

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.



Re-produced by the Exeter Children and Young People's Diabetes Team with the kind permission of the Paediatric Diabetes Team, Royal United Hospital, Bath.

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Introduction

You have just been told that your child has type 1 diabetes and we understand that this is a particularly difficult time for you. Exeter Children and Young People's Diabetes Team aims to support you, both in hospital, and when you have been discharged home. We will give you continuing support to manage your child's glucose levels throughout their childhood. We realise that it can feel like we expect you to learn a lot about diabetes quite quickly, but it is a step by step process and there will always be a member of the team to answer your questions so please don't be afraid to ask again ... and again. We want to support you.

It is important to realise that no one is to blame when a child develops diabetes and that diabetes can be managed. By working with us to manage your child's diabetes they will be back to good health. With a bit of extra planning they will be able to take part in all their usual activities that they enjoy and value. Everyone is different and it can take time to adjust to having diabetes, there may be good days and bad days, but the team will help you to think about what support you and your child may need.

This booklet has been written to help you understand more about the essentials of managing your child's diabetes. When reading this booklet, if a term seems a bit confusing then have a look at the glossary in the last few pages. We will also be happy to talk you through anything that you are not sure about. As time goes by, you will learn more and we will add to this information. There are many sources of information about diabetes available (e.g. online), but some of it will be out of date. If you are in doubt, please check with a member of the Diabetes Team.

The Paediatric Diabetes team

Different staff members make up the Paediatric Diabetes team; we all work together to help support you and your child.

Paediatric Consultant and Lead Clinician

Dr Christopher Moudiotis
Secretary: 01392 403695

Paediatric Consultant

Dr David McGregor

Speciality Doctor

Dr Sue Hellewell

Diabetes Team Administrator:

Natalie Barlow: 01392 403727

Paediatric Diabetes Specialist Dietitian:

Maria Leveridge: 07827 239019 (non urgent calls only)

Paediatric Diabetes Clinical Psychologist:

Dr Kathy Cox: 01392 403187

Paediatric Diabetes Specialist Nursing (PDSN) Team:

Heather Fisher, Lead PDSN
Ruth Dalton, PDSN
Emm Greenslade, PDSN
Jake Allison, PDSN

Out of Hours or Urgent / Emergency Contact:

Please contact 01392 403727 and leave a message for the Paediatric Diabetes Specialist Nurse for non-urgent advice. Alternatively email via rde-tr.PaediatricDiabetes@nhs.net

Out of Hours or Urgent / Emergency Contact:

The Paediatric Diabetes Specialist Nurse team are available daily from 9.00am - 5.00pm via switchboard on 01392 411611. Ask the operator for the Paediatric Diabetes Specialist Nurse On-call for urgent advice.

If you need advice after 5pm or before 9am, please telephone the switchboard on 01392 411611 and ask to speak to the on call Paediatric Registrar.

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 into hospital.

DigiBete app

Please download the DigiBete app (DB). This gives you access to all the diabetes and clinic information you need and we send out regular updates and news items to ensure you stay up to date. You can share your account with up to 6 phones with the same email and password log in. The clinic code is MCEPV.

You can find out more here:

www.digibete.org/digibete-app

The Paediatric Diabetes Team aims to:

- Provide your child, and you, with initial and on-going education about type 1 diabetes according to their needs, enabling them to manage the condition themselves more independently as they get older.
- Enable your child to lead an active and healthy life, with the knowledge and confidence to successfully manage their diabetes.
- Encourage your child, as they are able, to take part in every aspect of their diabetes management, with support from you, their family/carers.
- Promote open communication between your child, you (as parents/carers) and the Paediatric Diabetes Team.
- Teach your child about diabetes in a way that they can understand.
- Teach you about diabetes so that you are able to confidently care for your child.
- Discuss with you and your child the best choices regarding their diabetes management, and for you and your child to actively take part in decisions about this.

- Offer support and advice with the aim of keeping your child healthy and to protect body systems (heart, kidney, feet and eyes) that can be damaged by high glucose levels.
- Offer education and support to the staff at your child's nursery, school or college to enable them to safely look after your child during the school day.
- Ensure that your child is made aware of diabetes services for young people and that they are introduced to the Adult Diabetes Team, ensuring smooth transition into adult service as they get older.

Tips for dealing with difficult thoughts and feelings about Diabetes

Being diagnosed with, or your child being diagnosed with, diabetes can lead you to experience a whole range of emotions. Everyone is different and there are no right or wrong ways to feel. Your thoughts and feelings will change over time.

Here are some ideas you might like to try to support you and your child's emotional wellbeing following diagnosis:

- **Keep talking** - Communicating honestly with your family and your diabetes team is helpful. Support your child to speak about how they feel and let them know that it is ok to feel all the different emotions that they might have. It is also important that you have the opportunity to talk to family and friends about how you feel so that they can help support you. When you leave hospital keep giving your child opportunities to speak about their feelings, whether about diabetes or other things in their life.
- There may be times when you or your child feels upset, worried, resentful or angry about diabetes. All of these feelings are both OK and very understandable. Let your child know that it is alright to have these feelings, that having these feelings makes sense and that you are there to support them. Try not to give yourself a hard time about feeling this way either – remember, all these feelings are normal and will change over time.
- Find ways to let your feelings out – Sometimes it can be hard to talk about our feelings but think about other ways you might give yourself space to look after yourself, think about how you are and let your feelings out, like writing things down, doing exercise or by listening to some music.
- If you have other children try to explain diabetes to them in a way that is suitable for their age and understanding and offer them opportunities to ask questions and share how they feel. If they have a simple way of 'making sense' of what is happening, and why their brother or sister needs to do/not do certain things, it will feel less scary or worrying for them. Let them know that you are there for them too.
- You may want to reduce some less urgent life commitments for a while, to give yourself time and space to take everything in. Let people close to you know if there are practical or supportive things they can do to help.
- Try and keep family routines and boundaries in place as much as possible; this can help your child to feel safe and secure despite the changes that diabetes brings.
- Relax – Try to make sure that you all have some time to relax. Spending just a couple of minutes doing slow, deep breathing can really help to relax your body and help you to feel calmer.
- Plan things to look forward to – This might be going to see a friend, watching a film you like or spending time doing some of your favourite things when you go home.

- Remember, because diabetes is new to you all right now it might feel like it is a lot of what you are thinking and talking about, but how it fits into your life will change over time – It will become easier to make space again for all those things that you enjoy together. Make sure you have times when you talk about other things together too!

Clinical Psychology:

We have a Clinical Psychologist as part of the diabetes team; they will usually contact you within the first days or weeks after diagnosis. The Clinical Psychologist's role is to help think about how diabetes and its treatment affects you all, and how you can find ways to manage the thoughts, feelings and challenges that living with diabetes can bring - this might include things like worries about medical procedures, struggling with low mood and anxiety because of diabetes, feeling different or accepting and adjusting to living with diabetes. Support is available both at diabetes diagnosis and as your child grows up.

If you would like some support to think about how you or your child are feeling about diabetes then you can talk to any member of the diabetes team and they might suggest that you meet with the Clinical Psychologist. Please ask if you would like more information.

What is Type 1 Diabetes?

Type 1 diabetes is a condition caused by the lack of a hormone called insulin in the body.

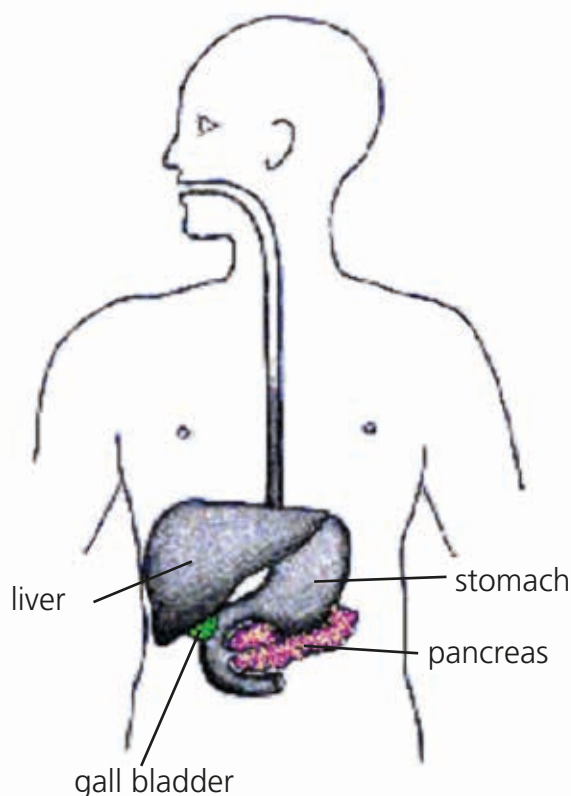
A gland, called the pancreas, which lies between the stomach and the backbone, produces insulin in cells called the Islets of Langerhans.

How does insulin work?

We require insulin to live. It is vital to the process of converting the food we eat into the energy we need to walk, run, sleep and grow.

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

Normally the pancreas automatically releases insulin to allow the glucose from our food to enter the cells, and to make sure that the amount of glucose left in the blood is 'just right'. Insulin acts as a 'key' to allow the glucose into the cell.



So what has happened?

Your child's pancreas is no longer producing the insulin required to move the glucose into cells in their body to be stored until they need energy. This means that there has been too much glucose building up in their 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 also have noticed they are more thirsty and drinking a lot.

Most children with diabetes will have lost weight by the time the diagnosis is made. This is because 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 as the waste product. 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 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, they indicate that there is too little insulin in the bloodstream.

Helpful video clips:

- Please download '**Deapp**' to your phone or tablet. This app provides you and your child with short, easy to watch animations on all aspects of diabetes that we are teaching while you are in hospital. Find out more at:
www.deapp.nhs.uk
- Explaining Diabetes: What is Diabetes? 2 minute guide from Diabetes UK:
www.youtube.com/watch?v=wZAJVQWbMIE
- Type 1 aware video:
www.youtube.com/watch?v=tYlQTylh_0M
- Digibete: Watch helpful videos about diabetes and the basics of treatment on their 'essentials' pages:
www.digibete.org

National recommendations for care of young people with diabetes can be found here:
www.digibete.org/national-documentation

What causes Type 1 Diabetes?

Type 1 diabetes is becoming more common in children and we do not know why this is. Many people are doing research to try and find out why.

It is important to realise that there are two different types of Diabetes. In type 2 diabetes, which is more common in adults, the pancreas is still producing insulin but it is either not enough, or it is not working properly.

Some children who develop type 1 diabetes have a member of their family with it too, so there is probably something about their genetic makeup that has made them more likely to develop diabetes. There may also be trigger factors, such as viral infections.

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 said or done
- Able to be caught, like you might catch a cold.

Treating Type 1 Diabetes

Although there is currently no cure for type 1 diabetes, it can be successfully managed.

Type 1 diabetes is treated with:

- Replacement **insulin**, either by injections or continuously via an insulin pump (insulin regimens). This insulin must be given regularly and be given with food or drinks which contain carbohydrate and/or be given if blood glucose (blood sugar) levels are out of the target range. Insulin cannot be taken as a tablet or medicine because it would be destroyed by the acidic juices in the stomach and would not work properly.
- A balanced, **healthy diet**, to keep your child healthy and to maintain their blood glucose close to target range as possible. It is also important to think about how much exercise/activity your child has.
- Regular **blood glucose checks** are important to know how effective the insulin is and to enable safe adjustments to insulin doses.

Insulin

There are different types of insulin:

- **BOLUS** insulin - Rapid acting insulin, e.g. Novorapid
- **BASAL** insulin - Long acting insulin, e.g. Lantus, Levemir, Tresiba

There are different insulin treatment 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
- Insulin is measured in **units**. There are 100 units of insulin per millilitre (100u/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.

Rapid acting insulin is adjusted in relation to the amount of food carbohydrate consumed and when glucose levels are out of target range. You will be taught how to work out the insulin dose you need for food carbohydrate using the **Insulin for Carbohydrate Ratio (ICR)**. The insulin to carbohydrate ratio is the amount of carbohydrate that 1 unit of insulin will need for it to move into cells.

If glucose levels are out of target before meals then a **correction dose** of insulin may also be needed. You will be taught how to calculate correction doses based on the **Insulin Sensitivity Factor (ISF)**. This is the amount of glucose (in mmol) that will be reduced by 1 unit of insulin.

Long acting insulin is given daily and is not related to food. It is vital that your child has insulin over the

whole 24 hour period to stay well and this is provided by your basal (long acting) insulin. We will help you understand how much insulin your child needs until you feel confident to make your own adjustments.

Long acting insulin should be given at the same time each day, with a difference of no more than an hour each day. Long acting insulin is usually given in the evening, but may be given at an alternative time of the day and this may be recommended by your Diabetes Team.

Storage of insulin

- The insulin cartridge, vial or disposable pen that is currently in use can be stored safely at room temperature and should be discarded four weeks after opening.
- Spare insulin cartridges should be stored safely in the fridge. Reusable pen devices currently in use must not be stored in the fridge, e.g. Novopen Echo, Novopen 4, ClikStar, Juniorstar.
- 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.

Learning how to give insulin injections

It is most helpful if one or both parents or carers learn how to give the insulin correctly. Children can be remarkably resilient and accepting of what is happening to them with explanation, and your support, encouragement and reassurance. They will also need ongoing support once at home, regardless of age.

Giving, or helping your child to give an insulin injection will become a normal part of your daily routine. The first few injections may be difficult, but you and your child will gradually find this easier.

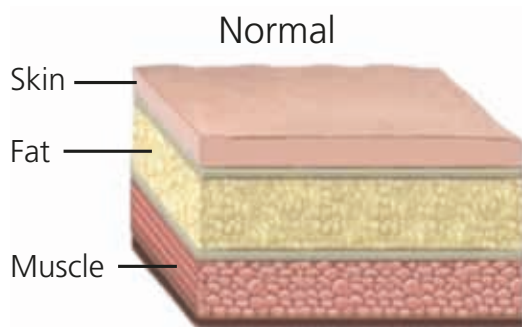
Give your child the opportunity to speak about how they are feeling about injections – this will help you come up with ways of supporting them if they are finding having injections hard. The diabetes team also have lots of ideas about how to help – just ask.

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

Where to give insulin injections

Injection sites

Insulin injections are given into the layer of fat just beneath the skin – the subcutaneous tissue. Insulin must be given into the subcutaneous tissue to ensure that insulin is reliably absorbed.



Insulin can be given in the outside of the thighs, in the back of the arms, 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 may stop the insulin from being absorbed properly. The insulin itself causes extra growth of the fat tissue – these are called **lipohypertrophy** or ‘fat pads’ and they contain both fibrous and fat tissue. Injections 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.

How to give insulin injections with a pen device

- Wash your hands before injecting
- Check the expiry date and the type of the insulin, especially 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 (when using a new cartridge/pen you will need to repeat this several times) 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 sits or lies in a position in which they are comfortable and relaxed
- It’s important that your child understands what is happening and why by giving them information appropriate to their age and understanding
- 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 needs be
- Hold the insulin pen upright, and securely, and inject straight down, using a lifted skin fold



- Push the needle into the skin 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.

Disposal of needles and lancets – we call them ‘sharps’

It’s 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.

When it is $\frac{3}{4}$ full (to the thick black line), snap it closed so that the lid ‘locks’ shut and contact your local council to arrange collection for disposal:

www.northdevon.gov.uk/bins-and-recycling/clinical-waste-collections

Clinical Waste collection contact numbers:

East Devon District Council

Tel: 01395 571515

Exeter City Council

Tel: 01392 665010 (option 1 then 4)

Mid Devon District Council

Tel: 01884 255255

West Devon Borough Council

Tel: 01822 813600 (option 1)

Teignbridge District Council

Tel: 0800 731 03 23

Torridge District Council

Tel: 01237 428734

North Devon District Council

Tel: 01271 374776

Plymouth City Council

Tel: 01752 668000 (option 5)

Torbay

Tel: 01803 701316



Food and drink

During digestion **carbohydrate** containing foods are broken down into glucose. The glucose is then absorbed into the bloodstream, causing a rise in your blood glucose level. Your body needs insulin with meals and snacks containing carbohydrate.

Carbohydrate is a good source of fuel (energy) for the body and is found in:

- **Starchy** foods like bread, potato, pasta, noodles, rice, corn, couscous, oats, grains, breakfast cereals and any foods made with flour
- **Milk** and **yoghurts**
- **Fruit** and some vegetables (sweetcorn and peas)
- **Sugary** foods like sugar, syrup, sweets, jam, honey, fruit juice, fizzy drinks (non diet)

Starchy carbohydrates, such as bread and potatoes, do not taste sweet and need to be broken down into smaller units before the glucose can be released into the bloodstream – this causes slow rise in blood glucose. Carbohydrates such as milk, yoghurt (**lactose**) and fruit (**fructose + fibre**) will also raise your blood glucose level slowly.

Sugary (**sucrose**) foods such as sweets, jams, sugar, honey, sweet (non-diet) drinks and fruit juice (**fructose**) get into the bloodstream and raise blood glucose faster, but also leave the bloodstream faster. You can incorporate small amounts of sugary foods into meals as long as they are balanced by adequate insulin and exercise.

We ask you to get most of your carbohydrate from starchy not sugary foods. Have a starchy carbohydrate at each meal, choosing wholegrain or wholemeal varieties. Over the next few weeks and months the Paediatric Diabetes Specialist Dietitian will meet with you and your parents or carers and help you work out how much carbohydrate there is in your meals and snacks and how to adjust your insulin.

You may be more hungry than normal when you are first diagnosed. This is because you may have lost some of the energy in your food when your blood glucose has been high. It is OK to eat more than you normally do and this hunger will go a few weeks after diagnosis.

What are the best drinks for children and young people with diabetes?

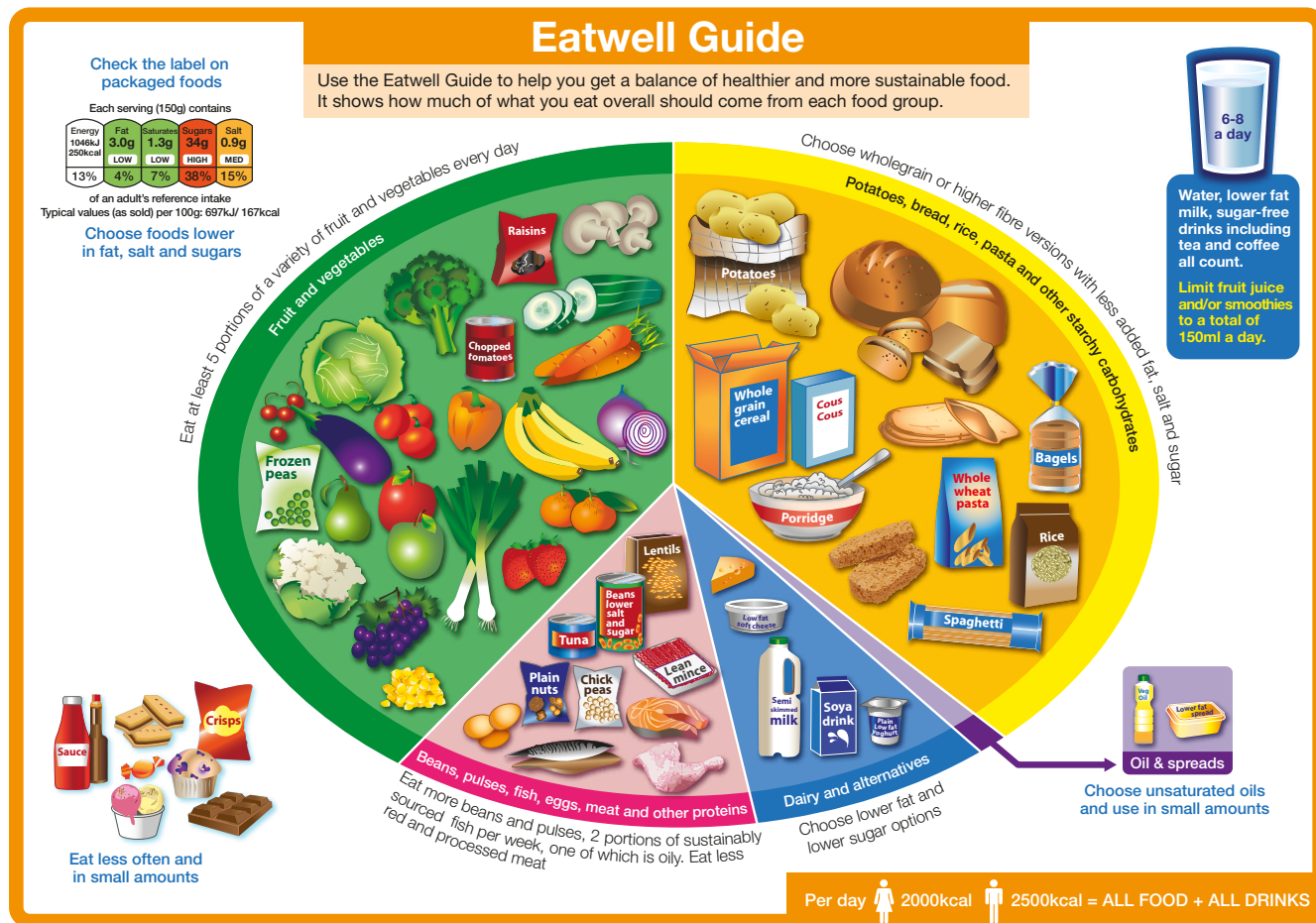
If you are thirsty drink sugar free drinks such as water, diet or no added sugar squash in between meals. You can drink milk at meals and we will ensure you have enough insulin to process the carbohydrate in these drinks. If you usually add sugar to drinks and cereals use artificial sweeteners instead.

Is there anything you can't eat if you have diabetes?

No, nothing is banned. People with diabetes can eat the same food as other people as long as any carbohydrate food is balanced with the amount of insulin. We do not recommend you go out and buy any foods labelled as 'Diabetic' though. Some chemists and shops sell chocolates, sweets and cakes that are labelled as 'suitable for Diabetics'. These often have more fat than 'non-Diabetic' chocolates, sweets and cakes, they use an artificial sweetener that can cause an upset stomach and diarrhoea, and are usually expensive.

What are the best foods for children and young people with diabetes?

Our diets are made up of foods that contain a combination of carbohydrate, protein, fat, vitamins and minerals and all are needed for the body to function normally, to grow and develop. When you have diabetes we ask you to eat the same healthy diet as any other young person of your age (see the Eatwell Guide below).



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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Protein foods (meat, fish, eggs, cheese, beans) are needed for growth. Fats (oil, butter, margarine) are needed in small amounts for energy. Fat and protein foods do not raise blood glucose, however meals containing large amounts of these may slow down how quickly the carbohydrates you eat are absorbed.

Top tips

- Eat regular meals and don't skip breakfast
- Try and include at least one portion of bread, rice, potatoes or pasta with every meal. Try wholegrain varieties.
- Aim for five portions a day – more vegetables than fruit.
- Try to have some milk and dairy foods such as cheese, yogurt and fromage frais every day.
- Try to have at least one portion of meat, fish, eggs or beans every day. Have fish twice a week, including oily fish.
- Try to eat just a small amount of foods and drinks that may be high in fat and/or sugar.
- Eat less salt
- Get active and try to be a healthy weight

Monitoring diabetes health

The aim of treating your child's diabetes is to keep their blood glucose levels as close to the blood glucose levels someone without diabetes would have. Therefore we aim to keep blood glucose levels in the range of 4.0-7.0mmol/l, whilst trying to avoid hypoglycaemia (low blood glucose less than 4mmol/l). We call this our 'target range' and we will teach you the tools to manage your insulin so you spend less time out of the target range. It is usual for glucose levels to rise after meals so we aim for 5.0-9.0mmol/l two hours after a meal (this is recommended in the National Institute of Clinical Excellence (NICE) Guidance <https://www.nice.org.uk/guidance/ng18>).

Aiming for these levels as much as possible helps young people to have healthy glucose levels. Each clinic we take a finger prick blood to check a glycated haemoglobin (HbA1c). This measures your glucose levels over a few weeks. The NICE guidance recommends young people aim to have HbA1c levels of less than 48 mmol/mol.

Getting the balance right means that the blood glucose levels are not too low or too high, and your child feels well. If the blood glucose levels are outside the range over many years, it may affect your child's health, growth and development.

Monitoring is achieved by:

- Blood glucose checks
- Blood Ketone checks

Blood Glucose Monitoring

Blood glucose monitoring tells you exactly how much glucose is in the blood at the time the check is carried out. It will give you a value in millimoles per litre (expressed as mmol/l).

You will be shown how to check your child's blood glucose level with a hand held **blood glucose meter**. Your team will provide you with the most suitable device for you and will provide you with spare/s for school. We will teach you how to download your meter to a computer or provide a method for it to automatically update to the cloud.

We recommend that blood checks are carried out at least five times per day. Example times:

- first thing in the morning
- before meals
- before bedtime
- before exercise
- if a 'hypo' (hypoglycaemia – a low blood glucose below 4mmol) is suspected
- extra checks may be needed at times of concern e.g. illness.

The glucose checks help to guide you, your child and the team in making adjustments to your child's insulin dose.

These glucose checks are often recorded in your device that we recommend you download regularly. It is vital for you and the team to see the information on the glucose level with the carbohydrate eaten and insulin dose given. You and the team can then make the safest adjustments to insulin doses.

Sometimes, especially during illness, more frequent checks will be needed. A ketone check will also be needed when ill.

Blood Ketone Monitoring

You will be shown how to check your child's blood for ketones on a meter using ketone strips. It will give you a value in millimoles (expressed as mmol). We aim for ketone levels to be under 0.6mmol/l. We cover what happens when levels are higher than this in the illness section.

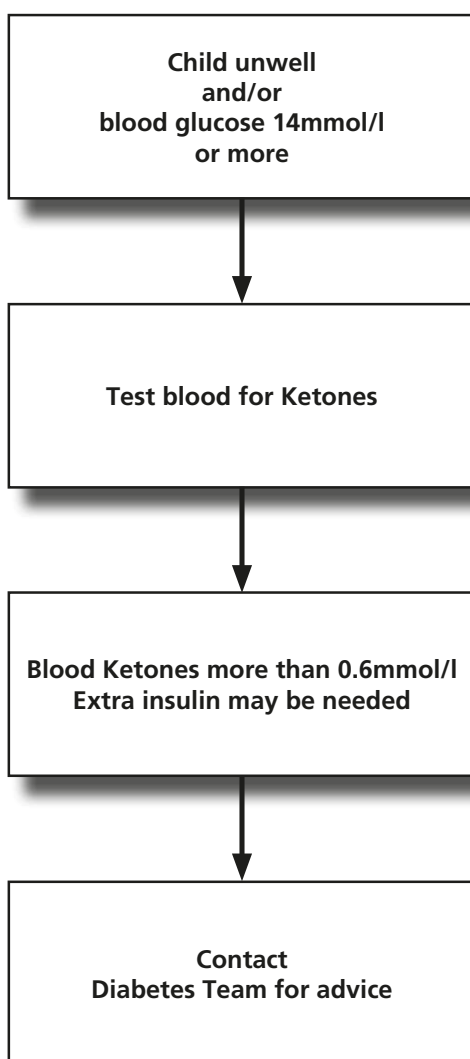
Ketones appear in the blood and urine when the body has a lack of insulin.

If ketones appear, this is a warning sign that your child may need more insulin. This may be because they are unwell or have an infection.

You should check for ketones if **your child is unwell and/or your child has a high blood glucose reading (14 mmol/l or above).**

Always check that the strips are 'in date' before use.

Blood ketone flowchart :



Hypoglycaemia (a 'Hypo')

low blood glucose = below 4mmol/l

Your child may have a 'hypo' because:

- they have not had enough food, i.e. missed or delayed meal or snack
- they have had extra exercise that was not anticipated
- they have had too much insulin
- insulin has been injected into muscle **not** fat
- injection sites have changed (moving from 'lumpy' to 'non-lumpy' sites)
- you may not know!

Having a 'hypo'

If your child has a 'hypo', they may feel:

- hungry.....
- just 'not right'
- wobbly
- tired
- grumpy
- tearful
- sweaty
- pins and needles
- have blurred vision

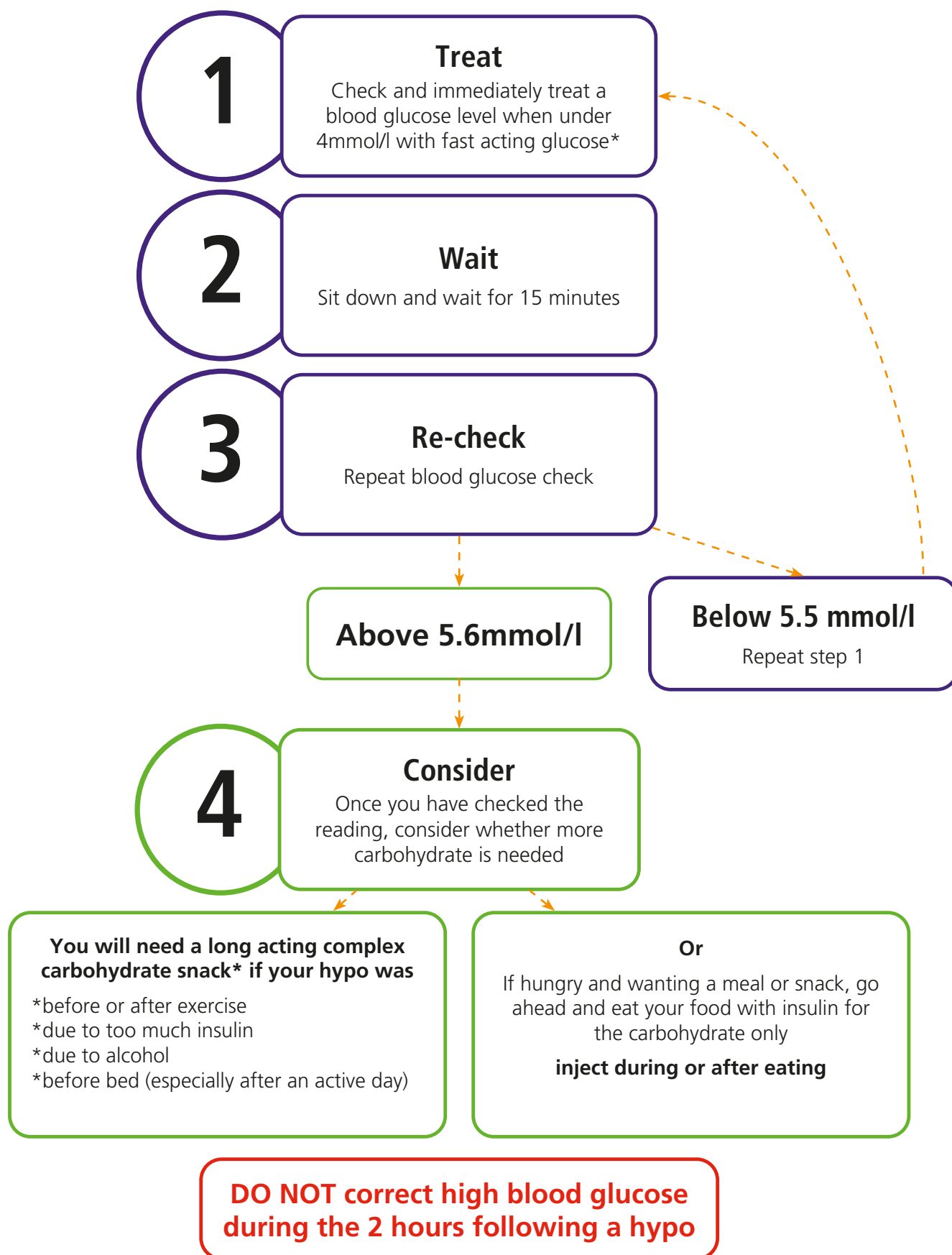


You may notice your child having a 'hypo' before they do. You may notice your child is pale, quiet, and dark under the eyes. Every child is different, and over time you will recognise the particular things that tell you that your child is having a 'hypo'. It is worth noting these, so that you can tell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

Treating a 'hypo'

Any blood glucose reading under 4mmol/l needs treatment. A mild hypo is where the glucose is under 4mmol and your child is able to co-operate with to safely take glucose treatment by mouth.

Treating a mild 'hypo'



Fast acting carbohydrate sources of glucose

Glucotabs®	4g per tablet*
Jelly babies	5g per Bassetts jelly baby*
Lucozade® Energy Original - contains caffeine	8.9g per 100ml*
Glucose tablets, e.g. Dextro® Energy	3g per glucose tablet*
LIFT® – 60ml	15g per whole bottle*
Fruit juice	8.6g per 100ml*
<i>*Please read label to assess exact carbohydrate content</i>	

How much fast acting carbohydrate do I need?

Source	Pre-school 5g carbohydrate	Primary school 10g carbohydrate	Secondary school 15g carbohydrate
Glucotabs®	1.5	3	4
Jelly babies	1	2	3
Lucozade® Energy Original - contains caffeine	55ml	110ml	170ml
Glucose tablets, e.g. Dextro® Energy	2	3	5
LIFT® – 60ml	20ml	40ml	60ml
Fruit juice	55ml	110ml	170ml




If the reason for a hypo is any of the following, have a 15-20g long acting (complex) carbohydrate snack **(without insulin)**:

- The hypo is just before or after exercise
- The hypo is just before bed
- Too much insulin has been given
- Alcohol is the cause of the hypo

Long acting (complex) carbohydrate snack ideas 15-20g carbohydrate

- 1 slice of toast
- 1 small banana or large apple
- 1-2 digestive biscuits
- Small cereal bar
- 300ml (half pint) glass of milk or a yoghurt
- Small bowl of cereal and milk, e.g. Shreddies® or 1x Weetabix®

Treating a moderate 'hypo'

Pre-school age (under 5years)	Primary school age	Senior school age
		
½ tube of glucogel (repeat if necessary)	1 tube of glucogel (repeat if necessary)	1 tube of glucogel (repeat if necessary)

- If your child was not co-operative in a 'hypo' but able to safely swallow, then squeeze glucogel (as directed above) into their mouth between their cheek and gum and massage the outside of the cheeks.
- Then wait 10-15 minutes, see how your child is and check their blood glucose level having re-washed their hands. Once their blood glucose level is above 5.6mmol/l should feel much better. If it is not above 5.6mmol/l, then repeat the above.
- When your child has recovered from the 'hypo' they should have some slower acting or starchy food to keep their blood glucose level up. This may be their snack or meal.

YOU SHOULD NEVER USE GLUCAGEL ON A CHILD WHO IS UNCONSCIOUS / UNABLE TO SWALLOW SAFELY.

Treating a severe 'hypo'

Pre-school age	Primary school age	Senior school age
GlucaGen HypoKit 0.5mg=0.5ml if under 25kg	GlucaGen HypoKit 0.5mg= 0.5ml if under 25kg 1mg=1ml if over 25kg	GlucaGen HypoKit 0.5mg=0.5ml if under 25kg 1mg=1ml if over 25kg

Severe hypos should be rare. Your child may have a severe 'hypo' and become drowsy, lose consciousness or even have a short convulsion/fit. In case this situation should arise, you will be shown how to use an injection called Glucagon (GlucaGen HypoKit). Glucagon is a hormone, which helps to raise the blood glucose level by releasing glucose from the stores in the liver.

If your child should have a 'hypo' fit, keep them safe from harm and turn them on their side (in the recovery/unconscious position). Call 999 so that you know you have medical help coming. Give the glucagon injection once the fit has stopped, and contact the Paediatric Diabetes Team for further advice.

General advice about hypos

- Your child should not be left alone when having a hypo
- You or your child should always carry glucose tablets or some other form of fast acting glucose at all times
- An occasional mild 'hypo' before a meal suggests that your child's glucose levels are probably very good

If you are concerned about your child having regular 'hypos', please contact a member of the Diabetes Team as your insulin ratios or long acting insulin may need adjusting.

Hyperglycaemia (high blood glucose = 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 blood glucose levels.
- Less exercise than usual
- Too much food
- Sudden excitement or stress

Signs of Hyperglycaemia	Signs of Ketoacidosis (high blood glucose + Ketones)
<ul style="list-style-type: none">■ Increased thirst■ Passing more urine■ Bedwetting■ Tummy ache	<ul style="list-style-type: none">■ Nausea and vomiting■ Cold, dry skin■ Deep rapid breathing■ Sweet smell on breath, similar to nail polish remover■ Drowsiness DIAL 999

If your child's blood glucose level is 14mmol/l or above, this is a sign that they need more insulin. The team will teach you how to use a 'correction dose' of insulin.

If your child's blood glucose level is 14mmol/l or above you should check ketones.

If ketones are present this is more worrying as it may be a sign that they are developing Ketoacidosis. You should contact the Paediatric Diabetes Team for advice if you are worried, particularly if your child is feeling sick or is vomiting.

If your child has a high blood glucose and feels sick or starts to vomit, you need to contact a member of the team **urgently for advice**. Contact the Paediatric Diabetes Specialist Nurse on-call on 01392 411611 and ask the operator to contact the Paediatric Diabetes Specialist Nurse on-call (9am-5pm daily) or Paediatric Registrar on-call for Bramble Unit (5pm-9am daily).

This is an urgent advice line only so remember in an emergency please call 999

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

What to do when your child is ill

When your child is feeling unwell it is important that they or you check their blood glucose level more frequently than normal – possibly 6–8 times/day - and check for ketones if blood glucose is 14mmol/l or above.

Never stop your child's insulin when they are ill, even if they are not eating as much as normal. They may even need more insulin. Please speak to a member of the diabetes team if you need advice on adjusting the dose.

Small and frequent snacks of food/ drinks containing carbohydrate should be offered. Also encourage plenty of sugar free fluids, to prevent dehydration.

You could try:

- One scoop of ice cream
- Three tablespoons of ordinary (carbohydrate containing) jelly
- Half a pot of sugar containing flavoured yoghurt
- A small bowl of thick soup.

If your child is feeling sick and is unable to eat, actively encourage sips of fluid containing sugar every 1-2 hours. This is to replace the normal diet and prevent low blood glucose levels.

Here are some ideas:

- half a small glass of pure fruit juice
- half a small glass of Lucozade (not sport)
- half a glass of ordinary (sugary) coke or lemonade (not diet or reduced sugar varieties)

If your child is vomiting or unable to take sips regularly contact the Paediatric Diabetes Specialist Nurse on-call. It may be necessary to admit your child to hospital and to give fluids by a drip until the vomiting settles.

Checking your child's blood glucose level more frequently will help you decide what to do.

The 'Honeymoon' Period / Remission Phase

You may find that shortly after diagnosis your child's daily insulin doses are reduced because of lower blood glucose readings. This is very common and is known as the 'honeymoon period', during which 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 stops producing 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.

Supplies and Equipment

A member of the team should complete this page for you so that you are clear on what equipment you have and why, and also to ensure that you leave hospital with all that you need.

You should leave hospital with enough of everything for two weeks. We recommend you arrange the repeat prescriptions with your GP soon after discharge.

Please note: All items that your child has on prescription to manage their diabetes will be free for the rest of their lives.

All of the equipment you and your child need is available on prescription **except** fruit juice, dextrose tablets and jelly babies. Please allow a week to get items on repeat prescription.

Reusable insulin pen: <ul style="list-style-type: none"> ■ NovoPen Echo (Red / Blue) ■ ClikSTAR (Blue / Silver) or JuniorStar 		
Insulin cartridges: 3ml <ul style="list-style-type: none"> ■ Insulin Aspart (NovoRapid) 3ml Penfill cartridge ■ Insulin Glargine (Lantus) 3ml cartridge 		
Insulin pen needles: <ul style="list-style-type: none"> ■ FinePoint needles (or practice preference) needles size 4mm 32 G 1 box of 100 		
Blood glucose meter strips: <ul style="list-style-type: none"> ■ Freestyle Optium blood glucose test strips (box of 50 x 2) 		
Lancets: <ul style="list-style-type: none"> ■ Accu-Chek Fastclix Lancets 		
Glucose 40% gel (3 x 23g pack)		
Glucagon <ul style="list-style-type: none"> ■ GlucaGen HypoKit 1mg vial 		
Ketone meter strips: <ul style="list-style-type: none"> ■ FreeStyle Optium β-ketone (blood testing) (box of 10 x 3) 		
Sharps box		
Blood glucose and ketone meter kit		

Clinic appointments

As your child grows their insulin requirements will change. You may find different challenges at different stage of life. It is important that your child is reviewed regularly by the Paediatric Diabetes Team.

After diagnosis glucose levels change rapidly and we ask you to be in contact with the Paediatric Diabetes Nurses regularly by telephone.

Your education on diabetes continues in every clinic and it is vital we see you and your child often. Immediately after diagnosis you are given four clinic appointments in the paediatric outpatients department with the multi-disciplinary team in the first three months and we encourage both carers/parents to attend. These appointments support you in your adjustments to living with diabetes as a family as well as making changes to your therapy.

After these initial appointments you will be asked to attend a clinic review every 3 months. We check your growth, injection sites and will monitor your health with blood or urine tests.

After the age of 12 years old you will be invited to attend an appointment to check your eye health with the retinal screening service. This is arranged via your GP and maybe at a local hospital to you.

As you have diabetes you are able to park at the hospital for free. You will need to ask for a vehicle clearance (Parking Exemption – Diabetes) when you arrive at reception (have your car registration handy). If you are arriving after 3.30pm you can complete the vehicle clearance yourself at the iPads at the main entrance.

Useful information

Returning to 'school' (we are using 'school' to mean any early years setting, school or college).

The team want to support children in returning to school as soon as is sensible. This will be dependent upon individual need. It will be the responsibility of your child's Paediatric Diabetes Specialist Nurse (PDSN) to make arrangements, as soon as possible, to provide education about diabetes for staff at your child's school. The school will then be offered further training if your child's needs change. The Paediatric Diabetes Specialist Nurse will make arrangements to meet with a key member of staff plus one or both parents to discuss managing your child's diabetes in school and you will be able to write a personalised 'school care plan' for your child. The care plan provides information about your child's medical needs while at school. The Paediatric Specialist Diabetes Dietitian is able to get estimates of the carbohydrate content of school meals if your child does not want packed lunch.

In our experience, school staff are very helpful and keen to do all that they can to enable children to return to school. In the short term, staff may need support from a parent while they are learning new skills e.g. how to do a blood glucose check, or give an insulin injection. This may mean a parent needing 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.

It is also important that your child is comfortable and confident with staff helping them to manage their diabetes – talk to your child about how they feel about their diabetes management in school.

No child should be excluded from any aspect of the curriculum and young people take part in residential and other extra curricular activities. Please let the Paediatric Diabetes Specialist Nurses know of any up and coming events so they can help with training.

Diabetes UK set out optimum care in schools

www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools

JDRF produced packs of information for schools

www.jdrf.org.uk/for-professionals/school-pack/type-1-diabetes-school-pack

Schools can learn more about diabetes with JDRF

www.jdrf.org.uk/for-professionals/school-pack/schools-e-learning-module

Disability Living Allowance (DLA)

Parents and carers of children with Diabetes are eligible to apply for a benefit called the Disability Living Allowance (DLA), until the child is 16 years old. Young people 16+ are entitled to claim for Personal Independence Payment, though this is harder to secure funding.

www.gov.uk/dla-disability-living-allowance-benefit

Being able to apply for this benefit is not because a child with diabetes is 'disabled', but the allowance helps with things like:

- extra travelling costs due to regular clinic visits
- possible increased cost of weekly shopping bill
- good fitting shoes.

It is not a means tested allowance.

Application forms are available from:

- your local Social Security office
- phone the Benefits Enquiry Line 0800 882200
- www.direct.gov.uk/disability-money

Different rates of Disability Living Allowance can be awarded – lowest, middle and higher. If you are awarded Disability Living allowance at the middle or higher rate, you may be entitled to claim for **Carer's allowance**. Please be aware of the following points:

- Need to spend at least 35hrs a week caring for a person
- It is not affected by any saving you have
- It is dependent upon incomes and other benefits
- www.direct.gov.uk - Money Tax and Benefits section

The form is lengthy, so be prepared. Diabetes UK have produced a detailed guide on completing the form www.diabetes.org.uk/how_we_help/helpline/your-rights/disability_living_allowance

The Local Paediatric Diabetes support group (Snackpack) will also be able to give you support to help you complete the form and one of the Paediatric Diabetes Specialist Nurses or Dietitian will complete the section of the form entitled 'Statement from someone who knows you/ your child'. Disability Living Allowance is not paid for the first three months following diagnosis.

Identification

It is a good idea for your child to always carry something on them showing that they have diabetes; you can get special necklaces, bracelet, and watches or carry a card

www.medicalert.org.uk



www.theidbandco.com



If they are out with friends or were to have an accident, it is important that others know that they have diabetes and how to contact a responsible adult if required.

Search for 'medical ID' for inspiration and also add medical information to young person's phone if they have one.

Diabetes technology:

Continuous Glucose Monitors (CGM)

A continuous glucose monitor (CGM) is a small device that you wear just under your skin. It measures your glucose (sugar) levels continuously throughout the day and night, letting you see trends in your levels and alerts you to highs and lows. It sends this information to a display device using Bluetooth. Some devices are linked to phones and others are scanned regularly with a reader device. A CGM is worn for 10-14 days before it needs changing.

A CGM doesn't measure your blood glucose levels; it measures the amount of glucose in the fluid that surrounds your body cells – called interstitial fluid. This means there is a small time delay between your blood glucose and interstitial fluid, especially after eating or if you're exercising. So your CGM result isn't always exactly the same as your finger-prick result. You will still need to do a **finger prick blood glucose check** on occasions where symptoms don't always match the reading from your CGM or during times of illness.

Insulin Pumps (Continuous Sub-cutaneous Insulin Infusion CSII)

- A CSII is a small device that delivers insulin constantly throughout a 24 hour period.
- There are different types of insulin pump. Tethered pumps have a cannula that sits just under the skin with tubing to an insulin pump device. A patch pump has a pod of insulin attached to the skin which is remotely controlled by a phone like device.
- CSII delivers insulin continuously at rates that are pre-set (**the basal rate**) 24 hours a day then each time the person eats the glucose level and carbohydrate amount is entered into the device and a **bolus** of insulin is given by the child or carer pushing a button on the device.
- Some newer CSII have computerised changes to the basal insulin delivery based on the Continuous Glucose Monitor it is linked to. These are called closed loop or hybrid closed loop.
- The CSII cannula or pod can be sited in the abdomen, the buttock or the outer thigh.
- All CSII have a short needle (6mm) which helps insert the plastic cannula under the skin and is then removed. The pod retracts the needle automatically into the pod after insertion. The plastic cannula can remain beneath the skin for 2-3 days before it needs to be changed. Tethered CSII have an alternative steel cannula which remains in the skin for 2 days which may be helpful for those with an allergy to standard cannula.
- The team would assess the individual needs of each child and family interested in all the various diabetes technologies available. Clinical criteria are set for each device nationally and the local clinical commission group ensure these criteria are used.
- We will discuss all technology that is available for you, including the advantages and disadvantages of each device. Following that discussion, education would need to be given by the Paediatric Diabetes Specialist Nurses and Paediatric Diabetes Specialist Dietitian before changes in therapy would be considered.

Glossary

Check your DigiBete app for more terms in the 'Dictionary' on the home page.

Basal insulin	The name given to insulin that covers the 24 hour baseline insulin requirement. This may be given by a once a day injection or from an insulin pump (pre-programmed or computer generated delivery).
Blood glucose	The level or concentration of glucose in the blood. This can be measured by a blood glucose meter and presented as a number in millimole per litre (mmol/l).
Bolus insulin	The name given to an injection of insulin (or from an insulin pump) that is given before food or to correct an out of target blood glucose level.
Carbohydrate	One of the three main energy giving nutrients in foods, it is composed mainly of sugars and starches.
Continuous Glucose Monitoring	This is a device worn on the skin that measures glucose in the interstitial fluid (rather than blood) and allows regular measures of glucose over the 24 hours. They need replacing every 10-14 days depending on the brand of the device.
Continuous Subcutaneous Insulin Infusion	A device (often referred to as an insulin pump) that a person wears all day and which delivers fast acting insulin only (via a cannula or pod). It is programmed to be individual to your child.
GlucaGen HypoKit	A box containing a syringe of sterile water and a vial of Glucagon powder to be prepared and 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 chief 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 a measure of the blood glucose level 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. Sometimes called a remission phase.
Hormone	A chemical substance produced in one of the glands in the body and carried by the blood to have a specific effect on the functioning of other cells in the body.
Hyperglycaemia	High blood glucose level
Hypoglycaemia or 'hypo' or 'low'	Low blood glucose level (under 4mmol/l)
Incidence	The number of diagnosed cases per year of a particular disease.

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.
Insulin to Carbohydrate Ratio (ICR)	This is the amount of carbohydrate 1 unit of insulin will need to get into the cells. You can have different ICR at different times of the day.
Insulin Sensitivity (ISF)	This is the number of mmol that 1 unit of insulin will reduce your glucose by. You can have different ISF at different times of the day.
Ketones	Fat is broken down to fatty acids when the body cells are starving due to a lack of glucose. The fatty acids are transformed into ketones by the liver, and ketones then appear in the blood and urine. This can occur when there is a lack of insulin.
Ketoacidosis	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 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.
Retinal screening	After 12 years old your eyes are checked every year by a special camera to ensure they are healthy.
Subcutaneous	In the fat tissue under the skin.
Target glucose	This is the range of glucose close to the range that a person without diabetes has. Research has shown trying to aim to keep glucose levels close to this leads to good future health. When we calculate doses we aim for 5.5mmol/l (which is midway between 4-7mmol).
Time in range	This is the amount of time a person has glucose levels in target range. This generally means the time your glucose has been between 4-7mmol/l before meals and below 10mmol/l after meals.

Other sources of useful information

www.diabetes.org.uk

www.childrenwithdiabetesuk.org

www.jdrf.org.uk

www.runsweet.com - a website about exercise and diabetes

Snackpack (local Children's Diabetes Group):

Website: <https://exeter-children-s-snack-pack.diabetesukgroup.org/>

Families with Diabetes (FWD) National Network:

Website: www.CYPDiabetesNetwork.nhs.uk

East Devon Juvenile Diabetes Support Group

Search Facebook for 'East Devon Juvenile Diabetes Support Group'

North Devon Juvenile Diabetes Group

Website: www.northdevonjuvenilediabetes.co.uk

E-mail: northdevonjdg@gmail.com

Available on line:

Type 1 diabetes in children and young people. Understanding NICE guidance – information for the families and carers of children with type 1 diabetes, young people with type 1 diabetes and the public. www.nice.org.uk/guidance/ng18/chapter/Recommendations (July 2015, updated December 2020), NHS National Institute for Clinical Excellence.

There are many books/ internet resources which are available about diabetes in children. Please be aware that many of the books that are available are written by American authors and management of diabetes in children differs in America to the UK. It can feel overwhelming at times with the amount of information you are able to access and some of this may conflict with what you have been told by the team. If ever you are uncertain about anything you read about diabetes, do please ask a member of the Paediatric Diabetes team to support you and your child and your individual situation.

Please be aware when reading anything about diabetes:

- To check that it is about type 1 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.
- The inclusion of a website does not indicate endorsement by the Royal Devon and Exeter NHS Foundation Trust

The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by RD&E staff undertaking procedures at the RD&E hospitals.

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