

Clinic Follow Up

We will meet with you and your child very regularly in the outpatient clinic. These visits are essential to help support your/your child's ongoing management following the diagnosis of diabetes.

Who should come to clinic?

We would like two carers/parents to attend with the child. It is not essential for very young children to attend every new patient clinic. However they must come to the 5th visit (new patient clinic) and to every review clinic appointment. If you have any queries, please check with a member of the diabetes team.

What should I bring to clinic?

Please always bring:

- Blood glucose monitoring diary.
- Blood glucose meter and finger prick device.
- Food/carbohydrate diary, if you have been asked to keep one.

What if I need to cancel the appointment?



It is very important to attend all clinic appointments.

If you/your child cannot attend, you must cancel your appointment and make another one.

Please see the Contact List for the appointments department contact number.

Please contact the diabetes nurse specialists if you wish to discuss the reasons for cancellation.



New Patient Clinic: Diabetes Education Programme

You will receive an appointment for your 1st visit from the ward staff **before** you leave the ward. The clinic is held on Mondays in the main outpatient department at the Royal Hospital for Sick Children.

The plan for the clinic is detailed below. At each visit, you/your child will have your/their height and weight measured, and be seen by a member of the diabetes team.

Clinic visits are approximately every 2nd week, from the 1st visit to the 5th visit. The number of visits can be increased or decreased to meet with individual requirements but the final visit will always be with the diabetes doctor.

Visit	Team Member	Actions
1 st visit 45 mins	Dietitian	Review: 1. Insulin doses 2. Consistent carbohydrate and check counting correctly 3. Healthy eating
2 nd visit 45 mins	Dietitian	Review: 1. Insulin doses 2. Carbohydrate consistency 3. Insulin to carbohydrate ratios and correction factor 4. Exercise management
3 rd visit 45 mins	Dietitian	Review: 1. Insulin doses, ratios and correction factor 2. Healthy eating 3. Glycaemic index
4 th visit 1 hour	Diabetes Nurse Specialist	Review: 1. Insulin doses, ratios and correction factor 2. Sick day management and blood ketones 3. Injection technique/sites
5 th visit 1 hour	Doctor	See next page

The plan for the 5th visit is to discuss the following 3 key areas

1. The knowledge you/your child have/has about diabetes care

- We want to be confident that you have a good understanding of the key knowledge required to manage diabetes, and ensure that you are able to manage your/your child's diabetes in various situations.
- We will review hypoglycaemia management and sick day management with some examples. If you do not feel confident with these, we can arrange further sessions with the dietitian or diabetes nurse specialist.

2. Current diabetes management

- We will review you/your child's current diabetes management (insulin doses and carbohydrate intake).
- We will review how you make insulin adjustments and go through some examples with you. Are you following the tips for managing your/your child's diabetes in the Day to Day Management section?
- We will plot your/your child's height and weight measurements on an electronic growth chart.

3. Future diabetes care

- We will discuss the importance of maintaining good diabetes control.
- We will explain how we monitor this with a finger prick blood test at clinic every three months, the HbA1c (see page 9). You/your child's HbA1c will be checked at this clinic visit.
- We will talk about the risk of longer term diabetes-related complications and how we prevent and monitor for these (see page 15).
- We will discuss the risk of other possible health conditions associated with diabetes and how we screen for these (see page 16).
- We will discuss future options for optimising diabetes control.

After the 5th visit you will be asked to make an appointment to come back to the Wednesday afternoon regular review clinic in approximately six weeks.

Regular Review Clinic

The children's diabetes clinic is held every **Wednesday** afternoon.

On the **first** Wednesday of every month the clinic is held in the diabetes department at St John's Hospital in Livingston. If you live in West Lothian, your regular follow up clinic will be at St John's Hospital.

On the 2nd, 3rd and 4th Wednesday afternoons the clinic is held in the main outpatient department at the Royal Hospital for Sick Children (RHSC). If you live in Edinburgh, Mid or East Lothian your regular follow up clinic will be at RHSC.

We see children with diabetes every three months at clinic – generally four visits a year, if all is going well.

At each clinic visit you/your child will:

1. Get height and weight measured and plotted on an electronic growth chart.
2. Get a finger prick blood test (HbA1c) – please remember to bring your own finger prick device (it is gentler than the hospital disposable devices). It takes 20 minutes for this to be processed in the lab before the result is available.
3. See a senior doctor in the diabetes team who will discuss general health and diabetes care. They will make an ongoing diabetes management plan with you. The meeting with the doctor will last about 30 minutes.
4. Make a follow up appointment before leaving. IF the doctor is concerned that your/your child's diabetes is not well controlled you will also be asked to make a follow up appointment for six weeks, to have a repeat HbA1c and to meet with the diabetes nurse specialist.



Please allow at least 60 minutes for the diabetes review clinic visit from start to finish.

We have doctors on our team who are in training and it is a very important part of their training to see patients in clinic. Sometimes you may see a senior trainee doctor, who will be directly supervised by a senior doctor from the diabetes team, joining them in the clinic.



Annual Review Visit

Once a year you/your child will have an annual review clinic visit, on a Wednesday afternoon. This visit is usually booked as the first visit after a birthday. You will be told when you need to book for this visit.

What is different about this visit?

1. Extra tests

- **Blood test:** The blood is taken from a vein. Some children prefer to have local anaesthetic cream or a freezing spray so they do not feel the blood test. The freezing spray is immediate. Ask your GP to prescribe it. The cream should be applied before you come to clinic as it takes an hour to work.
- **Blood pressure:** from age 7 years.
- **Urine test:** from age 10 years.
- **Eye test:** from age 12 years, but **not** at the clinic!
You will receive an invitation to attend your closest screening centre.

Why are these extra tests done?

These tests allow us to assess if there are any diabetes-related health problems.

Children with diabetes do have a slightly higher chance of developing other autoimmune conditions (see page 16).

We also do screening tests to make sure that there are no signs of any diabetes-related complications. We would not expect any problems in younger children but we know it is important to start monitoring for complications from a young age. Please read about complications on page 15.

2. Extra paper work

You will be asked to write down the food you/your child usually eats during an average week day and weekend day, which will be discussed when you meet the dietitian.

3. Extra people to see

Who will you see, and for how long?

- Outpatient nurse to measure height, weight and blood pressure.
- Phlebotomist to take blood sample.
- The diabetes nurse specialist for 25 minutes.
- The dietitian for 30 minutes.
- The doctor for 30 minutes.



Your total time at clinic with all the tests and the three sessions will be almost two hours. Please plan for this.



What will they talk about?

The diabetes nurse specialist will:

- Review aspects of your/your child's diabetes care, including treatment of hypo's and sick day management.
- Review your/your child's involvement in day-to-day diabetes management and give guidance as to appropriate age-related expectations. If additional support or more education is required then further sessions will be arranged.
- Examine the injection sites to check that they are not 'lumpy/full'.

The dietitian will:

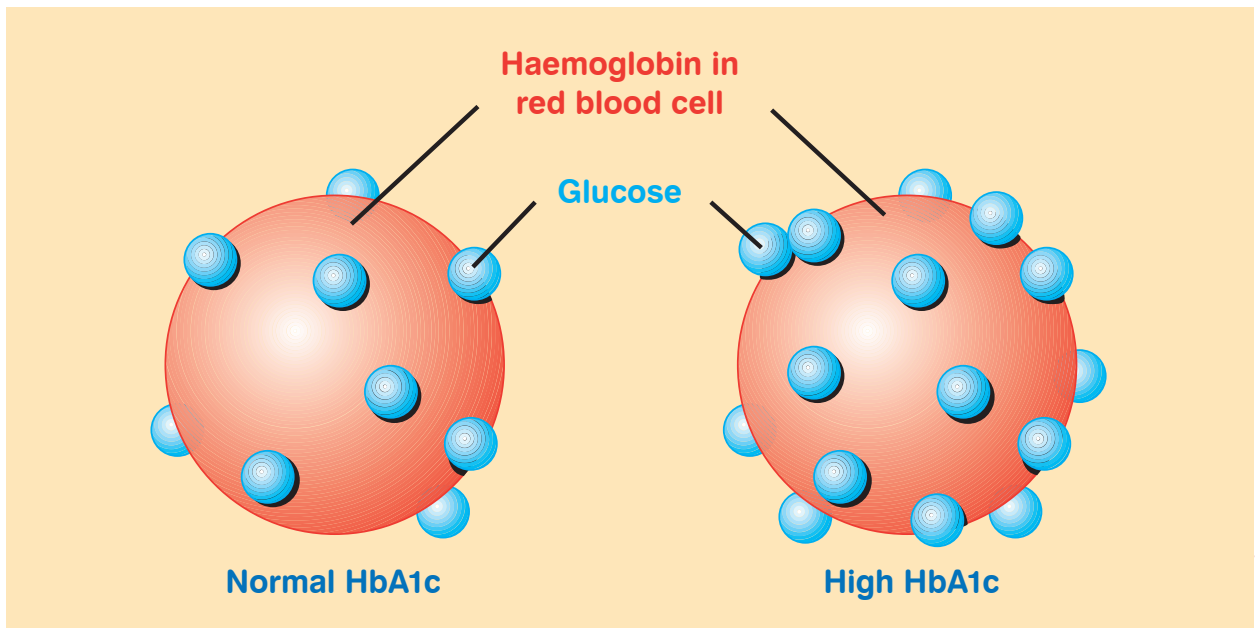
- Review the dietary history to ensure adequate intake of nutrients, including calcium and iron.
- Review your/your child's weight to ensure appropriate weight gain.
- Review carbohydrate counting and assessment of the amount of carbohydrate eaten for meals and snacks.
- Review any special dietary requirements, for example, a gluten-free diet if you/your child have/has coeliac disease.
- Discuss exercise: encouraging regular activity and giving advice on how to manage diabetes and activity.

The doctor:

The visit with the doctor is very similar to the regular review visit. They will also talk about:

- The additional tests that have been done, and ask about any symptoms of diabetes-related health problems.
- Growth (all children) and puberty (from age 10 years onwards).
- The importance of girls avoiding an unplanned pregnancy (this will be discussed from age 13 years onwards), and why this is relevant to diabetes.

Understanding the HbA1c test



What is haemoglobin (Hb)?

- Haemoglobin is the part of the red blood cell which carries oxygen from the lungs to the rest of the body.

What is HbA1c?

- It is a measure of the amount of glucose which the haemoglobin in the red blood cells 'picks up', when the red blood cells move around in the blood stream.
- It is normal for some glucose to attach to the haemoglobin, as the red cells need energy to move around the body.
- The amount of glucose picked up depends on the amount of glucose in the blood stream. When the average blood glucose level in the blood has been high, this will mean more glucose will be picked up. Once the glucose attaches to the haemoglobin, it stays there for the life span of the red blood cell – about 100 days.

What is the HbA1c test and why does it matter?

- The HbA1c test is performed every time you come to the diabetes review clinic. It is a finger prick test and you can use your usual finger-pricking device to obtain the blood, which will then be sent directly to the laboratory. The HbA1c result will usually be available 20 minutes later.
- It is normal for people with diabetes to have a slightly higher HbA1c result than people without diabetes. However the nearer your/your child's HbA1c result is to the optimal value for people without diabetes, the lower the risk of developing diabetes-related complications.
- The HbA1c value is measured in mmol/mol.
- The optimal HbA1c, as set by NICE (National Institute of Clinical Excellence) is 48 mmol/mol without significant hypoglycaemia. **The clinic target is less than 58 mmol/mol. Our clinic aim is that the majority of patients have an HbA1c of less than 58 mmol/mol.**

How does the HbA1c test relate to my blood glucose readings?

Please refer to the graph 'HbA1c - How are you doing?' below.

- The graph shows the relationship between the **average** blood glucose reading on your meter, measured in mmol/L, and the HbA1c result.
- An HbA1c result of 58 mmol/mol is equivalent to an average blood glucose reading of 9.4 mmol/L on your meter. An average blood glucose meter reading of 8.6 mmol/L equates to an HbA1c of 53 mmol/mol. Therefore **aiming for an average blood glucose reading of 8 mmol/L or less** would equate to the optimal HbA1c of 48 mmol/mol.
- It is rarely possible to get all the blood glucose readings in the target range on your meter and the aim is to get the **majority** of readings within or close to the target range.
- Remember that if the blood glucose levels are swinging from low to high, the HbA1c may be close to target, but this is not a good balance and you will not be feeling as well as expected.

HbA1c - How are you doing?

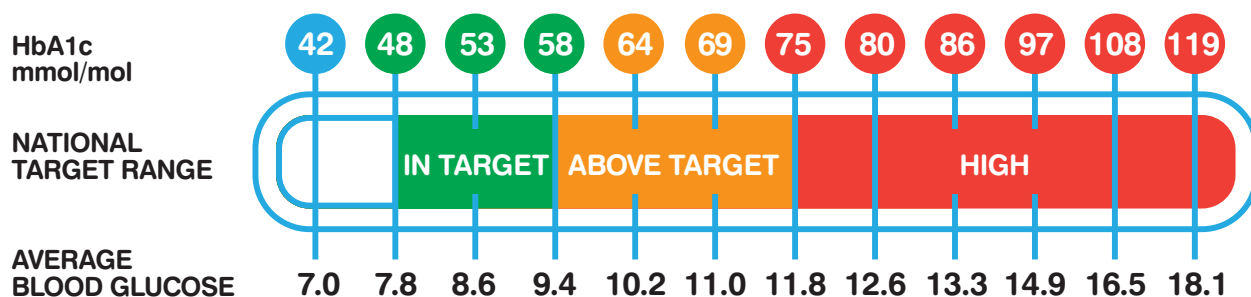


Diagram from NHS Lothian's 'Paediatric Guidance 2016

How does the HbA1c result affect the risk of complications?

- Diabetes-related complications are a result of damage to both large and small blood vessels, caused by high blood glucose levels.
- Good blood glucose control is vital in preventing long-term complications. An HbA1c in target, less than 58 mmol/mol, results from good BG control and significantly reduces the risks of diabetes-related complications.
- If the HbA1c is above target, a reduction in the HbA1c by 10 mmol/mol results in a 20% decrease in the risk of long-term complications of diabetes.
- An increase in HbA1c of 10 mmol/mol means that there has been an average increase of approximately 2 mmol/L in blood glucose levels compared to when the last HbA1c was taken.

If I improve my BG readings during the week before coming to clinic will this make my HbA1c test better?

- The HbA1c test is a measure of blood glucose control, mainly over the previous 6-8 weeks.

Table showing contribution of BG readings to HbA1c

Days before clinic	Contribution to HbA1c
1-6	Very low
7-30	50%
31-60	25%
61-90	15%
91-120	10%

- This means that if you have improved your BG readings during the week before clinic, this will have very little if any impact on your clinic HbA1c result.
- This highlights the importance of regular home blood glucose monitoring to ensure that you take appropriate action if the blood glucose readings start to run a little higher. Check your BG meter average regularly – at least every two weeks.

What are the complications of poorly controlled diabetes?

- **Short term:** symptoms of high blood glucose readings similar to those you experienced at diagnosis of diabetes – passing lots of urine during the day and night, drinking lots, feeling tired and grumpy, losing weight, blurred vision and the risk of developing diabetic ketoacidosis (DKA).
- **Medium term:** not growing to your full potential and generally lacking in energy and concentration. Remember that insulin is a hormone that helps your body store energy and grow and develop.
- **Longer term:** early signs of damage to the heart, large blood vessels and small blood vessels of the eye, kidneys and nerves may be found 10-20 years after the diagnosis of diabetes depending on the individual's HbA1c results. Persistently high glucose in the blood stream affects the lining of the blood vessels and damages them, which harms the parts of the body which they supply.



Good blood glucose control is vital in preventing short, medium and long-term complications. The diabetes team are here to work with you and your family to help you achieve this goal!

High HbA1c Policy: “80 – too high!”

- An HbA1c value ≥ 80 mmol/mol poses such a high risk of complications that **all** young people seen at clinic with an HbA1c ≥ 80 mmol/mol are started on the high HbA1c policy. If however, you/your child are still within the first year following diagnosis, the high HbA1c policy is set at '70 – too high', and all young people seen at clinic during the first year after diagnosis with an HbA1c ≥ 70 mmol/mol are started on the high HbA1c policy
- This is a supportive and structured approach to help families and young people work with the diabetes team to improve their diabetes care. It is not in any way a punitive measure; it is in place to minimise the risk of the development of long-term complications of diabetes, and importantly to help you/your child feel well on a day-to-day basis and to grow and develop appropriately.

What does being on the high HbA1c policy involve?

- This will be discussed fully with you at your clinic visit. You will be given a 'High HbA1c Policy sheet, '80 - too high', which will detail:
 - The main concerns and discussion points in clinic.
 - A reminder to review certain sections in 'Your Diabetes Handbook'.
 - A management plan.
 - A specific request to contact the diabetes nurse specialists weekly after clinic until the next HbA1c clinic appointment. Further plans will be discussed at that clinic visit about on-going expected contact.
 - An extra clinic appointment in 4-6 weeks time for a repeat HbA1c test. The diabetes nurse specialist will see you at this visit.
- If the HbA1c value has not improved significantly by the next diabetes clinic visit in three months time, the team will discuss a planned hospital admission with you to review your/your child's diabetes management (for those young people up to 16 years of age).

What happens if I am asked to come into the ward for 'review of glycaemic control'?

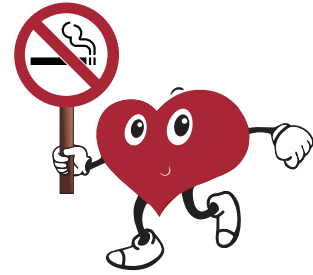
- This will again be discussed with you at the three month clinic visit after you/your child started the high HbA1c policy.
- The diabetes team will arrange a suitable admission time for you. You will be informed of this date and time by telephone. Generally this planned admission is from a Monday early afternoon until the Friday.
- It is **essential** that a parent/carer is available throughout the four days to take part in the education review plan and to meet with the necessary staff members at prearranged times. We appreciate that this may cause some inconvenience but we are sure that if this admission is required, you will recognise the importance of addressing the problems relating to diabetes control.

Does the '80 - too high' policy make a difference?

- The diabetes team have audited this policy over a number of years and we are confident that a sustained improvement in the HbA1c value, and importantly in the wellbeing of the young person with diabetes, is seen in most cases. It is well worth the effort involved.

Additional Medical Complications

Good diabetes control and avoiding frequent high blood glucose readings can reduce the risk of developing diabetes-related complications. Choosing a healthy lifestyle by not smoking, taking regular exercise and having a low fat diet will also help to reduce long-term complications developing.



Regularly screening for these complications, which can affect different parts of the body, is essential for early detection and appropriate management.

Understanding the risk of diabetes complications is a sensitive issue but is an important part of learning about diabetes. Complications from diabetes are rare in childhood but good diabetes control in childhood can reduce the risk of complications in later life.

Complications from diabetes can affect different parts of the body. They occur primarily due to the effects of frequent high blood glucose levels on small blood vessels (microvascular disease) and nerves in the body which can then cause damage elsewhere.

Small blood vessel (microvascular) complications

Kidney problems

The kidneys filter waste products from our bodies and pass them out into the urine. High blood glucose levels can damage this filter system resulting in more protein leaking into the urine. Although protein in the urine can be due to many causes, it may be an early sign of kidney complications and so needs to be investigated. If detected early, medication can be given to slow kidney damage although every effort must be made to improve long term control.

Eye problems

Persistently high blood glucose levels will result in damage to the eyes, although this is rare before the age of 10 years. The blood vessels become leaky in the retina at the back of the eye and can progress to new blood vessel formation which will further affect vision. All children above 12 years of age will have an annual photograph taken of the back of their eyes using a special camera. This is a safe and painless procedure which lets us look for any evidence of eye damage and allows early referral to an ophthalmologist for monitoring and possible laser treatment.

Large blood vessel (macrovascular) complications

Over many years poorly controlled diabetes can contribute to large blood vessels becoming narrowed, potentially resulting in an increased risk of heart attacks, stroke and poor blood supply to parts of the body in adult life. Maintaining good diabetes control along with a healthy lifestyle – low fat diet and regular exercise – can significantly reduce the risk of these complications.

Foot problems

Foot problems due to blood vessel or nerve damage are very rare in childhood and adolescence. They occur over many years due to persistently high blood glucose levels and so good control can reduce these problems (ulcers and poor circulation) in adulthood.

Good foot care is very important and a good habit to develop from childhood. Wearing well fitted shoes and appropriate nail cutting will help. If you/your child develop foot problems (ingrowing toenails or verruucas) professional advice can be sought from a podiatrist. They can be accessed through self-referral in Edinburgh, East and Midlothian or through your GP in West Lothian.

Dental health and problems

Please inform your dentist that you/your child have/has diabetes.

Poor blood glucose control can result in dental decay, gum disease and thrush. These problems and subsequent treatment can result in difficulties in eating which in turn can interfere with diabetes control.

The following measures can prevent many of these problems:

- Regular brushing of teeth - twice a day with fluoride toothpaste.
- Minimising sugary foods and drinks as well as keeping these to meal times. All juices (fresh fruit juice, fizzy, diet, diluting, no-added sugar, sugar-free and low sugar juices) can cause erosion/tooth 'wear'.
- Routine check-up visits to the dentist (six monthly).

Treatment can be carried out by your own dentist including procedures requiring a local anaesthetic injection. The paediatric dental team can provide specialist advice if requested by your dentist.



If your child requires a GENERAL ANAESTHETIC for any reason (dental treatment or other operation/procedure) please inform the diabetes team. The procedure will be carried out at RHSC, and the diabetes team will liaise with the relevant doctors and dentists to ensure that your child's diabetes is managed appropriately during the hospital admission.

Medical Conditions Associated with Diabetes

Diabetes is an autoimmune condition. This means that in people with diabetes the body makes antibodies against its own cells in the pancreas which produce insulin, and cause them to stop working. People with diabetes are at increased risk of developing other autoimmune conditions affecting other parts of the body, particularly affecting the thyroid gland, the small bowel causing coeliac disease and the adrenal glands. We therefore monitor for symptoms of these conditions and take bloods to screen for some of these conditions at annual review clinics.

Thyroid disease

The thyroid gland produces a hormone called thyroxine. Thyroid autoimmune disease usually causes an underactive thyroid called hypothyroidism. This can cause symptoms including weight gain, dry skin, dry hair, poor growth, lethargy and constipation. Bloods for thyroid disease are taken at every annual review. Hypothyroidism can be treated with tablets. Occasionally the thyroid gland can become overactive. This causes an increase in metabolic rate, so people are more hungry, but lose weight, and can feel anxious. An overactive gland is also treated with tablets.

Coeliac disease

This condition causes poor absorption of food due to inflammation of the gut lining. Antibodies are formed against “gluten” which is found in grains such as wheat and barley. When someone with coeliac disease eats gluten the lining of the gut becomes affected. Symptoms include abdominal pain, diarrhoea or constipation and poor growth. However, the condition can sometimes be difficult to detect so all children with diabetes are screened. This will be discussed at the 5th visit to the new patient clinic, and then as part of long term follow up as required. Coeliac disease is managed by having a completely gluten-free diet, with the help of expert advice from our dietitians.

Adrenal glands

The adrenal glands produce steroid hormones which help people cope with stress and illness and regulate salt levels in the body. Very rarely, antibodies against the adrenal glands cause the glands to become underactive resulting in hypoadrenalism or ‘Addison’s disease’. Symptoms can be vague and include poor energy levels, muscle weakness, dizziness due to low blood pressure and increased skin pigmentation. We only screen for this if symptoms are present.