

E: Preparing for Home

E1: Ongoing 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 you/your child attends school or nursery, we will go into school shortly 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 have learnt how to manage all aspects of caring for diabetes within the school environment. School staff will be asked to attend one of our regular school workshops to receive comprehensive education about diabetes management in school, and practise using the equipment.

Structured Education

You will be invited to attend structured education group sessions. We hold 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. We provide a week long course WICKED (Working with Insulin, Carbs, Ketones and Exercise in Diabetes) for young people aged 16+ years. We hold regular pump

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

Attendance at these is a really important part of diabetes care. Learning as much as possible about diabetes helps improve management.

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 you or your family find it hard to deal with these, we have psychologists in the team and can help with motivation to look after diabetes. Your diabetes nurse can talk to you about this.

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 you have diabetes. Make sure that you eat normally before the appointment in order to reduce the risk of hypoglycaemia.

If a general anaesthetic is required for treatment then you 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 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, 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 athlete's foot, verrucae or ingrowing toe nails

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). This is not means tested and does not mean that your child will be registered as 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; then you could apply for Personal Independence Payment (PIP).

You may obtain forms from the benefits agency on **0800 121 4600**. Alternatively, you can complete the forms online. Your specialist 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

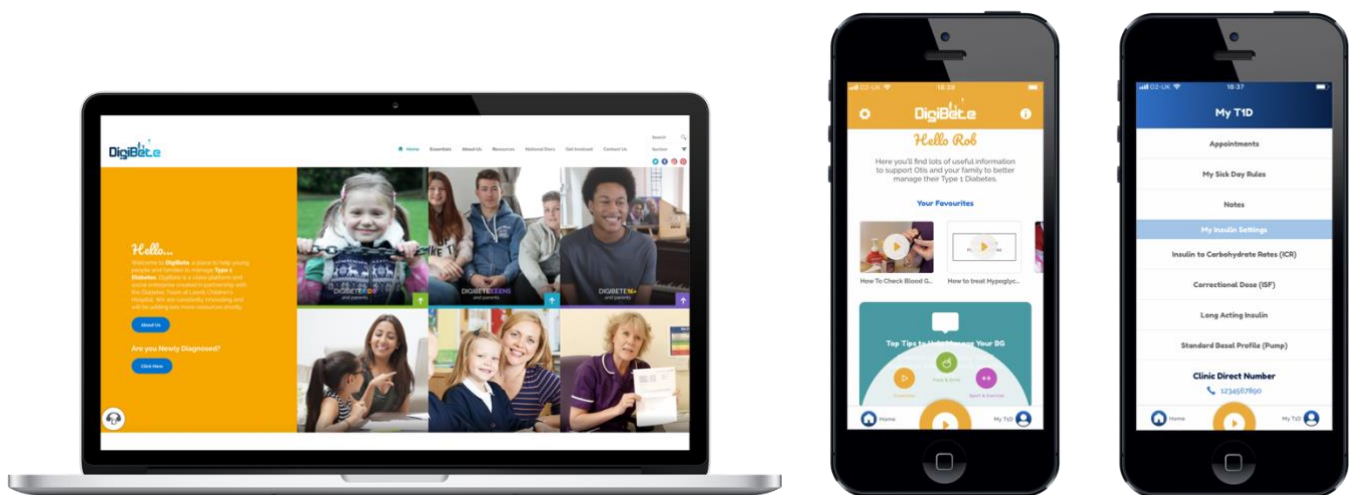
DigiBete is a video platform and App created in partnership with the Diabetes Team at Leeds Children's Hospital for use by families nationally. The videos are designed to help people and families self-manage their Type 1 Diabetes. Thanks to NHS Diabetes Programme and the Welsh Government the App is now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

There is now a free DigiBete App which not only houses video education and resources relevant to a young person's age but also enables the hospital team to send you useful updates, tips and invites to take part in activities that will support your self-management. Your diabetes team will give you a code to register as part of this service.

Please do visit www.digibete.org and <https://www.digibete.org/digibete-app/> to download the Free App today. We hope that you find these resources useful, and we welcome and feedback that you might have.

You can also keep in touch through:

Facebook: DigiBete
Twitter: @DigiBeteUK
Instagram: @DigiBete



JDRF



dedicated to finding a cure

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 and schools training for raising awareness

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

E3: Immunisations

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

E4: Clinic Information for Children and Young People with Diabetes

Children

The children's clinics are held on the First Floor of Multispeciality Outpatients, St James's University Hospital. You will see members of the Children's Diabetes Team, usually a Consultant, Children's Diabetes Nurse Specialist, a Dietitian and sometimes a psychologist. As this is a Teaching Hospital, 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, Dietitian or psychologist if you need a longer appointment.

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. You will be encouraged to download your data at home, to help you to see patterns and share your data with clinic, so we can discuss any changes over the phone or email, between appointments.

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, and discuss relevant lifestyle issues such as alcohol or smoking.

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. If you are unable to attend any of your appointments, please telephone 0113 2064996 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; we have separate clinics for those aged 13-16y and 16+years. These are held in the same place as the children's clinics (Multispecialty Out-patient Building, St. James).. You will see members of the Young People's Diabetes Team, including the youth workers. 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, 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. If you are unable to attend any of your appointments, please telephone 0113 2064996 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. One of our Youth Workers also attend the young adult clinic. 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. There will be a Diabetes Nurse for Young Adults, a Dietitian, and a psychologist available in clinic.

If you cannot attend an appointment, please telephone 0113 2064819 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.

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.

E5: Diabetes Youth Work

As part of the wrap-around care that is provided by the diabetes team, we also have a team of youth workers who offer a wide range of support for young people aged 13+.

There are a number of groups and activities delivered by the youth workers for young people with diabetes. These include:

- Youth Club
- Young Person's Forum
- Newly Diagnosed Patient Group

Alongside group work, young people can also have access to individual 1:1 support in areas such as:

- Alcohol & drugs
- Bullying
- Confidence & self-esteem
- Supporting NEET (Not in Education, Employment or Training)
- Careers / education advice
- Sexual health / relationships
- Healthy lifestyle advice
- Increasing independence
- Support to engage with the diabetes team
- Improving confidence in self-managing diabetes
- Signposting to other agencies

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

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. 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.

E6: 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. There is never a daft question! 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 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.