



# PAEDIATRIC DIABETES NEWS

Summer 2018



Dear Patients, Parents, Friends & Family,  
Welcome to the Summer edition of the Paediatric Diabetes News. Examinations for some will now be a thing of the past, just the tense time of waiting for results. Hopefully, we can look forward to more long hot summer days particularly when the school holidays begin. Some of you will be lucky enough to be going on holiday, please remember to order your holiday letters at least 2 weeks prior to travel:- Tel: 01524 583827. As a team we started an education programme for all of our patients but unfortunately this was not very well attended. Goals of Education sheets are being given out in clinic and these will continue for future hospital appointments. I am pleased to report that I have managed to persuade a few of our patients/parents to write for our newsletter and I am sure you will agree that they have done a good job. I am always on the lookout for patients, parents or perhaps even a sibling or grandparent to contribute to the newsletter. If you would be happy to write an article for our Christmas issue, please let me know on 01524 583827 or you can Email me at:

**glenys.mckay@mbht.nhs.uk**

The Team would like to wish you all a very good summer, may the good weather continue.



## Omnipod Users

Most of you will be aware that Insulet has taken over from YPSOMED for the Omnipod Service. There have been a few problems but things do now seem to be settling down.

Please ring the Customer Service number for supplies or pod queries: 0800011 6132

or order on line

Omnipod-GB@insulet.com



♦ If you want to continue with the recycle boxes you must opt in when making your order.

♦ Holiday loan pumps are still available, but please give at least 2 weeks notice.

♦ Please allow 3-5 working days for delivery of your order.

Please let your nurse or Glenys know if you are experiencing problems as we are logging these and discussing solutions with the company.

Hello

My name is Paul Dunstan and I am the Paediatric Dietitian currently working in the Paediatric Diabetes team covering Lancaster and Kendal. I have been a dietitian since 1989 and have always worked in diabetes.

When I first came to Lancaster I took the opportunity to volunteer as the dietitian for Diabetes UK young people's holidays from 1990-1999, after which staff usually came home and slept for a day after 7 nights of treating activity related hypos, from this, I have lots of respect for parents and carers supporting children 24/7.



**Paul Dunstan. Beginning of the Pedal7 bike ride 9.6.18**

In addition to paediatric diabetes, I also help to look after adults with Type 1 Diabetes and diabetes in pregnancy, and I am the paediatric dietitian for Lancaster and Kendal for all other conditions such as allergies, premature babies etc.

I'm lucky to work in some great teams including paediatric diabetes. I've seen the service develop, from sitting in the corridor talking to patients due to lack of space, everyone on the same inflexible insulin regimes to better facilities, insulins including pumps, electronic meter and pump downloads. The team has also expanded with paediatric diabetes nurse specialists, doctors with an interest and expertise in diabetes, psychologists and last but not least Glenys to organise us all.

I do usually see most of you during your routine clinic visits but I am always happy to offer extra dietary advice between clinic sessions and you can contact me direct on: 07989203079.

My interests at home include cycling and walking. We also have an allotment and I make a pretty good curry. I used to do woodwork projects for Christian Aid and might get back to that when I hang up my calculator. When we have time we disappear in our old but much loved motorhome and just because we don't have enough on we've taken on a guide dog puppy called Jimmy to keep us and our labradoodle Pip on our toes.

I recently took part in the Pedal7 challenge with Novonordisk and I was delighted to be asked to accompany one of our patients, Andrew, on the 90 mile adventure. What a fabulous day we had. Andrew has written a brief summary for the newsletter which I am sure you will all enjoy. **Paul Dunstan**

# Results of the Downloading Survey

Many thanks to all the families who completed the questionnaire about downloading your meter/pump at home. 40% of our families completed it across all 3 sites. We found the information very interesting and are using it now to plan how we can improve things further for everybody. I've put together a summary of the findings and our plans for the service.

Overall 26% of families are downloading at home at least once a month, and a further 33% have done it at some point. This still leaves 41% who have never downloaded. There is however a big difference between our 3 sites with only 26% of families seen in Kendal having never downloaded compared to 73% in Lancaster and 41% in Barrow.

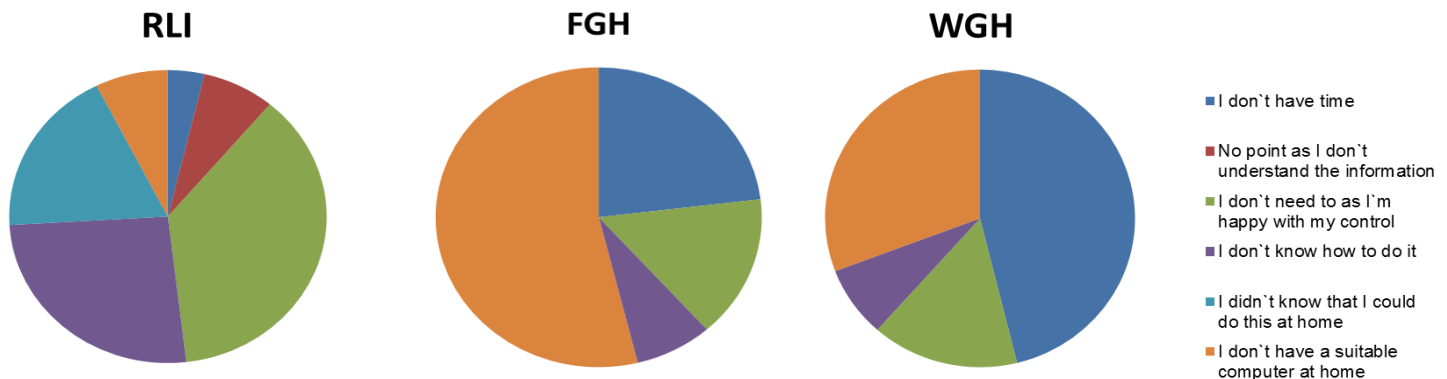
The reasons why people were not downloading regularly varied dramatically between the 3 sites. In Barrow the main problem was lack of access to a suitable computer. In Kendal the main reason was a lack of time. In Lancaster the main reasons related to not knowing how to do it or a belief that their control was good enough without downloading.

51% of families correctly answered that the target HbA1c is now 48mmol/mol or 6.5%. We are now aiming to keep blood sugars under 7mmol before meals. 33% of families identified 7mmol as the level they would consider to be too high when reviewing their download. 50% reported 10mmol as their threshold.

Confidence in interpreting the download varied from 1/10 to 10/10 on all 3 sites. Overall, Lancaster were the most confident and Kendal were the least. We were pleased to see that the vast majority of people would make a change to their settings immediately if they recognised a problem rather than waiting until the next clinic.

## So How Can We Help? . . .

We really believe that clear targets combined with regular downloading and adjustment of doses is the key to good



**we can help** control. We are going to be...

- ◆ Emphasising the need to aim for blood sugars between 4 and 7 mmol. An average blood glucose of 10mmol will give you an HbA1c of 63 mmol/mol. To achieve the target of 48 mmol/mol you need to have an average blood sugar under 8 mmol.
- ◆ Encouraging you to look at your own download and identify what changes to make. Please don't feel threatened by this; this is just to build your confidence so that in time you can make changes yourself. To help with this we are developing a resource file to have in clinic and step by step worksheets to help those of you who are not confident.
- ◆ Discussing when you are going to download next as part of the plan at the end of each contact.
- ◆ If you have any more suggestions or would like any more advice about downloading at home then please discuss this with your nurse or at your next clinic appointment.

# TIPS FOR THE HOT WEATHER



We have been experiencing some lovely sunshine recently, but this can have an affect on your diabetes. Here are some tips to help as the sunshine continues:-



Drink plenty of water, dehydration can be an issue in hot weather, and higher blood glucose levels can further increase this risk.



Keep diabetes medicines and equipment out of the heat as it can affect how it works. Use a cool bag to store Insulin if travelling. Keep your pump out of direct sunlight.



Heat can affect your blood glucose control. Hot weather can increase the risk of hypoglycaemia due to the bodies increased metabolism and also maybe partly due to increased outdoor activity. Hypo's can be harder to spot as they may be dismissed as just feeling hot. Never ignore these feelings, check your blood glucose to be sure.



Stay inside in when it's hottest.



You may need to adjust your insulin doses during changes in weather. If you are experiencing high or low blood glucose please contact the diabetes team for support.



Wear sunscreen, a hat and sunglasses when out in the sun. Avoid sunburn as it can stress your body and raise blood glucose.



Keeping active is key to a healthy lifestyle, but don't get active outdoors during the hottest part of the day. Get out early in the morning or in the evening when temperatures are lower.

## Diabetic Eye Screening

Diabetic eye screening is a key part of your diabetes care. People with diabetes are at risk of damage from diabetic retinopathy, a condition that can lead to sight loss if it's not treated.

Patients are encouraged to attend for annual screening appointments. These are offered to all diabetic patients from the age of 12 years in many local venues by the Retinal Screening Service.

The appointments are quick and easy, taking roughly 45 minutes maximum. The retinal screeners just need to do a quick eye test, add some drops to your eyes to make your pupils bigger, then take some photographs of the back of your eyes.

The drops can make your vision blurry for a period of time after and can sting slightly when going in, but this only lasts a few seconds.

Once you are seen, your results are sent to you, the Paediatric Diabetes Team and your GP in the post. If you need to be seen sooner than every year we will let you know. If it is felt that you need to see a doctor following your appointment, this will be arranged for you.

Clinic appointments are offered in the evenings and weekends. SMS text reminders can be sent to you with your appointment details.

For more info call us on:-

Cumbria Retinal Screening: 0845 0500 109

Lancashire Retinal Screening: 01282 570600



@CPFTDESP



@CPFT\_DESP

Hi all.

I have written in the newsletter before, but for those who do not know me, my name is Lesley and I was diagnosed with Type 1 aged 35, and exactly a year later our 5 year old son, Lucas was also diagnosed. Life has been tough but we try to cope with each new hurdle as it comes.

It's holiday time for us and as with every family holiday there is lots to organise, however, as a diabetic family you can double it!! It starts with looking for travel insurance and the extra cost as soon as you click 'existing medical condition', you then need a doctor's letter to confirm why you have enough stuff to open a pharmacy on your person.



Not too dissimilar to the norm but then you need to pack. Packing is a nightmare at the best of time; "Should I pack a jumper just in case?", "Are 50 tops enough for 2 weeks?" Then you need to think of **ALL** the diabetic kit you might need as well. We take spares of everything just in case anything gets lost or damaged during the holiday and after hearing horror stories of people's luggage going missing we pack the majority in hand luggage & guard it with our lives.

Nowadays, a trip to the airport isn't complete without getting to know security extremely well as they check over our insulin, hypo stuff, needles and funny contraptions for inserting pumps, iports or blood glucose monitors. Of course all of this adds on extra time but touch wood we have never had any problems and always managed to board the aeroplane on time.



So we have boarded the plane, the holiday has started and so has the excitement and adrenaline. As you all know, this affects your blood sugars and so the adjustments to your routine start. During the holiday these adjustments never stop as what worked only a few days ago in England have no bearing on what is happening now. The sun, swimming, fun activities, time differences, change in eating habits and times, not to mention the amount of food you eat, all play their part in ensuring a bumpy ride.



It does sound like a nightmare written down like this but in reality it is only what we are all used to doing on a daily basis, it's just more erratic. We have not changed how or what we do on holiday at all, we just monitor bloods a lot more, oh, and correct constantly! We have just returned from a fabulous family holiday to Turkey and survived the ordeal. Here's to the next adventure!

Archer-Baldwin and Lucas

Lesley

Lucas enjoying Turkey



Hello my name is Sophie and I have just come back from my first year at university. I survived and I am looking forward to Year 2, Here are some tips for diabetes and university:-



Sophie & Mum Nancy

- ◆ Understand how your prescriptions work and how to get them when you're not at uni. It's sometimes really confusing. I had only ever used electronic prescriptions before, so getting my first paper one was puzzling.
- ◆ When you go home and know you will need a prescription, ask the University Health Centre to send the prescription to the Pharmacy of your choice at home and inform the pharmacist here that your prescription is due to arrive shortly. You do not need to register with your home GP just for a prescription.
- ◆ Eye screening has been rather difficult, I did have an appointment prior to starting University but was sent a further appointment from Campus once registered. After a lot of investigation the Trusts agreed I needed to continue the eye screening from University in case I needed treatment. I did however, manage to put the appointment back until recently so it was more in line with my 12 month recall. I am sure different areas will have different rules, but persevere as eye screening is very important.
- ◆ You are on your own, so when it gets tiring and someone would usually help you, you just have to do it. It's not fun, and it can be pretty tough at times. It sucks, but you have to do it because it's worth it.
- ◆ Do carb counting before/during cooking, not after. Your food will go cold. :)
- ◆ You have to tell your flatmates about your diabetes, and it's not as hard as you think. Just a few words will do. Medical/nursing students are the best, they already understand.
- ◆ I had a fridge in my room for my insulin: personally, I recommend putting cheese in it!!



Hello from Nancy, mum to Sophie. Sophie is a twin and was diagnosed with type 1 at 14 years.

For those mums whose children are leaving for University soon I thought I would write to say I have survived the first year of Sophie being at uni! My trauma (apart from complete empty nest syndrome as her twin sister is at university in Aberystwyth) is when you are in the middle of a call, she says, 'I'll have to go, I've gone hypo and need to sort it!'. That's all well and good until a couple of hours later she still hasn't responded to messages asking if she's okay!!!! Of course, she was and wondered what all the fuss was about!

As time goes on the worrying becomes less! I realised only last week that for the last couple of months I haven't been as pre-occupied as previously which is good - but now she's home, carb counting starts all over again!

**Sophie and Nancy Shepherd**



# Pedal for 7



## Day 1 Sunderland to Masham 114kms

On 9th June, my son Andrew Huntington and Paul Dunstan (Diabetes Team Dietitian), joined cyclists from Team Novo Nordisk (the world's first all-diabetes professional cycling team) on day 1 of Pedal for 7 challenge.

As part of Diabetes week 2018 (9-15 June) anybody living with Diabetes or health care professionals were invited to cycle across the UK to inspire as many people with diabetes as possible to help support the control of their condition through a healthy and active lifestyle.

Andrew is 15 years old and was diagnosed with T1D at the age of 3. He cycles 100 miles or more of training every week so was easily up for the challenge. The only problem was that he needed to be accompanied by an equally competent adult used to endurance cycling! Luckily for us Paul met the criteria and was only too willing to step (or cycle as it were) in. We knew Andrew would be in safe hands and the day was indeed everything he hoped it would be.

It was a fantastic opportunity to ride with professional cyclists and has inspired Andrew to persevere with his dreams of cycling as a profession.

**Tricia Huntington**

Many people think that having diabetes means you won't be able to live the life you want to. I think Pedal for 7 and Team Novo Nordisk are changing diabetes and people's attitudes, I'm really proud that I was part of the team for the day.

Justin, a team cyclist was a particular inspiration to me, he told me **"Diabetes is a challenge but not a barrier"** and I think those words will stay with me for a long time. I will never forget the day and the new friends I have made.

Everyone was really supportive; the day was amazing and I came away feeling really good about myself and diabetes. Hopefully, the event will be repeated next year and I would love to apply. Paul was so encouraging throughout the day and we had some good sprints together (I even let him win one!).

**Andrew Huntington**



Andrew is a member of Salt Ayre Cog Set, a cycling club for young people aged 6-18 based in the Lancaster and Morecambe area. Cog Set is a welcoming and inclusive club for all abilities and affiliated to British Cycling. Saturday Sessions run from March to October 10 am until 12 noon with sign on from 9.30 am and the cost is £2.50 per child (£6 per family if you have three or more children attending).

Saturday morning sessions are about learning riding skills, being safe on your bike and having fun. Each child is put into a group that supports their level of skill, and each group is led by an appropriately trained coach. There are bikes available to borrow for Saturday sessions in a range of sizes. Saturday sessions are for children aged 6-16. This is a great way to start the weekend with refreshments for children half way through and tea/coffee for adults. The Cycle Track, is at Salt Ayre Sports Centre, Doris Henderson Way, Lancaster LA1 5IS

**For further enquiries contact:- [cogset@hotmail.co.uk](mailto:cogset@hotmail.co.uk) or join Cogset on facebook.**



## Local Support Groups

Our local support groups are always happy to welcome new families and you can contact them as shown below:

**Barrow Support Group** - The Barrow Group are hoping to arrange a trampolining trip to Preston in the summer holidays. They are also open to suggestions regarding future events.

**Please contact: Sarah Langhorn on 07715266543**

Facebook: Furness Paediatric Diabetes Family Support Group

### Kendal Support Group



On the 25th March our local support group went to Jump Rush in Morecambe. The children had an hour to play and had lots of fun and used up lots of energy. The parents had time to relax and catch up. The play time was followed by party food. This was another successful trip out as a group and was thoroughly enjoyed by all. Look out for details on our Facebook page for our next planned event as you are welcome to join us. We appreciate we are just starting summer, but we would like to remind you all of the Christmas party. The date for your diary is Sunday 2nd December, 12.00 pm -3.00 pm; DJ & food.

**Contact Sarah Metcalfe 07738377787**

**Lancaster**, does not have an active group but if anyone is interested in starting one, please speak to Helen Dring and support would be offered. Lancaster patients are welcome to join the Kendal Support Group.

## DigiBete has now been launched

This is proving to be a very useful resource, with new videos being added all the time.

On the site you will find ....

**Essential training films to share**

**Key Stage specific resources to help your school**

**Films of other families managing diabetes**

**Exercise Resources**

**Carb counted recipes**

**Opportunities to have your say**



**Check out the website: [www.DigiBete.org](http://www.DigiBete.org)**

**Email: [hello@dibibete.org](mailto:hello@dibibete.org)**

The Paediatric Diabetes Team are always working towards improving our services.



We are looking for **Parent Representative** volunteers to join part of our team meetings for approximately 1 hour every 3 months. We want you to think about how we can continue to offer high level, patient-centred support to all our children, young people and their families. The role would involve asking parents of children and young people with diabetes for feedback about the support they receive from the team and also providing feedback to parents following team discussions.

**WE WANT YOU!**

If you would be interested in becoming involved in this please can you contact **Glenys McKay on 01524 583827**

We hope you have enjoyed these few snippets of news and events and we will be producing another newsletter in December/January time. We would really welcome your feedback, suggestions for further articles and please send any pictures or news to

**[Glenys.Mckay@mbht.nhs.uk](mailto:Glenys.Mckay@mbht.nhs.uk)**

