

# BITESIZE

Exeter Children and Young People's Diabetes Service

Volume 1, Issue 3

April 2014

## Dr Chris says.....

The Exeter Children & Young Person's Diabetes Service has just had its first Peer Review. This is a process by which our service is benchmarked against quality criteria with the emphasis on providing support for the care we offer you. This process has been designed to drive up standards of paediatric diabetes care in the UK. We will await the full report, which will be available to the public but in essence they were very happy with our service. One of the areas the Peer Review team touched upon was transition.

Once a month the entire Paediatric team decamp to the Macleod Adult Diabetes Centre for the Transition Clinic. This is normally available to adolescents who are 16 years old & above and provides a more adult setting while still seeing the Paediatric team that

you know. We run this clinic alongside our Adult colleagues & increasingly we are doing joint consultations. Marie Dougal-Johnson and Tina Saunders are Adult Diabetes Nurses with a special interest in looking after young people & are very similar in experience to Julie Kitchen & her team. During the Transition Clinic, we will endeavour for you to meet the young Adult team & would normally transfer, if everyone is happy, from the age of 18 onwards. This is often the time of great change with new challenges & stresses and a growing sense of independence and importance. Please let us know if we are getting transition right.

Since October 2013, we have changed the way we start children and young people on insulin pumps. Pump starts have become more formalised since introducing

a validated method that breaks down pump education into chunks that are taught in structured lessons plans using age-appropriate resources. It includes using download software & continuous glucose monitoring to ensure each young person's initial pump settings are correct. We really must try & maximise the use of this fantastic technology but there is a challenge initially to getting to grips with it all. Research into pump technology continues to progress at a pace & is one method by which diabetes control could be improved. Please contact us if you wish any further information about insulin pumps.

Finally we have secured funding for the exercise project that I talked about in the last BITESIZE & we are currently going through the Ethics Committee with a view to recruiting at the end of 2014.

We ran out of space in this issue to talk more on nasal flu, look out for this in the Autumn

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## Disability Living Allowance (DLA) explained

On the 8th April 2013 changes were made to DLA & a new Personal Independence Payment (PIP) was created for those young people over 16 years of age. If you are already in receipt of DLA you will be asked to reclaim for PIP when you turn 16 years old.

The forms are lengthy & the Local Paediatric Diabetes support group (Snackpack) may be able to give you support to help you complete the form

A PDSN will complete the section of the form entitled 'Statement from someone who knows you & your Child'.

### Disability Living Allowance

Parents of children with Diabetes are eligible to apply for DLA, until the child is 16 years.

This is not because a child with Diabetes is 'disabled' but as a recognition that when you have diabetes you have extra expenses like hospital & clinic visits, a healthy diet & hypos treatment. It is not a means

tested allowance.

Application forms are available from:

- your local Social Security office
- phone the Benefits Enquiry Line 0800 882200
- [www.direct.gov.uk/disability-money](http://www.direct.gov.uk/disability-money)

How much you get depends on how much your condition affects you & they look at the amount of care you need.

Current DLA care component rate (as of 8th November 2013):

- Highest rate £79.15 / week
- Middle rate £53.00 / week
- Lowest rate £21.00 / week

DLA is not paid for the first three months following diagnosis. [www.gov.uk/dla-disability-living-allowance-benefit](http://www.gov.uk/dla-disability-living-allowance-benefit)

### Carer's allowance.

If you are awarded Disability Living Allowance at the middle or higher rate, you may be entitled to claim for Carer's allowance.

To be able to claim Carer's allowance

- You need to spend at least 35hrs a week caring for a person
- It is not affected by any saving you have
- It is dependent upon income and other benefits
- Weekly rate £58.45 (as of 15/8/12)
- [www.direct.gov.uk](http://www.direct.gov.uk) - Money Tax and Benefits section

### Personal Independence Payment (PIP)

Young people aged 16 years or over are entitled to apply for PIP.

The payment rate for the daily living component (as of 27/12/13):

- Standard rate £53.00 / week
- Enhanced rate £79.15 / week

PIP awards are made on a case by case basis and are not guaranteed. You are able to appeal the decision. The PDSNs may be able to give a statement to support your appeal.

## Websites for

### physical activity

- <http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-young-people.aspx>
- <http://www.nhs.uk/Change4Life/Pages/become-more-active.aspx>
- [http://www.teenweightwise.com/being\\_active.html](http://www.teenweightwise.com/being_active.html)
- [www.kidnetic.com](http://www.kidnetic.com)
- <http://www.runsweet.com/>
- <http://www.excarbs.com/>

## SNACKPACK COFFEE MORNING

Come along & support  
Snackpack, meet other parents  
& young people with Diabetes  
and eat delicious cake ☺

**Bradninch Guildhall**

**10th May 2014**

**at 9.30 - 11.30am**

That same weekend there will  
be an exhibition upstairs in the  
Guildhall with embroideries,  
memorabilia, letters and  
information dating from WW1.

## SnackPack Update by Marie McAdams

At the Snackpack AGM on  
27th January Marie  
McAdams was unanimously  
voted in as the new  
chairperson of Snackpack.  
Barrie & Ellen (& the rest  
of the outgoing commit-  
tee) were thanked for  
their hard work & dedica-  
tion over the past decade.

We are still hoping for  
the Snackpack weekend  
away at River Dart - 4<sup>th</sup> -  
6<sup>th</sup> July. This weekend is  
heavily subsidised by

Snackpack unfortunately due  
to a recent reduction in  
Snackpack income we will  
have to increase the cost  
this year.

The Junior Committee mem-  
bers are also hoping to de-  
cide on a venue for a family  
outing early in the summer.

We are in need of fund  
raising activities as the last  
grant applications have been  
turned down. So anyone out  
there with an idea for an  
event that might add some

cash to the coffers - your  
SnackPack needs you!

With the resignation of  
several of the committee  
members, we are also in  
need of new members to  
keep the numbers & energy  
at an optimum.

Any volunteers? Please let  
me know.

My contact details are Ma-  
rie McAdams on 01392  
882247 or via email at  
[snackpack@post.com](mailto:snackpack@post.com)  
or our [Facebook page](#)

### EXPERT bolus advice meters

It has come to our attention that  
the Expert meter does not give  
correction dose advice when the  
meter reads HI (high). It is very  
important that you give additional  
insulin using your usual correction  
dose. Call the Diabetes team for  
advice to manage your high blood  
glucose if you are unsure.

## Introducing Marie McAdams

Hello I am Marie and I was  
born in Bantry, Co Cork  
though I spent my early  
childhood in Canada. I quali-  
fied as an RGN & Health Visi-  
tor and my working life was  
within the NHS & Broadmoor  
Hospital.

My granddaughter Niamh was  
diagnosed with Type1 diabetes  
three years ago, & I organised a  
coffee morning in Bradninch that  
year. This has become an annu-  
al event and is well supported by  
the local community as well as  
friends and SnackPack members.



## Don't be a DNA!



**Percentage of young people  
who DNA their appointment in  
the past year**

#### Paediatric outpatients

Diabetes clinic 3.3%

Annual review 5.3%

Dietetic review 29.3%

#### Young person's outpatients

Diabetes clinic 22%

Annual review 20%

**Excludes March 2014**

## Our clinics

We aim to see you in clinic  
every 3 months. The purpose  
of clinic visits is to give you  
the opportunity to let us know  
how you are and to help you  
plan any support you need.

While you are growing your  
insulin and food requirements  
change rapidly so it is also a  
chance to adjust your  
diabetes management so you  
get the best treatment  
quickly.

These clinics are called  
CRM7A (paediatric outpatient  
department) and CRM7Z  
(MacLeod Adult Diabetes  
Centre).

Each year you are offered an  
annual review clinic which is  
your yearly health screening  
check. We check your eyes,  
feet and a full range of blood

tests as well as talking about  
how you manage your  
diabetes as you get older.  
These clinics are called  
CRMAR (Paediatric OPD)  
and CRMYP (MacLeod  
Centre).

Every year you also are  
invited to meet with the  
dietitian to talk about the  
foods you like to eat and to  
learn new facts about food.  
This clinic is called CRM7D  
and is held only at the  
Paediatric OPD.

**A DNA is someone who Did  
Not Attend for their  
appointment and did not tell  
us beforehand.**

Each year we have young  
people who fail to attend their  
appointments. If we don't know

you are unable to keep it, we  
aren't able to offer your  
appointment to someone else  
who needs it.

We want to reduce the number  
of missed outpatient  
appointments, which will allow  
us to see you when you want &  
reduce the time that you have  
to wait.

Getting in touch to cancel  
or change your outpatient  
appointment

**Please help us by telling  
us as soon as possible if  
you cannot make your  
appointment by calling  
the number on the letter.**

Please speak with the team  
to talk about why you find it  
difficult to make your  
appointment so we can  
help.

## Jamie Johnson's shortbread

### 10 servings, 20g carbs (153kcal) per serving

#### Ingredients

100g spreadable butter  
50g caster sugar (plus 10g for sprinkling on top)  
150g plain flour  
25g cornflour

#### Method

1. Preheat the oven to 165°C (150°C fan assisted), 325°F, gas mark 3. Prepare a baking tray (page 9).  
2. Using a wooden spoon, cream the butter and sugar together in a mixing bowl until pale and creamy.

3. Sift together the flour and cornflour and add to the creamed mixture, encouraging it to blend in the back of the spoon.  
4. Turn out the dough (even if it's still in separate lumps) on to a work surface dusted with flour.  
5. Work it gently with your hands until it comes together. Don't overdo it or the dough will become oily and tough.  
6. Place the dough on a baking tin and press into a 20cm round (you could use a flan ring or the sides of a loose bottom cake tin as a guide).  
7. Score gently into 10 equal wedges.

Closing date for the next issue is 17th June

Bake for 25-30 minutes or until the edge turns golden brown.

8. Remove from the oven and, with the handle of a teaspoon flute around the outside edge. Use a fork to make little holes and cut into 10 pieces. Sprinkle with 2tsp caster sugar while still warm.

You can make it even healthier (lowering the saturated fat) by changing the butter for olive oil based margarine. (Jamie made this from a Jane Asher recipe)

## Diabetes burnout by Sophie Bishop, Paediatric Clinical Psychologist

Managing diabetes requires constant attention to what you eat, how much physical activity you do, and how much insulin you give. Whether you are a young person with diabetes or a parent, it's easy to get worn out with all this effort. This can lead to what we call "diabetes burnout".

#### How do I know if I have diabetes burnout?

##### Parents and young people

- ◇ Do you feel overwhelmed and defeated by diabetes?
- ◇ Do you feel angry or frustrated about diabetes and the treatment regime?

◇ Do you feel alone with diabetes and the difficulties in managing it?

##### Young people

- ◇ Do you worry you are not taking care of your diabetes well enough but feel unable, unmotivated or unwilling to change?
- ◇ Do you tell yourself managing diabetes is not important and complications won't happen to you?
- ◇ Do you try to 'ignore' diabetes and tell yourself there is no problem?

If these things sound like you, you might be experiencing diabetes burnout..

There are some important things you need to know about this:

- ◇ Diabetes burnout is common – you are not alone!
- ◇ You are not a bad person – living with diabetes can be really hard
- ◇ Your situation is not hopeless – you can conquer burnout

Over the next few issues of BITESIZE, we will be talking more about coping with diabetes burnout. If you feel worried in the meantime, have a chat with one of the team about how you are feeling.

## Book Review

### Diabetes Through the Looking Glass

#### Seeing diabetes from your child's perspective by Dr Rachel Besser

*Combining her own experience with interviews with children and adult who share their stories, Dr Besser provides an illuminating insight into what it feels like to grow up with diabetes.*

A book about diabetes for adults, written by an adult who was diagnosed type 1 as a child, is as ideal as it comes. The book is laid out so that you can dip into the chapters at your own pace or read it in one go. It gives medical information for managing and caring for

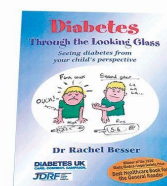
diabetes but without feeling you are reading medical text book. It also gives the basics without being patronising and Rachel gives her own personal views throughout which is insightful, especially as she is now a medical professional.

As this is a general book, it doesn't cover babies and toddlers, and there is hardly anything about pumps, except a very basic explanation. It would have been nice to have had a chapter on how different children reacted to having

pumps, both good and bad.

Overall, this book is a good insight into how children think and feel about their diabetes, and will help parents empathise and assist their children through different scenarios they will face such as school, high and low blood glucose, blood tests, injections, teenage years and leaving home. I would definitely recommend it especially to newly diagnosed families, but there is still much to learn from it for old-timers too.

Can you recommend a good book about diabetes? Would you be prepared to write a short piece (about 250 words) for BITESIZE? Please email Maria at maria.leveridge@nhs.net



This book review was written by Julia Roebuck, mum to Alexander (4) who was diagnosed with type 1 aged 11 months old.

## Exeter Children and Young People's Diabetes Service

(Medical) Dr Chris Moudiotis, Dr Sue Hellewell;  
(PDSN) Julie Kitchen; Ruth Dalton, Heather Tabram,  
Emm Mortimore;

(Dietitian) Maria Leveridge;

(Clinical Psychologist) Dr Sophie Bishop

(Admin) Emma Tootell

(Secretaries) Janet Churchward, Rennie Canhye

Royal Devon and Exeter   
NHS Foundation Trust

Royal Devon & Exeter Hospital  
(Wonford)  
Barrack Road, Exeter, EX2 5DW

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

Phone: 01392 403727

Fax: 01392 402828

E-mail: [rde-tr.PaediatricDiabetes@nhs.net](mailto:rde-tr.PaediatricDiabetes@nhs.net)  
non urgent dietetic number - 07827239019

**Young people at the  
centre of diabetes care**

## National Peer Review

We mentioned in the last issue that we were due to be visited by some Health Professionals from other Diabetes Teams to look at our Paediatric Diabetes service here in Exeter. It is very similar to an OFSTED visit your school would have.

Our visit took place on 11th March 2014 and we were visited by Dr Fiona Campbell from Leeds; Jan, a PDSN from Northampton & Marie, a Diabetes Network coordinator from the Midlands.

They looked at all the information we give & how we organise the work we do with you. They were particularly positive about how we work with managers in the Trust, how we organise clinic (especially transition clinic in the MacLeod Adult Diabetes Centre) & the amount of contact we have with you & your families. They were impressed with the feedback you give us on what we do (from the National Patient Experience forms you complete in clinic). They particularly liked the BITESIZE magazine & how we use it both to let you know what is happening and how you all contribute to what is in the magazine. The Peer Review team felt the Trust needed to increase the medical staffing in the team & therefore acknowledge that we need an extra Consultant in the team to join Dr Moudiotis & Dr Hellewell.

They will write a report & we will let you know when it is published on the internet so you can read it (November 2014).

**Concerned about a health related news item? Check out  
'Behind the Headlines'—Your guide to the science that makes the  
news <http://www.nhs.uk/News/Pages/NewsIndex.aspx>**

**Q & A** Got a query that you feel everyone will want the answer? Send your questions to us by post, at clinic or at [maria.leveridge@nhs.net](mailto:maria.leveridge@nhs.net) and put BITESIZE in the subject line



*Carb free brownies just a quick 'thank you' to you team (& Kye's Nan, Brenda!) for the gluten-free chocolate brownie recipe in your latest newsletter. Both Jack & Lucy really enjoyed them, although we did find the dark chocolate a little bitter so used milk chocolate for our second batch instead! They were so delicious we did have difficulty cutting them into 30 small squares—far too small!!! 16 pieces was much more like it!!! This obviously put the carb content up but they were still less than 4g each - considerably less than a 'normal' chocolate treat! We look forward to your next recipe! Jo, John, Jack & Lucy*

**Please like FWD & share your opinions and experiences of your diabetes care with us**

## Families with Diabetes

*The Families with Diabetes (FWD) National Network was formed in December 2012 to provide a national voice for Families with Diabetes.*

The aims of the FWD National Network are

- ◇ To ensure that Parent, Patient & Carer views and experiences are considered equally important as those of health care providers.
- ◇ To represent a wide variety of families across all 10 networks
- ◇ To promote good practice.

◇ To provide engagement opportunities to increase patient involvement using meetings & social media

◇ To share the experiences & views of Families with Diabetes with Clinicians across the UK through local Parent Representatives & by publishing articles in Paediatric Diabetes.

◇ To engage with influential individuals & organisations within the Paediatric Diabetes Network

The parents who represent families in the South West are Karen Harrison and Louise Arnold.

They can be contacted by email at [kd.ra.harrison@gmail.com](mailto:kd.ra.harrison@gmail.com) and [louise@larnold.co.uk](mailto:louise@larnold.co.uk) or by post at 52 Hill Road, Wotton under Edge GL12 7LW.

<https://www.facebook.com/groups/351695801609372/>