

F: Preparing for Home

F1: On going Support

Contact

You will be offered a home visit shortly after discharge from hospital. The dietitian may also be able to make a visit with your specialist nurse.

How often you meet with your nurse will be a joint decision between you. We offer nurse led appointments in our children's and young people's diabetes centre. It is a pink building just at the entrance to St James's hospital and is known as the multispecialty outpatient department (MSO).

School visits



If your child attends school or nursery we will go into school shortly after discharge to teach staff how to look after 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 will need to go into school initially until the designated staff have learnt how to manage all aspects of caring for diabetes within the school environment

Structured Education

You and your child/young person will be invited to attend structured education group sessions. We hold regular sessions for newly diagnosed children and their families as well as further update sessions. The classes include subjects like carbohydrate counting, exercise and lifestyle management and insulin pumps.

Attendance at these is a really important part of diabetes care. Learning as much as possible about diabetes helps achieve much better control.

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. If these feelings continue and your family and your child find it hard to deal with these, we have a psychologist who is a member of our team and can help with motivation to look after the diabetes. Your diabetes nurse can talk to you about this.

Annual review

Routine clinic attendance is every 3 months. Sometimes you will be asked to attend more often if the diabetes is being a challenge to control. One appointment each year will be an annual review. At this appointment as well as weight, height, HbA1C and meter downloads, the following will be performed:

- Injection technique and sites checked
- Feet looked at and foot care advice
- Education update
- Blood sample taken to check for coeliac disease, thyroid problems and other blood levels such as cholesterol
- Urine sample taken to check for protein
- When over 12 years, we will begin to talk about healthy lifestyle issues such as smoking and alcohol
- Retinal screening

Coming to clinic is a really important part of diabetes care; the team are there to help support you in the management of diabetes and to help you to keep the best control that you can achieve in order to stay well, attend school/ college and to grow and develop.

If you have any questions or worries about these checks then please don't hesitate to discuss them with the diabetes team

Dental Health



Caring for teeth is also an important part of good diabetes care.

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

Children under the age of 7 will need help and supervision.

Visiting the dentist regularly for check ups, preventative advice and treatments will help to keep a healthy smile. Remember to tell the dentist that your child has diabetes. Ensure that your child eats normally before their appointment in order to reduce the risk of hypoglycaemia. Morning appointments are preferred.

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

Foot care



The blood vessels supply oxygen and nutrients to the muscles and nerves. The blood vessels in the feet can be damaged by persistent 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, good foot care for children with diabetes is important

We would advise the following

- 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

If you have an **urgent** foot problem please contact your local hot foot phone line for advice.

Alternatively, a member of the diabetes team can refer your child to the podiatrist.

Disability Living Allowance

All children with diabetes are eligible to apply for the Disability Living Allowance. This is non means tested and does not mean that your child will be registered disabled. The payment is to help with the extra care and attention that children with diabetes require. It is not usually paid to children over the age of 16, unless there is another medical condition.

You may obtain forms from the benefits agency on **0800 882200**. Alternatively, you can complete the forms online. Your specialist nurse will be able to help you.

Diabetes UK



This is a charity helping people living with diabetes. It is free for children and families to join for the first year. They provide support and information for people with diabetes, their families and also have a professionals section. We would advise joining Diabetes UK as they organise link 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

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 and provide information and resources such as the "Talking T1" toolkit for raising awareness

F2: Parents and Children's Diabetes Support Groups.

The specialist diabetes nurses will talk to you about local support and will give you appropriate contact numbers. The possible options are listed below:

1. If you want to be paired with another parent in your area to discuss how you are doing and share ideas, then discuss this with your Diabetes nurse and she will arrange an appropriate contact.
2. Diabetes UK Leeds can be contacted at diabetesleeds@hotmail.co.uk.
Website - <http://leedsdiabetes.btck.co.uk/>
3. JDRF has lots of local branches and is a great source of information for type 1 events and research. See <https://jdrf.org.uk/if-your-child-has-just-been-diagnosed/>
4. Digital Resources. There are lots of groups on Facebook you can join including CWD UK, Parents of Children with Type 1 Diabetes in the UK and lots of regional network groups. Twitter is also a great source of Type 1 bloggers and to connect with diabetes specialists.

F3: Important information you may need to write down and keep where you can see it
e.g. pinned to your fridge.

Important information on your insulin regimen.

Date last changed:

My insulin to carbohydrate ratio at **breakfast** is 1 unit of insulin to: _____ grams of CHO

My insulin to carbohydrate ratio at **lunch** is 1 unit of insulin to: _____ grams of CHO

My insulin to carbohydrate ratio at **evening meal** is 1 unit of insulin to: _____ grams of CHO

My insulin sensitivity or correction factor is 1 unit of insulin for every _____ mmols/L of blood glucose above 5mmols/l.

My long acting insulin is called Glargine/Detemir and the dose of long acting insulin is: _____ units and I give it at _____ (time).

My glucose tablets are stored: _____

My glucagon kit for emergency hypo treatment **is in the fridge** (check expiry date).

Section for added comments

F4: Immunisations

It is important that all children and young people with diabetes receive their routine immunisations. It is also 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 as well.

F6: Clinic Information for Children and Young People with Diabetes

Children

When visiting the clinic, you will see members of the Children's Diabetes Team, usually a Consultant, Children's Diabetes Nurse Specialist and a Dietitian. Psychologists sometimes attend as well. There may be a visiting doctor, nurse or medical student, but you can ask to be seen without them being in the room if you prefer. You can see any member of the Diabetes Team on their own if you would like to discuss something privately, or make a separate appointment to see your Diabetes Nurse or the Dietitian if you need a longer appointment. You will also have the opportunity to be referred to our Psychologist or a Social Worker.

You will have your height, weight, blood pressure and HbA1c measured at each clinic appointment. We will also download your blood glucose meter(s) and pump if you have one. It is very important that you bring all of your meters to clinic so that we can use all the information to help you to manage your diabetes. Once you are familiar with this, you may be able to download your data at home and email it to us before you come to clinic, in order to give us longer to consider it before we see you to discuss any changes which might help you.

Once each year, you will have an Annual Review, which is a bit like an MOT for a car. We will check your injection/cannula sites and your feet, and advise you about keeping them healthy. You will be asked for a urine sample to check your kidneys are working well and you will have a blood test to screen for coeliac disease or thyroid conditions, and to check other blood levels like cholesterol. After the age of 12, you will have retinal screening to make sure the back of your eyes are healthy.

You will always be offered a clinic appointment every 3 months, but we may ask you to come more often if there are difficulties with managing your diabetes, or you need frequent changes of insulin doses whilst you are growing rapidly. You may also have separate appointments with your Diabetes Nurse for things like Continuous Glucose Monitoring or if you want to look at insulin pumps.

If you are unable to attend any of your appointments, please telephone to arrange another appointment. We can then give your unwanted slot to somebody else.

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 but you will move to the Transition clinic around 16 years. This is held in the same place as the children's clinics (Multispecialty Out-patient Building, St. James). The Transition Clinic is held on every Wednesday morning and some afternoons of each month. You will still see members of the Young People's Diabetes Team, also called the Transition Team. Dr Ramzi Ajjan from the adult service will also be in clinic for those who are aged 18 to 19 years so that you get to know him before you move to the Young Adult clinic.

You will see your consultant, young people's diabetes nurse and dietitian. 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 good control of blood glucose. 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. If you are unable to attend any of your appointments, please telephone 0113 2066897 to arrange another appointment and allow us to use that one for someone else.

Young Adults

Whilst you are attending the Transition Clinic, you will be introduced to one of the Adult Consultants. When you are about 19 years old, you will be transferred to the care of the Young Adult Team. Our Youth Worker can attend your first appointment there with you if you like, and you will still be under the care of your young people's diabetes nurse (and be able to contact her) until you attend your first appointment and meet the young adult nurse who is going to be your new nurse.

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. You will be asked to have any blood tests taken in the blood room

or at your GP surgery a couple of weeks before you come to clinic. You will see the Diabetes Nurses for Young Adults and the Dietitian.

Because you are now an adult, you are responsible for your own diabetes management, although the Young Adult Diabetes Team will help you with this. If you cannot attend an appointment, please telephone 0113 2065066 to rearrange it. This means that you will get another appointment to suit you and we will be able to see someone else. If you don't ring to rearrange and don't turn up for an appointment, you will be discharged from the hospital diabetes service and you will then have to ask your GP to re-refer you for another appointment with the specialist team.

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.

F6: Diabetes Youth Work

In the diabetes team we have a youth worker who offers a range of support for young people with diabetes.

There are a number of groups and activities delivered by the youth worker for young people with diabetes including the steering group, newly diagnosed patient support group, buddy system and school workshops in partnership with psychology.

Alongside a range of group work, young people can have access to individual support in areas such as:

- Confidence and self-esteem building
- Bullying
- School Issues
- Supporting NEET Young People (Not in Education, Employment or Training)
- Careers advice
- Drugs and alcohol
- Sexual Health Advice
- Healthy Lifestyle advice / Group work
- Support increasing independence
- Social relationships and friendship issues
- Supporting young people to engage with the Diabetes team (if not attending clinic)
- Support young people in improving communication skills to aid their engagement with Diabetes
- Improving confidence in self-managing diabetes and increasing independence

Young people who are aged 13 and over can access a C-Card from clinics which enables patients to get access to chlamydia and gonorrhoea screening, pregnancy tests, free condoms and information on sexual health and relationships. This is a confidential service and if you would like more information, please speak to a member of the team or youth worker.

Diabetes with 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. We can advise people with diabetes who do smoke and refer to Leeds Smoking Cessation Service. We will discuss driving regulations and can advise on careers, leaving home etc.

You will be screened for any early signs of complications by having your urine, blood pressure and eyes checked. We do not expect to find any problems, but if any are found, the right treatment can begin straight away. You will have an Annual Review every year like you did before.

F7: 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 here to help. Please email or contact your nurse if you are not sure what to do next. Always ring the office or emergency numbers (if urgent out of hours). Some ideas about when to contact us are listed:

Hypoglycaemia

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

High Blood glucose levels

- If there is a trend with your blood glucose levels rising into double figures.
- If your weekly average blood glucose level (see meter) is rising above 9.5mmol/l

Variable swinging blood sugars

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

E mail the results to your diabetes specialist nurse.

Make a note of questions you may want to ask.