Royal United Hospitals Bath
NHS Foundation Trust

Paediatric Diabetes Services

Newly Diagnosed Patient Booklet

Everyone Matters

We work to empower people to have a positive and healthy relationship with diabetes

Working Together

For continuous improvement and the best possible outcomes for young people with diabetes

Making a Difference

By treating everyone with compassion, respect and fairness, providing an equitable service

Contents

The Team

Consultants

- Dr Clare Edmonds
- Dr Lynn Diskin
- Dr Ed Coxson

You are invited to attend 4 clinics a year to meet a consultant. In conjunction with the team, the aim is to establish the best way to support individuals and families with their diabetes management.
This will involve advice on insulin regimes, medical issues and concerns, with goal setting and positive planning

Paediatric Dietitians

- Gillian Purcell

Registered dietitians are experts in nutrition and meal planning. They will explain how food affects your glucose levels ensuring you're getting enough food to grow, develop and be active.

Paediatric Diabetes Clinical Psychologist

- Dr Vineeta Gupta

The clinical psychologist will help you and your child deal with the emotional side of diabetes. This can include doing practical work on worries about injections or learning stress management techniques. Meeting with a clinical psychologist can be a space to consider difficult feelings such as sadness or anger.

Paediatric Diabetes Specialist Nurses (PDSNs) & Nursing Assistant (NA)

- Alice McCann (Lead PDSN)
- Anna Zatchij, Helen Edwards, Nina Roles, Charlotte Pearce, Grace Shaw
- Imogen Fowler (Nursing Assistant)

PDSN's are experienced, registered Paediatric Nurses who specialise in working with families and education providers in the management of Type 1 diabetes.

Team Administrator

- Molly Priestley

Our administrator supports the team with patient administration, finance and IT systems management.

The First Few Days…

The first 24-48 hours is tiring and emotional. Your child will remain an in-patient for at least 5 days from the point of diagnosis, where time on the ward will be busy with education sessions and learning activities. Arranging time off work may be necessary to concentrate on adjusting and being with your child during this difficult time. A letter can be provided for your employer.

When your child is first diagnosed with diabetes the most important things are:

- No-one is to blame, nothing you have done has caused this. Type 1 diabetes does not develop through lifestyle choices, it is because the pancreas no longer produces the insulin the body needs.

- Like all children, your child will still be able to eat a wide and varied diet that does include sugar; in moderation as part of a healthy balanced diet!

- Your child will still be able to do all activities, sports, sleepovers etc., it will just need a little more planning.

- Before leaving hospital you will, under supervision, start to administer insulin treatment to ensure glucose levels can be lowered safely and appropriately.

- The paediatric diabetes team offer support and advice Monday—Friday 9am until 5pm (01225 825331) with out of hours advice from the on-call Paediatric Registrar (01225 428331). Remember no question or concern is ever silly, we are here to help.

- Until the age of 18, the paediatric team will provide ongoing medical support and education to your family and school staff.

- As a paediatric service our practice is to mail all correspondence to the parents/carer/legal guardian of the young person until they are 16, at which point written consent has to be given by the young person for the parents/carer/guardian to be copied in clinical correspondence.

- Correspondence: Please ensure address, telephone numbers and email addresses are kept up to date with both your GP and the diabetes team.

Thoughts, Feelings and Emotions

Having a child diagnosed with diabetes is an emotional time where everyone in the family may experience a range of feelings. Everyone is different and there are no real rules as to how you should feel. You may find it's a roller coaster ride, especially at first, with many ups and downs. Some families experience it as a grieving process and experience feelings of shock, denial, anger, guilt, fear, loss, questioning why? All these feelings are normal and it takes time to adjust, but please do talk to your team about them.

Top Tips

- It's natural to feel worried, down or angry at times, don't give yourself a hard time about this.
- Try and keep routines and boundaries as much as possible for the children. However, you may want to reduce some less urgent life commitments to give yourself time and space to take everything in.
- Keep talking: Don't bottle up feelings. Different family members may have different thoughts and feelings. Communicating honestly with your family and your diabetes team is helpful.
- If you don't like talking, find other ways of letting your feelings out, for example exercise, play music or write a diary.
- Plan things to look forward to: go see a friend, watch a favourite film etc.
- Keep breathing. Spending just a couple of minutes doing deep breathing can really help to relax your body and mind. There are QR codes for mindfulness apps at the end of this booklet.
- If you need support to deal with your feelings, talk to your team who may suggest a meeting with the Clinical Psychologist. Ask for more information.

Education on the ward

DEAPP (usual timescale 5 working days)

Deapp T1 Diabetes Education

@DeappEducation · 71 subscribers · 193 videos

Diabetes Education Video is part of the Deapp Education Series. ...more

Subscribe

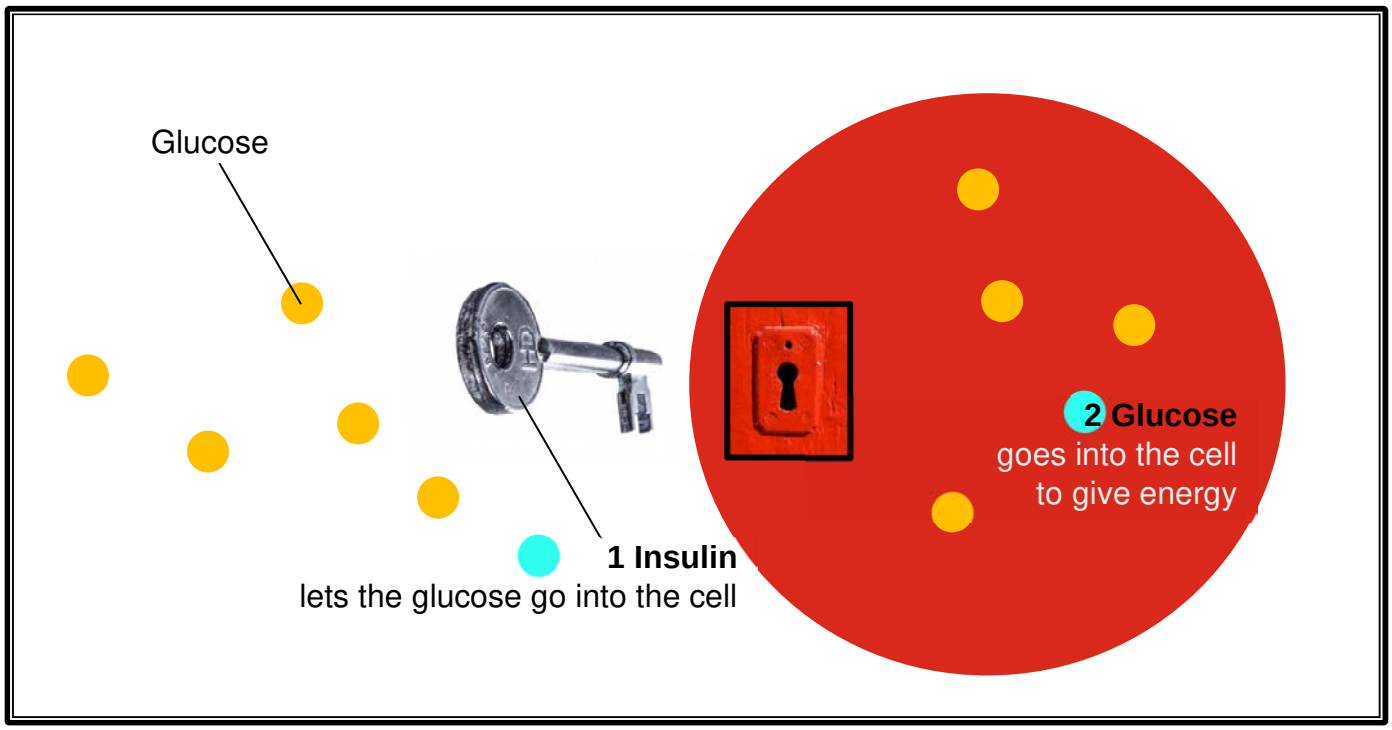
Step One Please go to www.youtube.com and search for @deappeducation
Step Two – There are 50 short videos in total, and these cover the basic information needed for newly diagnosed children and young people to learn about Type 1 Diabetes.
Please watch all the videos before discharge.
Step Three – Once you have started to progress through the different sections on the app, your diabetes team will visit you each day to support you with learning using physical props and games to ensure the information was clearly explained to you.
Step Four – The information in this newly diagnosed booklet and the additional recommended online resources will complement your learning with Deapp. Please read it during your admission.
Step Five – We wait until education is complete and glucose levels are within target range pre meals and overnight before discharge. This usually takes 5 working days. Please ask the team if you require a letter for your employer.

What is Type 1 Diabetes?

Type 1 Diabetes is a condition caused by a lack of the hormone 'insulin' in the body. A gland, called the pancreas, which lies between the stomach and the backbone, produces insulin.

How does insulin work?

Insulin is vital in the process of regulating the body's blood glucose; insulin acts like a 'key', allowing the glucose to move from the blood stream into the body's cells to be used as fuel for all our daily activities.



Some of the food we eat (the carbohydrate) is broken down into glucose in the small intestine. This glucose goes into the bloodstream, and needs to get into specific cells in muscles, fat and the liver to be stored until we need energy.

So what has happened?

Your child's pancreas is no longer producing the insulin required to move the glucose into the body stores. There has been too much glucose building up in the blood and the energy stores are empty, which leaves your child feeling tired.

The excess glucose in the blood is removed by the kidneys and goes into the urine. This glucose in the urine acts like a sponge and draws water from the body. This explains why your child has been going to the toilet a lot and may have been bed-wetting. You may have noticed they were thirsty and drinking a lot.

Most children with diabetes will have lost weight by the time the diagnosis is made. The energy stores are empty and the body has switched over to breaking down protein and fat for energy. When fat is broken down for energy, Ketones (acids) are produced. These cause a sweet smell, like nail polish remover, on the breath. If ketones are allowed to build up in the body they can cause a condition called Diabetic Ketoacidosis, which can be dangerous. Ketones can build up over hours or days and make your child feel unwell. Symptoms include tummy pain, vomiting, drowsiness and deep or difficult breathing.

Once your child is treated with insulin, these symptoms gradually disappear. If ketones build up in the body again it indicates that there is too little insulin in the bloodstream.

Over the coming weeks, when the time is right, your nurse will discuss ketones and the use of a ketone meter with you.

What Causes Type 1 Diabetes?

Type 1 diabetes is becoming more common in children; many people are doing research to try and find out why.

It is important to realise that there are two different types of diabetes. Type 2 diabetes develops when the body still makes insulin but it cannot work effectively because the body is resistant to it.

Type 1 diabetes is the most common type of diabetes in children and is not linked to lifestyle factors. We don't fully understand why some children develop Type 1 diabetes, but it occurs when something triggers the immune system to destroy the insulin producing cells in the pancreas; in some cases the trigger may be a viral infection.

It is important that you and your child understand that Type 1 diabetes is not:

- caused by eating too many sweets or junk food
- caused by anything you, or your child, has done

Treating Type 1 Diabetes

Although there is currently no cure for Type 1 diabetes, approximately 25,000 children and young people successfully manage their diabetes daily; leading healthy, happy and successful lives.

Type 1 diabetes is treated with:

- Replacement insulin, either by injections or continuously via an insulin pump. Insulin cannot be taken in tablet form as it would be destroyed by the juices in the stomach and would not work properly.
- Regular glucose checking is vital to know how effective the insulin is and to enable safe adjustments to insulin doses.
- A balanced, healthy diet, to keep your child healthy and to maintain their blood glucose as near normal as possible.

The ‘Honeymoon’ Period

You may find that shortly after diagnosis your child’s daily insulin doses are reduced because of lower glucose readings. This is very common and is known as the ‘honeymoon period’. During this time your child’s pancreas is still producing a small amount of its own insulin.

This ‘honeymoon period’ may last from a few weeks to, occasionally, two years, but unfortunately there is no treatment to prevent the inevitable time when the pancreas ceases to produce any insulin.

This is the natural progression of the condition, and does not mean that the diabetes is getting worse. As pancreatic insulin production ceases, the body’s requirement for insulin given by injection increases.

Insulin

Types of Insulin

- Rapid acting insulin, e.g. Novorapid
- Long acting insulin, e.g. Lantus

There are different insulin regimens, and we will advise on which one we think will be best for your child at the moment. The amount of insulin your child needs will change as they grow, and a different regimen may be more suitable in the future.

Insulin is available in:

- cartridges for use with insulin pen devices
- disposable insulin pen devices
- vials for use with insulin pumps or syringes

Insulin is measured in units. There are 100 units of insulin/millilitre (100units/ml). Your child may need more insulin if they are ill or have an infection and less insulin if they are exercising. The decision to change the insulin dose depends on your child's blood glucose readings and the team will teach you how to do this.

Storage of insulin

The insulin cartridge, vial or disposable pen that is currently in use can be stored safely at room temperature but should be discarded four weeks after opening.

Spare insulin cartridges should be stored safely in the fridge. Reusable pen devices must not be stored in the fridge, e.g. Novo pen Echo, Junior Star

Insulin must not be stored in the freezer.

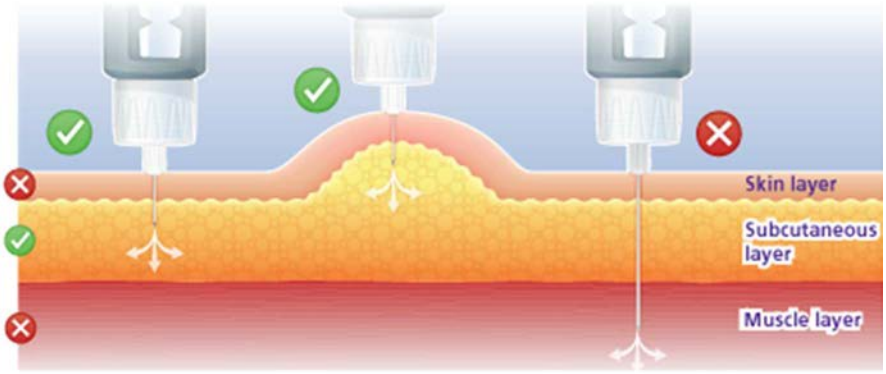
Insulin must not be exposed to strong light or heat, e.g. sunlight

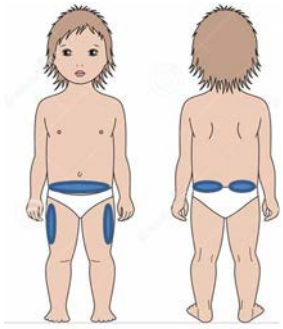
When travelling by air, insulin must be stored in hand luggage, not in the hold of the plane as this is too cold. If travelling abroad please advise the team who will provide travel documents for airport security with further supporting information.

Where to Give Insulin Injections

Injection Sites

Insulin injections are given into the layer of fat between the skin and the muscle. Insulin must be given here to ensure that insulin is reliably absorbed.





Insulin can be given in the outer aspect of the thighs, in the tummy, either side of the tummy button or in the buttocks; especially in young children.

It is important to rotate the injections round the various sites to prevent one part becoming lumpy, which will stop the insulin from being absorbed properly. The insulin itself causes extra growth of the fat tissue and these 'fat pads' contain both fibrous and fat tissue. Injecting into fat pads will usually result in a slower and more erratic absorption of insulin, which can cause variable blood glucose readings.

When a new injection site is chosen, free from any fat pads, the insulin will have a quicker action. Long acting insulin is best given into the buttocks or legs.

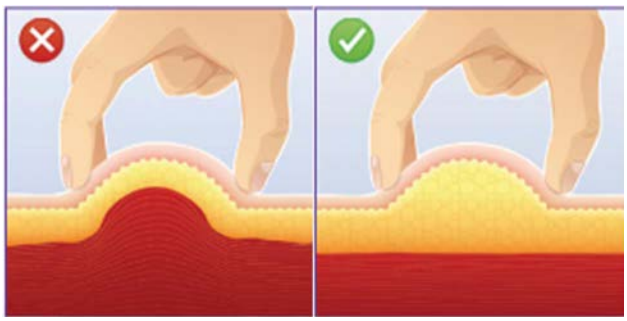
Giving insulin injections with a pen device

- Wash your hands before injecting
- Check the expiry date and the type of the insulin if using a new cartridge
- Make sure the cartridge is loaded correctly and has enough insulin in it for the injection
- Attach a new needle to the pen device for each injection making sure it is firmly screwed on
- Do a 'test shot', dial up two units: if using a new cartridge/pen dial up 8-10 units) point the pen into the air and push the plunger. Ensure insulin is coming out of the end of the needle, if not, repeat from the beginning.

Dial up the dose

It's important that your child understands what is happening by giving them information appropriate to their age and understanding. Try to be as relaxed as possible; have your child sit or lie in a comfortable position.

For a young child, we will discuss positions and ways to help you with their insulin injection. We can also discuss this with the play specialists on the Children's Ward and the clinical psychologist if needed.



Hold the insulin pen upright, and securely, and inject straight down, using a lifted skin fold.

Push the needle in gently but firmly, to the hub, and administer the insulin by pushing the plunger. Once the dose has been delivered, leave the needle in place for a slow count of 10 or a fast count of 20 before pulling it out.

Sometimes you may notice a spot of blood when the needle is pulled out. This means that the needle has pricked one of the tiny blood vessels underneath the skin. This will not harm your child. Small bruises can be a sign of the insulin going into muscle.

Insulin Injections – A Few Tips

We understand that receiving injections and learning to give them can cause some worry and anxiety. In most cases this anxiety will fade as you and your child get used to it.

Try and act calm yourself, even if you're not. Anxiety can be contagious. A nervous parent can make the child feel more nervous.

Think of a swan swimming on a lake. They look calm and in control on the surface even if their legs are paddling furiously underneath!

We recommend that children are supervised by an adult when giving their bolus injections until they are about 11 years old and sometimes older.

It is highly desirable for an adult to supervise the long acting insulin

TRY AND RELAX YOUR CHILD - Stress can make you tense up and if the child's muscles are tense a needle can hurt a bit.

DISTRACTION - Toys/games/books etc. Bubbles are great for younger children as it makes them do deep breaths as well as being distracted. Listening to Music can be calming and distracting.

BEING IN CONTROL - Children and adults who don't like injections can often feel out of control. Try and involve the child and give them some limited, practical choices. Even small things can really help, such as "would you like the injection in the lounge or bedroom?" Please talk to the team for further advice and relaxation resources.

DEEP BREATHING – taking long, slow, deep breaths can slow the heart rate down which reduces the physical symptoms of anxiety. Take a deep breath in through your nose and say the word "smooth" on the way out – you may feel silly but it does work!

Aims of Treatment

Every child and young person with Type 1 diabetes has to manage their condition to live a healthy, happy life. This quick guide shows the blood glucose readings that you should be aiming for.

After meals

5 – 9 mmol/l

7-day average

Sensor glucose

Aim for 8 mmol/l

Time in range at least 70%

Before meals and on waking

(Including breakfast)

4 – 7 mmol/l

HbA1c

(Shows control over 3 months)

Less than 48 mmol/mol

Give insulin 15 minutes before food

Check glucose levels at least 5 times a day

Improve your Carb-counting skills

Lots of things can affect your blood glucose levels — keep in regular contact with your diabetes team who can offer extra help and support

Glucose Monitoring

- ## Blood glucose finger prick checks

Blood glucose meters rely on a finger prick and resulting drop of blood to monitor blood glucose levels.

Continuous glucose Monitoring

- Sensors measures the interstitial (between cells) glucose level at all times.
- May be inserted on the ward. This sensor lasts for 14 days Libre or 10 days Dexcom.
- Sensor readings can be used in place of blood glucose finger prick checks (with a few exceptions).

Freestyle Libre 2 plus and Dexcom G7 - Age 2 and over

Libre 3 - Age 4 and over

Diabetes Daily routine

Daily routine using Glucose Sensor :Libre® or Dexcom® with mylife® APP

NHS
Royal United Hospitals Bath
NHS Foundation Trust

CONTACT: Mon-Fri 9am-5pm:
Paediatric diabetes team
01225 825331.
Ruh-tr.paediatricdiabetesteam@nhs.net
Out-of-hours: Paediatric registrar on-call via the RUH Switchboard:
01225 428331

On waking
Enter sensor glucose (SG) into myLife App and give fast acting insulin as advised.
If eating breakfast, also enter carbohydrate and give insulin as advised.

When eating
Enter SG reading and carbohydrate into myLife App and give fast acting insulin as advised.
Aim for 3 nutritious meals per day.
If snacks are eaten, keep them small.

During the day
2-4 hours after a fast acting insulin dose is given enter reading into myLife App and give fast acting insulin as advised.

At bedtime
Enter sensor glucose (SG) into myLife App, give fast acting insulin as advised.
This is recommended as late as possible and at least one hour after eating.

Give long acting insulin once a day as advised.

Arrows
If SG **4.5mmol/l** or less with a downward arrow give glucose to prevent a low .
(Amount is half usual hypoglycaemia treatment)

Diabetes management recommendations
- Give insulin 15 minutes before all meals.
- During the day use mylife App at least every 4 hours to enter SG and give insulin as advised. .
- Overnight a maximum of 10 hours between bedtime and waking checks.
- Look at SG averages weekly. Aim under 8mmol/l & time in range 70%. Contact team if above 8mmol/l for 2 weeks.
- Maximum of 5 mild episodes of hypoglycaemia a week (4% SG readings)
- Follow hypoglycaemia guidance if SG below 4mmol/l. Follow hyperglycaemia guidance if SG above 14mmol/l.

Finger-prick BG check is needed If symptoms do not match SG readings.

= Sensor (Libre ® or Dexcom ®)

= Bolus calculator APP e.g. mylife

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Understanding the Numbers

Why is it important that at least 5 glucose checks are done per day?

Frequent checking of glucose levels is the most accurate way of knowing your child's glucose level. This enables you to make safe decisions, for example to manage a 'hypo', to give a correction dose of insulin, to manage high blood glucose levels during illness and will inform the best action to take for sport.

Why is it important to aim for my child's glucose level to be between 4-7 mmol/l?

The body is designed to keep glucose levels in the blood within a very narrow margin (4-7.0 mmol/l). This is therefore the aim for children with Type 1 Diabetes. A study in the United States (DCCT) showed very clearly that good control of glucose levels really reduced the risk of complications and this effect lasted for many years. It is therefore very important to try and get good control from diagnosis and then maintain it. We recognise this is challenging, requiring a lot of hard work from you and your child, but it is possible using intensive insulin regimens i.e. multiple daily injections, or for some children insulin pump therapy.

How will we know whether our child's overall control is where it needs to be?

The **HbA1c blood test** is a marker of glucose control. NICE guidance recommends that the **nearer the HbA1c is to 48 mmol/mol** without lots of hypoglycaemia the better, to minimise short and long term complications of diabetes. The HbA1c blood test is done every 3 months when you come to clinic. It is done from a usual finger prick and we have a result from the machine with 6 minutes.

In between clinic appointments you need to review your child's Mylife download every two weeks. If the average glucose levels are over 8mmol this indicates that more insulin may be needed. We are also looking to achieve a time in range value close to 70%.

What do you mean by 'complications of diabetes'?

Having a high HbA1c (70mmol/mol or over) significantly increases the risk of developing complications of diabetes, such as eye disease, kidney disease, heart disease, stroke or impotence. This can be further discussed in your child's clinic appointment at a suitable time. A high HbA1c has a negative effect on general health, education, performance and psychological well-being. Research shows any reduction in HbA1c will reduce your child's risk of developing complications from diabetes in the future.

How will you monitor my child's health?

All children with Type 1 Diabetes must have an Annual Review to assess their overall health. We will look for conditions often associated with diabetes and complications resulting from living with diabetes.

The annual review will include:

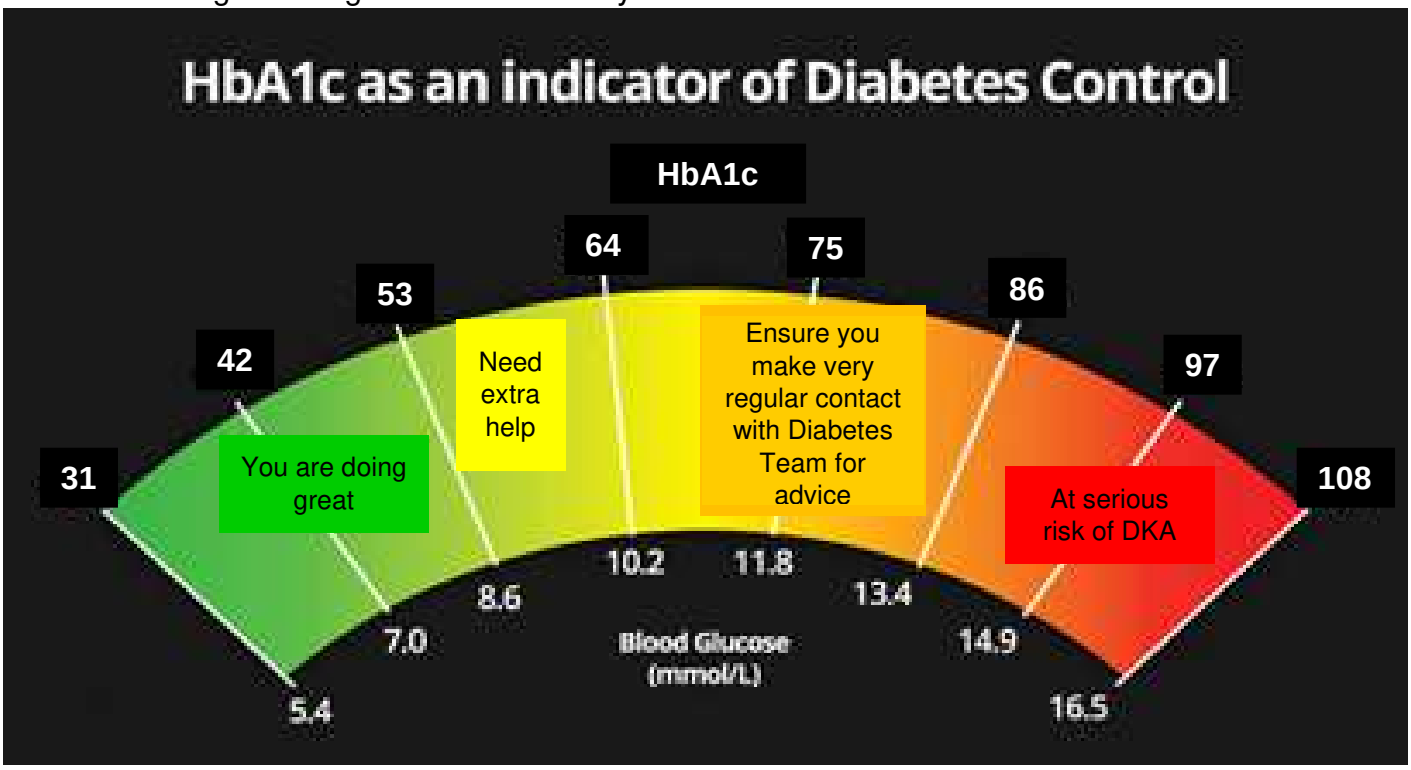
- A blood test, taken from a vein, will check for coeliac disease, Thyroid gland disease and kidney function. For children over the age of 12 the blood test will also check their cholesterol level. This blood test should be arranged at the GP's surgery or in Children's Outpatients at the Royal United Hospital.
- Additionally all children over the age of 12 will have an eye check (retinal screening), blood pressure check and a urine sample to assess kidney function.
- Psychology Assessment You will be asked how you are feeling about diabetes and how it affects your day to day life. We can make a referral to our team psychologist if you feel this would help you.
- Dietitian review, everyone with diabetes should be seen by the dietitian at least once a year. During this review, the dietitian will check that your diet is healthy and well-balanced (including being gluten-free if appropriate). They will be able to help you with your diabetes management. They can also help with any other dietary related concerns you may have – for example, how dietary management of your diabetes can help with sports performance. This is usually offered as a virtual appointment.
- Feet check, we will ask you if you have any problems with your feet. If there are any concerns about your feet, we will look at them with shoes and socks off and examine for infections, such as ingrowing toenails, nerve and circulation problems. Most CCGs now allow self-referral for foot problems via their websites.

What Does Your HbA1c Mean?

HbA1c is the name given to the finger prick blood test that you do each time you come to clinic.

The **HbA1c blood test** is a marker of glucose control and is related to average blood glucose. National guidance recommends that the **nearer the HbA1c is to 48mmol/mol** without a lot of hypoglycaemia the better to minimise short and long term complications of diabetes.

It is a measure of the number of red cells in the blood which have glucose stuck to them. As red cells last about 3 months before they are replaced by the body, it reflects the blood glucose levels over 2-3 months. If your blood glucose levels are mostly high, your HbA1c will be high. The link between average blood glucose levels and your HbA1c number is shown here:



Risks to health significantly increase when HbA1c is 70mmol/mol or above

There can be many reasons why your child's HbA1c may rise to 70mmol/mol and above, but the key reason will be that your child is not getting enough insulin. If this should happen, the Paediatric Diabetes Team will discuss this with you in clinic and will make plans to give you and your child whatever extra support and education is needed with the aim of reducing the level back down to as close to 48mmol/mol as possible.

Having a **high HbA1c (70mmol/mol or above)** significantly increases the risk of developing complications of diabetes, such as eye disease, kidney disease, heart disease, stroke or impotence.

Disposal of Needles and Lancets – 'Sharps'

It is important to dispose of the 'sharps' safely. This is a legal requirement. You will be given a yellow 'sharps bin', to put your sharp items in when you leave hospital. These are available on prescription.

When it is ¾ full (to the thick black line), snap it closed so that the lid 'locks' shut and take it to your GP surgery for disposal. If your GP surgery is not able to dispose of the sharps bin, you can arrange for collection from your home through your local council:

Mendip District Council Customer services 0300 303 8588
Email: customerservices@mendip.gov.uk

Wiltshire – you need to register – call 0300 456 0102

BANES – Council Connect 01225 394041
Email: councilconnect@bathnes.gov.uk

You can also use a needle clipper (BD Safe Clip), which cuts off the insulin pen needles. This is available from your GP on prescription. Your diabetes nurse can show you how to use it. (Do not use Safe Clip for lancets from finger pricking devices).

Going Back to School

Children usually return to school fairly quickly, however this will be dependent upon individual need. Your child's lead nurse (PDSN) will make arrangements, within the first few days of diagnosis, to provide education about diabetes for staff at your child's school.

Your nurse will meet with a key member of staff plus one or both parents to discuss and write an 'individual health care plan' (IHCP). The care plan provides information about your child's medical needs while at school.

School staffs are very helpful and keen to do all that they can to enable children to return to school. In the short term, particularly with younger children, school staff may need support from a parent while they are learning new skills e.g. how to check glucose and give an insulin injection. It is also important that your child is comfortable and confident with staff helping them manage their diabetes. The team also provide specialised and annual refresher training to primary school staff.

Parents may need to take some time off work. The team realise that this is not always easy. If a letter of support from the diabetes team to the employer would help, please let us know.

Working Together

Clinics are held at the RUH, Chippenham Hospital and Frome Medical Practice. The RUH 14+ clinic encourages teenagers to have part of their appointment on their own in preparation for transition to the Adult Care Team at the age of 18.

The RUH Paediatric Diabetes Team follow Best Practice and National Institute for Health and Care Excellence (NICE) guidance ensuring delivery of the best treatment, care and ongoing education for our patients and their families.

Type 1 diabetes is a life-long chronic condition and this is recognised in our commitment and ability to offer:

- Advice and education within 24 hours of diagnosis
- Training of school staff and creation of an Individual Health Care Plan
- Psychology support within 6 weeks of diagnosis
- Four 30 minute multi-disciplinary clinics a year, to include a more detailed annual review; blood tests together with a dietary annual review
- At least 8 additional team contacts per year
- Retinal Screening programme for those aged 12 and older
- Access to a nurse led helpline during working hours and support from the on call Paediatric Registrar for out of hours concerns
- Team delivery of specialised ongoing education sessions

We acknowledge that parking at the RUH and Community Hospitals can be challenging. We respectfully request that you allow enough time to park and check in with your nurse at least 5 minutes prior to your appointment time.

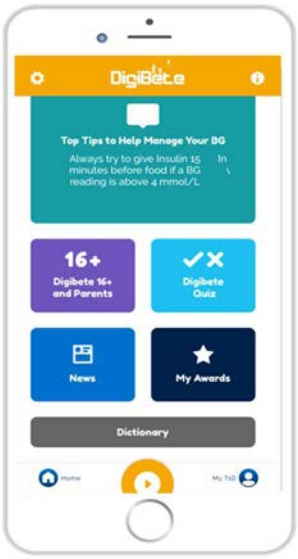
Every effort is made to see patients in a prompt and timely manner. We may be unable to see families who arrive more than 10 minutes late due to the knock-on effect to other patients. Clinics cannot run to time when patients arrive late; your understanding and support with this is greatly appreciated.

Should you need to cancel a clinic/psychology/dietitian appointment or training session we ask that you do so as far in advance as possible to enable us to offer the appointment to another family.

Our service is required to document when children and young people are ‘not brought’ to clinics. Where an appointment has not been cancelled the appointment is logged as a ‘Was Not Brought’ (WNB). Green, amber and red reminder letters are subsequently issued. Your nurse will explain this process and the important reasons why, although time consuming, clinic appointments are key to embedding good diabetes management for long term health benefits.

DIGIBETE

We thoroughly recommend you download the Digibete App it is for you to use at home, to support communication with your clinic and provide additional education resources for you to view at home.



Here are the **3 reasons** for you to download the Digibete App today from either the App Store or Google Play….

⇒ **Better Communication**
Your diabetes teams can send you relevant information and resources about managing your type 1 diabetes at home – newsletters, as well as updates.

⇒ **Store Ratios**
You will have a place in the App to store all your insulin ratios. You will also be able to store care plans, future appointments and notes.

⇒ **Essential help, resources and awards!**
You will have direct access age to over 200 type 1 diabetes films including sick days and age appropriate resources to support self-management, including exercise and all essential training.

Download

1. On downloading the Digibete App, you will be asked to enter either '**log in**' or '**sign up**'.
2. You will need to press **'sign up'** on your first visit
3. You will then create an account and enter your unique clinic code.

Your Clinic Code is: FTXSI

You can find a guide on how to register and how best to use the App here: https://www.digibete.org/digibete-app/

Please sign up with one family email address and a password that can be shared with carers. Up to 6 devices can the access the same App.

Food & Drink

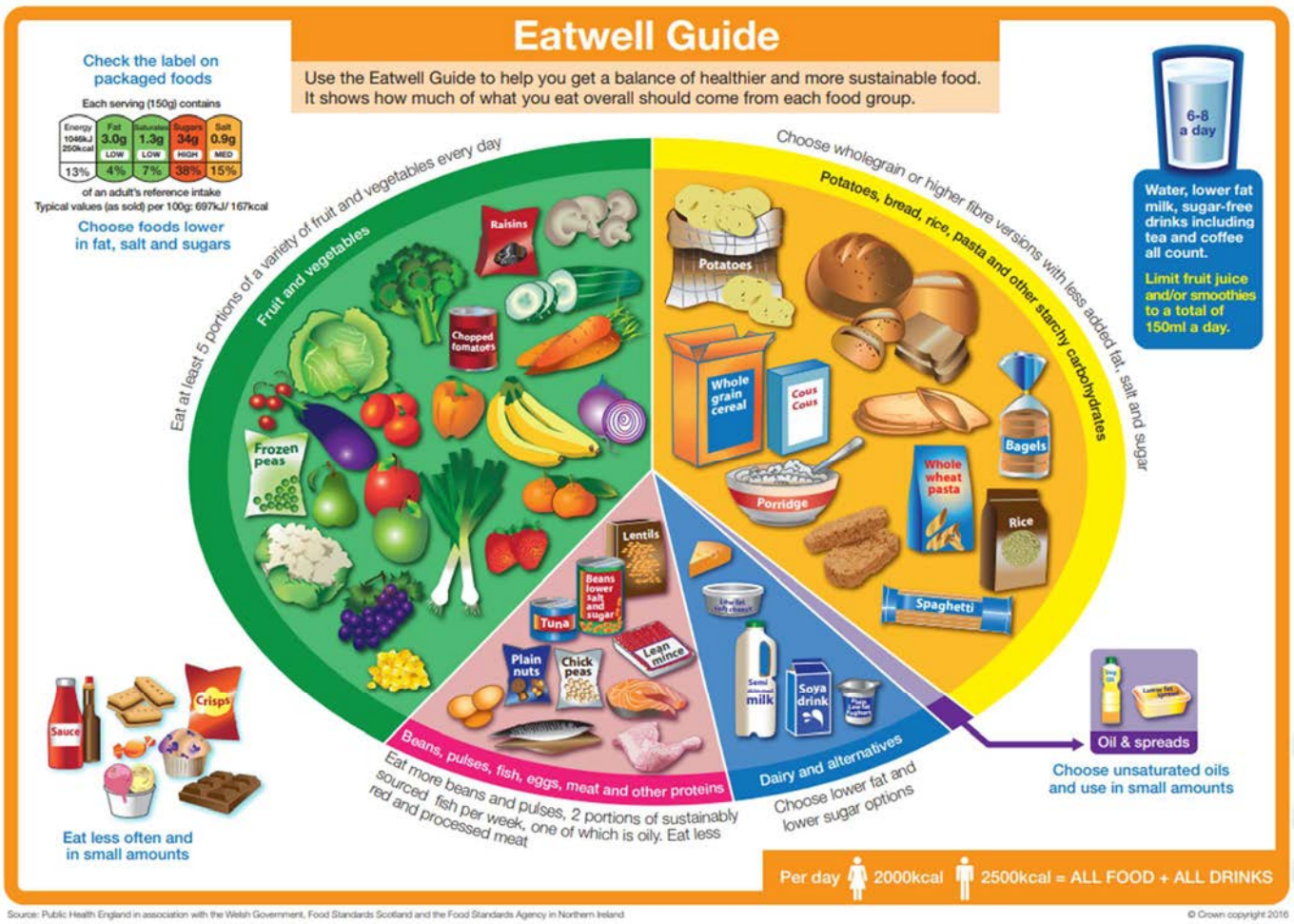
Role of the Dietitian

Registered dietitians are experts in nutrition and meal planning.

They will explain how food affects your glucose levels and make sure you're getting enough food to grow and develop properly. When you meet with a dietitian, expect to answer a few questions about your eating habits and activity levels. It would be really helpful to write down examples of meals and snacks you regularly eat.

The dietitian will:

- explain carbohydrate counting and meal planning techniques
- make adjustments to your meal plan based your lifestyle habits, on the types of exercise you do, and any other special events or holidays that may come up
- help you learn about making healthy food choices
- teach you to read food labels and find out the carbohydrate content of foods when food labels aren't available
- suggest some healthy snack ideas



Healthy Eating

There is no special diet for children and young people with diabetes. They need the same amount of energy and nutrients to promote growth and development as all other children and young people. They should eat a healthy balanced diet that all the family can enjoy. No foods need to be avoided but some foods are better choices than others.

Using the eat well guide, try to eat regularly and choose a variety of foods from the green, yellow, pink and blue groups every day to provide all the nutrients the body needs. Foods from the purple group – food and drinks that are high in fat and/or sugar are not essential and should form the smallest part of the diet.

Aims for 3 nutritious meals per day if snacks are eaten keep them small

Meal Planning:

- **Bread, Rice, Potatoes, Pasta and other starchy foods**: Include in every meal. Choose wholemeal and wholegrain varieties.
- **Fruit and Vegetables**: Aim for at least five portions a day – more vegetables than fruit.
- **Milk and Dairy**: Try to have 2-3 portions of milk and dairy foods such as cheese, yogurt and fromage frais every day.
- **Meat Fish Eggs Beans**: Include meat, fish, eggs or beans/lentils at main meals, **not** generally as snacks. Have fish twice a week, including oily fish.
- **High Fat and High Sugar Foods**: Try to eat just a small amount of foods and drinks that may be high in fat and/or sugar.
- **Salt**: Intake of salt should be kept to a minimum as too much can lead to health problems. Processed food such as crisps, ham sausages, bacon and ready meals contain often a lot of salt so try not to eat these often.

Ideas for healthy snacks:

- Vegetables – sticks of carrot, peppers, cucumber, celery, baby sweet corn, mange tout or any other vegetable
- Crackers, breadsticks or oatcakes –with hummus, taramasalata, salsa, guacamole, cottage cheese or low fat cream cheese
- Plain biscuits – Rich tea, digestives, garibaldi, small cereal bars
- Yogurts – fruit varieties or try natural yogurt with added fruit
- Fruit – fresh or dried (keep to a small portion size).
- Nuts – try unsalted. Plain popcorn

Carbohydrate Counting

Glucose in the blood comes from the digestion of carbohydrates.
So by calculating how many carbohydrates have been eaten, one is able to adjust the rapid-acting insulin to match the amount of glucose coming from food. This is known as carbohydrate counting.
Carbohydrates are found in many foods and provide important nutrients and energy to help your child grow, play and do other physical activities.

Foods contain different types of carbohydrates

• **Starchy carbohydrates** including potatoes, rice, pasta, noodles, breakfast cereals, bread, couscous, lentils, beans and products containing flour	
• **Fructose** including – fruit, fresh or frozen, dried fruit Tinned fruit, fruit juice and honey	
• **Lactose** including – milk, yogurt, ice cream and custard.	
• **Sucrose** (table sugar) including – syrup, sweets and sugary drinks	
• **Glucose** e.g. including Lift glucose drink or Lift glucose chews or dextrose energy tablets	

Food Labels

When looking at food labels, always look at the total 'Carbohydrates' as this will include all the types of carbohydrates

Reading Labels

Example 1

The total carbohydrate is the important value

The amount of carbohydrate is always written per 100g on food labels

It may also give the amount per portion or per item. In this example per wrap

8 x Wholemeal Wraps

Nutrition

Typical Values	per 100g	per wrap
Energy	1228kJ	752kJ
-	292kcal	179kcal
Total Fat	8.9g	5.1g
(of which saturates)	3.7g	2.3g
Carbohydrate	41.6g	25.5g
(of which sugars)	3.7g	2.3g
Fibre	8.8g	5.4g
Protein	8.4g	5.1g
Salt	1.38g	0.84g

Example 2

Amount of Carbohydrate per 100g =12.4g of carbohydrate

The amount of carbohydrate in 1g of yoghurt is 12.4/100=0.124g

Therefore in 143g pot of yoghurt the amount of carbohydrate is 143x0.124=**17.5g carbohydrate**

Net Contents

143g e

Nutrition

Typical Values	(Per 100g)
Energy	440kJ (105kcal)
Fat	2.8g
of which saturates	2.5g
Carbohydrate	12.4g
of which sugars	11.9g
Protein	4.3g
Salt	0.17g

Example 3

Amount of carbohydrate of cooked food is given for 4 fish fingers as 24g carbohydrate

To find out how much carbohydrate is in 3 fish fingers divide the amount by 4 to find out how much in one fish finger and then multiply by 3

24/4 =6g carbs in one fish finger. 6x3=**18g of carbs in 3 fish fingers**

Nutrition

Typical Values	As Sold 100g Provides:	Per 4 Fish Fingers (112g) Oven Baked Provides:
Energy - kJ	811kJ	1024kJ
-	194kcal	245kcal
Fat	8.0g	10.0g
- of which Saturates	1.4g	1.7g
Carbohydrate	21.0g	24.0g
- of which Sugars	<0.5g	<0.5g
Fibre	0.8g	1.0g
Protein	13.0g	14.0g
Salt	0.72g	0.80g

Carbs and Cals book and APP

Use the Carbs and Cals book to work out the carbohydrate in your meal:

Estimating method

Carbs and Cals book

Step 1 .Look at your meal. Identify which items contain carbohydrate

Step 2 Open the carbs and Cals book /search on the APP for the food item

Step 3 . Match as far a possible the food about to be eaten to the image .

Step 4. Then the amount of carbohydrate is found in the green box(CARBS)

Carbs and Cals APP

Step 1 .Look at your meal. Identify which items contain carbohydrate

Step 2 Search on the APP for the food item

Step 3 . Match as far a possible the food about to be eaten to the image .

Step 4. Click on the portion of food matched to your portion

Step 5. Then the amount of carbohydrate is found in the green box(CARBS)

Carbs and Cals APP https://www.carbsandcals.com/

Weighing Method of carbohydrate counting (recommended)

Option 1 –using information from Carbs and Cals APP

Carbs and Cals APP

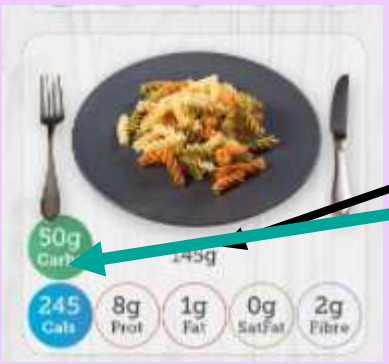
Search for the item of food

Zero your plate, weigh the food

Edit the weight of the food to the amount about to eat

View carbohydrate your portion provides

Option 2 –weighing the portion that is shown in the Carbs and Cals Book



If you weigh out **145g** of Pasta

it will contain **50g** of carbohydrate (green)

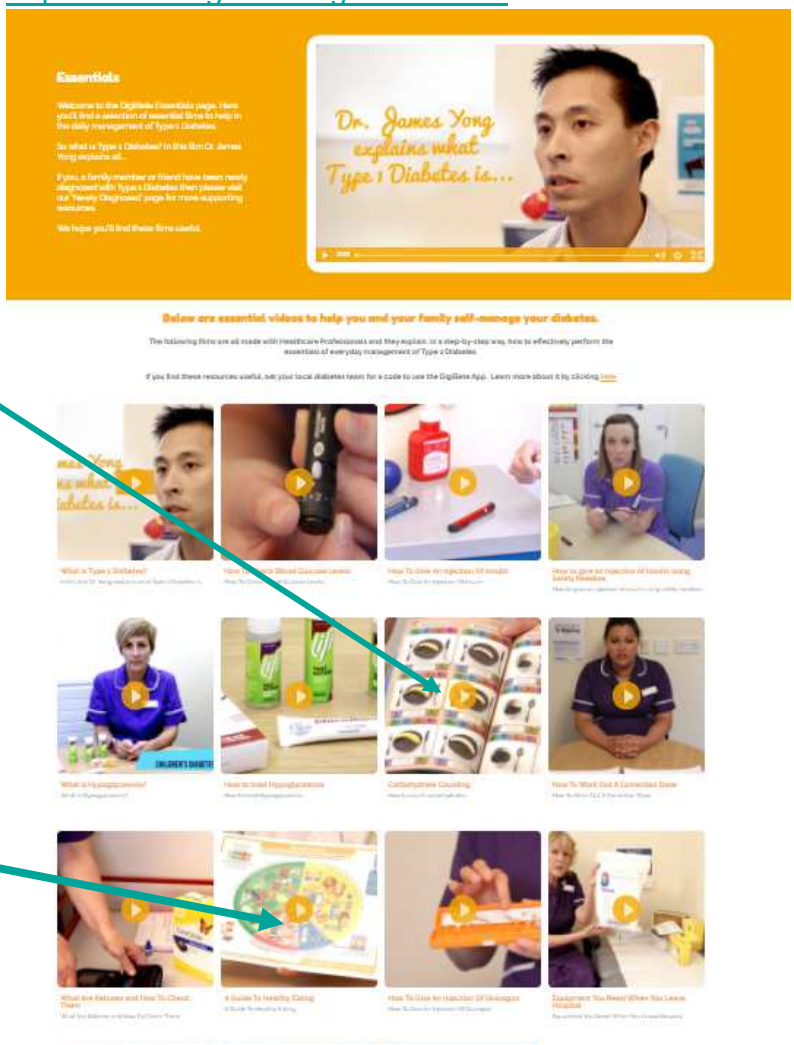
Option 3 –using Food Label

1. Weigh your portion.	1. **40g**
2. Look at the label and check the amount of carbohydrate in 100g of the product (remember it is the largest value that shows the **total carbohydrate** not just the 'of which sugars/starch').	2. **75g CHO per 100g**
3. Work out how much carbohydrate is in 1g. Divide the amount of CHO in 100g by 100 to tell you how much is in 1g.	3. **75 ÷ 100 = 0.75g in 1g**
4. Work out how much carbohydrate is in your portion. Multiply the CHO in 1g by the weight of your portion to tell you how much CHO is in your portion.	4. **0.75 x 40 = 30g CHO**

Digibete Resources to support Healthy Eating and Carbohydrate Counting

Aim to watch before discharge to support practical carbohydrate counting

https://www.digibete.org/essentials/



https://www.digibete.org/frances-kitchen/

Making and carbohydrate counting simple family friendly meals

Primary School Meals

How to assess Carbohydrate content of meals

- If the meals are provided by a **private outside caterer** ask for the Carbohydrate content of the meals, as this is usually available on request.
- If not available dietitian can provide you with carbohydrate values of standard portions. If using standard portion sizes, then we recommend the catering team ensures portion sizes are consistent and in line with the standard weights given.

Aim: To know the carbohydrate content of a meal in advance of the meal being served as insulin dose is given 15 minutes before eating

Parents: Will inform school teaching and support staff of the carbohydrate value of meal chosen each day. Often using a Parent/School diary

Packed Lunches

Provide the school with the amount of carbohydrate in your child's packed lunch. It may be helpful to label each item –or to put a list of carbohydrate content into lunch box.

Senior School Meals

Food portion sizes are usually larger and may include snack items such as toasted Panini, ask dietitian for more information to assist carbohydrate counting.

Hypoglycaemia (Hypo)

Low Glucose level (below 4mmol/l)

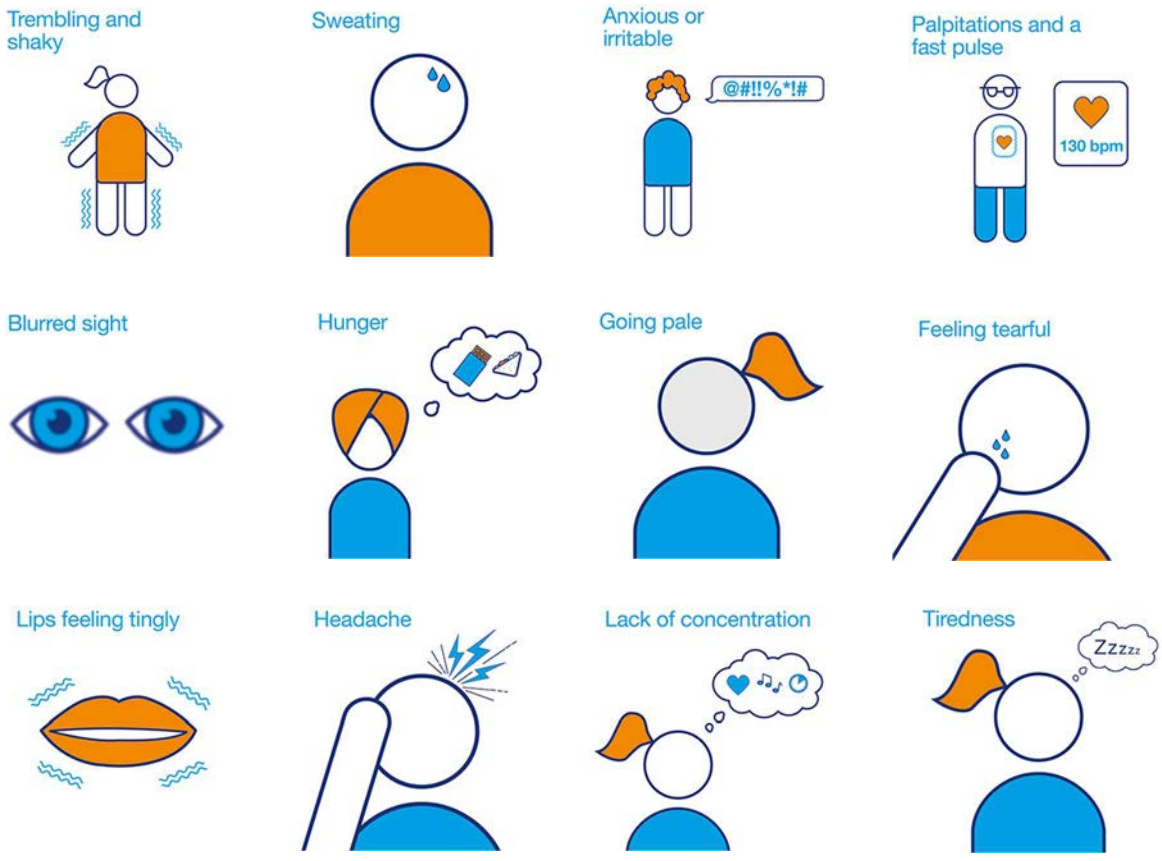
Your child may have a ‘hypo’ because:

- they decided not to eat the full meal/snack
- too much insulin was given
- insulin was injected into muscle not soft fat
- they participated in exercise during the day that was not adjusted for
- they consumed alcohol

It is acceptable to have up to 5 hypos per week

How might your child feel or look when having a ‘hypo’?

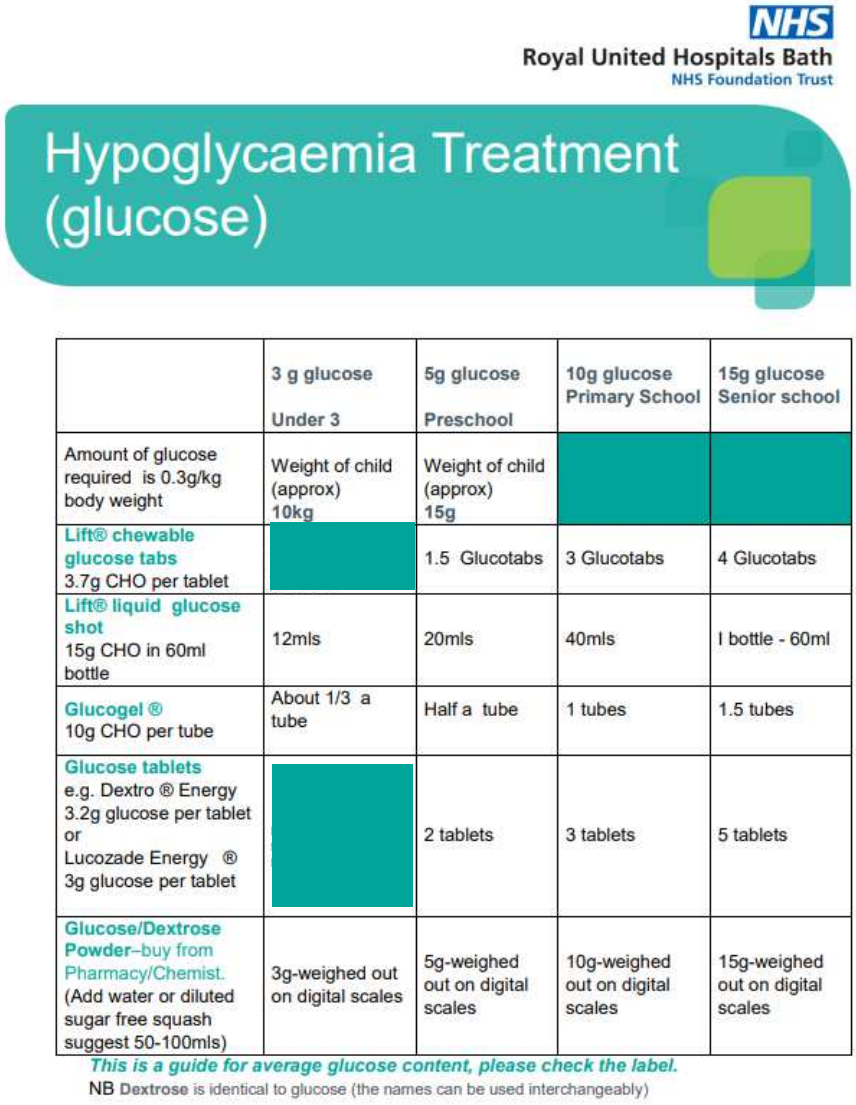
You may well notice that your child is having a ‘hypo’ before they do. You may notice your child is pale, quiet, and dark under the eyes. Every child is different, and over time you will recognise the particular things that tell you that your child is having a ‘hypo’. It is worth noting these, so that you can tell others what to look out for.



age source: Diabetes UK

Management of glucose levels below 4mmol/l

(Go to Digibete App for most up to date flowchart)



NHS
Royal United Hospitals Bath
NHS Foundation Trust

Hypoglycaemia Treatment (glucose)

	3 g glucose Under 3	5g glucose Preschool	10g glucose Primary School	15g glucose Senior school
Amount of glucose required is 0.3g/kg body weight	Weight of child (approx) 10kg	Weight of child (approx) 15g		
Lift® chewable glucose tabs 3.7g CHO per tablet		1.5 Glucotabs	3 Glucotabs	4 Glucotabs
Lift® liquid glucose shot 15g CHO in 60ml bottle	12mls	20mls	40mls	I bottle - 60ml
Glucogel ® 10g CHO per tube	About 1/3 a tube	Half a tube	1 tubes	1.5 tubes
Glucose tablets e.g. Dextro ® Energy 3.2g glucose per tablet or Lucozade Energy ® 3g glucose per tablet		2 tablets	3 tablets	5 tablets
Glucose/Dextrose Powder–buy from Pharmacy/Chemist. (Add water or diluted sugar free squash suggest 50-100mls)	3g-weighed out on digital scales	5g-weighed out on digital scales	10g-weighed out on digital scales	15g-weighed out on digital scales

This is a guide for average glucose content, please check the label.

NB **Dextrose** is identical to glucose (the names can be used interchangeably)

Key Advice about Hypos

You and your child should always carry glucose tablets or some other form of fast acting glucose at all times

If your child is having regular 'hypos', please contact a member of the diabetes team.
Things I Need to Know

I need to give fast acting glucose if my glucose level is under _____ mmol/l

My 'hypo' treatment is

Management of glucose levels when exercising

(Check Digibete App for most up to date exercise flowchart)

Key points

We strongly recommend exercise and participation in sports if you have type 1 diabetes.

We will support you and explain the extra steps needed to manage blood glucose whilst exercising.

Exercise and sport can affect your blood glucose levels. Depending on the type of activity you do, it may cause your blood glucose levels to rise (hyperglycaemia) or drop (hypoglycaemia).

Moderate exercise that lasts a while, like walking or cycling, can cause a slow drop in blood glucose levels.

Some exercise, like sprinting or doing weights at the gym, might cause your blood glucose levels to rise

- **Check glucose levels before, during and after exercise.**
- **Have available hypoglycaemia treatment (e.g. glucose tablets) and the ability to check sensor glucose or a blood glucose using a blood glucose meter whilst exercising.**
- **Wear suitable protective footwear.**
- **Drink plenty of water during exercise**

Hyperglycaemia (Hyper)

High Glucose level (14mmol/l or above)

Common reasons for hyperglycaemia

- Not enough insulin
- Forgotten insulin dose
- Infection or illness – children with diabetes do not experience more illness or infections than other children. However, any illness may upset their diabetes
- Sudden excitement or stress

Signs of Hyperglycaemia	**Signs of Diabetic Ketoacidosis** (high blood glucose + ketones)
• Increased thirst • Passing more urine • Bedwetting • Tummy ache	• Nausea and vomiting • Cold, dry skin • Deep rapid breathing • Sweet smell on breath, similar to nail polish remover • Drowsiness

If your child's glucose level is above target range, this is a sign that they need more insulin; you will be taught how to use a 'correction dose' of insulin.

If your child has a high glucose level and feels sick or starts to vomit, you need to contact a member of the team immediately on 01225 825331 (working hours only) or ring the RUH on 01225 428331 and ask to speak to the Paediatric Registrar on call (24-hours a day).

Your child should not be left unsupervised in this situation, whatever their age and whatever they may tell you – they are sick.

Management of glucose levels above 14mmol/l

(Go to Digibete App for most up to date flowchart)

Management of glucose levels when unwell

(Go to Digibete App for most up to date flowchart)

Supplies and Equipment

A member of the team should complete this page for you before you leave hospital so that you are clear on what equipment you will need and why.

You will leave hospital with supplies for two weeks. Please ensure you contact your GP to organise your monthly repeat prescription.

Durable Insulin pen:
- Novo Pen Echo Red (Novo Nordisk)
- Junior STAR Blue (Sanofi)

Insulin cartridges: 3ml
- Novorapid (Insulin Aspart) 3ml Pen fill cartridge
- Lantus (Insulin Glargine) 3ml cartridge

Insulin pen needles:
- BD Micro-Fine insulin pen needles (0.23mm (32G) x 4mm)

Blood glucose and ketone test strips:
- GlucoRX HCT Blood Glucose Strips (50 strip pack)
- GlucoRX HCT Blood Ketone Strips

Lancets:
- Accu-Chek FastClix Lancets

Libre 2 – 2 sensors per month (***any replacements must be requested from the company***)

BD Safe Clip Needle Clipper

Glucose 40% gel (3 x 23g pack)

Sharps Box

Please note: there are no prescription charges for the items your child requires to manage their diabetes. However most ***hypo treatments*** such as: Lucozade, dextrose tablets ***are not available on prescription.***
Meters, pens and consumables are charged to your GP and Diabetes Team. We ask that consumables are ordered as needed, and that essential blood glucose and ketone meters are kept safe and are registered with the manufacturer. Please contact the manufacturer for control solution, a spare meter and for a replacement should it break or be lost. (Tel: 0800 701000 accu-chek.co.uk)

Please allow a week for your GP surgery to process repeat prescriptions.

Identification

It is a good idea for your child to always carry something on them showing that they have diabetes, such as a necklace, bracelet, and watch or card (e.g. Medic-Alert Tel 0121 200 1616, or something similar). If they are out with friends or were to have an accident, it is important that others know that they have diabetes.
Medical Alert

www.medicalert.org.uk www.theidbandco.com

Disability Living Allowance (DLA)

Parents of children with diabetes are eligible to apply for a benefit called the Disability Living Allowance (DLA), until the child is 16 years. Newly diagnosed young people 16+ can apply for Personal Independence Payment, where specific criteria are met.

Application forms are available from your local Social Security office or online.

For further information and support regarding DLA and PIP please contact:

Telephone Benefits Enquiry Line 0800 882200
www.direct.gov.uk/disability-money
www.gov.uk/dla-disability-living-allowance-benefit

Glossary

Blood glucose	The level or concentration of glucose in the blood
Carbohydrate	One of the three main energy giving nutrients in foods, composed mainly of sugars and starches
Diabetic Ketoacidosis (DKA)	A serious condition caused by a deficiency of insulin, which results in body fat being used for energy instead of glucose. Ketones (acids) can be detected in blood
CGM e.g. Libre or Dexcom	Continuous glucose Monitor A way to measure glucose levels in real-time throughout the day and night. A tiny electrode called a glucose sensor is inserted under the skin to measure glucose levels in tissue fluid. It is connected to a transmitter that sends the information via wireless radio frequency to a monitoring and display device.
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
Hyperglycaemia	High glucose level (over 14 mmol/l)
Hypoglycaemia or 'hypo' or 'low'	Low glucose level (under 4 mmol/l)
Insulin	A hormone produced by the beta cells of the pancreas, which lowers the blood glucose level by enabling transport of glucose from the blood into the body cells. This allows the cells to use glucose for energy
Ketones	Ketone is a waste product that is produced when the body is forced to burn body fat instead of glucose for energy. It may be a sign of lack of insulin in the body. The Ketone test measures the amount of ketone concentrated in the blood.
Pancreas	A large gland situated near the stomach, which produces digestive enzymes, insulin and other hormones

Sources of Useful Information

Social media has pros and cons. It can be a useful source of support and information, but please be aware that every individuals experience is different and advice is not always based on evidence or professional recommendation. We ask that you respect people's privacy and do not mention anyone's name, patient or professional, on social media.

We would like to encourage you to engage with the Families with Diabetes National Network (FWDNN). This organisation runs in parallel to the South West Diabetes Network and offers you a chance to get involved with the paediatric diabetes care that your family receives and to gain mutual support from other parents/patients in the South West Region.

The Paediatric Diabetes Network has a website with a South West section:
https://www.facebook.com/groups/southwestnetwork/

Local parent support group**:** Diabetes in Children Mendip Support Group
Contact Emma 07913284132 or Annabel 07834772076
Facebook: Diabetes in Children – Mendip Support Group

Recommended websites, publications and apps:
www.diabetes.org.uk

Care Events: Diabetes UK offer weekend and week-long opportunities for children to have fun, make friends and learn more about their diabetes
https://www.diabetes.org.uk/How_we_help/Care-events/

www.jdrf.org.uk

Change4Life recipes app & web-based: Change4lifeerecipes (carbohydrate counted when you click on the green 'nutritional information')
https://www.nhs.uk/change4life/recipes

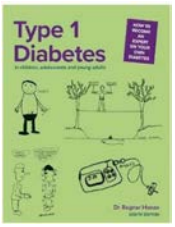
BBC good food guide - lots of meal ideas, many are carbohydrate counted
https://www.bbcgoodfood.com

DIGIBETE – Frances cooking shows you how to make simple meals and how to carb count them
https://www.digibete.org/frances-kitchen/

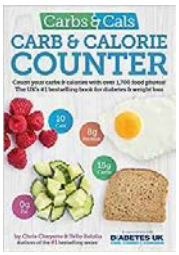
British Nutrition Foundation has a new calculator allowing you to calculate the nutritional value from recipes
http://explorefood.foodafactoflife.org.uk/Calculator/Recipe

(Continued next page)

There are many books available about diabetes in children, please note that many are written by American authors and management of diabetes in children differs in America to the UK.



Type 1 Diabetes in children, adolescents and young adults. How to become an expert on your own diabetes (2022)
8th edition
By Dr Ragnar Hanas
Publisher: Class Publishing, London



Carbs & Cals: Carb and Calorie Counter (also available as an app)
By Chris Cheyette & Yello Balolia
Publisher: Chello Publishing Limited

Things to note when reading anything about diabetes:

- Ensure it is about Type1 Diabetes 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 good knowledge of diabetes

Research

There are multiple studies running in the paediatric department across several specialties. If you/your child are eligible to participate in any research studies, you will be approached and given information about the study.

QR Codes for Mindfulness Apps

Smiling Mind

Stop, Breathe & Think

Headspace

Insight Timer

Tell Us What You Think

The Paediatric Diabetes Team is available Monday – Friday, 9am to 5pm
By email: ruh-tr.PaediatricDiabetesTeam@nhs.net
By phone: 01225 825331

Our aim is to provide the best possible service to the young people and families in our care. We review our practices and procedures regularly with a view to continuous improvement.

If you have any comments please tell us, any compliments please tweet us @RUH or if you are unhappy with your care and feel unable to tell us please contact PALS:

PALS is a free, accessible and confidential service for patients, relatives and carers and it aims to help sort out problems quickly on your behalf:

Email: ruh-tr.PatientAdviceandLiaisonService@nhs.net
Telephone: 01225 821655/01225 826319

Your named nurse is:

You will have contact with all members of the team, however this is the person who will take the lead with your child's education and ongoing support.

You may choose to correspond with your nurse by email, however if you do not receive a response within 48 hours please contact the office directly as your nurse may work part time, be on annual leave, training or teaching in the community.

Out of Hours or Emergency Contact

If you need advice out of hours (i.e. after 5pm, weekends and bank holidays):

Telephone the RUH switchboard 01225 428331, tell them you have a child with diabetes, and ask to speak to the ***on call Paediatric Registrar***. Advice is available 24 hours a day.

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.