

BITESIZE

Exeter Children and Young People's Diabetes Service

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Dr Chris says...

Advances in technology & treatments for diabetes have been frequently in the news over the past few months. It is exciting times ahead for both researchers looking for a cure & using new technologies to make the burden of day to day management of diabetes easier. Here are a few examples.

Harvard University published results in the journal 'Cell', a laboratory study that aimed to develop a generation of insulinproducing pancreatic beta cells from stem cells. In the person with diabetes the beta cell from the pancreas no longer produces insulin. The results showed that these manufactured beta cells function similarly to normal adult beta cells, both in the laboratory & in the live mouse they transplanted the cells into. The research is still in the very early stages, with studies only having been carried out on a small number of live mice. Further development is needed to see whether it could be possible to

perform human trials to see whether stem cell-derived pancreatic cells could function normally in people with type 1 diabetes. Other areas of research include using insulin pump therapy & a real-time glucose sensor continuously monitoring the person's sugar level (by measuring the level in the interstitial fluid that surrounds body cells) overnight & then tomatically increases or decreases insulin delivery in response to this, as would normally happen in the human body with a healthy pancreas. The research was carried out by Cambridge, Sheffield, Southampton, & King's College London and was funded by Diabetes UK. This closed-loop system improved time spent in the target range in all but 3 of the 25 adult participants. It also reduced the average overnight sugar level and the time spent above the target range without any increase in hypoglycaemia. This study was only carried out at night (while resting) so the next steps will be to look at developing the device to

respond to carbohydrates & exercise. In Boston University 2 trials have been carried out in adults (20 adults during their normal work routines) & 32 adolescents (at a diabetes camp) with an insulin pump (containing insulin & a hormone glucagon) & a real time glucose sensor to measure their blood glucose. The insulin lowers blood glucose however when the blood glucose falls to hypo levels the glucagon is released to raise the blood glucose. Overall, the device improved blood glucose levels while significantly reducing hypos in adults & reducing the frequency of hypos in adolescents. More trials are planned with a greater number of participants. We are sure it is frustrating to hear about these new advances knowing it may be some years until they are ready to be used by you. As a team we are committed to making sure that we use the best available technology & practical advice to suit you & your parents or carers.

Merry Christmas

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NHS Health Apps library

launched in March 2013, contains about 200 apps, which have been reviewed by the NHS and clinicians to ensure that they are safe and trusted.

Some are adult diabetes related (particularly type 2) but they also contain some useful apps on healthy lifestyles, alcohol and giving up smoking.

http://apps.nhs.uk/

PDSN on call arrangements for Christmas & New Year

The Paediatric Diabetes Specialist Nurse Team will continue to provide urgent telephone advice during the Christmas period, from 8am-6pm via the hospital switchboard. From 6pm-8am calls will continue to go through to the Paediatric Registrar on-call for Bramble Unit. As usual, non-urgent calls should be made via our office telephone number: 01392 403727 and will be replied to on the next working day (Monday-Friday).

Please ensure you have adequate supplies of insulin and equipment prior to the festive period. Please call us for urgent queries.







Though I have not tested the Count and Count Carbs (not android ready yet) other dietitians say it is very useful and have recommended it — Maria

Cook & Count Carbs is for enabling people who cook at home to be able to easily find and total the carbohydrate content of whatever they are cooking. This makes it easier for them to avoid processed foods, ready meals and takeaways, thereby improving their health.



Foodswitch app for healthy eating

Foods can be surprisingly high in salt, fat, saturated fats and sugar, but sometimes it is difficult to understand nutrition labels on food packaging. Food-Switch is an award-winning, free smartphone app that helps you make healthier food choices (it doesn't give information on total carbohydrate contents).

Consensus Action on Salt & Health (CASH) and partners have produced a free and simple to use app for smartphones to help you find out what's in the food you're eating, so you can make simple switches to healthier options. Food-Switch allows you for the first time to scan the barcodes of your food and drinks products and instantly see whether they are high (red), medium

(amber) or low (green) in fat, saturates, sugars and salt per 100g.

It also searches the database for similar but healthier alternative products, making it easier than ever to switch to healthier food choices. FoodSwitch is available as a free, UK-only download from iTunes and Google Play. See www.foodswitch.co.uk for more information

Here are some internet resources our parents and young people advise

Julia, Alex's mum recommends the following

1) Many T1 Facebook groups exist support but this one is the best: CWD (Children With Diabetes) Facebook page: https://www.facebook.com/groups/UKCWD/ They also have a Teen page (for the kids which is moderated) and a schools page (for parents having school issues) linked from the main site. If you request to join you will be asked to confirm by Admin that you have a child with Type 1 etc.

- 2) INPUT is an advocacy group to give help and advice about insulin pumps and CGMs. They have very well written, clear English information about pumps and CGMs. http://www.inputdiabetes.org.uk
- 3) Professor Peter Hindmarsh a leading endocrinologist in the UK and based at UCLH has a blog with some very interesting and useful info about Paediatric Type 1: http:// theprofsblog.tumblr.com
- 4) Ninjabetic Blog of a 20 something woman with diabetes. She gives good insight into the struggles of someone living with Type 1 and helps us parents

understand the pressures and issues of a Type 1. http:// ninjabetic1.blogspot.co.uk

5) Also, on Twitter if you search for the hash tag #doc (Diabetes Online Community) you'll get all sorts of helpful and interesting tweets with a varied and wide-ranging spectrum of T1 issues, news and viewpoints.

Jo, Jacks' mum says that as a parent of 7 and a half year old boy who has had diabetes for 5 years I have had plenty of time to cry, feel sorry for myself and generally despair! But there is plenty of technology out there that can make your life a little easier and make managing this condition do-able! Here's a couple of my favourite Apps. Please do share anything that you find useful too!

- 1) Carbs and Cals An essential App for anyone who is carb counting. For a few pounds it lists hundreds of food items and their associated carb, fat and calorie content. It also has the facility to set up and save the carb content of whole meals and allows you to track your daily exercise.
- 2) Gluten Free on the Move This is a great free App for any diabetics who also have coeliac disease – as you will know balancing the two conditions can

be tricky as can finding appropriate snacks. It contains a local venue guide showing pubs and restaurants with a GF menu as well as having a comprehensive food and drink directory (you need to be a member of coeliac UK to access this bit!) identifying hundreds of GF products from the main supermarkets as well as having a scanning facility so you can check product suitability as you shop.

Dan, a young person with diabetes says "that soon after I started carbohydrate counting, I discovered the Carbs & Cals app for the iPhone and iPod Touch, as well as for Android smartphones which costs £3.99 and is great for being able to work out carbohydrate content on the go."

"I found it very useful for being able to work out carbohydrates when I was eating out and not having to carry the book with me. When it came to working out carbohydrates for a meal, I could tap a button which would add it to a meal so I could calculate the overall carbohydrate values right within the app, I could find my portion, tap the button and it would add all the carbohydrates up and give me an overall total."



Easy American style pancakes (low fat and low sugar)

recommended by Jamie's mum

140g self raising flour

225ml semi skimmed

milk

1 egg

1 complete pear grated, including skin and core.

Mix all ingredients together.

Drop spoonfuls into a hot frying pan previously sprayed with oil.

Turn when bubbles appear.

Make 8 pancakes (17g carbohydrate each)

Serve with fruit compote or banana and drizzle of honey and a blob of 0% fat Greek yogurt.



Q & A

Got a query that you feel everyone will want the answer to? Send your questions to us by post, at clinic or at maria.leveridge@nhs.net and put BITESIZE in the subject line

Help Yourself Online

by Dr Sophie Bishop Clinical Psychologist

The internet can be a fantastic source of information. However some sources of information can be more reliable than others. If you are feeling overly anxious or worried about things (not just diabetes) some of these sites below provide useful information on how to help manage your fears.



The following sites are suitable for teenagers and parents of younger children. Here are some of our favourites:

Anxiety BC: This interactive and friendly website provides parents and young people with information about managing all types of anxieties http://www.anxietybc.com/

The Site: An amazing website for 16-25 year olds that gives general life advice. Here you can find information on everything from mental health to money and travel and everything in between. http://www.thesite.org/

The Calm Zone: This website is aimed at young men who are experiencing low mood providing a webchat and helpline for those who need support. https://www.thecalmzone.net/

Young Minds: This is a place for both parents and young people providing information and knowledge regarding the emotional wellbeing and mental health of young people and even have a parent helpline. http://www.youngminds.org.uk

...and for diabetes specific information and advice visit:

Diabetes.org.uk: Many of you will have probably already visited this site. It's fantastic for parents and there are even 'my life' sections for children and teenagers. (http://www.diabetes.org.uk/)

Snackpack Website: The snackpack website, as many of you will be aware, is a great source of support and advice containing links to other resources and details of local events for families. (http://www.snackpack.org.uk/Core/snackpack/Pages/Default.aspx)

South West Paediatric Diabetes Network Parents Group is also an great resource for parents of children with diabetes and this links into the National parents network. . You will find them on Facebook https://www.facebook.com/groups/351695801609372/ or email your parent representatives Karen Harrison (kd.ra.harrison@gmail.com) and Louise Arnold (louise Arnold (louise@larnold.co.uk)).

Although the internet community is a fantastic support & information resource, the online community will not know your child as well as you or your diabetes team. If your child is ill please call us on the emergency on call service for individualised & safe advice.

Staying Safe Online

- 1) Don't post any personal information online like your address, email address or mobile number.
- 2) Think carefully before posting pictures or videos of yourself. Once you've put a picture of yourself online most people can see it and may be able to download it, (and its there forever).
- 3) Keep your privacy settings as high as possible.
- 4) Never give out your passwords
- 5) Don't befriend people you don't know
- 6) Don't meet up with people you've met online. Speak to your parent or carer about people suggesting you do
- 7) Remember that not everyone online is who they say they are
- 8) Think carefully about what you say before you post something online
- 9) Respect other people's views. Even if you don't agree with someone else's views.
- 10) If you see something online that makes you feel uncomfortable, unsafe or worried: leave the website, turn off your computer if you want to and tell a trusted adult immediately.

http:/

www.safetynetkids.org.uk/ personal-safety/staying-safeonline/



Exeter Children and Young People's Diabetes Service

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Royal Devon and Exeter NHS



NHS Foundation Trust

Urgent & out of hours call 01392 411611 & ask for PDSN on

> Phone: 01392 403727 Fax: 01392 402828

E-mail: rde-tr.PaediatricDiabetes@nhs.net Non urgent dietetic number - 07827239019

Young people at the centre of diabetes care

What would you like to see in the next issue of BITESIZE? Send any items to maria.leveridge@nhs.net by 17th February 2014.

Technology equipment loans

We are sure that many of you have by now been lent one of the CGMS (Continuous Blood Glucose Monitoring) systems to wear at home for 6 days to enable us have some continuous blood glucose data to be able to suggest treatment changes to improve your (or your child's) diabetes control.

You may not be aware but these pieces of equipment are very expensive at £1500 per system and are purchased by kind donations made to our charitable fund. We are unable to insure them via the Trust and therefore we are asking parents to sign a loan agreement form when these are lent to you. This is to ensure that the value of the equipment is acknowledged and every effort is taken to ensure it is returned to the team, for use on other patients, in a good condition.

We of course do not wish to deter anyone from using this very useful tool. To reassure you, the iPRO sensor, when it is inserted, is taped securely to the body and is extremely unlikely to fall off the skin and therefore the chance of losing the item is extremely unlikely to occur.

"Merry Christmas" from all the Diabetes team

- Wesolych Swiat (Polish)
- I'd Miilad Said Oua Sana Saida (Arabic)
- Kung His Hsin Nien bing Chu Shen Tan (Mandarin)
- Feliz Navidad (Spanish)
- Sheng Tan Kuai Loh, Nathar Puthu Varuda Valthukkal (Singapore)
- a Salamet Hari Natal (Indonesi)
- Hauskaa Joulua (Finland)
- Selamat Hari Krimas (Malaysia)



Families with Diabetes The Families with Diabetes National Network (FWDNN)

The Families with Diabetes National Network is working with the medical teams around the country who support children and young people with Diabetes. The teams are reviewing their practises and achievements and are agreeing plans for the future to ensure all our children have the best possible outcomes.

All parent representatives have been asked to find out what matters most to us, the parents, in terms of outcomes for our children. Outcomes' can mean anything that is important to you. We also asked children with diabetes what worried them about their diabetes. 'We produced these two surveys and now sharing it with the Paediatric Diabetes Teams.

Most of you know that the Department for work and pensions (DWP) is hopelessly inconsistent when dealing with claims for Disability Living Allowance for children with type 1 diabetes. They state that all claims are assessed individually and then time and time again dismiss them based on sweeping assumptions about the illness.

The Families with Diabetes National Network are working with Diabetes UK to lobby the DWP to review their guidelines. A 'Take Action Tool kit' has been produced now we need everyone to get involved. We want each and every one of you to write to you MP urging them to push the DWP to undertake such a review.

We would also really like to know about any responses that you receive from your MP. This is our chance to take some positive collective action and try to affect some meaningful change.

To find out more and to receive a copy of the 'Take Action Tool Kit' please join the "South West Paediatric Diabetes Network Parents Group" on Facebook https://www.facebook.com/ groups/351695801609372/ or email your Parent Representatives Karen Harrison (kd.ra.harrison@gmail.com) and Louise Arnold (louise@larnold.co.uk)