach and backbone.

So what has happened?

In Type 1 Diabetes, the pancreas is no longer able to produce insulin, so the glucose is unable to move from the bloodstream into the cells to be stored to make energy. This means that the level of glucose becomes too high in the bloodstream, and your child will feel tired.

The kidneys will try to remove the excess glucose from the bloodstream, and it will spill out into the urine. When there is glucose in the urine, it will act like a sponge, drawing water away from the body. This is why you will have noticed your child going to the toilet a lot, and possible bedwetting. It will also cause extreme thirst as the body tries to replace the lost fluid.

Most children will also have lost weight by the time they are diagnosed. This is because the body switches to breaking down protein and fat to make energy.

When fat is broken down for energy, a waste product called **Ketones** (acids) is produced. Ketones cause the breath to smell sweet; like nail polish remover. When ketones build up in the body they can cause a dangerous condition called **Diabetic Ketoacidosis** (DKA). Ketones can build up over hours or days and make your child feel very unwell. Symptoms include abdominal pains, vomiting, drowsiness and deep or difficult breathing.

How does insulin work?

We must have insulin to survive. The body needs it to convert the food we eat into energy which allows the body to work properly, and to grow and be active.

When we eat **carbohydrate**, it is broken down into **glucose** (sugar) in the small intestine. This glucose then goes into the bloodstream and from here it needs to move into specific cells in muscles, fat and the liver to be stored until we need energy.

Insulin is the 'messenger' which tells these cells to allow the glucose in, to be stored for energy.

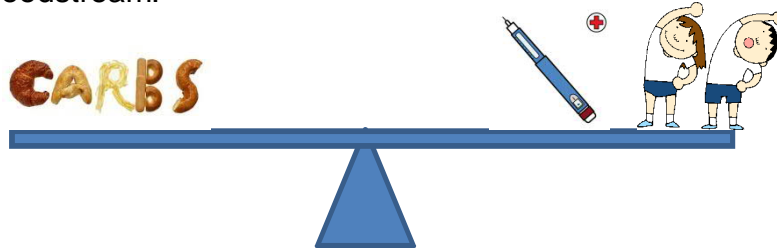
Each time we eat food containing carbohydrate, the level of glucose in the bloodstream rises. Normally the pancreas automatically releases insulin to allow some of the glucose to enter the cells, and leave just the right amount in the bloodstream.

How is Type 1 Diabetes Treated?

Although there is not currently a cure for Type 1 Diabetes, it can be successfully managed.

Type 1 Diabetes is treated by replacing the insulin which the pancreas can no longer make and balancing this with the carbohydrate food that is eaten, and exercise or activity to try to keep the blood glucose levels as close to the target range as possible (The target range is 4 - 7 mmol/L)

Once your child is treated with insulin, the symptoms described earlier will settle down and gradually disappear. If ketones start to build up again, it means that there is not enough insulin in the bloodstream.



Insulin has to be given by injection, either intermittently using an insulin pen, or continuously via an insulin pump.

It is not possible to take insulin as a tablet or medicine because the juices in the stomach would destroy it and it would not work properly.

Another important part of managing Type 1 Diabetes is to have a healthy and balanced diet. This will ensure that your child grows properly and remains healthy. It is also important to encourage physical activity.

Regular blood glucose testing is essential to be able to tell how well the insulin is working, and to help both you, and the team to make adjustments to insulin doses safely.

What causes Type 1 Diabetes?

Type 1 is becoming more common in children, but we do not know why this is. Many people are carrying out research to try to find out the reasons.

There are two different types of diabetes. Type 2 Diabetes is more common in adults, and the pancreas is still able to make insulin, but it is either not enough, or the body is unable to use it properly. In many cases there is also a link to obesity.

Type 1 is the most common type to affect children, and is **not** linked to obesity. Some children may have another family member with it too, so there may be something in their genetic make-up that has made them more likely to develop diabetes. It is thought that there may be a trigger factor involved such as a viral infection. Type 1 diabetes is **not** caused by eating too many sweets or junk food, or because of anything you have done and you cannot 'catch it', like a cold.

Insulin

We use two types of insulin to manage blood glucose levels.

Insulin doses are measured in **units**.

Insulin comes in 3ml cartridges, each containing 100 units, and is given using an injection pen device and a very small, thin needle.

Lantus (also called Glargine)

- This is long acting, 'background' insulin.
- It is given once a day, preferably around the same time each day, generally at bedtime
- It must be given in a separate site to the fast-acting insulin (we suggest the buttock or thigh)
- The pen device used to give Lantus is a 'JuniorSTAR' for younger children or an 'ALLSTAR' for older teenagers.



JuniorSTAR pen



ALLSTAR pen



Insulin cartridges

Novorapid

- This fast acting insulin
- It is given before any meal or snack which contains carbohydrate 10 – 15 minutes before where possible, and the dose will be different each time, because it depends on how much carbohydrate is to be eaten and what the blood glucose level is at the time.
- The pen device used to give Novorapid is a 'Novopen Echo' for younger children or a 'Novopen 5' for older teens.



Novopen Echo



Novopen 5



Insulin cartridges

How to store Insulin

The insulin cartridge and re-usable pen that you are currently using can be stored at room temperature for up to 4 weeks. After 4 weeks throw away any insulin left in the cartridge. Spare insulin should be kept in the fridge.

Insulin must not be exposed to extremes of temperature, if it becomes too hot from being in the sun, or it freezes, it will not work properly.

Learning to Give Insulin Injections

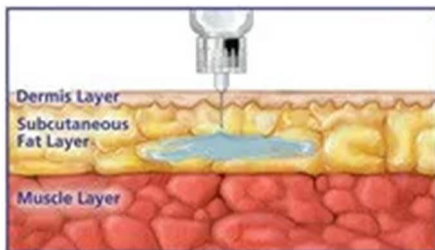
Parents and carers need to know how to safely give an insulin injection. This may feel strange at first, but you and your child will get used to doing this and children generally adapt and cope remarkably well. They will continue to need help, reassurance and support no matter how old they are.

It is recommended that children are supervised by an adult when giving their insulin injections until they are about 11 years old and sometimes older.

Injection sites

Insulin needs to be injected into the layer of fat just beneath the skin called subcutaneous tissue.

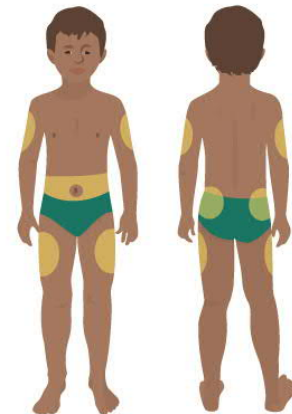
This will ensure that the insulin is absorbed reliably.



Insulin can be given in these places:

- Tops and sides of thighs
- Tummy – either side of the tummy button
- Tops of the buttocks

- Upper arms – ‘bat-wing’ area



It is really important to rotate the injections round all the different sites.

Repeatedly injecting insulin into the same place can cause the development of fatty lumps which means the insulin is not able to be absorbed properly. Erratic absorption can cause swings in blood glucose levels.

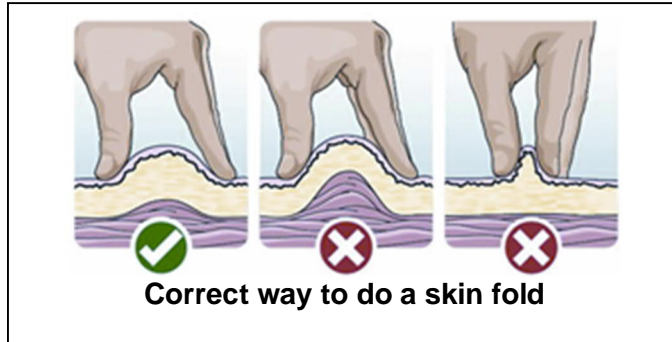
How to give insulin using a pen device

- Where possible wash hands before injecting
- Check you have the right type of insulin and the expiry date
- Check that the cartridge is properly loaded in the pen and that there is enough insulin for the dose needed
- Attach a new needle to the pen device
- Do a 2 unit ‘air shot’ to make sure there is no air in the needle, and insulin has come out of the end. (when using a new cartridge you may need to do this several times, or do a bigger air shot e.g. 8 -10 units)
- Make sure dial has returned to zero, then dial up dose required
- Gently ‘lift’ the skin (skin fold), hold the insulin pen upright and push the needle gently into the skin
- Push the plunger down completely and count slowly to 10 before removing the needle to let the last few drips go in
- Dispose of used needle in a sharps disposal bin

Do not worry if.....

There is a spot of blood or small bruise after giving an injection; this can happen if the needle catches a small blood vessel. It will not do any harm.

There is a small amount of insulin left on the skin surface. Do not be tempted to give more insulin, but keep an eye on the blood glucose levels. Always make sure you slowly count to 10 before removing the needle from the skin



Disposal of needles and lancets ‘sharps’

It is important to dispose of ‘sharps’ safely, as it is a legal requirement to do so

You will be given a yellow ‘sharps bin’ to take home with you from hospital.

When it is $\frac{3}{4}$ full contact your local council who will take it away and supply you with a new one.

Torbay Council – 01803 701316
www.torbay.gov.uk/clinicalwaste

South Hams Council – 01803 861234
www.southhams.gov.uk/sharpscollection

Teignbridge Council – 01626 215838
www.teignbridge.gov.uk/clinicalwaste

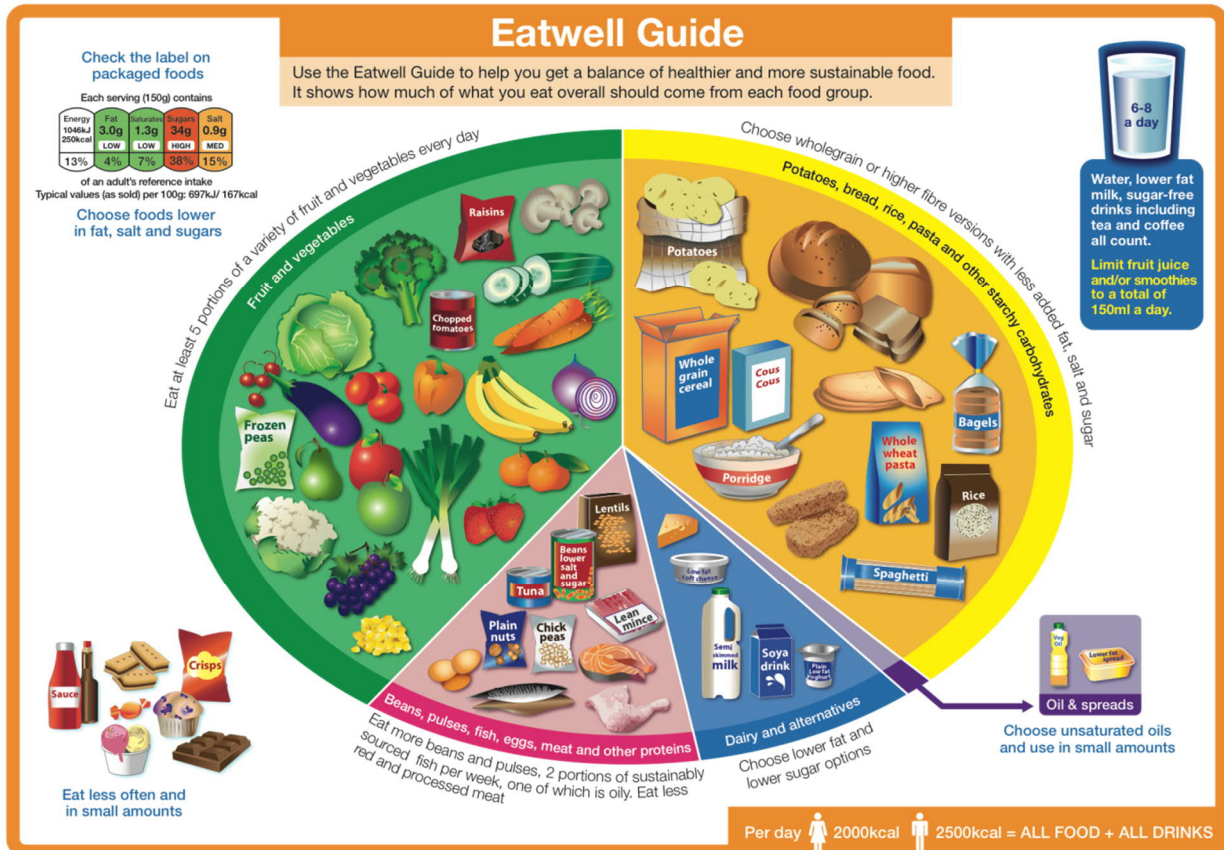
West Devon Council – 01822 616408
www.westdevon.gov.uk/sharpscollection



Ensure the lid is firmly locked shut before you put it out to be collected.

Eating With Type 1 Diabetes

There is no special diet for people with Type 1 diabetes; however, it is important to remember that food choices are important in its management. Children and young people should eat a healthy balanced diet that everyone in the family can enjoy. This will give them the energy and nutrients that they need for growth and development as well as helping to prevent some of the long-term complications often associated with Diabetes.



Source: Public Health England in association with the Welsh government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

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Tips for Healthy Eating for the whole family

- Aim for at least 5 portions of fruit and vegetables a day
Try to have vegetables from a 'rainbow' of colours and to eat more vegetables than fruit as they are lower in sugar.
- Chose wholegrain starchy carbohydrates
- Reduce saturated fats such as butter, lard and ghee. Switch to unsaturated fats such as olive oil or rapeseed oil which are healthier for your heart.
- Eat less salt. Aim for a no added salt diet.
- Stay active and take part in activities you enjoy examples include walking, skating, cycling, playing sports
- Try to eat regular meals, including breakfast.
- Group snacks together, rather than grazing. Carbohydrate snacks will need insulin.

Carbohydrate Counting

It is mainly the carbohydrate in the diet that affects blood glucose levels. When they are digested, carbohydrates are broken down into glucose, which is then absorbed into the blood stream, where it travels around the body to be used as energy by the brain, muscles and cells.

To get the correct amount of glucose from the blood into the cells, you need to have just the right amount of insulin. Counting the carbohydrates in the food allows you to match them with the insulin, and for this you will have an insulin to carbohydrate ratio.

Carbohydrates that need to be counted		
Starchy Carbs	Natural Sugars	Added sugars
Bread Cereal Pasta Potatoes Rice Couscous Quinoa Pastry	Fruits <ul style="list-style-type: none"> • Fresh • Frozen • Dried e.g. raisins • Milk • Yoghurt 	Sugar Full sugar drinks e.g. squash, cola Cakes and desserts Biscuits Ice-cream Custard Jam and honey Processed food Takeaways

Other foods that contain carbohydrates include beans and pulses, and vegetables.

The amount of fibre in these foods means that many people can eat them without affecting their blood glucose levels. In time, you will see if you need to count them for your child. Baked beans are the exception to this, and will usually need to be counted because they are in a sugary sauce.

Glycaemic Index

The Glycaemic index describes how quickly the glucose from the food is absorbed into the blood stream.

Eating low glycaemic index carbohydrates can make blood glucose levels easier to control because they are digested more slowly, and can better match the way the insulin is absorbed.

The table below shows some of the food swaps you can do.

Higher GI	Lower GI
White bread, white baguettes, bagels	Granary, seeded, multigrain bread
Mashed, baked, instant potatoes	New potatoes or sweet potatoes
Instant or short grain sticky rice	Basmati, brown, long-grain rice, Quinoa or Couscous
Cornflakes, Rice Krispies, Weetabix	Porridge, All-Bran, Shredded Wheat
Cakes and biscuits	Whole fruit

How to Count the Carbohydrate in Food

The dietitian will show you the different methods you can use to work out how much carbohydrate is in the food to be eaten.

Carbs and Cals



'Carbs and Cals' is available as both a book and an app that can be downloaded onto a tablet or a smartphone.

To use this method you need to first look at the pictures and choose the one that looks like the portion size your child is going to eat.

The carbohydrate value for that size portion can be found next to the picture. In this example is shown in the green circle, but may be shown slightly differently in other versions of the book.

Food labels

Most food packets have nutritional information printed on them and this can help you work out the carbohydrates in the food.

There are a few things to be aware of when using food packaging:

- The amount of carbohydrate shown may be per 100g of the product and not the actual portion size
- What the packet says is a portion may be different to your child's portion size , especially with things like breakfast cereals
- Be careful to use the 'Total carbohydrate' and NOT the part which says 'of which sugars'

Lasagne

Is this how much you are going to eat?

Nutrition	per 100g	per pack	% adult Ri
Typical values (oven cooked as per instructions)		254g	31%
Energy kJ	655	609	46%
Energy kcal	157	609	46%
Fat	8.2g	31.9g	46%
of which			
- saturates	4.0g	15.6g	78%
- mono-unsaturates	3.3g	12.8g	-
- polyunsaturates	0.3g	1.2g	-
Carbohydrate	13.6g	52.9g	23%
of which			
- sugars	2.5g	9.7g	19%
- starch	11.1g	43.2g	-
Fibre	1.7g	6.6g	-
Protein	7.1g	27.6g	62%
Salt	0.55g	2.14g	36%

Ri = Reference intakes of an average adult (8400kJ/2000kcal)

SLEEVE - CARD widely recycled
TRAY - PLASTIC check local recycling
FILM - PLASTIC not currently recycled

This packaging uses a minimum of 90% recycled board

Produced in the UK using British beef and stock produced using British bones for Sainsbury's Supermarkets Ltd, London EC1N 2HT.

Our ingredients
British Beef (39%); Tomato, Durum Wheat Semolina, Onion, Tomato Purée, Passata, Water, Cows' Milk, Double Cream (Cows' Milk), Carrot, Mushroom, Red Wine, Roast British Beef Stock (British Beef Juices, Water, Tomato Purée, Onion, Carrot), British Free Range Egg, British Free Range Egg White, Extra Virgin Olive Oil, Cornflour, Wheat Flour (Calcium, Iron, Thiamin, Niacin), Butter (Cows' Milk), Mozzarella Cheese (Cows' Milk), Breadcrumbs (Wheat Flour (Calcium, Iron, Thiamin, Niacin), Yeast, Colour; Caramel, Paprika Extract, Curcumin, Salt, Sunflower Oil), Salt, Rapeseed Oil, Potato Starch, Garlic, Oregano, Black Pepper, Nutmeg, White Pepper, Bay, Acid: Citric Acid.

Allergy advice
For allergens, including cereals containing gluten, see ingredients in **bold**.

Want to find out more?
sainsburys.co.uk

Weighing Food

Weighing the food will give a more accurate carb count than trying to estimate it by looking at the pictures.

You can use either the food label information per 100 grams, or the carbs in a portion as shown in the Carbs and Cals book to then work out the amount in your actual portion.

To use the food label

- Weigh the actual food portion
- Find out how many carbs per 100grams
- Use the calculation below

$$\frac{\text{Carbs in 100g}}{100} \times \text{the weight of actual food portion} = \text{the carbs in your portion}$$

To work out from a Carbs and cals picture

- Weigh the actual food portion
- Find out the weight of the Carbs and Cals portion

$$\frac{\text{Carbs in a portion from Carbs and Cals}}{\text{Weight from Carbs and cals}} \times \text{the weight of actual food portion}$$

You will require a set of digital scales to use these two methods



Monitoring Diabetes treatment

Blood glucose levels are measured in **millimoles per litre (mmol/L)** The level of glucose in the blood of people who do not have diabetes stays within a tight range of around 4 – 7 mmol/L.

When treating Type 1 Diabetes, we aim to keep the blood glucose levels as close to this range as possible, avoiding both high and low readings.

In getting the balance right, your child will feel well and be able to grow and develop as they should. It will also help to prevent problems both now and in the future.

To do this, we need to be able to ensure that the insulin dose is right and make adjustments to treatment as necessary. Insulin doses will change as your child grows, and the amount of insulin will vary in different situations e.g. if they are unwell or if they are going to be doing a lot of exercise.

Blood Glucose Monitoring

Blood glucose testing tells you exactly how much glucose is in the blood at the time the test is carried out. We will show you how to do a blood test using a hand-held blood glucose meter.

We generally use an Accu-Chek 'Aviva Expert' meter.

This meter not only measures the blood glucose levels, but also will help you to calculate the required dose of insulin at meal and snack times.

We recommend that the blood glucose level is checked at the following times:

- First thing in the morning
- Before meals and two hours after the meal
- Before bedtime
- Before exercise
- If a 'hypo' is suspected
- If there is any cause for concern such as your child feeling unwell or during illness



Frequent testing is particularly important just after diagnosis to help us to get the insulin doses right.

It is a good idea to record the blood test results in a special diary that we can give you, or to download the blood glucose meter weekly onto 'Diasend' using a computer (we will show you how to do this at home). This will enable both you and us to see where any adjustments to treatment are needed.

Hypoglycaemia ('hypo')

Low blood glucose level = below 4mmol/L

A 'hypo' may happen if:


- your child has not had enough food e.g. if they have missed a meal or snack
- your child has done extra exercise that was not planned for
- your child has had more insulin than they needed
- insulin was injected into the muscle instead of the fatty tissue
- injection sites have been moved from a lumpy area to a new site
- the weather is hot

but sometimes 'hypo's' may happen for no obvious reason.

Hypoglycaemia Symptoms

If a child has a hypo they may feel:

- Hungry
- 'not quite right'
- Wobbly
- Tired
- Grumpy
- Tearful
- Sweaty
- That they have pins and needles or tingly lips
- Blurry vision



You may notice your child is having a 'hypo' before they do. They may look very pale with dark rings around their eyes. Every child is different and over time you will learn to recognise the subtle signs that they are having a 'hypo'.

Treating a 'hypo'


Any blood glucose reading under 4 mmol/L needs immediate treatment and fast-acting glucose should be given immediately

Guide to treating Hypoglycaemia

Weight of Child	Hypo Treatment	Dextrose Tablets	Fruit Juice or sugary drink
10kg	3g	1	20ml
15kg	5g	1	30ml
20kg	6g	1-2	35ml
25kg	8g	1-2	50ml
30kg	9g	2	50ml
35kg	10g	2	60ml
40kg	12g	2-3	70ml
45kg	14g	3-4	80ml
50kg	15-20g	4-5	100ml

General Advice about 'Hypo's

- Never leave a child alone when hypoglycaemic
- Keep a supply of glucose or other fast-acting sugar everywhere!
- In their school bag, in your bag, in the car, in the classroom
- Occasional (once or twice a week) mild hypo's before meals suggest that the diabetes is well controlled and are not a cause for concern
- If you are concerned about regular hypo's, please speak to a member of the Diabetes Team

Example of a Hypo'kit	Things you could put in a Hypo' kit
	<p>Fast-acting sugar:</p> <ul style="list-style-type: none"> • Packet of glucose tablets • Small pack of jelly type sweets • Sugar lumps • Small fruit juice carton • Small bottle of glucose juice • Glucogel tubes <p>Follow-up snack if needed:</p> <ul style="list-style-type: none"> • Small cereal bar • Plain biscuit • Piece of fruit e.g. banana, apple

Severe hypoglycaemia

Very occasionally a child can have a severe hypoglycaemic episode, where they may become drowsy and lose consciousness, and possibly have a short convulsion or fit.

You will be supplied with an injection kit for a hormone called **Glucagon**, which can be given if this happens. We usually teach you how to do this a few weeks after diagnosis.

Glucagon works by making the body release any glucose it has stored in the liver into the bloodstream.

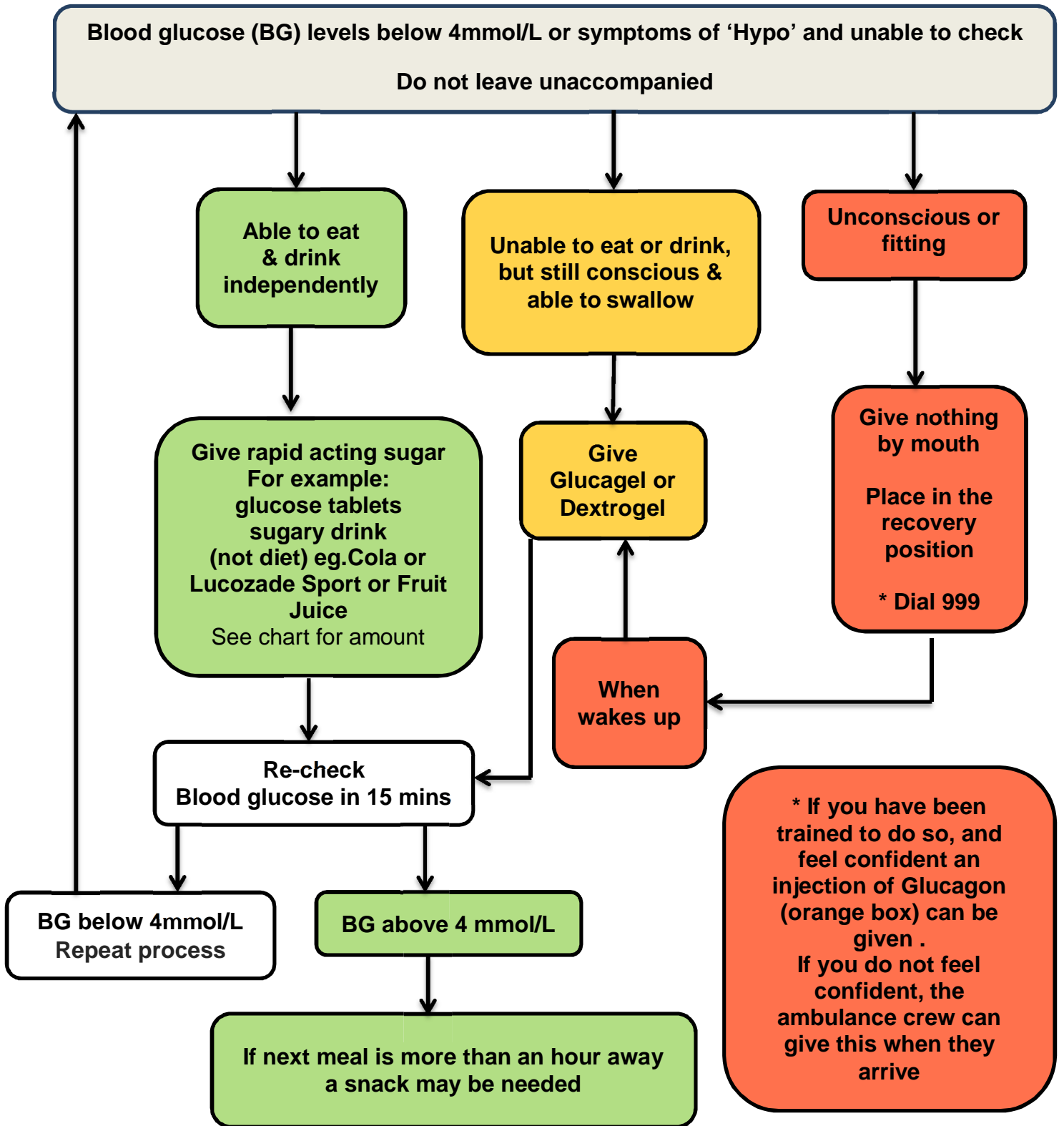
If your child should have a severe hypo'

- Keep them from harming themselves
- Place them on their side in the recovery position
- Call 999 so that you know help is on the way
- Give the Glucagon injection once the fit has stopped



Let the Diabetes Team know that this has happened for further advice

TREATMENT OF HYPOGLYCAEMIA
(‘Hypo’ or ‘Low Blood Glucose’)



We do have to tell you what to do in the event of a severe hypo, but please be aware, that this is an uncommon occurrence and there is usually an exceptional reason why it has happened.

Hyperglycaemia

High Blood Glucose = 10mmol/L or above

High blood glucose levels can occur for the following common reasons:

- Not enough insulin has been given
- A dose of insulin has been forgotten
- Your child has been less active than usual
- More carbohydrate has been eaten than injected for
- Excitement or stressful situations
- Illness or an infection somewhere (children with Diabetes do not experience more illness than other children, but any illness they do get, can upset blood glucose levels)

Hyperglycaemia Symptoms

Early signs of high blood glucose levels

- Increased thirst
- Passing more urine with frequent trips to the toilet
- Bedwetting
- Tummy pains
- Feeling tired
- Feeling grumpy
- Finding it harder to concentrate

Signs of ketoacidosis (high blood glucose + ketones)

This is serious and needs hospital treatment

- Nausea and vomiting
- Deep rapid or sighing breathing
- Sweet smell on breath similar to nail polish remover or pear drops
- Drowsiness

If the blood glucose level is above 10mmol/L it is a sign that more insulin is needed.

You will be taught how and when to give a 'correction dose' using the blood glucose meter.

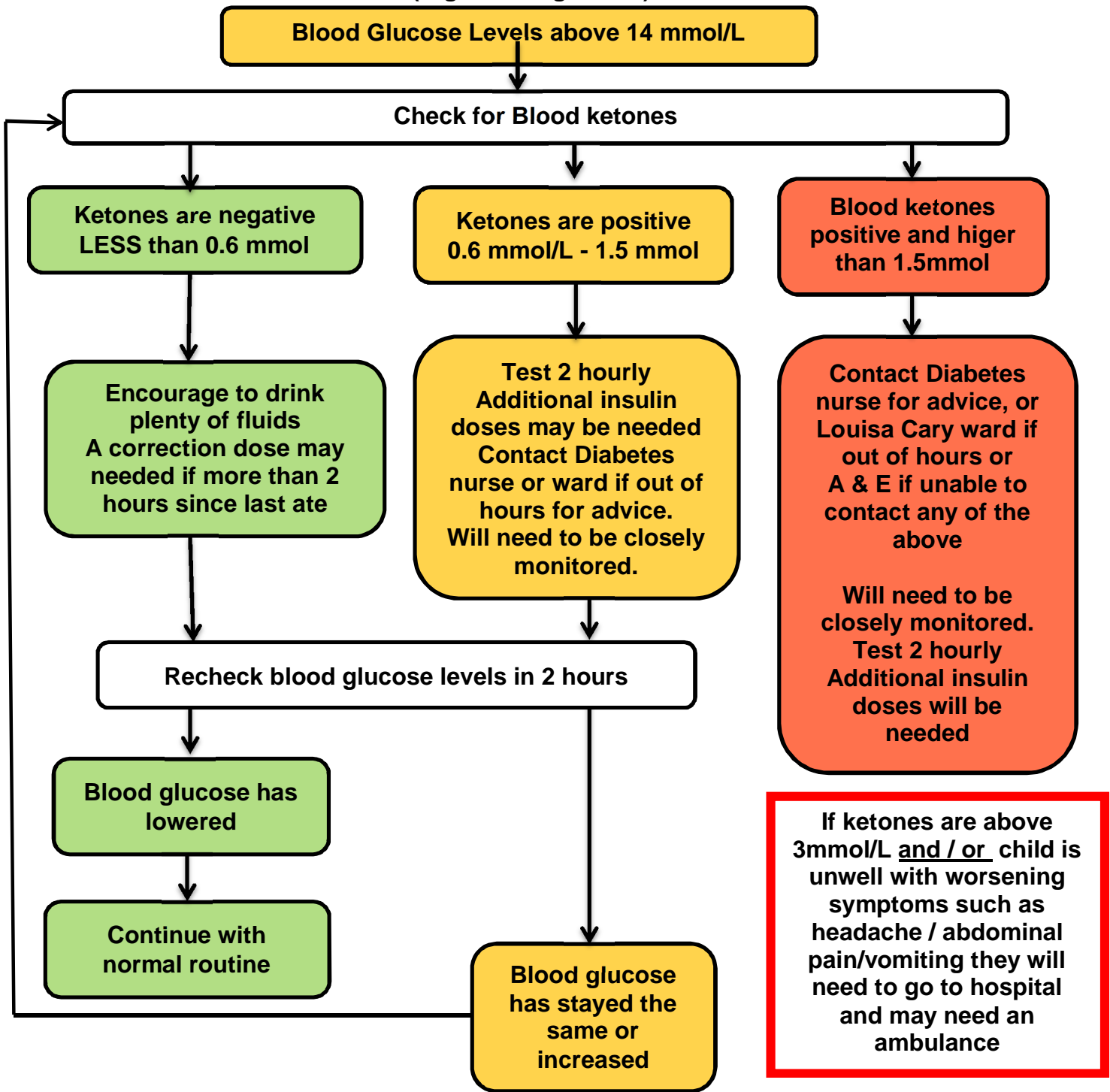
When the blood glucose level is 14mmol/L or above, you may also need to carry out a blood test for ketones.

Ketones appear in the blood when the body is lacking insulin and may be a warning sign that your child may need more insulin and they may be developing ketoacidosis.


This may be because they are unwell or have an infection somewhere.

If your child has a high blood glucose level, is feeling sick or starts to vomit, you need to contact the Diabetes Team or hospital immediately, especially if they also have a positive ketone test.

TREATMENT OF HYPERGLYCAEMIA
 (High blood glucose)



Blood Ketone Test Meter and what the result means

	0.0 – 0.6	Negative – no action needed
	0.6 – 1.5	Correction dose needed. Encourage to drink sugar-free fluids
	1.5 or higher	Correction dose needed, and contact Diabetes Team or Louisa Cary ward for advice

What to do if your child is ill - “Sick day rules”

During times of illness, it is important to keep a very close watch on blood glucose levels.

Illness can cause the body to need more insulin than normal, and if this is not given, there is a risk of the condition Diabetic Ketoacidosis (DKA) developing.

DKA is a very serious condition which will require hospital admission and which we will try to prevent from developing as far as we can.

The following will help to reduce the risk of DKA

Sick Day Rules

- Contact the Diabetes team for advice at an early stage or if unsure what to do
- Test more often than normal – generally every 2 hours.
- Check for ketones 4 hourly
- Do not stop the insulin, even if your child is not feeling hungry – they may even need more insulin than usual
- Offer small frequent carbohydrate snacks (see table below)
- Encourage plenty of sugar-free fluids to prevent dehydration
- If feeling sick and not able to eat, encourage sips of sugary drinks every hour to prevent low blood glucose levels (see table below)
- **If vomiting or unable to keep fluids down – contact your Diabetes Nurse or Louisa Cary ward and ask to speak to the registrar on call as your child may need admission to the hospital to have fluids via a drip until the vomiting settles.**

Snack suggestions for illness	Sugary drink suggestions
<ul style="list-style-type: none"> • One small scoop of ice-cream • A few spoons of ordinary jelly • Half a pot of yoghurt (not sugar free) • A small bowl of soup • Plain biscuit e.g. crackers 	<ul style="list-style-type: none"> • Half a small glass of fruit juice • Half a glass of Lucozade (not Sport) • Half a glass of sugary coke or lemonade • A cup of milk

Going home

Supplies and equipment

You should leave the hospital with enough supplies to last around two weeks.

We recommend that you make an appointment to see your GP as soon as possible to find out how their repeat prescription works and to get one set up for future supplies. If it is difficult to get an appointment, pop in and speak to the receptionist.

It is a good idea to put your first request in early in case they have to order anything in for you.

You will be given 2 copies of a letter listing all the items needed on prescription – give one copy to your doctor and keep the other copy for your information.

Prescriptions for items needed to manage Diabetes are currently free, for both children and adults.

Follow-up

It can feel a bit daunting when you leave the hospital, but you will not be discharged until you have the necessary skills and knowledge to manage the diabetes at home. Your diabetes nurse and dietitian will visit you at home to provide on-going support and education.

Your child should be seen in the outpatient clinic within a few weeks, appointment slots permitting. They will then have follow-up appointments 3 monthly. Once a year, they will have a slightly longer Annual Review appointment.

We also offer various group education sessions which we would strongly recommend you to attend. These sessions provide you and your child / young person opportunities to meet with other families who will understand the challenges you face and your worries or concerns. They also give you a chance to speak to other members of the team in a less formal setting.

Returning to School










We would encourage your child to return to school, nursery or college as soon as is sensible. This will depend on individual need.

Your keyworker will arrange to visit the school to provide education about diabetes and training for members of staff. We like you to attend one of these sessions too so that we can work together to write a school care plan, which will explain your child's individual diabetes care needs, and what to do if they are unwell.

We find that schools are generally keen to support children with diabetes, but they may need some support from you whilst learning practical skills such as giving injections, or doing blood tests.

If you find that time off from work causes any problems with this, the Diabetes team can write a letter of support to your employer if this would help.

Prescription items

<p>Re-usable insulin pens You will need to have a spare of each Novopen Echo (red or blue) for Novorapid JuniorSTAR for Lantus</p>	
<p>Insulin cartridges You will need a regular supply of these, keep cartridges in fridge Novorapid insulin 3ml penfill cartridges Lantus (also called Glargine) 3ml cartridges</p>	
<p>Insulin pen needles You will need a regular supply of these BD Micro-Fine + Pen Needles, 4mm x 0.23mm (Box of 100) BD Autosheild™ Duo Safety Needles (5mm) (Box of 100)* *You will only need Autosheild needles if someone else gives injections e.g. school teachers.</p>	
<p>Blood Glucose test strips You will need at least 200 strips or 4 boxes a month Accu-Chek Aviva Blood Glucose test strips (boxes of 50)</p>	
<p>Lancets You will need at least one box per month Accu-Chek Fastclix Lancets box of 200+4</p>	
<p>BD Safe Clip needle Clipper You would only need to order if you need a replacement</p>	
<p>Glucose 40% Gel Glucogel (3 x 23g pack)</p>	
<p>Glucagon GlucaGen HypoKit (1mg vial)</p>	
<p>Ketone testing FreeStyle Optium β-ketone blood testing strips (Box of 10)</p>	
<p>Sharps disposal Sharps bins are supplied by local council</p>	

Disability Living Allowance (DLA)

Parents of children with diabetes are eligible to apply for a benefit called Disability Living Allowance (DLA) until the child is 16 years old.

This is not because a child with diabetes is “disabled”, in fact the opposite is true. The allowance can help with things like:

- Extra travelling costs due to clinic visits
- Possible increased cost of weekly food shop
- Well-fitting shoes
- To purchase optional additional equipment to support your child’s diabetes care

It is not a means tested allowance.

Application forms are available from:

Benefits Enquiry Line 8088 882200 or www.direct.gov.uk/disability-money

The form is lengthy, and may take an hour or so to complete. Your Diabetes nurse can help you if necessary, and will write a supporting letter to send with the form.

DLA is not paid for the first three months following diagnosis.

Carer’s Allowance

If you are awarded DLA at the middle or higher rate, you may also be entitled to claim Carer’s Allowance. Please be aware of the following:

- You need to spend at least 35 hours / week caring for a person
- It is not affected by any savings you may have
- It is dependent upon income and other benefits

Further information is available at www.direct.gov – Money Tax and Benefits Section

Identification – Medical ID

It is a good idea for your child to always carry something on them to say that they have diabetes, such as a bracelet, necklace, watch or card.

If a child or young person is out with friends or were to have an accident, it is important that others know they have diabetes.

Some mobile phones are also able to display medical information accessible either on the home screen or via an app.

A few examples are given here (many others are available):



www.medicalert.org.uk

www.theidbandco.com

www.zingengraving.co.uk

www.icecard.co.uk-pack

The 'Honeymoon Period'

Sometimes, shortly after diagnosis you may find that we need to reduce the insulin doses because of lower blood glucose readings. This is very common and is known as the 'Honeymoon Period'. It occurs when the pancreas is still producing a small amount of its own insulin.

The 'Honeymoon' can last from just a few weeks in most cases to as long as two years in just a few. It will come to an end when the pancreas is no longer producing any insulin.

This is the natural progression of the condition and does not mean that the diabetes is getting worse. As the insulin produced by the pancreas dwindles, the injected doses will need to increase.

Technology

Diabetes care and management is constantly developing and new technologies become available. Some of these will be available on the NHS, but others have to be self-funded.

Examples of these include insulin pumps and continuous blood glucose monitoring devices.

If you would like to find out more information about anything you have heard about, please ask a member of the team.

Other Sources of Useful Information

Websites

www.diabetes.org.uk/Guide-to-diabetes/kids

General information about children with diabetes.

www.diabetes.org.uk/Guide-to-diabetes/kids/what-is-diabetes/what-is-type-1-diabetes

You may find the following clips helpful to explain diabetes

www.childrenwithdiabetesuk.org

Support website run by families of children with diabetes

www.jdrf.org.uk

General information about Type 1 diabetes in children.

www.runsweet.com

A website about managing exercise with diabetes

www.DigiBete.org

Free films and resources to help manage Type 1 Diabetes.

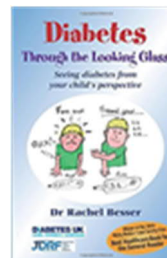
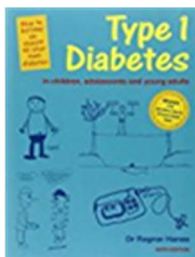
Books

Type 1 Diabetes in Children, adolescents and Young adults. How to become an Expert on your own Diabetes by Ragnar Hanas (Class Publishing)

Diabetes care for babies, Toddlers & Pre-schoolers. A reassuring Guide by Jean Betschart. (Chronimed Publishing)

Diabetes Through the Looking Glass – Seeing diabetes from your child's perspective by Rachel Besser

Carbs and Cals. A visual Guide to Carbohydrate & Calorie Counting for People with Diabetes (Chello Publishing)



These are only some of the resources available about diabetes in children.

Please be aware of the following when reading anything about diabetes:

- That there are many resources from other countries where the management of diabetes may differ slightly.
- That it is about Type1 and not Type 2
- That it is about children with diabetes not adults
- That it is up to date
- That it is written by someone with a good knowledge of diabetes.

If you are at all unsure about anything that you see or read about diabetes, please ask a member of the Diabetes Team.

The inclusion of a website does not indicate endorsement by Torbay Hospital or the Torbay & South Devon NHS Foundation Trust.

Glossary

Blood Glucose	The level, or concentration of glucose in the bloodstream
Carbohydrate	One of the three main food groups composed mainly of sugars and starches
GlucaGen HypoKit	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 main source of energy for the body
Glycosuria	The presence of glucose in the urine
Glycosylated Haemoglobin	See HbA1c
HbA1c	A blood test that measures how much glucose is joined to red cells in the blood. It gives an indication of the blood glucose control 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 cells to have a specific effect on the functioning of other cells in the body
Hyperglycaemia	High blood level
Hypoglycaemia or 'hypo' or 'low'	Low blood glucose level (under 4 mmol/l)
Incidence	The number of cases of a particular disease diagnosed per year
Insulin	A hormone produced by the beta cells of the pancreas. It lowers the level of glucose in the blood by allowing the glucose to move from the blood into the body cells. The glucose can then be used to make energy
Ketones	Ketones are a waste product produced when fat is broken down to make energy. This happens when the cells are 'starving' if there is a lack of insulin, and the glucose cannot get into them.
Ketoacidosis	A serious condition caused by a lack of insulin which means the body uses fat for energy instead of glucose. Ketones can be detected in the blood and urine

Microalbuminuria	Very small amounts of protein in the urine
Pancreas	A large gland situated near the stomach which produces digestive enzymes, insulin and other hormones
Subcutaneous	The fatty layer just beneath the skin surface