DigiBete Living with Diabetes Workbook



All the information you need to make your diabetes management more effective.



With acknowledgement to Leeds Children's Hospital.





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Chapter A

Introduction and Explanation of Type 1
Diabetes and Treatment





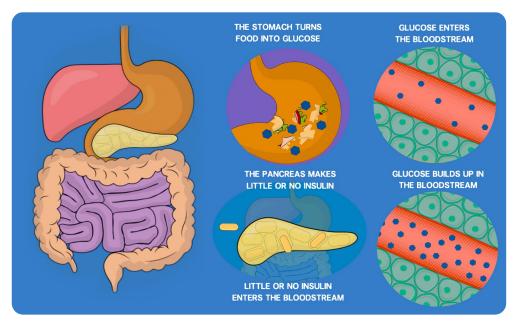
A: Explanation of Type 1 Diabetes and Treatment

A1: What is Type 1 Diabetes?

The most common type of diabetes in childhood in the UK is Type 1 Diabetes. It affects over 30,000 children in the UK. Type 1 diabetes should not be confused with Type 2 Diabetes, which is usually diagnosed in adults and can often be managed with lifestyle changes and medication.

In Type 1 diabetes your body loses the ability to regulate the level of glucose (sugar) in your blood due to a failure to make insulin. Glucose levels in the blood are usually controlled very accurately between about 4 to 7mmol/l.

Insulin is one of the key hormones that regulate the body's blood glucose levels. Insulin is made in Islet cells found in the pancreas. Type 1 diabetes occurs because the body's own immune system attacks these cells and the body is unable to make enough insulin. Getting glucose levels in range early will help preserve some islets cells for a time, making it easier to maintain normal blood glucose levels.



Key message: Type 1 diabetes is due to the body's inability to make sufficient insulin and control glucose levels.

How Insulin Works

Insulin helps convert the food we eat into energy, by allowing glucose to pass from the blood to all the cells in the body. The sweet and starchy food we eat and drink, (carbohydrates) are broken down into glucose in the stomach and intestines; glucose then passes into the bloodstream. Insulin allows the glucose to be used as fuel for all our daily activities, even for sleeping, to ensure adequate growth and to repair cells when damaged. Insulin also transfers any extra glucose in the bloodstream to muscles, fat cells and the liver to be stored until it is needed for energy.





Extra energy is required for exercise and during emergencies, e.g. when we are unwell. The body uses up the energy stored in our muscles and liver for these occasions. If the energy stores are empty due to a failure of glucose to cross from the blood to tissues, the body uses fat for energy. This explains why tiredness and loss of weight are common signs of diabetes.

Without insulin, the glucose from food and drink stays in the blood stream causing the blood glucose level to rise; some is filtered through the kidneys and then passed out of the body in the urine, taking water from the body along with it. This explains why many children drink (polydipsia) and wee a lot (polyuria), before diagnosis. High glucose levels can also increase the risk of infections.

The amount of insulin being produced would have been slowing down for a considerable time (weeks-months) so sometimes the onset of the symptoms may have been gradual and can often go unrecognised for some time. Occasionally presentation can be dramatic with severe dehydration, rapid breathing and vomiting. This is diabetic ketoacidosis (DKA) and requires urgent and careful treatment and is potentially life threatening.

How We Can Treat Diabetes

We can do this by giving you insulin that your body is not able to make itself. Insulin has to be delivered to the area under the skin and it is therefore given by an injection or tiny cannula (if using an insulin pump).

Insulin is given in a dose which matches the carbohydrate content of the food and drink we eat at meals and snacks; called "carbohydrate counting". The dose of insulin given with food and drink is called "bolus insulin". Your body, also requires a low level of insulin in the blood stream to deal with glucose released from the liver and muscles. This is called "basal insulin", and is given once or twice daily and is not related to food.

What is Type 2 Diabetes?

It is possible to be diagnosed with type 2 diabetes as a young person even though it is often considered to be a disease in older people. It is just as serious as type 1 diabetes but will require different treatments and education sessions. With type 2 diabetes the body does make insulin but the insulin does not work well enough to keep the blood glucose in the normal range.





Other types of Diabetes

There are other types of diabetes, including steroid induced diabetes, cystic fibrosis related diabetes, some rare genetic syndromes and types of monogenic diabetes.

Monogenic diabetes is diabetes caused by a change in a single gene. It runs in families and is passed on directly from a parent to a child so does not 'skip a generation'. It includes Neonatal Diabetes and types of MODY (Maturity Onset Diabetes of the Young). This can be caused by a change in quite a few different genes and the treatment needed will depend on which gene is affected. Further information www.diabetesgenes.org

A2: Diabetes supplies and medication

A variety of equipment and medication is required to look after your child's diabetes at home. Not all equipment will be needed every day, but may be needed for illness management.

Equipment and medication to be kept at home

- Insulin Bolus Insulin and Basal Insulin 1 box of 5 cartridges or 1 box of 5 disposable pens or an insulin vial.
- Insulin pen(s) with half or full unit increments
- · Pen needles 1 box of 4mm needles.
- Safety Pen needles For school or nursery.
- Finger-pricking lancets.
- Blood glucose test strips.
- Blood ketone test strips.
- Glucose & Ketone meter
- Glucose gel
- Glucose tablets
- Glucose drink
- Glucagon kit.
- · Sharps bin



The above items are available on prescription. You will be given a small supply on discharge and will need to obtain further supplies from your GP. The diabetes team will write to your GP and request a repeat prescription to be set up.

Your GP/ Health Centre should help dispose of sharps bins.

You will also be given a finger-pricking device, a blood glucose and ketone meter.





Storage and use

Insulin

- Store unopened insulin in a refrigerator. Do not freeze. Insulin will last until the expiry date when stored this way.
- Protect from excessive heat and light.
- After opening do not refrigerate. Store below 30°C. Use within one month.

Pen needles and lancets

- · A new pen needle or lancet should be used for each blood check or injection.
- Dispose of all needles and lancets into a sharps bin*.
- Remove pen needle after injection and store pen without a needle to prevent air from entering the cartridge, and reduce the risk of injury

Insulin pens

- These are obtained through your GP on prescription
- · Make sure you have the correct pen for the insulin
- Use a different colour pen for each type of insulin to prevent errors
- Keep a spare at home.

Blood glucose and ketone strips

- · Store strips at room temperature away from direct sunlight and heat
- Do not refrigerate
- Keep strips within the closed container or sealed in foil paper
- Do not use strips if they have been damaged or are out of date

Glucagon

- Store either in a refrigerator (2°C to 8°C), or out of a refrigerator below 25°C for up to 18 months before the expiry date.
- Store in original package to protect from light
- Do not freeze, to prevent damage to the product
- Use immediately after preparation do not store for later use
- · Do not use after the expiry date stated on the label.
- Do not use if the solution, looks like a gel or if any of the powder has not dissolved properly
- Use the correct dose smaller children will not require the full amount.

GlucoGel/Dextrogel

- Keep GlucoGel/Dextrogel at room temperature. If the gel has been kept in the fridge, allow it to reach room temperature again before using it will become thicker and harder to administer
- Ask your pharmacist how to dispose of medicines which are no longer required.





Chapter B

Practical Skills





B: Practical Skills

B1: Glucose meters

Blood glucose meters help you to keep an accurate idea of your blood glucose levels; they are a key part of your diabetes management. Your diabetes team will discuss the different meters available

Meters must be compatible with to be uploaded at clinic, which not all meters are.



Meter tips:

- When you come to clinic bring all your meters as we will download them and go through the results with you.
- Explore your meter and look at your average blood glucose readings.
- Make sure the time and date are correct on the meter.
- If you would like to upload your meter from home ask your diabetes nurse for more information.
- · If your meter stops working, contact the company who makes it to request a replacement.
- For your meter to keep accurate results it is important to use it properly and keep it clean. You will also been shown how to test your meter with control solution.
- Replace your meter battery when it indicates to do so and take some spare batteries on holiday.





Glucose and Ketone test strips:

Glucose and Ketone test strips: These are specific for each meter so it is important your GP prescribes the correct strips. You will need at least 5 glucose strips per day and some spare. Your diabetes nurse will inform the GP of the type of strips you will require.



B2: Blood Glucose checking

Procedure for checking / supervising blood glucose check

Equipment needed: Blood glucose meter, test strips, finger-pricking device, lancet, sharps bin and cotton wool or tissue.

- Ensure hands are washed and dry them thoroughly. (If hands are cold, run them under warm water or shake them to warm them up).
- 2. Insert new lancet or advance the fastclix lancet as taught.
- 3. Insert strip into blood glucose meter.
- 4. Prick the side of the finger (it is less painful than the finger tips) and wipe away the first drop of blood with cotton wool or tissue.
- 5. Squeeze a small drop of blood by milking the finger from the base to the tip.
- 6. Hold the strip to the blood and allow the strip to suck up the blood. The meter will beep or the display will start counting down when enough blood is received.
- 7. After a few seconds the blood glucose level should appear on the screen. (If an "error" appears on screen this may be due to insufficient blood sample therefore repeat the test.
- 8. Dispose of lancet and test strip as taught.
- 9. Record blood glucose result.

The above is only a guide; always perform/supervise the test as taught by the children's diabetes nurse specialist.





Blood glucose checking tips:

- Make sure your hands are clean before you begin. Use water rather than wet wipes (wet wipes contain glycerine that could alter the result).
- Prick the side of the finger, not the middle, or too close to a nail. Using the side is less painful.
- Use a different finger each time and a different part; this will hurt less.
- If you don't get much blood, hold your hand down towards the ground. This should make more blood flow to the fingers.
- Make sure your hands are warm if they are really cold it's hard to draw blood, and finger-pricking will hurt more.

When to check:

- Before all main meals (breakfast, lunch and tea) this allows you to correct your blood glucose by adjusting your dose if you are too high or too low.
- Bedtime to make sure you are not too high or low before bed.
- If you are unwell this is essential. You may need to check every 2 hours and give extra insulin if blood glucose is high to avoid ketones and DKA.
- In relation to episodes potentially associated with hypoglycaemia, increased exercise or alcohol ingestion.
- If suspected hypoglycaemia, check to confirm. If unable to get to meter quickly treat first, then check.
- If your blood glucose has been high (greater than 8mmol/l) in the day time and you have given a correction dose, recheck within 2-4 hours to see that your glucose level has returned to target range.

B3: Insulin Pens

These hold 3 mls of insulin (usually 300 units) either in cartridges or as disposable pens. Your diabetes team will advise on the most appropriate pen, as it depends on the type of insulin and whether you need 0.5 unit doses or larger doses.



Make sure you have a spare pen (via GP prescription) and choose different colours for the rapid and long acting insulin so you do not get muddled.





Needles

These are attached to the pen and are very fine so that it reduces any discomfort to a minimum. They should only be used once. For children and teenagers the 4 mm needle is recommended. It is important to be careful with needles and dispose of them safely in the special sharps bin.

Needle bins

These can be obtained from your GP but usually have to be collected by the council when full.



B4: Injection techniques, site care and insulin delivery

A Diabetes Nurse or a member of the ward team will be there with you at first injection until you feel you can help manage this without their help. By using the guidelines every time, it will soon become part of your daily routine.

Please talk to one of the CYP diabetes nurses if you would like further ideas around supporting injection times. Talking through and involving children in a way that is appropriate for their age, distraction techniques and using soft toys for role play are some of the strategies which can help.

Insulin

- Check that the insulin you are to use has not passed its expiry date. Once insulin is in use, it lasts for four weeks and may be stored at room temperature. Unopened insulin must be stored in the fridge.
- Ensure that you give the injection in accordance with the insulin type and the manufacturer's instructions. Rapid acting insulin (eg. Novorapid, Humalog) is to be given as a bolus and is usually injected 15-30 minutes before food. Long acting or basal insulin (eg. Levemir, Tresiba) is given at a set time of the day and is not related to food. Your Diabetes Nurse will advise you on what you should do.

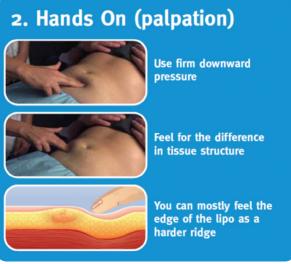


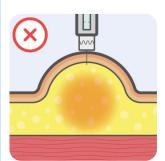


Injection technique and rotation

- Observing the nurse perform the first injection will enable you to see the correct technique, sites and also how to support your child during the procedure.
- It is important to move around the injection area and to change sites as fatty lumps (lipos) can develop if you keep using the same area. These lumps can affect the absorption of the insulin and lead to swinging blood glucose levels.
- If you are unsure ask the diabetes team to help and advise you.
- Remember to regularly check injection sites for lipos as: "Lipos can cause Hypos".







Injection Sites

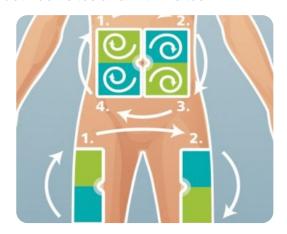
The preferred site is the top of the buttocks. This area has the most subcutaneous (fatty) tissue which means insulin is less likely to be injected into the muscle. Injecting into the muscle can be more painful and insulin absorbed quickly and unpredictably.

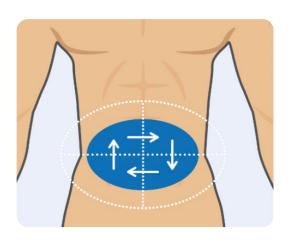
If your child is about to do some activity or exercise such as running or football, insulin injected into the legs will be absorbed very quickly.

Site rotation pattern suggestions

There are several rotation methods (see below) that help to prevent excessive use of one injection site and ensure the ideal absorption of insulin and will reduce the risk of lipos.

Rotation between sites and within sites





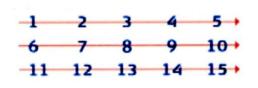


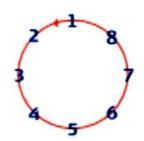


"Keyboard method" useful for abdomen and thighs

"Circle or Clock method" useful for hips and buttocks

"S method" useful for abdomen and thighs







Injection Technique





Children under the age of seven will usually need someone to do the injection for them. If your child needs an injection to be administered for them by a member of staff (school or hospital) or a carer, then a safety needle (BD Autoshield 5mm) is required to prevent needlestick injuries.

Before Injection



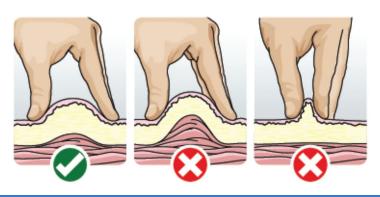


After Injection

At all other times use of the shortest needle possible is recommended and these currently are 4mm in length.

Talk to the diabetes nurse about coping and distraction techniques which may help. If you have already tried these strategies an appointment with the diabetes team psychologist may help.

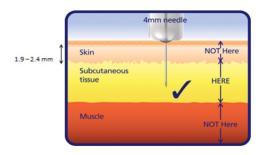
- Remove the pen cap
- · Attach a new pen needle
- Prime the needle with 2 units of insulin, holding the pen with needle upright
- Once a drop of insulin has been seen, the pen is ready to use. If a drop of insulin has not been seen repeat the procedure
- Dial the number of units calculated for a meal, snack or correction.
- Choose the injection site and lift a wide skin fold. This helps to hold the skin steady and avoids injecting into the muscle. A lifted skin fold is recommended for all ages but especially 2-6year olds.







• Inject the pen device needle at 90° and press the button/plunger as far as it will go. The dial will reset back to zero to indicate that the dose has been administered.



- Count to 10 before removing the pen device to reduce insulin leakage
- Following the injection, remove the pen needle from the pen using the outer cover (do not try to replace the inner needle cover) and discard carefully in the sharps container
- · Replace the pen cap on the pen device
- Always remove the needle after every injection to minimise the risk of accidental injection and prevent reuse of a blunted needle which will be more painful and cause more trauma to the skin.
- Remember that fast acting bolus insulin should be injected into a different site to long acting basal insulin.

Your Diabetes Nurse will help you with this and will be able to advise you in the first few days following diagnosis.

Safety devices

Recent European legislation requires that if a safety needle is available, those caring for a person requiring an injection should use this device to protect themselves from a needlestick injury and exposure to blood borne infections.



The diabetes team recommend ward staff demonstrate to children and families injection technique with a 4mm needle (on a soft toy or similar). Actual administration by the nurse will then be done using the safety device (see picture above). School staff and carers will also be encouraged to use this device. Once your child is able to inject themselves the 4mm pen needle will be used.



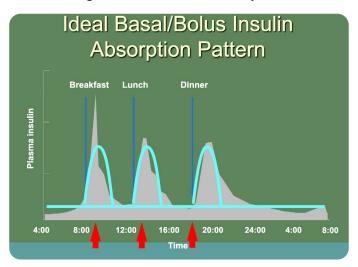


B5: Guide to insulin regimes

The two most common types of insulin regimes used are **Multiple Daily Injections (MDI)** and **Insulin Pump therapy (IPT)**, also known as continuous subcutaneous insulin infusion or CSII. Both of these involve a basal and bolus insulin being delivered and so are sometimes referred to as "Basal bolus regimes".

Multiple Daily Injections (MDI)

MDI involves two different types of insulin - a rapid acting insulin given as a **bolus** with each meal or snack and a long acting **basal** insulin given once or twice a day.

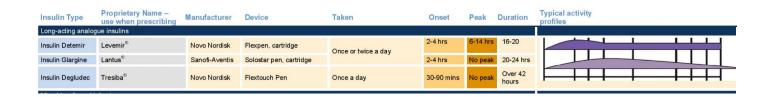


Long acting insulin (Basal)

Long acting insulins such as Levemir and Tresiba are given once or twice daily to provide a low level of background insulin (Basal). This long acting insulin provides a steady release to keep the blood glucose level stable throughout the day and night. Long acting insulin has a slower onset time and lasts much longer than the rapid.

Long acting insulin should be given at a similar time each day.

The long acting insulin is required even when not eating or drinking. It is not fast enough to be used for food or corrections.







Rapid/Fast acting insulin (Bolus)

Rapid acting insulin is given for the food to be eaten and when needed to correct a high blood glucose (BG) level.

Rapid acting insulins such as Novorapid are absorbed more quickly than basal insulin and lasts for 3-5 hours. They are designed to be given before food/drink containing carbohydrate (CHO) to prevent a high blood glucose level or correct back into the target range (4-7mmols/l).

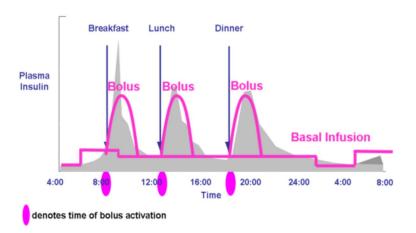
- The insulin to carbohydrate ratio (ICR) is the calculation used to work out how much insulin to give before each mealtime. Your diabetes team will guide you re what insulin to carbohydrate ratios to use. It is not uncommon to use different insulin to carbohydrate ratios at each meal. Rapid acting insulin works best if given 15-30 minutes before food.
- The Insulin Sensitivity Factor (ISF) or Correction dose is the amount of insulin required to bring the BG level back into the target range (4-7mmol/l) e.g. if 1unit lowers the BG level by 5 mmol/l, this will be written as 1:5.



Insulin Pump Therapy

An insulin pump is a battery operated device which delivers only fast acting insulin. It is programmed to deliver insulin in small amounts constantly throughout the day to mimic the working pancreas and this is known as the pump basal rate. At mealtimes a bolus of insulin is given by pressing a sequence of buttons to deliver the mealtime bolus after carbohydrate counting and if needed for a correction dose.

- Long acting insulin is not used in insulin pump therapy
- · Comprehensive pump training will be provided if you choose to use this method of insulin delivery.



Multiple daily injections and insulin pump therapy offer intensive management and aim to replicate the workings of a normal pancreas whilst also allowing flexibility and tiny, dose adjustments so that diabetes fits your lifestyle.





B6: Diabetes Technologies

Diabetes Technology options are available to support diabetes care. These include Insulin Pump Therapy, continuous glucose monitoring and automated insulin delivery systems.

Insulin Pump Therapy

Insulin Pump Therapy (IPT) is another way to deliver insulin under the skin. Insulin is infused in the background over 24 hours (basal insulin) and to match meal carbohydrate or corrections. IPT can provide more flexibility and further options but for some people they can feel like more work. There are a number of insulin pumps including those manufactured by:

- Medtronic
- Insulet
- Tandem
- Ypsomed

Each pump comes with a four year warranty and therefore a four year commitment to the chosen pump. Further discussion with the team helps to ensure individual needs and preferences are considered to ensure the most suitable choice is made.

If you would like to know more about pump therapy, please ask your diabetes nurse or any of the diabetes team. There is an expectation that the family will work closely with the team and a change to this therapy will involve extra nurse-led clinic visits, before and after pump start.

Continuous Glucose Monitors

Real time Continuous Glucose Monitoring (CGM) can be used with insulin pump therapy or injection therapy and can reduce the variability of glucose levels. This will in turn increase the Time in Range (TiR) when the blood glucose is between 4 and 10mmols/L.

Sensors will show a sensor glucose (SG) reading every 5 minutes and an arrow showing the direction of change. However SG readings lag behind BG readings by approximately 5-10 minutes.







Automated insulin delivery (Closed Loop) systems

Automated insulin delivery (Closed loop) systems consist of three parts:

- Insulin Pump
- · Continuous Glucose Monitor
- Algorithm that determines insulin delivery



They can improve Time in Range and minimise glucose variability by suspending and also increasing insulin delivery based on the sensor glucose (SG).

Technology is evolving all the time and we are committed to ensuring our children and young people with diabetes have access to the most appropriate technology to help them manage their diabetes. This means an individualised approach.

Our diabetes team is here to support all families to ensure they have all the knowledge and skills required to integrate diabetes care into everyday life.

B7: Monitoring and taking care of your diabetes

Your body works best if your blood glucose levels are not too high and not too low. People who do not have diabetes have blood glucose levels that stay between 3.5 and 7 mmol/L. If you have diabetes, the goal is to keep your blood glucose levels between 4 and 7 mmol/L before meals and on waking, and between 5 and 9 mmol/l approximately 2 hours after meals most of the time. Careful balancing of your insulin doses, diet and exercise will help towards achieving this.

Measuring your blood glucose is the only way of knowing exactly what your levels are. If you go by how you feel, you will only know when you are very low or very high.

Daily blood glucose monitoring

This can be done at home, school or when out and about by doing regular finger prick checks, with the equipment we will give you or by using a sensor (see blood glucose checking).

It is recommended that you check at least before each meal, before bed and when you feel low (hypo) or unwell.

Extra checks may be needed at other times such as during illness, following a hypo, stressful periods such as exam time or during a growth spurt.





Patterns and trends of blood glucose levels that are too high or too low are more easily identified with regular monitoring.

If blood glucose levels are significantly high (14mmol/L or more), check for blood ketones.

If blood ketones are above 0.6mmol/L and rising, immediate action must be taken because you are in danger of becoming seriously ill very quickly. (See sick day rules).

The importance of measuring and monitoring blood glucose levels

The number displayed on the meter tells you how much glucose is in the bloodstream at the time that the test was carried out. It is measured in units called millimols per litre.

Recommended blood glucose target ranges for children with diabetes are:-

On waking: 4 to 7 mmol/L

Before meals at other times of day: 4 to 7 mmol/L

After meals: 5 to 9 mmol/L Before driving: At least 5mmol/L

The blood glucose result indicates the action you will need to take to manage your diabetes well on a day to day basis.

Insulin doses are adjusted according to patterns and trends of the blood glucose levels to achieve better control.

If the blood glucose level is high e.g. 8mmols/L or more before a meal then additional insulin is recommended. This is called a **CORRECTION DOSE**.

This extra insulin is added to the food bolus insulin which has been calculated from carbohydrate counting. Within 2-4 hours or by the next meal the blood glucose level should then return into the target range. You will be informed of your correction dose ratio by the diabetes team. The correction dose ratio will change over time as you grow.

Before changing insulin doses you need to consider other things, such as injection sites, rotation, exercise and food (see insulin adjustments and problem solving).





B8: Average blood glucose levels and meter uploads.

At home

The HbA1c level effectively represents average glucose levels over a period of 6-12 weeks. A way of monitoring how you are doing between clinic visits is by looking at your average blood glucose levels over 1-2 weeks and you can do this on your glucose meter. The relationship between an average glucose level and HbA1c is shown in this chart below.

HbA1c(mmol/mol)	Average glucose(mmol/L)
20-42	3.8-7
<50	<8.1
50-60	8.1-9.5
61-70	9.6-11.1
71-80	11.2-12.5
81-100	12.6-15.4
>100	>15.4

In order to meet the national target for an HbA1c of 48mmol/mol or less, we would suggest that you aim for a weekly average blood glucose level of 8mmol/L or less (It is important to note that the average blood glucose level is useful only if at least 4 blood glucose checks are done per day).

If your blood glucose average is regularly above 8mmol/L or if you are having hypos more than 10% of the time please contact the clinic so that we can help to see if any changes need to be made to insulin doses or timing.

In Clinic

When you attend your diabetes outpatient clinic you should expect that your meter(s) will be uploaded and then the results discussed with you at your consultation. The same will apply to your pumps if you are on a pump. It is therefore essential that all your meters are brought to clinic and that the time and date is correct on the meter. If you wish to obtain a new meter, then please check with the team that it will upload.

Most clinics targets now:

Average BG (over 14 days) 8mmol Standard deviation (variability) 3 Time in range (4-10mmol) 70%

B9: Uploading and sharing data

The data collected on the technology you have been provided with is to aid the management of your diabetes. This can be loaded and viewed by yourself and your diabetes team. This allows a visual representation of your blood glucose levels and other information from your meter or sensor over a set time e.g. 2 weeks. Changes to your diabetes management can be made from this data to optimise your diabetes control.





Glooko allows easy uploading of information from most, but not all, glucose meters, insulin pumps, CGM and mobile apps. For technology that does not upload to Glooko other companies have different platforms to upload their devices. Please discuss your technology with your nurse for further information.

B10: HbA1c or Glycated Haemoglobin

HbA1c or glycated haemoglobin is an indication as to what your blood glucose levels have been over the last 6-12 weeks.

What does it measure?

Haemoglobin is present in red blood cells (the Hb of HbA1c) - this is what makes your blood red. Glucose sticks to red cells and the more glucose there is around in the blood, then the more red cells have glucose attached. The average lifespan of a red cell is 120 days and therefore if we measure how many red blood cells have glucose attached to them, it gives us a guide as to the glucose levels in your blood over the last 120 days (3 months).

What it does not measure?

It is not a measure of blood glucose as you would get if you are doing a finger prick and testing your blood with a meter. It does not measure sudden changes in your blood glucose and it will not reflect a single day or week.

What are normal levels and how does it relate to your blood glucose?

Small blood vessels run throughout the body and get damaged by persistently high blood glucose levels which lead to long-term complications of diabetes such as kidney and eye problems. An HbA1c target level of 48 mmol/mol (6.5%) or lower is ideal to minimise the risk of long-term complications. It can be difficult to achieve, but is worth it. It is important to note if HbA1c levels are above the ideal target of 48mmol/mol or less, that any reduction in HbA1c level reduces the risk of long-term complications.

We will support children and young people with type 1 diabetes and family members to safely achieve and maintain their individual agreed HbA1c target level.

How often is it measured?

We aim to measure HbA1c at every clinic visit, at least every 3 months. If it is above 69 mmol/mol (8.5%), we will arrange more frequent appointments to provide you with additional support. After diagnosis of Type 1 diabetes, the first 2 years are really important. Research has shown that achieving target glucose levels and an HbA1c less than 48mmol/mol within the first 12-24 months is protective of future health. We will help you to reach this glucose target within 3-6 months of diagnosis and maintain for as long as possible, by proactive management, using technology and providing practical and emotional support to your family. The First Year of Care Pathway is to help achieve a good start with diabetes.



Chapter C

Food & Diabetes





C: Food and Diabetes

C1: What can I eat?

Food choices are an important part of managing diabetes, but there is no special diet for children or young adults with diabetes. The food you eat should be based on healthy eating that can be enjoyed by all your family and friends. However, eating fatty, sugary or processed foods frequently can make diabetes much harder to manage.

Why is food important?

Food is important to give us energy, for thinking, walking, running, playing, and to grow properly. Food contains many vitamins and minerals that keep us healthy. It is important to eat the right amount of food for age, size and level of activity. When people are first diagnosed with diabetes, they often feel very tired, weak and may have lost some weight.

How do bodies use energy?

Some of the food that we eat is broken down into glucose by our body. This glucose goes into the blood stream. Insulin is a hormone, produced by cells in your pancreas, which opens the cells and allows glucose in so that it can be used as energy. Insulin also allows us to store energy in our muscles and liver.

In diabetes the cells in the pancreas stop producing insulin, so the glucose in the blood cannot be used. This causes high blood glucose levels (hyperglycaemia) which can make you feel tired, thirsty and unwell. This is why insulin is needed.

Blood glucose

There are three main food groups:

- Carbohydrate
- Protein
- Fat

Carbohydrate foods provide energy and allow us to grow. Carbohydrate foods are broken down by the body into glucose. Glucose helps us to learn, play and be active. Carbohydrate foods will have the biggest effect on blood glucose of all the food groups.

There are two types of carbohydrate:

- Complex or starchy carbohydrate
- Simple carbohydrate





Complex/Starchy Carbohydrate

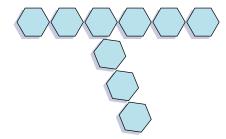
This type of carbohydrate are found in the following examples of food:

Bread, potatoes, rice, pasta, couscous, quinoa, grains, chapati, naan bread, plantain, porridge and flour.



These types of carbohydrates cause a steady rise in blood glucose over a long period of time. The glucose in these foods is joined together in long chains, which are what causes them to be 'complex':





Starchy carbohydrate foods are low in fat and help to fill you up. They should be included as part of every meal and snack (if you need them) and spread evenly throughout the day.

Sugary Carbohydrate

This type of carbohydrate are found in the following examples of food:

Sugar, honey, jam, fizzy drinks and cordial, energy drinks, milkshakes, fruit juice, smoothies, sweets, chocolate, sugar-coated cereals, cakes, biscuits and puddings.



Glucose/Sugar



The glucose in sugary carbohydrates is not linked together in chains.





These foods are broken down more easily which causes your blood glucose to rise quickly.

Normal fizzy drinks, table sugar, honey, jam and fruit juice should be avoided as they have a big effect on your blood glucose and it is difficult for insulin to match their effect. There are sugar free alternatives that can be chosen e.g. sugar-free cordial, diet/zero fizzy drinks; but as they still damage your teeth, they should always be consumed as part of a balanced diet.

Natural sugars: these are found in milk and yoghurt (lactose) and fruits (fructose). Natural sugars will affect your blood glucose and will need to be matched with insulin but the foods they are found in are healthy and should be included.

How does food and insulin fit together?

Blood glucose will always increase after food one to two hours after eating. The amount of glucose and fibre in foods will affect how quickly the food is broken down and therefore will affect the rise in blood glucose. It is better for you to have a small rise in blood glucose after meals, rather than a big spike.

Insulin

Insulin is needed when food is eaten. It should always be taken before food, fifteen minutes before eating. The amount needed depends on how much carbohydrate you have eaten and your insulin to carbohydrate ratio (I:C ratio).

On multiple daily injections, three or more of these injections will go with food (bolus) and another one or two provide background insulin (basal) which is unrelated to food. The diabetes team will explain how the insulin you have works. Remember you may also need insulin with snacks as insulin is not restricted to meal times.

Sometimes rapid acting insulin can be taken to correct a high blood glucose value, even without eating.

www.digibete.org





The Eatwell Guide

This is a useful guide to help you manage your diabetes and food. There is no special diet for people with diabetes. The model is based on healthy eating principles and therefore can be used for the whole

family.



You need a variety of foods from each of these groups to stay healthy, and give you the right balance of nutrients, vitamins and minerals that you need.

Fruit and Vegetables

These foods are good sources of vitamins, minerals and fibre.

'5 a day' - It is recommended that you should aim for 5 portions of fruit and vegetables every day to give you all the vitamins and minerals your body needs. Vitamins and minerals are protective against the damage that higher blood glucose can do to blood vessels. Due to the sugar content of fruit, they should be limited to 2-3 portions per day. However, you can never have too many vegetables!

Children often prefer raw vegetables to cooked ones which are also great as a snack between meals (e.g. slices of cucumber, sliced carrot, celery sticks, sugar snap peas, chopped peppers, olives).

Meat, Fish and Alternatives

These foods give you protein, which is necessary to help the body grow and repair body tissues. Protein foods include:

- · Pulses e.g. baked beans, red kidney beans, lentils, chickpeas, mung beans, butter beans, hummus
- Soya, Quorn, TVP, Tofu
- Nuts
- Eggs
- All types of meat, poultry and fish fresh and frozen





Milk and alternative milk products.

Milk, yoghurt, cheese, and alternative milk products are all good sources of calcium. Calcium is important for healthy bones and teeth.

Milk products such as yoghurts or milky puddings often contain sugar. Try to choose products that have no added sugar or contain a sweetener. Only dairy, oat and soy milk are recommended for children and young people.

Choose reduced fat products for children over the age of two years e.g. yoghurts, semi-skimmed milk, reduced fat cheeses. Children under the age of two years should be given full fat milk as they need the energy in this to grow.

Vegetarian and Vegan diets

The reasons some people choose to follow a vegetarian or vegan diet are varied. When well planned, balanced and nutritionally complete, these diets can be very healthy.

Eating Out

Eating out can be enjoyed with family and friends - it is just a question of being prepared. Restaurants, particularly chains, sometimes have nutritional information on their websites or app.

If the information is not available think about the usual size portion you would have at home and estimate it from that.

Takeaways

Take away foods generally contain a good deal of fat combined with large quantities of carbohydrate. This combination may cause a spike in blood glucose for a sustained amount of time and may require an extra correction dose following the meal. Takeaway meals can be enjoyed as part of a balanced diet but should be eaten no more regularly than fortnightly.

Cultural or Religious Festivals

If you require any advice around cultural or religious holidays or festivals, our diabetes team is always happy to support you and answer any questions you may have. You can also find more information at www.digibete.org





C2: Carbohydrate counting

Carbohydrate counting means calculating the amount of carbohydrate you are eating so that you can give a matching insulin dose. The amount of insulin needed varies between different people and your diabetes team will advise you on how much you need.

Carbohydrate foods have the greatest effect on blood glucose. Protein foods, most vegetables and fats have less immediate effects on blood glucose and are not usually included in insulin calculations. Protein foods and vegetables are important for other nutrients and should be eaten regularly.

What foods need to be counted?

Those containing starchy carbohydrate:

Bread, potatoes, pasta, rice, chapattis, breakfast cereals, noodles, bread products and things containing flour, couscous, quinoa, bulgur wheat, yams, cassava, plantain, squashes, sweet potato, parsnips, pastry, crackers, pulse vegetables (beans, peas, chickpeas, lentils, dhal, baked beans, mushy peas), oat milk.

Those containing natural sugars:

- · All fruits, fruit juice, fruit smoothies, dried fruit (contain the sugar fructose)
- Milk, yogurt, fromage frais, drinking yoghurt, milkshakes, custard, rice pudding (contain the sugar lactose)

Those containing added sugars (sucrose):

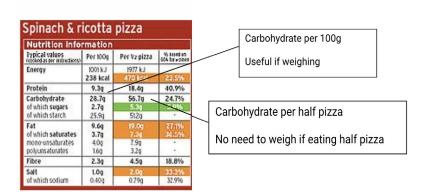
- Biscuits, cakes, muffins, cookies, brownies, doughnuts
- Sweets, chocolate, chocolate biscuits
- Ice cream, mousse, trifle, cheesecake, other desserts
- Sweet cereals
- All foods containing "added sugar"

How to Count Carbohydrates

Practical ideas

Food labels

Use the nutritional labels on a product, giving values per 100g and/or per portion. You need to use the 'total carbohydrate' figure NOT the 'of which sugars'. The 'traffic light' labelling on the food packaging only gives the sugars value.







If you are weighing food, you can use the 'per 100g' figure. The 'per portion' value is useful for quantities you can easily count e.g. per slice of bread, per biscuit, per fish finger etc.

Carbs and Cals (approved resource for Diabetes)

Use Carbs and Cals book or app to estimate carbohydrate portion size. Use this book at home by weighing your portion size and compare with the same weighed portion in the book. Your dietitian can show you how to do this.



Weighing foods

This is the most accurate way to count carbohydrate in foods without labels or when the portion size varies. Foods that are good to weigh include pasta, rice, potatoes (roast, mashed, chips, and jacket), couscous, noodles, quinoa, plantain, grains, breakfast cereals, porridge oats, home-made recipes and fruits.

A pair of digital scales and some maths will help you work out how many carbohydrates are in the food. Remember: the actual weight of a food measured on scales, is NOT the same as the amount of carbohydrate that food contains.

How to Calculate the Carbohydrate Content of Your Food using 'per 100g' values on labels:



Other apps can help with calculations





C3: Snacks

These are some suggestions for snacks that you may need between meals. Snacks might be for an activity, or because you are hungry. It is not always necessary to snack if you are eating meals regularly.

Some people need insulin with snacks, especially snacks that contain carbohydrate.

Snacks Containing 10g (Or Less) Carbohydrate

Food	Quantity	CHO (g)	
Small pear, apple, orange	1 small, 80g	10	
Plum, Kiwi, Satsuma	1 small, 50g	5	
Rich Tea, Malted Milk, Sports, Morning Coffee biscuits.	2 biscuits	10	
Digestive, Hob Nob, Ginger Nut Biscuits	1 biscuit	10	
Muller Light Yogurt	1 small, 100g	8	
Fromage Frais	1 small	7	
Frube	2	9	
Box of Raisins	small	10	
Dried Apricots	small handful	10	
Cream Crackers	2	10	
Breadsticks	3	10	
Rice Cakes	each	3	
Ryvita Crispbread	each	5	
French Fries, Wotsits, Quavers, Skips	small bag, 13g	9	
Cereal Bar (Alpen Light, Special K)		7-10	
Glass of Milk	150ml	7	
Highlights/Options Chocolate Powder	Made with water Made with milk	6 13	
Oatcakes	1	5	
Strawberries	10	9	





Snacks Containing No Carbohydrate

Low or No fat	Contain Unsaturated Fat	Contain Saturated Fat	
Pickled Onions	Nuts- peanuts Cheese		
Cherry Tomatoes	cashews, almonds Cheese Strings		
Cucumber Sticks	pistachios, walnuts Mini Babybel		
Carrot Sticks	Olives	Peperami	
Raw Peppers	Sunflower, pumpkin seeds Cocktail sausages		
Tuna, shellfish	Hummus	Pepperoni, salami	
Cooked chicken (no skin), ham	Nut butters		
Cottage Cheese	Eggs- cooked without extra fat.		
Sugar Free Jelly	Avocado		
Sugar free ice pops			
Diet/Zero drinks			

Only 1 snack between each main meal should be eaten. More than this will require insulin. In order to stay as healthy as possible, we recommend that people eat less saturated fat, so the snacks in the first two columns should be the first choice, with the third column being an occasional snack.

C4: The Glycaemic Index (GI)

Carbohydrate containing foods are all digested by the body and release glucose into the bloodstream at different rates. This is due to many different things including the amount of carbohydrate in the food; the fat, fibre and protein content. Carbohydrate foods that are digested rapidly and release glucose quickly into the blood are described as **high glycaemic index (high GI)** foods. Foods that are broken down more slowly are described as having a **low glycaemic index (low GI)** and cause a slower rise in blood glucose.

Studies have shown that diets based on **low GI** foods can improve blood glucose control, preventing a rapid rise in glucose levels after meals. This is very helpful for managing diabetes. Naturally **Low GI** foods are good for gut and heart health. It is therefore important to include as many low GI foods in your diet as possible.





How do I include low Glycaemic Index foods?

Cereals

- Choose oat based breakfast cereals (e.g. overnight oats, porridge, Oat Bran Flakes, Oatibix, homemade granola, unsweetened muesli).
- · Choose wholegrain bran cereals (e.g. Bran Flakes, All Bran).
- · Choose oatmeal biscuits (e.g. Hobnobs, Oat Cakes).

Bread

Choose granary, mixed grain or seeded breads in preference to white, brown or wholemeal bread.

Pulses

- Beans, peas, lentils and barley (e.g. butter beans, kidney beans, baked beans, haricot beans, cannelini beans, chickpeas, soya beans, and hummus).
- Dahl, channa dahl
- Add pulses to casseroles, stews and soups. Tinned beans and lentils are available in the shops that require no soaking.
- · Baked beans on toast is a good breakfast or lunchtime meal.
- Adding pulses to meat dishes will make the dish go further, and add flavour
- · Add beans to a salad to add texture, colour and flavour.

Pasta, grains, potato

- Use pasta or noodles to replace potatoes more often at meal times (pasta has a lower GI value than potatoes). Sweet potato and boiled new potatoes are slower acting than mashed or jacket potato.
- Quinoa (pronounced 'keenwah') or buckwheat, can be used as alternatives to rice or couscous.
- · Consider pasta salad as an alternative to sandwiches in your lunch box.
- Brown basmati rice has the lowest GI of rices

Fruit

- Apples, cherries, dried apricots, dates, figs, grapefruit, peaches, plums, oranges, grapes and pears are all low glycaemic index foods.
- Include them as a snack between meals or at meal times e.g. added to breakfast cereal, with yoghurts as a pudding.

Milk and Alternative Milk Products

- Diet / Greek-style/ Icelandic / high protein yoghurts are useful as a dessert or snack
- Use full fat natural yogurt as an alternative to milk on cereal
- A drink of milk with breakfast.



Chapter D

Low and High Glucose Levels





D: Low and High Glucose Levels

D1: Low blood glucose levels (Hypoglycaemia)

Hypoglycaemia - what is it? How to recognise and treat with confidence.

In someone without diabetes, the body is able to balance the blood glucose (BG) level between 3.5 and 7mmol/L the majority of the time. In Type 1 diabetes, where insulin is injected either by pen or pump it is much harder to keep the BG between this narrow range.

In diabetes we define Hypoglycaemia (Hypo's) if a BG level goes below 3.9mmol/L

What sort of things can cause a hypo?

- · Too much insulin too large a dose or too many doses in a short time
- Being more active
- Missing a meal or loss of appetite due to illness
- Drinking alcohol
- Stress, hot weather
- Lipohypertrophy also referred to as lumpy injection sites

How will you know if your child is having a hypo?

Your child will usually experience some of these sensations first as their body tries to correct the hypo.

This may include: - Shaking, pounding heart, hungry, sweating, dizzy, feeling weak

The effect of low BG levels on the brain means that it may then become:-

More difficult to concentrate or perform skills as well as usual or they may complain of a headache.

Their behaviour may also seem different to usual. You may notice they seem more:-

Irritable, Tearful, Quiet, Drowsy or Uncooperative, Pale

Hypoglycaemia at night time

Some children have hypos at night without it disturbing their sleep, so can be more difficult to detect. If they have a number of hypos this can also affect awareness so identifying and preventing them is important.

Bedtime BG levels do not necessarily predict the BG overnight so checks around 2-3am may be recommended by your diabetes team. If wearing a sensor, alarms can be set.

If your child has exercised in the afternoon or early evening hypos later in the evening or overnight (approx. 7-11 hours later) can be more likely so checking overnight is a good idea.





How to treat a hypo

Take some fast acting glucose. For many children over about 10yrs of age 15g glucose carbohydrate is required.

To calculate this more precisely use 0.3g/kg of body weight

Here is a chart showing the usual amounts of fast acting glucose required for children of different ages and include 2g, 5g, 10g and 15g hypo treatment. This will raise BG level by about 3-4mmols.

	2g glucose Less than 2 years old.	5g glucose 2-5years old	10g glucose 5-10years old	15g glucose Over 10years old
Lift glucose shot	10mls	20mls	40mls	60mls
Lift glucose tablets (1 tablet contains 4g)	-	1 tab	2-3 tabs	4 tabs
Lucozade energy tablets (1 tablet contains 3g)	1	2	3	5
Dextrosol (1 tablet contains 3g)	1	2	3	5
Jelly sweets (average weight)	3g	6g	12g	18g
Dextrogel	¼ tube	½ tube	1 tube	1½ tubes

Recheck the BG after 15mins, if still below 3.9mmol/L repeat the hypo remedy as you won't do any harm but will help your child to recover quickly.

If you find you regularly need to repeat the hypo remedy please discuss with your diabetes team.

Dextrogel / Glucogel

This treatment can be used if your child is sleepy or uncooperative and not wanting to eat or drink.

Glucose gel can be placed on fingertip and put in the mouth or squirted in the side of the cheek onto the gums and massaged on the outside.

Chocolate is not recommended for hypos.

This is because it contains fat which slows the absorption of glucose, and lactose which is a more slowly absorbed carbohydrate so your child will likely take longer to recover.

Fructose (fruit sugar) is absorbed slightly slower than glucose but not as slowly as lactose. It may be an option if apple or orange juice is more acceptable, and you find it works quickly enough.





In the case of a severe hypo

This is a rare occurrence which can lead to loss of consciousness and/or seizure and requires assistance by another person to administer Glucagon. There is a short video on how to administer this intramuscular injection on the Digibete essential videos section.

As young children are less able to communicate their needs, they are at risk of severe hypo. With the use of newer technologies including continuous glucose sensors and hybrid closed loop insulin pumps severe hypos have reduced considerably.

Key points to consider

- Prompt treatment can prevent severe hypos
- Make sure there is always a supply of glucose tablets or sugary drinks
- · Monitoring blood glucose levels regularly can reduce the risk of hypos
- Encourage children and young people to let their friends know that they have diabetes and know what to do in the event of a hypo
- Wearing some form of identification is a good idea
- · Is this a one off event or is there a pattern of low blood glucose levels?
- Try to work out the cause so you can try and prevent hypos in the future
- Monitor more frequently during the next 24 hours following a hypo to prevent a repeat
- Monitor blood glucose and ketone levels 2-4 hourly if hypo and ill
- 2-3 mild hypos per week are not unusual when diabetes is well managed and BG are close to target.

D2: High blood glucose levels (Hyperglycaemia)

Why do I need to treat high blood glucose levels?

If you do not treat a high blood glucose level you may stay high for several hours. This might make you feel unwell in the short term (thirsty, less able to concentrate, irritable) but if happens frequently can contribute to a rising HbA1c.

Common reasons for high glucose (above 9 mmols) may be:

- Mis-match of insulin to food timing or dose
- Missed Insulin
- Growth / puberty / hormones/ periods
- Sugary foods/ drinks
- Reduced activity
- Stress / exams
- End of honeymoon phase
- Illness





How do I work out how much correction insulin to give?

If glucose levels are above target, your app/pump bolus calculator will automatically calculate the dose of insulin needed to match both carbohydrate eaten and to bring the glucose level back down to target range.

Please see table below for blood glucose levels and the relevant action and treatment advice.

BG level (mmol/L)	Treatment Advice	Insulin	
7.0-8.9	BG level above target if done before a meal.	Give additional insulin if about to eat a meal or snack.	By using a pump/meter/app bolus calculator, the dose of insulin will be automatically increased to match both the carbohydrate eaten and bring BG level back down to target range.
9.0-13.9	BG level too high (hyperglycaemia)		By using a pump/meter bolus calculator, the dose of insulin will be automatically calculated to bring BG back to target range. Check BG 1 hour later if on pump Check BG 2 hours later if on injections Change insulin cannula (if using an insulin pump) if BG does not come down after initial correction
Above 14	BG level too high (hyperglycaemia) & risk of DKA	Check for ketones Give additional correction dose of insulin	If ketones below 0.6, follow advice above (9.0-13.9 mmols/L) If ketones above 0.6, insulin dose calculated by pump/meter bolus calculator needs to be overridden and increased (see sick day rules section) All correction insulin needs to be given by injection Change insulin cannula if using an insulin pump Check BG and ketones in 1 hour

What is 'Active insulin' or 'insulin on board'?

This refers to how much insulin is still working from previous insulin injections or boluses. It is a safety feature to prevent overcorrection of high glucose levels.

Having high glucose levels immediately after meals does not necessarily mean you need more insulin, as the insulin given may still be working to bring the glucose level down. If your pump suggests that you give a reduced amount of correction insulin or no correction insulin, this may be because you have insulin active in your system from a previous bolus.





If you use an insulin pump or bolus calculator app, these will take active insulin into account every time a correction dose of insulin is calculated. Active insulin is usually set at 3 or 3.5 hours as the majority of the bolus will be used in this time.

If you do not use a bolus calculator app or insulin pump, you should not give a correction dose within 2 hours of a previous dose of fast acting insulin.

High glucose level patterns

If you notice a pattern of high glucose levels at a particular time of the day, the usual dose of insulin affecting that time period may need adjustment. Please upload your pump/meter or send a photo of your glucose diary and give the team a call to discuss.



Chapter E

Preparing for Home





E: Preparing for Home

E1: Ongoing Support

Contact

You will be offered a home visit shortly after discharge from hospital. The nurse may be able to make a visit to home within the first few weeks.

How often you meet with your nurse will be a joint decision between you.

School visits



If you/your child attends school or nursery, a nurse will go into school soon after discharge to discuss with staff how to manage diabetes in school. It is helpful for parents and children to attend this first meeting so that a care plan can be discussed and agreed. Parents may need to go into school initially until the designated staff feel confident to manage all aspects of caring for diabetes within the school environment. Training will need to be updated annually.

Structured Education

You will be invited to attend structured education group sessions. They are sessions for newly diagnosed children and their families as well as days for children and young people at specific times like moving to high school or leaving home/going to University.

There are regular pump showcase events for those thinking about insulin pump therapy or those changing pump after a 4 year contract.

Psychology

A diagnosis of diabetes is a big event and it is normal to experience a number of feelings such as sadness, being shocked, angry and upset. As part of our team a psychologist may be available during your clinic appointments. If these feelings continue or you are worried, our psychologists in the team can try and help. Your diabetes nurse can talk to you about this.







Dental Health

Caring for teeth is also an important part of good diabetes care. Hypo treatments are sugary and can damage teeth without good tooth care. It is important to rinse your mouth with water after treatment.

Brushing twice a day with a small headed toothbrush and a small amount of toothpaste will help to remove all the debris from food that causes plaque, a sticky film of bacteria that causes gum disease.

Visiting the dentist regularly for check ups, preventative advice and treatments will help to keep a healthy smile. Remember to tell the dentist that you have diabetes.

If a general anaesthetic is required for treatment then you would be referred to a specialist dentist.

Foot care

Good foot care for children with diabetes is important

- Wear slippers or shoes at all times
- · As children's feet grow quickly, check that shoes and socks are well fitting
- Check for blisters and cuts and see a doctor if they are not healing
- · Seek advice for infections such as athletes foot, verrucae or ingrowing toe nails

The blood vessels supply oxygen and nutrients to the muscles and nerves. The blood vessels in the feet can be damaged by persistently high glucose levels. This means that they cannot supply enough oxygen and the nerves can be damaged. This causes reduced sensation in the feet, so that small injuries that are usually noticed are not felt.

Because of this, you can be referred to a community podiatrist if there are problems with feet.





Disability Living Allowance

All children with diabetes under 16 years old are eligible to apply for Disability Living Allowance (DLA). Everyone can apply but it does not mean that your child will be registered as disabled. The payment is to help with the extra cost and attention that children with diabetes require (attending appointments) It is not usually paid to children over the age of 16.

You may obtain forms from the benefits agency on **0800 121 4600**. Alternatively, you can complete the forms online. Your nurse will be able to help you.

https://www.gov.uk/disability-living-allowance-children/how-to-claim

E2: Support groups for Parents and Children

DigiBete



DigiBete is a video platform and App created in partnership with the Diabetes Team at Leeds Children's Hospital for use by families nationally. The videos are designed to help people and families self-manage their Type 1 Diabetes. The App is now available to every family in England and Wales, your clinic will give you a code. The DigiBete App also complements the information in this workbook.



JDRF

The Juvenile Diabetes Research Foundation is a charitable organisation that funds research into diabetes. They are committed to fundraising and increasing the awareness about the condition.



dedicated to finding a cure





Diabetes UK

This is a charity helping people living with diabetes. They provide support and information for people with diabetes and their families. They organise weekends for children and families and provide holidays for children of different ages. They have a care line and online information on their website www.diabetes.org.uk



E3: Immunisations

It is important that all children and young people with diabetes receive their routine immunisations. It is recommended that all children and young people on treatment for diabetes have an additional immunisation against pneumococcal infection after the age of 2 years and annual influenza immunisation after the age of 6 months.

E4: Transition

As you become older, we will start to prepare you for becoming more independent and eventually transferring your care to the Young Adult Team. We will make sure that you know how to manage your diabetes, as your parents may have done all this for you if you were very young when you were diagnosed with diabetes.

Transition starts around 12-13 years of age; we have separate clinics for those aged 13-16y and 16+years. You will see your consultant, young people's diabetes nurse, dietitian and sometimes a psychologist. You will usually see the team on your own first, before your parents are invited into the room. This is to encourage independence and to allow privacy. You will also have the opportunity to see the nurse or dietitian to discuss any issues in private. Your information is confidential and will not be given to anybody else without your permission, unless you are at risk of harm.

You will be offered an appointment at least every 3 months, but may be asked to come more often. Adolescence is a difficult time and the effects of hormones mean that it is difficult to achieve an HbA1c close to target of 48mmol/mol. You will need to increase your insulin doses quite often whilst you are growing rapidly, and may need to decrease them when you stop growing.

Young Adults

When you are about 19 years old, you will be transferred to the care of the Young Adult Team. You will attend the Young Adult Clinic and will usually see the Consultant on your own; however, you can bring a friend, relative or partner to clinic with you if you feel more comfortable.

When you reach the age of 25, or sooner if you feel ready, you will be transferred to the general Adult Clinic. This could also mean a change of Consultant, Nurse or clinic day.

For young women who wish to become pregnant there is a special preconception clinic. Women who become pregnant will be referred to diabetes ante natal clinic, irrespective of age.





Diabetes, drugs and alcohol.

Drinking excessive alcohol or taking drugs can be dangerous for anyone, and there can be added risks for young people with diabetes. It is important that you feel comfortable talking to the team about drugs and alcohol and that you ensure you get the appropriate advice if this is something you are involved in. The nursing and dietetic team can advise you on managing your diabetes around alcohol. We can also talk to you about drugs and help you find support if you feel like it has become a problem in your life. You will not be judged for any of the things you are doing, and we may be able to help you maintain your personal safety if you speak with a member of the team.

Information and conversations shared with the team is confidential, unless it is felt that the individual is putting themselves or someone else at serious risk.

It is very important not to start smoking, as the combination of diabetes and smoking leads to an increased risk of heart disease. People with diabetes who smoke can be referred to a Smoking Cessation service. We will discuss driving regulations and can advise on careers, leaving home etc.

E5: When to contact the team

Guide for when to contact the diabetes team so that changes can be made before the next clinic appointment.

The diabetes team is there to help. Please email or contact your nurse if you are not sure what to do next. There is never a daft question! Always ring the office or emergency numbers (if urgent out of hours).

Some ideas about when to contact the team are listed:

Hypoglycaemia

- Following a severe hypo.
- If there are more hypos than usual or they occur regularly with exercise.
- If there is impaired hypo awareness or night time hypos.
- · Always contact your team if you have any worries or questions.

High Blood glucose levels

- If there is a trend over a few days with your blood glucose levels rising into double figures.
- If weekly average blood glucose level (see meter) is rising above 9.0mmol/l.

Variable swinging blood glucose

If glucose levels are swinging and you are uncertain what to do.



Chapter F

Emotional Well-being and the Diabetes Psychology Service





F: Emotional Well-being and the Diabetes Psychology Service

F1: Living well with Diabetes

A diagnosis of diabetes is a big change in most people's lives and it takes time to find the best ways of fitting diabetes into life.

Children and young people with diabetes live very fulfilling lives.

People with diabetes perform at the highest levels in sport, education, performing arts.

Visit the celebrities page on Diabetes UK website and explore their experiences at

https://www.diabetes.org.uk/Guide-to-diabetes/Teens/Fun-stuff/Celebrities/

F2: Emotional impact following diagnosis

There is no such thing as 'normal' following diagnosis, and you may even notice that everyone responds differently in your family. It is common to feel shock, fear, sadness, anger, frustration, fed-up, guilt, relief and many other feelings. We expect that these feelings will gradually reduce over time.

Living with diabetes has its ups and downs, which are not the same for everyone. We know that making a good start and having support (from family, friends, school/college, and diabetes team) are really important.

Changing glucose levels can have a big impact on how people feel and behave. It is important that diabetes is not used as a reason for young people not being able to do things as this can build resentment. Think about what you would allow a child or young person to do if they did not have diabetes, and then find a way for diabetes to fit into this - the diabetes team can often have ideas about ways of managing different situations so always get in touch to ask.

F3: Promoting emotional wellbeing for children and young people with diabetes

There are several ways that we can promote emotional wellbeing for children, young people and their families with diabetes. The way we (as family, friends, teachers, professionals) talk to young people about diabetes impacts how they think and feel about it.

How to support children and young people to build resilience:

- Talk about diabetes in a way that makes space for thoughts and feelings listening to how children and young people feel is so important to them and you do not need to have all the answers: listening is not doing nothing).
- Pay attention to the child or young person as well as diabetes.
- Help children and young people to build confidence in diabetes care gradually over time, by letting them get involved in parts of diabetes care that are appropriate for their age
- Make space for mistakes, this is how we learn.
- Practise how to share about diabetes with new people can help with new situations (e.g. moving to a new school, starting a new club)





Team working

Caring for diabetes can be demanding and teamwork between children, young people and their families is important. Team working can be more difficult to negotiate during teenage years. It can be hard to achieve a balance between care for diabetes and supporting the development of independence, which is a very important developmental task. Young people tend to be focused on the present, friends and activities they enjoy - which can mean that diabetes care struggles to be prioritised. Think about how you can best work together as a family to care for diabetes. This includes negotiating about reminders, checking in and managing if glucose checks or insulin has been missed.

Siblings can also be impacted by a diagnosis of diabetes, they may feel their needs come second, so include siblings in understanding about diabetes. Provide opportunities for support as needed.

F4: Emotional support for children, young people and their families living with diabetes

Living with diabetes has ups and downs and this means sometimes it can feel more difficult to live with. Struggling emotionally can make it harder to care for diabetes and living with diabetes can contribute to emotional difficulties. Support is available at these times either via the diabetes team or your GP.

Within the diabetes team there will be clinical psychologists. Some of the reasons that children, young people or their families come and talk to psychologists are:

- Feeling sad or down
- Feeling that diabetes has taken over life
- Feeling "stuck" in relation to diabetes.
- · Arguments and relationship problems caused by diabetes at home
- Worries about weight or body image
- Stress around living with diabetes
- Fears or anxieties about diabetes
- Difficulties managing the treatment regime
- Feeling different
- Difficulties with diabetes in school/college or work
- many other reasons

We work together with families to understand what you are struggling with and to help things to move forward.



Chapter G

Lifestyle and Activity







G: Lifestyle and Activity G1: Physical Activity

All families should take part in physical activity for at least 60 minutes per day. There is no upper limit! Exercise may have beneficial effects on lowering blood glucose; you may need to reduce insulin

Why exercise?

- Improves heart health
- · Helps maintain a healthy weight
- Insulin works better
- Makes bones stronger
- Helps self-confidence and socialisation with friends
- Lowers cholesterol

Screen Time

All families should minimise the amount of time spent sitting (watching TV, computer/gaming, driving).

- Agree a family limit for screen time each day
- · Set 'no screen time' rules to encourage kids to be active
- At weekends and holidays try to plan family activity time
- Make bedrooms a TV/laptop/tablet free zone this also helps sleep





Physical activity

for children and young people







MAINTAINS HEALTHY WEIGHT



DEVELOPS CO-ORDINATION



STRENGTHENS MUSCLES & BONES



MPROVES SLEEP



IMPROVES CONCENTRATION & LEARNING



IMPROVES HEALTH & FITNESS



MAKES YOU FEEL GOOD

Be physically active

Aim for

Spread activity throughout the day



at least

minutes everyday should make you breathe faster & feel warmer

All activities













Include muscle and bone strengthening activities

3 TIMES PER WEEK









Sit less



Move more

Find ways to help all children and young people accumulate at least 60 minutes of physical activity everyday

UK Chief Medical Officers' Guidelines 2011 Start Active, Stay Active: www.bit.ly/startactive





G2: Exercise

This information has been produced by Francesca Annan Paediatric Diabetes Dietitian, University College Hospital, the UK's leading diabetes and exercise expert. We are grateful to her for allowing us to share this.

Information about exercise and diabetes for children and young people on multiple daily injection therapy (MDI)

Being active is an important part of a healthy lifestyle.

Physical activity may be daily activities like walking or playing or sports.

About exercise

Different types of exercise (aerobic or anaerobic) have different effects in your blood glucose levels. Exercise that lasts for longer than 1 hour will typically have more of blood glucose lowering effect.

What happens when you exercise?

This will depend on the type of exercise you do, the amount of insulin working in your body and how long you exercise for.

Different types of exercise have different effects on your blood glucose;

Aerobic exercise (which uses oxygen) will usually lower your blood glucose dropping during and after exercise, examples include running, swimming, cycling.

- If your exercise lasts longer than 30 minutes you will probably need to reduce your insulin and/or have extra fast acting carbohydrate
- For exercise that lasts for less than 30 minutes you may not need to lower your insulin but you may need a little extra carbohydrate

Anaerobic exercise (does not need oxygen) may make your blood glucose rise during the exercise and fall after the exercise. Anaerobic sports are usually short, sharp & fast or strength and power sports. Examples include, sprinting, basketball, weight lifting.

• Some sports will be a mixture of aerobic and anaerobic exercise; e.g. football and team sports. Mixed exercise may produce steady blood glucose levels.

You will need to learn how different activities affect your blood glucose both during and after your exercise. To do this check your blood glucose levels before any exercise, every 20 minutes during exercise and at the end of the exercise and between 2 & 3am after vigorous/hard or long bouts of exercise.

Adjusting your insulin

You should aim to keep your blood glucose level around 7-8mmol/L before and during exercise you can adjust both the long acting background (basal) and fast acting food (bolus) insulin to do this.





Fast acting meal time insulin (bolus insulin)

If you eat 1-2 hours before exercise then you can make a reduction in your mealtime fast acting insulin dose to help prevent low blood glucose levels during sport. Make a similar reduction with food eaten after exercise to prevent low blood glucose levels after exercise.

You may need to lower your insulin by 25-75% if you give an injection with a meal 1-2 hours before exercise.

Background insulin

Your long acting background insulin may also need to be adjusted to help prevent low blood glucose levels after exercise. You may find this easier if you have 2 injections of long acting insulin a day, one in the evening and one in the morning. This will mean you can adjust your day time and night background insulin levels separately.

Long acting insulin doses will need to be reduced when you are going to be active all day, when your activity is strenuous and if you are exercising again the next day. Background insulin may need to be reduced by 25-50%.

Blood glucose before exercise

Aim to have a blood glucose level around 7-8mmol/L before and during exercise. If your blood glucose level is above 14mmol/L you should check for ketones. You can exercise with a higher blood glucose level without ketones, but you must check your blood glucose levels and drink plenty of fluid. If your blood glucose level is between 5 and 8mmol/L start having any exercise snacks at the beginning of your activity.

Use the table as a guide

Blood Glucose	Aerobic Exercise	Anaerobic Exercise
<5mmol/L	Bring blood glucose back to normal, have extra carbohydrate at least 1g/kg per hour of exercise	Bring blood glucose back to normal, have extra carbohydrate at least 1g/kg per hour of exercise
5 -8mmol/L	Have exercise snacks, 15g for each 30minutes of activity.	No changes required if the activity is <30minutes. Consider exercise snack if exercise lasts longer than 30minutes.
8 – 11mmol/L	No change required for activities <45 minutes. If exercise lasts longer than 45minutes exercise snacks will be needed.	No changes required if exercise is <30 minutes. Exercise snacks may need additional insulin.
Check for ketones and correct* blood glucose. Have exercise snacks with insulin for performance. Drink fluid during exercise		Check for ketones and correct* blood glucose. Have exercise snacks with insulin for performance Drink fluid during your exercise

^{*}Only use half corrections during exercise





If you have a high blood glucose level and ketones you should delay exercise until the ketones are no longer present.

Keep a record of the insulin adjustments you make and your blood glucose responses to different types of exercise. This will help you to plan the insulin adjustments you need to make.

Exercise Snacks

If you are exercising for 60 minutes or longer it is a good idea to have some carbohydrate during your exercise. Try and spread your extra carbohydrate across the exercise by having something every 20 minutes. If your activity lasts 60 minutes or longer, you should also think about eating some supper before bed.

Aerobic exercise that is intense or that lasts longer than 45 minutes can need 1g carbohydrate for every kilo you weigh. You will need more carbohydrate if you have not adjusted your background or food insulin doses.

To start, try having 15g of carbohydrate for each 30 mins of activity and monitor regularly (every 30 minutes). If you have adjusted your insulin doses you should need less carbohydrate to prevent hypoglycaemia.

Suitable exercise snacks include:

- Sports drinks/gels
- Jelly sweets
- · Ordinary sugar containing drinks
- Dried fruit
- Jaffa cakes







Drinks for Sport

It is also important when you are being active that you have plenty to drink.

- Drink 2-300ml before any exercise.
- Try and drink during your exercise as well, about 100ml every 10-15 minutes.
- If you are exercising for an hour or more always have a sports drink, then you get the fluid you need and the extra carbohydrate as well.
- If you are exercising for less than 60 minutes water is fine.







After exercise

After exercise you may have low blood glucose levels for up to 12 hours later. Usually after exercise you will be more sensitive to your insulin and may need less.

Eat a snack/meal before bed whenever you do 60 minutes or more exercise in the afternoon or evening. A mixture of carbohydrate and protein helps your muscles and liver to replace their energy stores. Examples of good bed time snacks include milk shake and fruit, cereal and milk, crumpets with peanut butter. The bedtime snack usually does not need any fast acting insulin.

If you have high blood glucose levels at the end of exercise you can use a $\frac{1}{2}$ correction dose. Wait 30 minutes and recheck the blood glucose to see if it starts to fall on its own before giving a correction dose.

- Check BG levels regularly, as after 1-2hours the BG will fall.
- You may find that high levels at the end of exercise will fall without additional insulin.
- If your BG is always raised at the end of exercise make changes to your insulin to prevent this from happening.

G3: Sleep

When thinking about diabetes, we know that there are four important factors that help to keep blood glucose stable:

- 1. insulin
- 2. healthy food
- 3. exercise
- 4. sleep

Sleep helps to maintain a healthy weight as well as controlling glucose levels. Growth hormones are released when you are asleep. It is important to get the right amount of sleep to grow properly. Sleep heals and repairs heart and blood vessels, especially important for people with diabetes. With regard to mental health, a good night's sleep helps the brain work properly. It helps us to learn, remember, solve problems, be creative and make decisions, as well as safeguarding against stress, mood swings and depression.

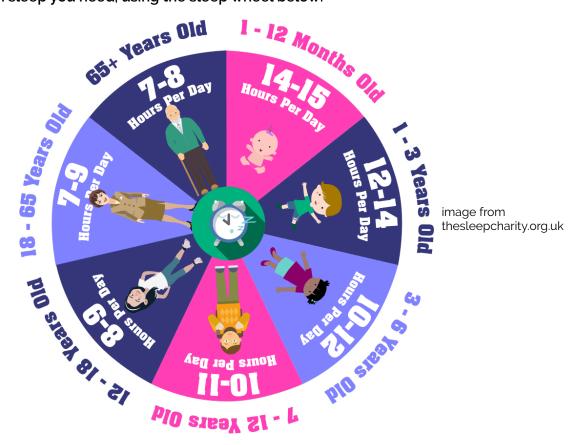
How much sleep do I need?

The average person spends around a third of their life asleep. In this time, our bodies are able to replenish energy stores and make repairs, while our minds organise and store the memories of the day before. The amount of sleep you need depends on your age, sex, health and other elements. Sleep cycles change as we grow older.





Find out how much sleep you need, using the sleep wheel below:



Top 10 Tips for a Healthy Sleep Cycle

- 1. Keep a regular sleep/wake schedule (have an alarm for bedtime as well as morning time). Having a 'going to bed routine' is also helpful for getting your body and mind ready to go to sleep. Keep track of what activities help you relax and try to incorporate these into your routine (e.g. reading/journaling/listening to music/turning off phone).
- 2. Get out into natural light as soon as is practical in the morning (preferably around the same time every day).
- 3. Engage in daytime exercise (but avoid at least 2 hours before bedtime as too close to bedtime it can prevent sleep).
- 4. Avoid stimulants that contain caffeine 8 hours before bedtime (Cola drinks, energy drinks, coffee, tea,).
- 5. Don't eat too close to bedtime as doing so can disrupt sleep (our body is concentrating on digesting food, instead of repairing and replenishing our energy stores).
- 6. Eat regular meals at regular times, instead of snacking throughout the day (this helps strengthen our internal body clock and keep us a healthy weight).
- 7. Reduce electronic use at least an hour before bedtime and avoid electronic use in the bedroom. Consider turning off the WiFi when young people go to bed.
- 8. Ensure the bedroom is cool, dark and quiet before bed (this helps us relax and drift off to sleep easily).
- g. Ensure that bedroom clocks are not visible as this can be distracting and stressful.
- 10. Avoid alcohol and nicotine (if applicable) as this disrupts sleep patterns by acting as a stimulant and making our sleep fragile.

The above information has been taken, with thanks, from the UK sleep charity website. For further information, tips and sleep resources, please access the sleep charity website on: https://sleepcharity.org.uk/



Chapter H

Holidays-how to manage diabetes safely





H: Holidays-how to manage diabetes safely

Holidays can affect your diabetes. It is best to discuss with your diabetes team before going away particularly if you are travelling far away. Plan well in advance and get supplies ready a week or two before. Ask for a travel letter from clinic as this may be required at the airport.

1. Temperature (see also exercise below)

Hot Temperature: Insulin needs to be kept out of direct sunlight, this is particularly important with pumps, so put them under a towel or clothing when in the sun. Use a cool bag/ Frio bag to carry insulin. Keep spare insulin in a fridge if you have access to one. When you return from holiday start with new insulin that has not been away with you.

Cold temperature: Insulin does not tolerate being frozen, so keep it somewhere cool. Wear pumps under clothing and protected from freezing temperatures if you are skiing or walking outdoors in cold temperatures.

2. Exercise

Many holidays involve more exercise, swimming, walking etc. More frequent glucose checking will be needed to see the effect of the extra activity. Here are some ideas:

- If on a pump, use an exercise target setting
- If on injections, reduce your long acting insulin (Levemir, Tresiba) by 10-20% on the day you leave the UK.
- Food insulin: keep your usual ratio to start with but this may need reducing. E.g. 1: 10 to 1:15.
- You may be able to have extra snacks without insulin if you are exercising a lot.



3. Time zones

Local flights to mainland Europe require no change to insulin. However if more than 3-4 hours time change requires planning and should be discussed with the diabetes team. Remember to change the time on any devices, so that the right amount of insulin is delivered at the right time.





4. Alcohol

- If you want to drink alcohol it is best to combine it with food.
- If you are drinking a lot you are at risk of hypos, remember the symptoms of hypo and being drunk can be the same.
- Make sure your friends know what to do and how to treat a hypo.
- Carry some ID saying you have diabetes.

5. Spare equipment

Make sure you have enough insulin, needles and glucose checking kit. If on a pump you must have emergency pens and insulin in case the pump fails. You may need to go on injections until the pump can be replaced. You will need to know your basal rate and bolus ratios in case this happens.

Do not put it all in your main luggage as it will be too cold in the luggage hold of the plane and it may get lost. Split it up into different hand luggage. Insulin should always go in hand luggage.

If on a pump, take the pump manufacturers emergency contact number in case it breaks. They may be able to send a new one to your holiday destination. If not, use injections until you return to the UK.

6. Extreme sports

You must inform companies providing extreme sports that you have diabetes Check your blood glucose before to make sure you are not low. Adrenalin or nervousness can cause high or low glucose levels. Do not correct a high glucose level in case it is due to adrenalin. If the activity requires a lot of physical activity make sure you have some extra glucose available. You may need glucose gel sachets or Dextrogel for water based activities. It is your responsibility to make sure you are safe.

7. Insurance

Make sure you have health insurance covering your diabetes. Admission to hospital can be very expensive.

Your insulin pump should already be on home insurance - check whether this is covered if stolen on holiday, or if it needs to be listed on travel insurance.

Most importantly have a good holiday!!



Chapter

Problem Solving and Adjusting Insulin





I: Problem Solving and Adjusting Insulin

11: Insulin adjustment

These guidelines relate to basal bolus regimens where you are giving rapid acting insulin with carbohydrate and long acting insulin once or twice per day.

If there is a pattern of three or more blood glucose levels higher or lower than the target range, review time last insulin dose given and food given, portion size of meals and snacks, carbohydrate counting, whether snacks require insulin. Once considered, discuss with the team as the insulin to carbohydrate ratio may need to be adjusted.

If the current Insulin to carbohydrate ratio (ICR) is 1unit:10grams and the average amount of carbohydrate is 50g. Calculate how much insulin this would be if changed to 1 unit:8 grams). One change at a time and review after 2-3 days before making further changes is recommended.

Exercise and activities such as school sports/ swimming/dancing/shopping can all affect your glucose levels and may need insulin doses to be adjusted before and or after. Please see activity and exercise section for further information. Hormonal activity during growth or menstrual cycle can also affect glucose levels.

If in any doubt always ask a member of the diabetes team.

12: How to adjust insulin - Frequently Asked Questions

- What to do if you are high
- What to do if you are low at certain times of the day
- What to do if you have missed your insulin
- What to do if you have given the wrong insulin
- · What to do if you have given the wrong amount

These guidelines relate to basal bolus regimens where you are giving fast acting insulin with carbohydrates and long acting insulin as a background.

It is important to remember **Don't Panic if you have given the wrong insulin or amount**. **Please ring the team or advice line**.





What to do if your glucose is 'High'

Q: Is your glucose level above 7mmol/L on most mornings before food?

Yes:

- First check a blood glucose level around 2-3am to ensure you are not going low overnight.
- Make sure you are going to bed with a glucose level in target, if so check your glucose level is within target in the morning.
- If your bedtime glucose is within target but your blood glucose levels rise during the night then increase your long acting Insulin by 0.5-1unit (depending on dose and weight) if taken at night. Wait 2-3 days and repeat if still above 7 mmol/L. on waking.
- If your bedtime glucose levels are above target at bedtime which then makes them high in the morning you need to concentrate on improving your before bed glucose levels.

No: Leave your long acting dose the same.

Q: Is your blood glucose level above 7mmol/L before lunch on most days?

Yes: If you do not eat a snack mid-morning, consider increasing your meal ratio with breakfast. If you have a mid-morning snack you may need extra insulin with this, or consider omitting snack, or limit carbohydrate amount/ consider type. If unsure what to do discuss with your diabetes team.

No: Keep your ratio with breakfast the same.

Q: Is your blood glucose level above 7mmol/L before tea on most days?

Yes: If you do not have a snack mid-afternoon, consider increasing your meal ratio with lunch. If you have a snack mid-afternoon you may need insulin with this, or consider omitting snack, or limit carb amount. If unsure what to do discuss with your diabetes nurse.

No: Keep ratio with lunch the same.

Q: Is your blood glucose level above 7mmol/L before bed on most days?

Yes: Consider increasing meal ratio with tea if no other snack eaten.

No: Keep ratio with tea the same.

Q: Have you eaten anything and forgotten to give Insulin?

Yes: Give rapid acting insulin now for carbohydrates eaten.

No or not sure:

Recheck blood glucose in 60 mins and give correction if necessary. Use your Insulin Sensitivity Factor/correction dose (ISF) to work this out. See chart.

Q: Have you given insulin in the last 90 mins?

Yes: Do nothing and recheck blood glucose in 60 mins.

No: Give a correction dose using rapid acting Insulin. Or you could wait until the next meal to give a correction if answer to next question is no.

Q: Do you have blood ketones over 0.6mmol/L?

Yes: Consider contacting the Diabetes team for urgent advice. Give a correction dose of Rapid Acting Insulin now, giving a sick day dose for ketones. (unless you have given insulin in the last 90mins, then recheck blood glucose and ketones in 60 mins)

No: Add a correction dose of Rapid Acting Insulin to next meal.





What to do if your blood glucose is 'Low'

Q: Is your blood glucose level below 4.0mmol/L on most mornings before food?

Yes: Reduce your long acting Insulin by 0.5-1unit if taken at night. Wait 2-3 days and repeat if still

3.9mmol/l or below.

No: Leave your long acting dose the same.

Q: Is your blood glucose level below 4.0mmol/L before lunch on most days?

Yes: Decrease your meal ratio with breakfast.

Alternatively, consider giving small snack mid-morning without insulin. If unsure what to do

discuss with your diabetes nurse.

No: Keep your ratio with breakfast the same.

Q: Is your blood glucose level below 4.0mmol/L before tea on most days?

Yes: Decrease your meal ratio with lunch.

Alternatively, consider having small snack mid-afternoon without insulin. If unsure what to do

discuss with your diabetes nurse.

No: Keep ratio with lunch the same.

Q: Is your blood glucose level below 5.0mmol/L before bed on most days?

Yes: Consider decreasing meal ratio with tea.

No: Keep ratio with tea the same.

Q: Are you low following exercise/activity?

Yes: Consider having extra carbohydrates before, during or after. This could be either as a sports

drink or eaten as light snack.

Alternatively consider giving less insulin with your meal if exercise is within 2 hours.

No or not sure:

Discuss with your diabetes nurse or dietitian for further advice.

Q: Have you given a correction dose within the last 2 hours?

Yes: Consider adjusting your correction dose to give less insulin. If you are unsure how to do this

discuss with diabetes nurse.

No or not sure:

Ring to discuss

If low before meals or at several times during the day discuss with team as basal insulin may need to be reduced





What to do if you have forgotten to take your long acting insulin

Q: Do you normally take your long acting insulin at night?

Yes: Take usual dose as soon as you remember. Check blood glucose more frequently and if more

than 10mmol/l correct at meal times with fast acting insulin. The following day adjust timing by

2 hours each day to get back on track.

No: See next question.

Q: Do you normally have your long acting insulin in the morning?

Yes: If you remember your missed dose before mid-day take your normal dose immediately.

Yes: If you remember your missed dose after mid-day, Take your usual dose straight away. Test your blood glucose levels more frequently. Correct at meal times with fast acting insulin. The following

day give your normal dose 2 hours earlier each day until you get back on track.

What to do if you have forgotten to take your rapid acting insulin

Q: Is it within 30 mins of eating?

Yes: Give fast acting insulin for carbohydrates eaten.

No or not sure:

Check your blood glucose levels 1 hourly for the next 4 hours and give extra food containing carbohydrates (without insulin). Treat hypoglycaemia with fast acting glucose. Call the diabetes team for further advice.

What to do if you have given the wrong insulin

Q: Have you given rapid acting Insulin instead of long acting Insulin?

Yes: Check your blood glucose levels 1 hourly for the next 4 hours and give extra food containing carbohydrates (without insulin). Treat hypoglycaemia with fast acting glucose. Call the diabetes team for further advice.

Q: Have you given long acting Insulin instead of rapid acting Insulin?

Yes: Call the diabetes team for advice.



Chapter J

Diabetes During Illness - Ketones





J: Diabetes During Illness - Ketones

J1. Understanding Ketones: How to Treat Ketones & Avoid DKA

Insulin acts as a key to allow glucose to move from the blood into the cells, where it is used for energy. If you have diabetes and do not have enough insulin, the body cannot use glucose properly. The body then tries to release more glucose from its own stores and starts breaking down fats for energy. This leads to ketone production. The body will also produce ketones if you starve for more than a few hours as the body will run out of glucose.

Ketones provide the body with energy in the short term but also make your body more resistant to insulin. This means that the body generally needs more insulin than usual to work effectively. Ketones are acids and can make you very ill. If they are not treated they can lead to diabetic ketoacidosis (DKA). Your body will try to get rid of ketones in the urine and in your breath. They smell like Pear Drop boiled sweets but not everyone can smell ketones.

Early identification of rising ketone levels and prompt management supported by the diabetes team can potentially avoid an emergency situation or a hospital admission.

Managing ketones may take up to 24 hours and usually requires extra insulin doses, careful observation of food and fluid intake and regular telephone contact. Individual assessment is essential and in some cases admission to hospital may be unavoidable.

J2. Situations Where The Body May Make Large Amounts of Ketones

Sub-optimal diabetes control with high HbA1c:

When your HbA1c is high, there is regularly not enough insulin in the body and blood glucose levels are high most of the time. Glucose cannot effectively get into the cells from the blood to be used as energy so the body is more likely to produce ketones.

Illness:

Children and young people whose diabetes control is optimised should not experience more illness or infections compared to children and young people without diabetes. However, even routine childhood illnesses (e.g. flu, tonsillitis or chicken pox) can make diabetes management more challenging and increase the risk of DKA. This is because during illness, particularly those associated with high temperatures, the body works much harder and it demands more glucose. Blood glucose levels are also raised due to higher levels of stress hormones, which encourage the body to release more glucose and make it harder for the insulin to work properly. The body then breaks down fat leading to ketones.

Illness associated with vomiting and diarrhoea (e.g. gastroenteritis) may lower blood glucose levels and lead to ketone production secondary to starvation.

Illness can affect glucose levels prior to the onset of the illness, during illness and for several days after and therefore it is extremely important to monitor both blood glucose levels and ketones when unwell.





Starvation:

If you miss food, particularly carbohydrates, the body will naturally form ketones for energy if the blood glucose is low. This can happen more quickly if your child is unwell, particularly if illness is associated with vomiting and/or diarrhoea (e.g. gastroenteritis). .

Stress:

During periods of stress, the stress hormones cause the body to release more of its own stores and make the body more resistant to insulin. If extra insulin is not given to compensate, the body may produce ketones.

Growth and Puberty:

During times of rapid growth and puberty the body needs more insulin as the pubertal hormones make your body less responsive to insulin.

Exercise:

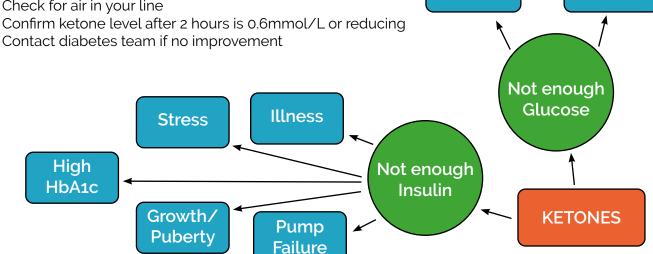
Exercise demands energy and if there is not enough glucose from carbohydrate, more fats will be broken down to form ketones. Exercise is good for you but if your blood glucose is high or low and ketones are present you should not exercise until your ketones have gone and blood glucose normalised.

Pump failure:

When you are on a pump, there is no long acting insulin in the body, only rapid acting insulin. Being on a pump puts you at greater risk for developing ketones and DKA if your pump insulin runs out, your insulin becomes disconnected for too long or the pump is not working properly. If you feel unwell or have high blood glucose with or without ketones, always consider "is my pump working?"

Pump users must be more vigilant and check for ketones after any raised blood glucose result that has not been resolved by one correction dose by the pump. Pump users should follow these rules:

- Check ketones
- Correction dose by pen injection if ketones are present
- Change pump to a new site
- Check you had not run out of insulin
- Check the old cannula was not bent
- Check for air in your line



Starvation

Illness





J3. Avoiding Ketones

General tips:

- Try to eat a healthy varied diet at regular intervals.
- Accurate carbohydrate counting is essential.
- Try not to forget insulin. You should aim for 4-7 boluses per day, with food or as corrections. Doses should be based on a recent glucose level and accurate carbohydrate value if eating. If your glucose is elevated a correction dose will also be required.
- Aim for an average glucose of 8mmol/L or below over a two week period. If higher than this it is likely that your insulin needs review. Please contact the diabetes team if you are unsure what to do.
- Regular uploading to check for patterns or trends of elevated glucose can indicate if a change to insulin is required.

Illness Management:

If your child is vomiting, has abdominal pain, fast breathing, is drowsy, confused or feels cold you must seek urgent advice.

- Check blood glucose and ketones to establish the specific diabetes action required. During illness blood glucose can be normal or elevated. In some situations, particularly gastroenteritis (vomiting and diarrhoea), the blood glucose can be low due to starvation. This requires slightly different treatment to that described below.
- Drinking plenty of sugar free fluids to flush ketones out of the body and maintain hydration is essential
- Carbohydrate as food or drink is essential during illness matched with insulin. If your child cannot eat, give your child sugary drinks (e.g. Lucozade, milk or fresh orange) with insulin. If your child is struggling to drink, they can suck glucose tablets or sweets instead.
- **NEVER** stop taking your insulin even if you are not eating. If blood glucose is low, insulin may need reducing but should never be stopped.
- You usually need more insulin when you are unwell. Your usual basal dose may need to be increased and extra fast-acting insulin may need to be given more regularly than usual.
- It may be necessary to adjust your correction dose for the duration of the illness.
- It may be necessary to temporarily increase the basal rate if you are on a pump.
- You may be advised to see your GP depending on your specific symptoms.

J4. Ketone Monitoring

A blood ketone meter should be available at all times. Blood ketones are measured by a finger prick. The result tells you whether the ketone level is normal or elevated. **The higher the result the quicker you need to act**.









Ketones must be checked if:

- Your child is feeling unwell regardless of the blood glucose
- · When the blood glucose levels are 14mmol/L and above
- · Your child feels sick or has vomited
- · Your child is feeling under stress

Levels of blood ketones (traffic light alert):

- Less than o.6mmol/L (normal)
- 0.6-1.5 mmol/L (small to moderate elevation)
- 1.5-2.9 mmol/L (moderate to large elevation) needs urgent treatment
- 3 mmol/L or greater (very large elevation) needs urgent treatment

J5. Ketone Management (Sick Day Rules)

The blood ketone and blood glucose level help to determine the specific treatment advised. The box below highlights the key principles of ketone management with more detailed information in the flow charts and table below. This advice is based on those using multiple daily injection regimens and insulin pump therapy. For patients on alternative insulin regimens, Fast Acting insulin will need to be used and the diabetes team should be contacted for advice.

The aim is to achieve:

- Blood glucose levels 4 -10mmol/L
- Blood ketones <0.6mmol/L

Key Points

- Ketones must be checked if your blood glucose is 14mmol/L and above OR if you feel unwell regardless of your blood glucose level.
- Check your blood glucose and ketones every 1-2 hours.
- Contact the Diabetes team URGENTLY if your child is vomiting or you are at all unsure. Vomiting could be a sign of DKA.
- NEVER STOP INSULIN even if not eating.
- The body needs food, fluids and insulin to stop ketone production. Drink plenty of sugar free fluids to flush ketones out of the body. Replace food with small amounts of carbohydrate containing liquid if not hungry (e.g. fruit juice, ice cream, yoghurt, sugary drinks) with adequate insulin.
- Additional insulin doses should be given every 2-4 hours by pen injection until glucose is normal and ketones are less than 0.6mmol/L. If you are on a pump you must give the first correction via a pen injection and then change your pump cannula.
- Contact your GP for general care of the illness. Most medications are sugar free. If not, the amount contained is negligible.

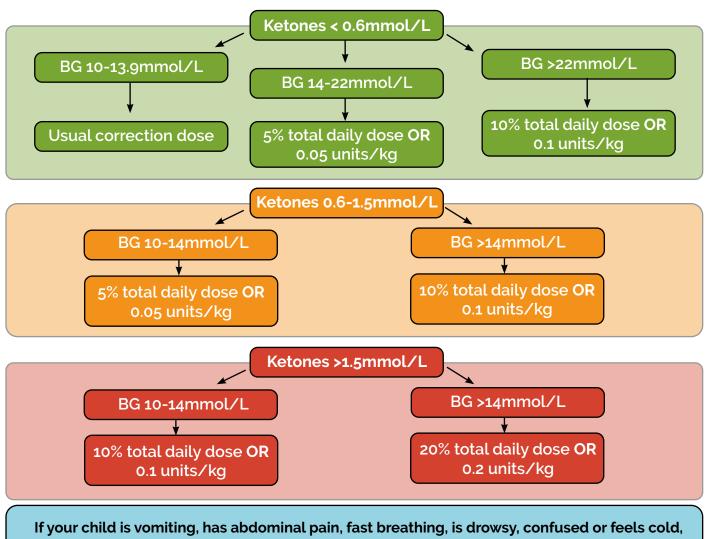




Flowchart for Ketone Management (Sick Day Rules)

General Principles

- 1. Never stop insulin
- 2. More frequent BG and ketone monitoring is required. Check ketones if BG 14 or above OR if your child feels unwell.
- 3. Aim for BG levels between 4-10mmol/L and ketones below 0.6mmol/L
- 4. Insulin treatment is guided by the BG and ketone numbers as outlined below and corrections should be at least 2 hours apart guided by regular BG and ketone monitoring (ideally 1-2hourly).
- 5. If you are on a pump, you must assume your pump is not working if you have ketones, and give a pen injection before re-siting the pump.
- 6. Drink plenty of sugar free fluids to push ketones out of the body.
- 7. Where possible eat food matched with your usual food insulin. If you cannot eat, replace food with small amounts of carbohydrate containing fluids and match with adequate insulin.
- 8. Treat underlying illness and symptoms.



you must seek urgent medical advice.

If ketones remain >1.5mmol/L despite additional insulin and adequate hydration please seek urgent medical advice.





Table for Ketone Management

Blood Glucose (BG) Level	Blood Ketone Level	Recommended Actions
BG 10 – 13.9 mmol/L	Below 0.6 mmol/L (normal)	 Give usual correction dose to get back to your target blood glucose level. Recheck BG and ketone in 2hrs. Have food as usual with insulin.
BG 14 - 22 mmol/L	Below 0.6 mmol/L (normal)	 Additional correction dose is needed for high blood glucose level – give 5% of total daily dose OR 0.05units/kg. Pump users can try to deliver additional insulin via the pump. Give extra sugar free fluids. Recheck BG and ketones in 2 hours. Have food as usual with insulin or liquids if struggling to eat.
BG greater than 22 mmol/L	Below 0.6 mmol/L (normal)	 Additional correction dose is needed for high blood glucose level – give 10% total daily dose OR 0.1 units/kg. Pump users can try to deliver additional insulin via the pump. Give extra sugar free fluids. Recheck BG and ketones in 2 hours. Have food as usual with insulin or liquids if struggling to eat.
BG 10 – 14 mmol/L	0.6-1.5 mmol/L (moderate)	 Give extra insulin immediately - give 5% total daily dose OR 0.05 units/kg. Pump users to give additional insulin dose using a pen injection and re-site pump cannula. Recheck BG and ketones in 2 hours. If unsure of how much further insulin to give contact the diabetes team for further advice. Give extra sugar free fluids. Despite these actions your child could deteriorate very quickly into the high-risk category. Any signs of nausea, vomiting or abdominal pain, seek advice immediately or take to the Emergency Department.





BG greater than 14 mmol/L	0.6-1.5mmol/L (moderate)	 Give extra insulin immediately - give 10% total daily dose OR 0.1 units/kg. Pump users to give additional insulin dose using a pen injection and re-site pump cannula. Recheck BG and ketones in 2 hours. If unsure of how much further insulin to give contact the diabetes team for further advice. Give extra sugar free fluids. Despite these actions your child could deteriorate very quickly into the high-risk category. Any signs of nausea, vomiting or abdominal pain, seek advice immediately or take to the Emergency Department.
BG 10-14mmol/L	Greater than 1.5mmol/L (high)	Your child is at risk of developing DKA. Watch for signs of abdominal pain and vomiting. High ketones levels will mean your child will no longer feel hungry but you MUST Give extra insulin - give 10% total daily dose OR 0.1 units/kg. Contact the diabetes team. Recheck BG and ketones in 1 hour. Encourage sips of sugary fluids with insulin. After two hours repeat the higher insulin correction dose if ketones have not decreased. If your child develops DKA symptoms take them to the Emergency Department immediately.
BG greater than 14mmol/L	Greater than 1.5mmol/L (high risk)	Your child is at risk of developing DKA. Watch for signs of abdominal pain and vomiting. If present take your child immediately to the Emergency Department. Your child may not feel hungry. You MUST Give extra insulin - give 20% total daily dose OR 0.2 units/kg. Contact the diabetes team. Recheck BG and ketones in 1 hour. Encourage sips of sugary fluids with insulin. After 2 hours repeat the insulin correction dose if ketones have not decreased.
BG may occasionally be near normal but usually high	Greater than 3.0mmol/L (serious risk)	The ketone level is seriously high. Your child needs insulin immediately and a rapid assessment of severity of DKA. TAKE TO EMERGENCY DEPARTMENT IMMEDIATELY If dehydrated and breathing fast it is very unlikely that further insulin under the skin will work and hospital admission is required. If at night do not wait until the morning but seek advice immediately.





Examples of dose calculations

You can calculate your child's total daily dose in the following way:

- Multiple daily injections add the long acting dose to the average amount of Novorapid your child has for each meal. For example, Levemir 10 units once a day, 4 units Novorapid for breakfast, 3 units for lunch and 3 units for evening meal, the average total daily dose = 10 + 4 + 3 + 3 = 20 units
- **Pump therapy** the pump will give you an average total daily dose based on the basal rate and boluses given.

If you are not sure about your child's total daily dose, weigh your child in kilograms. Most children need 1 unit insulin per kg of weight. If 40kg = TDD is 40 units.

Please note that if your child has a high HbA1c or often misses insulin doses using their weight will be more accurate than estimating their total daily dose.

Example

Your child has developed a cough and cold symptoms with a temperature of 38 degrees. You check their blood glucose and their ketones.

BG 20 mmol/L Ketones 2 mmol/L Total daily dose 50 units Weight 50 kg

Additional insulin is required via a pen. Novorapid is required 20% of the total daily dose **OR** 0.2 units/kg based on their numbers.

20% of 50 units = 10 units OR 0.2 x 50 kg = 10 units

You would give your child 10 units of Novorapid via pen injection and recheck their blood glucose and ketones in 2 hours. Call diabetes team for advice.

2 hours later....

Your child's temperature has improved and they are feeling a bit better. You recheck their blood glucose and ketones.

BG 16 mmol/L Ketones 1.2 mmol/L

You would now need to give another correction as the ketones are still elevated. This time the amount of Novorapid required is 10% of total daily dose OR 0.1 units/kg based on their recent numbers.

10% of 50 units = 5 units OR 0.2 x 50 kg = 5 units

You would give your child 5 units of Novorapid and recheck again in 2 hours. Update the diabetes team with the new numbers.





J6. Starvation Ketone Recognition and Management

Starvation ketones can be challenging to manage, particularly if your child has diarrhoea and vomiting. They do not usually rise above 1.5mmol/L. Please call the diabetes team early for advice.

Key Points:

- If your child is hypoglycaemic (BG < 4.0) treat appropriately with fast acting glucose and recheck BG after 15 minutes.
- Give extra carbohydrate as food where able otherwise give your child regular sugary fluids.
- Insulin should not be stopped but it may need reducing.
- If your child is on a pump we may recommend a temporary basal rate reduction.
- BG and ketones should be checked every 2 hours (unless ongoing hypoglycaemia where it should be checked and treated every 15 minutes until hypoglycaemia has resolved).

J7: Diabetic Ketoacidosis (DKA)

DKA is a **VERY SERIOUS** potential complication of diabetes. Ketones are acids and ketoacidosis describes how acidic the blood has become because there is **NOT ENOUGH INSULIN** in the body. Ketoacidosis can develop within a few hours, especially if you are on an insulin pump.

DKA can be life threatening. Early recognition and prompt treatment may avoid hospital admission and the need for intravenous insulin and fluids. Please ring the diabetes team for advice.

Recognising DKA

High ketone levels affect the way the heart, lungs, digestive system and brain function. In the worst situation they can cause coma and death.

EARLY Signs that your child is developing ketoacidosis

- Blood glucose level is rising and typically greater than 14 mmol/L
- Ketones are present (the higher the level the greater the risk of DKA)
- Confusion
- Tiredness
- Increased thirst
- Becoming dehydrated

LATE signs that your child has developed or is developing ketoacidosis

- * Seek Urgent Medical Attention
- Nausea
- Vomiting
- Headache
- Abdominal pain
- Breath smells of acetone /pear drops (remember not everyone can smell ketones)
- Deep/Sighing breathing



Chapter K

Future Health





K: Future Health

Introduction:

Lots of young people and their families ask for information on the possible long term impact of diabetes. Working with the diabetes team to aim for blood glucose levels between 4 and 10 mol/L will considerably reduce the risk of these complications occurring.

At diagnosis, parents may search the internet and read all about these problems and be worried. The Diabetes team is here to help to minimise this risk. Please discuss it with the team - it is really important to understand how you can reduce this risk to very low levels by keeping blood glucose in the target range where possible from the beginning.

Background:

The body is designed to keep glucose levels in the blood within 4-7mmol/L. If glucose levels are running high for a long time or there are large swings in blood glucose, it can irritate and damage the blood vessels, particularly small vessels as seen in the eye and kidney. They can bleed and small clots can form.

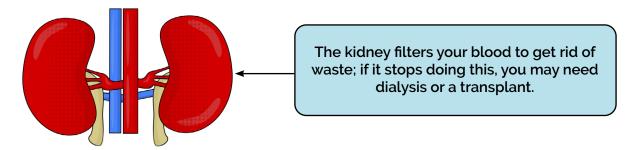
A study in the United States (DCCT) showed very clearly that maintaining blood glucose levels in target range for most of the time really reduced the risk of all complications and this effect lasted for many years.

The HbA1c test is a marker of glucose levels; the nearer that is to 48mmol/mol or 6.5% without lots of hypoglycaemia the more benefit for health, whether you have had diabetes for 2 years, 20 years or beyond. Even if you have a period of higher HbA1c, it is worth improving to reduce your risks of longer-term problems.

Nephropathy (kidneys)

One of the first signs of problems occurring in the kidney is the leakage protein into the urine. Urine will be checked for this once per year.

Another important sign of a kidney problem is a rise in blood pressure. This should be checked at clinic and if it is significantly high, then medication will be required.



To minimise the risk of these problems occurring it is important to:

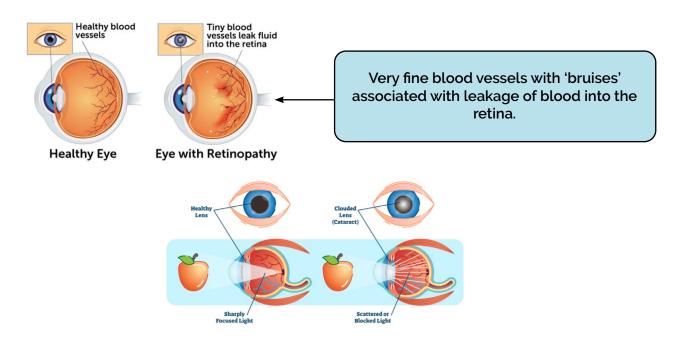
- Keep blood glucose control in the target range as much as possible
- Avoid smoking. Smoking increases the risk considerably.
- Maintain a healthy weight for your height.





Retinopathy (eyes)

The small blood vessels at the back of the eye are at risk of damage from high blood glucose levels and large swings in blood glucose. Over time, this can lead to leakage of blood into the back of the eye (retina) and damage your ability to see.



To minimise the risk and to stop further problems if any are detected, it is important to:

- Maintain blood glucose in target range as much as possible, reducing it slowly if it has been high for a while. Please discuss this with your diabetes team.
- Avoid smoking.
- If recognised, it can be treated by using a laser but it is better to try and avoid the complication if at all possible.

Neuropathy (nerves)

Problems associated with the nerve supply to your body are rarely seen in childhood but can start to appear very slowly:

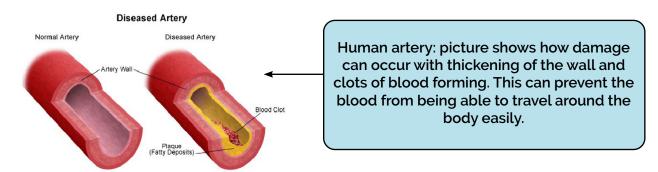
- The long nerves to your legs and arms can lose the ability to feel 'touch and sensation'. This can
 make it difficult to feel and pick up small objects and you could tread on a sharp object such as a
 stone or piece of glass without noticing.
- The nerves to your stomach can be affected, making it unable to empty properly leading to a feeling of sickness, pain and at its worst, frequent vomiting.





Blood vessels

The large blood vessels in your body can collect fat this narrows blood vessels and increases risk of heart damage. This is important to everyone whether they have diabetes or not and blood is checked every year for cholesterol (fat) levels



- Avoid smoking and make every effort to stop if you have started or are exposed to a smoky environment.
- Make healthy food choices including your 5 fruit and vegetables each day.
- Aim to keep blood glucose levels in the target range.
- Try and be active for 60 minutes per day. See sections G1 and G2 about physical activity and exercise.

Sexual Health

As you reach adult life the ability for normal sexual relationships becomes increasingly important.

In females, high glucose levels can be damaging in pregnancy. If you are planning to have children it is very important to discuss this with your diabetes team before you are pregnant. There is a specialist pre-conception clinic for women with diabetes to help with keeping glucose levels in target. By doing this, you can have a healthy pregnancy and have a healthy baby. If you think you are pregnant, please let us know immediately so that you can have a test, be given appropriate advice and be referred to the specialist antenatal clinic if appropriate.

High blood glucose levels can be associated with difficulty achieving an erection for men and can affect the sex life of both males and females with diabetes. Treatments are available if problems do occur. Please discuss this with your diabetes team if you have any questions.





K2: Research

There may be opportunity to take part in diabetes research
If we think you or a family member might be suitable for one of our studies, we will contact you with
more information.

Taking part in a study is entirely voluntary and you will be given age appropriate information and have the opportunity to discuss the study with a member of our research team before agreeing to participate.

If you decide you don't want to take part your clinical care will continue and will not be negatively affected. You will never be pressured to take part in a study.

Taking part in studies can offer you the opportunity to try new ways of managing diabetes, help us learn more about different types of diabetes and help new treatments become available in the future.

K3: Useful web addresses

General

DigiBete
Diabetes UK
Juvenile Diabetes Research Foundation
Lenny the lion teaching site:
Change for life-health advice.

www.digibete.org www.diabetes.org.uk/ www.jdrf.org.uk/ www.lenny-diabetes.com/ www.nhs.uk/Change4Life

Medical alert wearables

Medi tag alert bracelets Universal medical ID Medical tags The ID band company

Insulin pump accessories

www.medi-tag.co.uk www.identifyYourself.com www.medicaltags.co.uk www.theidbandco.com

www.funkypumpers.com www.diabete-ezy.com