

R.H.S.C. DIABETES NEWSLETTER

For those attending Paediatric and Adolescent Clinics in Lothian

February 2015

Don't forget about 'Your Diabetes Handbook'!

Sometimes it can be very easy to forget where to turn for extra tips and advice about diabetes management when things seem difficult and hard to make sense of.

Do remember to look at your diabetes handbook either as a hard copy (if you have one) or on-line (easiest way is Google: Lothian Paediatric Diabetes Handbook 2013, or use the link:

<http://www.nhslothian.scot.nhs.uk/Services/A-Z/DiabetesService/Pages/ChildrenAdolescents.aspx>)

Here are some useful sections of the diabetes handbook to refer to:

1. **Hypoglycaemia chapter:** page 2 'Treating a Hypo' and page 5 'Individualised hypo management'
2. **Clinic chapter:** page 9-12 'Understanding the HbA1c test'
3. **Sick Day Management chapter:** page 4-5 'Examples of Sick Day Management'
4. **Day-to-Day Diabetes Management chapter:** a useful whole chapter to revisit
5. **Exercise and Sport:** a useful whole chapter to revisit.

Please do not hesitate to ask a Diabetes Team member if you need further help with any diabetes-related problem.

HbA1c Target

As you all know, a blood sample is taken and sent for an HbA1c test each time you come to clinic. This gives an indication of the overall control of diabetes over the previous three months.

In our handbook we say that the target HbA1c is "less than 60mmol/mol." However, the national target is an HbA1c of **less than 58mmol/mol.**

This result will be achieved if the average blood glucose over the three months is 9mmol/l or less. If you keep a regular check on the averages on your meter and the averages are creeping above 9, please review the chapter in the handbook about 'Day-to-Day diabetes management', and call the team if you are having ongoing difficulties and need more support.

It is our standard practice to document on all the clinic letters a comment regarding the HbA1c value. You will therefore see one of the following:

- The HbA1c result is in the target range for people with diabetes.
- There is an increased risk of health problems if the HbA1c persists above 58mmol/mol (58-75mmol/mol).
- There is an extremely high risk of short and long term health problems / complications if the HbA1c persists above 75mmol/mol.

Update to our High HbA1c Policy

You will hopefully be aware of our previous High HbA1c Policy "85 – too high", detailed on page 13 of the Clinic chapter in 'Your Diabetes Handbook 2013.' This is a supportive and structured approach to help families and young people work with the diabetes team to improve their diabetes care, when their HbA1c is significantly above target. It is in place to help you and in no way is it to be seen as a punishment. We have reviewed the HbA1c value, which now 'triggers' the need for support with the high HbA1c policy. The new policy is as follows:

- **"80 – too high"** for all young people who have been diagnosed with type 1 diabetes for a year or more.
- **"70 – too high"** for those who have been diagnosed for less than 1 year.

This will be discussed fully with you at your diabetes clinic and please remember that the whole team are here to support you!

Please don't be a clinic 'non attender'

Missed clinic appointments can deny other people access to a clinic appointment slot. If you are unable to keep an appointment, please

1. Contact RHSC Appointments on 0131 0814/0150 as soon as possible to rearrange
2. Leave a message on the Diabetes Nurses answering machine (0131 536 0375).

This is particularly important for annual review appointments because of the limited number of available slots. A missed clinic appointment costs NHS Lothian an estimated £200 per appointment.

Diabetes review clinics are given three-monthly in order to support and monitor you/your child's diabetes management, and to observe and chart your/your child's growth and general health. Your next clinic appointment should be made as you leave clinic, which will hopefully ensure that you receive a suitable time and date. If the clinic staff are not available to make the appointment, you will receive a letter in the post with your next appointment.

Please contact RHSC Appointments on 0131 536 0814/0150 for an alternative appointment if that one is not suitable for you.

A positive message from Ellen

"Before I had diabetes I loved sports and since I was diagnosed almost five years ago, I've started playing and doing more and more sport. About a year ago I took up rowing and while I still enjoy hockey, netball and swimming, rowing has definitely become my favourite sport. I train for five days a week and I have to make sure I plan my insulin really carefully so that I can get the most out of training.

"In December my coaches wanted me to compete in the Scottish Indoor Rowing Championships. I was a bit wary about doing it as I hadn't been rowing long. As the competition got nearer, my blood levels were starting to go a bit crazy but I knew I wanted to compete and wouldn't let my diabetes stop me. On the day, I managed to win 4th place for S3 girls, 5th for under 15 girls, and 1st for the under 16 girls relay. Over the two days my blood levels were definitely tough to manage but I got through it and I'm glad I didn't let diabetes stop me.

"After my races it was the adaptive rowers' competition. All of them had at least one limb missing and it was incredible to watch. After watching them I realised diabetes definitely isn't the worst thing to have. Now I know what I can achieve, I have goals for this year and I'm ready to work hard to achieve them."

Recipe time – one to try!

Red Lentil Soup

A tasty soup ready in 30 minutes!

Serves 2.

Ingredients:

- 100g/3½oz red lentils
- 1 small onion, chopped
- 1 carrot, chopped
- 1 clove garlic, crushed
- 600ml/1 pint good vegetable stock
- 2 tablespoons light crème fraiche
- 1 tablespoon fresh parsley, chopped
- Salt and freshly ground black pepper.

Instructions:

1. Place the lentils, onion, carrot, garlic and stock into a pan, bring to the boil and simmer for 20-25 minutes until the lentils are tender.
2. Transfer to a blender with the crème fraiche and parsley and blend until smooth. Season and serve with a chunk of bread.

Nutritional information:

Each serving contains: 75 calories, 4g protein, 14g carbohydrates, 3g fat.

Diabetes websites for Children and Young People with Type 1 Diabetes

There are so many places on the internet to search for further support and information about type 1 diabetes that at times it can seem overwhelming. We would like to suggest some websites that we think are particularly relevant:

- www.diabetes.org.uk Click on '**Guide to Diabetes**' then choose from 'My Life – info for children', or 'Info for teenagers', or '#Type1Uncut for young adults'
- www.justduk1t.org.uk See the article on the following page
- www.diabetesinscotland.org.uk Click on '**Groups**' and then 'Childhood and Adolescent Diabetes Scotland'

JUST DUK 1T – an online resource for young people with Type 1 diabetes

In 2013, young people from across Scotland came together to produce a website that was relevant and accessible for other young people living with Type 1 diabetes. The overall aim of the website is to make sure young people have access to the information they need to ensure they have optimal knowledge of their condition, can build confidence, and have the necessary skills to self-manage, whilst engaging in the activities and challenges any young person faces.

JUSTDUK1T.org.uk has seen 42,909 visitors since its launch in September 2013. The young people have full ownership of the website and regularly post engaging and thematic content on the site and the associated Facebook and Twitter pages, with over 500 followers on each account.

The website itself hosts a wide range of information from what to expect at diagnosis, to how you can keep yourself safe in social situations, and how to stay fit and healthy. It also has many links and references to other useful sites and resources for young people to make use of and explore.

The biggest benefit of this site is that it has real-life examples of young people's lived experience of Type 1 diabetes – making it easier for young people to relate to it all. Another focus of the group was to use this website to reach out to other young people and connect with them, removing the isolation that many face.

What does JUST DUK 1T mean?

For the young people in this group, they felt that sometimes it can feel like nobody understands how difficult it can be living with Type 1 diabetes and that often it feels like you are expected to 'just get on with it'. They have all faced with comments such as: "oh so you JUST have to do a couple of blood tests or injections every now and again and you're fine" or "so you JUST have to watch what you eat."

The clever tagline 'DUK the highs, DUK the lows, DUK diabetes' represents getting on with your life and dealing with all the highs

and lows of diabetes as you go. The group have purposely incorrectly spelled the work 'DUK' as a link to the charity Diabetes UK (DUK). However, feel free to take from it what you wish!

You can find out more by visiting:

www.JUSTDUK1T.org.uk
www.facebook.com/JUSTDUK1T
www.twitter.com/JUSTDUK1T

A message from Lothian Families with Diabetes Voluntary Group

The Lothian Families with Diabetes Voluntary Group was set up in 2011 and currently has membership of around 50 families.

The group was set up with the primary focus of helping children to make friends with other local children with diabetes and enable parents and carers to share experiences, tips and knowledge. They run a series of informal and fun events during the year from 'The Panto' to BBQ's, giving families a chance to get together if and when they can. They also encourage the children to get involved in sponsored events or fund-raising like bag packing or can-collecting to raise funds for Diabetes UK and support the Group's activities.

They would love to hear from you!

Our contact details are:

Email: LFWD@hotmail.co.uk

Website:

<http://edinburgh.diabetesgroup.org/home/lothian-families-with-diabetes.asp>

Facebook: Lothian Families with Diabetes

Hello from a new member in our Diabetes Team

"Hi everyone! I'm Leigh Owens and I am the newest dietitian in the Diabetes Team. I work here two days a week – mainly Thursdays and Fridays, alongside Cat and Mary. I have worked as a dietitian in Lothian for over 11 years, covering many areas of dietetics, and have most recently been involved in setting up the Lothian Paediatric Weight Management Service.

"I am very excited to be part of the RHSC Diabetes Team and look forward to meeting you all in the future."

Medalists of the Future, by Dr. Harriet Miles

"In November, I attended the annual British Society for Paediatric Endocrinology and Diabetes Conference. Professor Edwin Gale, from Bristol University, gave one of the keynote lectures entitled 'The Future of the Child with Diabetes.'

"Professor Gale is an Epidemiologist; he looks at statistics. Recently, life expectancy has increased across the whole population. Over the 20th century, three months' average life expectancy can be added for every calendar year of birth, which means that epidemiologists predict that for children born in 2012, 1 in 3 girls and 1 in 4 boys will live to the age of 100 years.

"The life expectancy of a person with type 1 diabetes diagnosed before insulin was widely available was 1-2 years; by 1945 a newly diagnosed 10-year-old had a life expectancy of 45 years, and in 2004 the life expectancy for people with diabetes was about 15 years less than the general population. It will take a generation for the effects of the new insulins and ways of delivering insulin to affect the predictions for 2014. However recent estimates from Sweden are that the gap has decreased to 8-10 years.

"A famous American diabetes doctor, Dr. Joslin, first began awarding medals as recognition of hard work and success to people with diabetes in 1948 with a 25-year Victory Medal. He believed that excellent self-management was the key to minimising long-term complications and the medals served as an incentive for those committed to good, though challenging, diabetes control.

"As more and more people lived long healthy lives with diabetes, it finally became the 25-year Certificate that is awarded today. In 1970, Joslin expanded the programme and began awarding a 50-year bronze medal and Joslin presented the first 75-year medal in 1996.

"Since 1970, the Joslin Diabetes Centre has presented more than 2905 "50 year" medals and 28 "75" year medals.

"The Joslin Centre asks their 50-year medalists to fill in a research questionnaire. The study attempts to understand what factors contribute to the longevity of individuals who have received this honour. Professor Gale reported that medalists can be divided into three groups: Survivors who get complications but live longer, Delayers who get complications but later, and Escapers who are never seriously damaged by diabetes.

Professor Gale stated that escapers tend to be "self directed people with strong personalities." The medalist population are also likely to have metabolic protective factors against complications and there is ongoing research to try to identify these from DNA and blood samples. We have learnt from studies of tight control that benefits of an initial period of good glucose control has a long lasting effect. The term metabolic memory has been applied to this observation.

"Our advice to children and young people in our Diabetes Clinics about target HbA1c comes from these trials. We all wish to see our patients equipped with the knowledge and ability to achieve good glycaemic control to allow them to become the 75-year medalists of the future."



We'd like to hear from you

If you have any comments on the content of this newsletter, or would like to suggest ideas for future articles, please e-mail us at marion.henderson@nhslothian.scot.nhs.uk or write to The Diabetes Team, Royal Hospital for Sick Children, 9 Sciennes Road, Edinburgh, EH9 1FL. We would welcome your feedback and suggestions.