



Parents' Bulletin

December 2011

Christmas Tips

Christmas is a mixture of many things – presents, excitement for children [and adults] and a busy time for everyone. But if you or a member of your family has diabetes, Christmas can be a worrying and stressful time too, especially if this is your first time with diabetes. Celebrating Christmas is not just a time for presents but also about food! We all eat a lot more than we should and we tend to eat much more of the sort of food that is not exactly ideal for children or adults with diabetes. Sadly, you can't take a day off from it but it is important to remember that it is a time to be enjoyed with family and friends.

Remember!

- Excitement tends to lower blood glucose levels, this especially applies to children with Type 1 diabetes.
- Stress tends to raise blood sugars.
- Eating more than usual can raise blood sugars.
- Exercise lowers blood sugars, so a walk after a big Christmas dinner will help to lower them.
- Try to keep meal times as near as possible to your usual times but if meals are later, then remember to give your child a snack.
- Avoid keeping extra food around as this will tempting to eat anytime.
- Maintain blood glucose testing routine as far as possible and test more often if the family has been eating frequently or at irregular times.
- Staying active - exercise reduces stress, burns excess calories and helps control blood sugars.

- To parents – pamper yourself! This may be taking a relaxing bath or curling up with a book but make time for yourself as this can help to prevent holiday stress from building up.
- Planning – make sure that you have enough insulin and other medications to cover the Christmas and New Year holidays.

Treating a Christmas hypo

The standard treatment for a hypo [hypoglycaemia, low blood glucose] is a glass of orange juice but if it is a mild hypo and your child is able to eat and drink, then use chocolate as a treat. Chocolate contains more fat which slows down the action of its sugar content, but it is Christmas after all! [See IDDT Leaflet ‘Hypoglycaemia’ for general advice on hypoglycaemia.]

Food Tips

How to decrease sugar in your favourite recipes

Use less sugar, use sugar-free gelatins for desserts, substitute sweeteners for sugar and/or substitute sugar-free drinks in punches or other drinks.

Christmas Dinner – in terms of carbohydrate content, it is similar to Sunday lunch with some extras, such as cranberry sauce and stuffing. You aren’t obliged to eat everything, so choose what you like best and pass on the rest or just have smaller portions. Take a family walk after lunch to walk off the extras – it’s good for everyone and a convenient way of lowering blood sugars without anyone else thinking about it!

Mince Pies – make your own so that they have thinner pastry and are smaller than bought ones! Adding finely chopped apples to bought mincemeat will reduce the sugar content.

Nibbles – as well as the usual carbohydrate-containing nibbles, have plates of raw vegetables and low calorie dips around. Nuts and dried fruit are a good idea too – two tablespoons of nuts are only 10 grams of carbohydrate and half to one tablespoon of dried fruit is the same.

Fruit is always good too – there are 10 grams of carbohydrate in a

medium sized banana, apple, orange, two plums, two tangerines and a handful of grapes or cherries.

A useful little book - ‘Carb Counter’ is a very useful little book which gives the carbohydrate values of over 2000 foods – plus calories, protein, fat and fibre. It can be ordered from IDDT at the reduced price of £2.99, telephone 01604 622837.

Christmas dinner – no need to spoil the enjoyment!

By Dr Mabel Blades, Consultant Dietician

IDDT asked Dr Mabel Blades some ideas for Christmas dinner. To those of us who have lived with diabetes for some time, this may be old-hat but for families facing their first Christmas with diabetes, we hope the information will help to take some of the stress out of cooking.

All calculations have been based on average portion sizes for an adult, remembering that many teenagers eat as much, if not more than an adult! For smaller children the portion sizes can be reduced, to reduce the carbs. Mabel has also given us some ways to cut the carbs even further and there is a list of ‘Christmas Swaps’ so that you can interchange foods or amounts to suit your child’s needs.

Traditional dinner adult-sized portions

Portion of roast turkey, chipolata wrapped in bacon, stuffing, roast potatoes, brussel sprouts and gravy
Christmas pudding and custard made with skimmed milk

114g carbohydrate, 39g fat, 13.0g saturated fat and 3.2g salt, 1040kcal

Mabel says, “Christmas is a time for celebration and enjoying lovely food. Here are some ideas for how to cut down fats and carbohydrate in an easy way.”

- Cutting down on the potatoes and dry roasting them.
- The Christmas pudding can be home made to a lower calorie recipe.
- Fruit salad can be substituted for the Christmas pudding.

Homemade Christmas Pudding

If you would like Mabel's recipe for homemade Christmas Pudding, email enquiries@iddtinternational.org or just give us a call on 01604 622837 and we'll send it to you.

Don't let diabetes spoil your day!

Christmas swaps

Food	Calorie Content (kcal)	Carbohydrate Value (g)
Starters		
Bowl of soup	30-70	10-15
150g Melon	40-50	10
Mains		
Chipolata in bacon	102	1
80g vegetables like sprouts	20	0-5
50g stuffing	135	10-15
100g Roast potatoes	536	20
100g Dry roast potatoes	140	30
110 g Turkey roast	186	0
Afters		
80-100g fresh fruit salad or 2 satsumas	40-70	10-15
100g Christmas pudding	329	50-55
50 g Brandy butter	320	0
150g Custard with skimmed milk	120	20
25g Cheese	104	0
2 digestive biscuits	140	20
2 plain crackers	95	10
2 oat cakes	80	10
1 scoop of ice cream	70	10
Mince pie	239	30
Alcohol		
Small glass wine (125)	85	-
Spirits tot	55	

96% of children and young people with diabetes may not have received all of the essential key tests

The National Paediatric Audit 2009/10 for England and Wales looked at the records of 19558 children and young people between the ages of 0 to 24 years. Of these 18451 were between the ages of 0 to 17 years. Nine key tests are recommended for all age groups with diabetes although some of them may not be necessary in children - the guidelines specify a starting age of 12 years.

- 94.3% were recorded as having Type 1 diabetes and 1% Type 2 diabetes. 52% were male.
- 96% of children and young people may not have had all the 9 key tests carried out and this has fallen by 1% since the 2008/09 audit.
- 89.3% of children and young people had their HbA1c results recorded but in children and young people over 12 years, only 4.1% had all 9 key tests recorded.
- Only 14.5% of HbA1c results were within the NICE recommended target of less than 7.5% [59mmol/mol] and this is worse than previous years. The highest numbers who achieved the targets were children from 0 to 4 followed by the 5 to 11 age group. Over 30% of children and young people have high risk HbA1cs greater than 9.5% [82mmols/mol].
- 9.0% had 1 episode of DKA [diabetes ketoacidosis] in 2009/10. DKA was more common in girls than boys, more common in the teenage years and often recurrent.

There was a large variation in DKA recurrence rates and considerable variations in meeting HbA1c targets between treatment centres. The audit concludes that even though everyone is using the same treatment tools, some approaches are systematically better than others. Worryingly, this has remained unchanged from previous years. It is expected that if the more effective systems are more widely used, then overall improvements would be achieved.

What are the key tests?

NICE recommends that adults with diabetes should receive 9 key tests at least once a year, at your hospital or GP appointment for your diabetes.

- Weight measurement
- Blood pressure
- Smoking status
- HbA1c
- Urinary albumin
- Serum creatinine
- Cholesterol
- Eyes
- Feet

As said above, not all 9 tests apply to children but check this out with your diabetes specialist nurse.



News

Shortage of Apidra

There is a shortage of the rapid-acting Apidra (insulin glulisine). The manufacturers, Sanofi, have had a production problem at their factory and as a result, some people may have a problem obtaining supplies of Apidra in cartridges and pens. Although the problem is solved, it is likely to be the end of March before normal supply is resumed, not the end of December 2011 as first said.

Some adults may not be able to obtain supplies during this time and their doctor or nurse will need to look at what other insulin may be suitable as a temporary measure until Apidra is available again. However, Sanofi are keeping some supplies back for 'vulnerable patients' and those who could be considered on case by case basis. Children and adolescents under 18 years fit into the category of 'vulnerable patients'. Sanofi's criteria are as follows:

Criteria for automatic 'vulnerable patient supply':

- children and adolescents under 18 years,
- those over 70 years,
- pregnant women.

Criteria for case by case discussion:

- people in whom a transfer to a different insulin could cause an adverse outcome, such as those with brittle diabetes,
- people with significant disability,
- people who have previously not tolerated other types of insulin.

Where can you obtain more information?

Sanofi has a 24 hour-a-day Patient Support Line: 08000 35 25 25. Your doctor, nurse or pharmacist will be able to help you if you still have questions.

Levemir on the way to approval now approved in children aged 2 to 5 years

In the August 2011 Bulletin, we reported that Novo Nordisk had applied for approval of Levemir [insulin detemir] to be used in children between 2 and 5 years. In the first stage of this process, the European committee has given its backing to this use [September 2011]. Novo Nordisk said in a statement that data reviewed by the committee demonstrate that the basal insulin analogue is an equally efficacious treatment option for two to five-year-old children with Type 1 diabetes, compared with neutral protamine Hagedorn insulin [NPH] eg Insulatard and Humulin I.

It is expected that the European Commission will give its approval in the coming months and this will make Levemir the only long-acting analogue approved for use in this very young group of children.

Pump News

In October the Scottish government announced that a quarter of young people with Type 1 diabetes in Scotland will have access to insulin pumps by 2013. At the same time it was also confirmed that over the next three years the number of people of all ages with Type

1 diabetes will almost triple to more than 2000. These plans are part of the Diabetes Action Plan for Scotland published in August 2011.

Drug company, Eli Lilly joins with Disney!

Insulin manufacturer, Eli Lilly has announced a major partnership between its Lilly Diabetes division and Disneyonline. The collaboration is to help families who have children with Type 1 diabetes receive education and practical advice in a fun, friendly way.

New Meter With Cheaper Strips, And It Talks...



SuperCheck 2 is a new blood glucose meter with the additional option to provide the user with audible spoken instructions and blood glucose test results which will be of great help to people who are visually impaired or elderly and so the RNIB has tested and adopted it.

The SuperCheck 2 which has the look of an mp3 player, includes alternative site testing, 500 test memory, PC download option, alarm reminders. A small blood sample is required and a quick time for results.

The SuperCheck meter and starter pack is being supplied **FREE** to GPs and diabetes specialist nurses and the strips can then be prescribed on the NHS. The cost of the strips to the NHS is only £8.49 for 50 – a great saving for the GP budget when compared to many other strips. More information is available by visiting:

www.supercheck2.co.uk

Prescribing information for children

New advice over children's prescribing

In July 2011 new guidelines, the BNF for Children, were issued for healthcare professionals working with children. Health officials are

highlighting the importance of using the guidelines when prescribing medicines for children and young people to avoid prescribing errors. There are more prescribing errors in paediatric prescribing than for adults due to the complexity of prescribing for an age range of birth to 18 years. It is very important that children are given the right dose of a medicine at the right time.

Calpol labels

The recommended doses of paracetamol for children are being revised because of concerns that they are given too high a dose of the medicine. The Medicines and Healthcare Products Regulatory Agency [MHRA] want to make the dose clearer for babies and young children.

Warning over flu vaccine

In July the European Medicines Agency [EMA] issued a warning about adverse reactions caused by the flu vaccine, Pandemrix, prescribed for millions in the UK at the height of the 2009/10 flu pandemic. The regulators say that Pandemrix is not ideal for young people and it should only be prescribed to those under 20 years if the recommended seasonal trivalent influenza vaccine is not available, as this group still need immunity to the H1N1 strain of flu.

The warning is as a result of adverse reaction reports from Finland and Sweden that some children and adolescents were suffering from narcolepsy after being given Pandemrix. According to the EMA, studies have shown a 13 fold raised risk of narcolepsy in children and adolescents vaccinated with Pandemrix compared to unvaccinated children.

If this affects you or your children, we advise that you discuss your options with your doctor.

Research

A first - artificial pancreas used outside hospital

For the first time in the world, the artificial pancreas was tested outside the hospital situation by a team of specialists in Israel. This is a significant landmark in research as it showed that the artificial pancreas does have the potential of a 'normal' life for children, adolescents and others with Type 1 diabetes.

The "MD-Logic Artificial Pancreas" consists of a subcutaneous glucose sensor that monitors the glucose level and an insulin pump. These are connected to a computer that programmes the information and works out the amount of insulin that should be released into the body to maintain blood glucose balance.

The trial was carried out as part of the 3-day DREAM Camp for children with diabetes at an hotel near Jerusalem in 18 young people between the ages of 12 to 15 years. Nine children were connected to the artificial pancreas on the first night of the camp and eight children were connected on the second night. Monitoring the night-time glucose levels is extremely important since most cases of severe hypoglycemia occur during the night and blood glucose levels are not within the desired range in many of the patients while they are asleep. The team of engineers and medical staff were in the control room at the hotel, from where they were able to supervise and monitor the glucose levels by remote. [October 2011]

Preventing delayed diagnosis of Type 1 diabetes in children

At diagnosis many of us as parents have to watch our children being very ill and rushed into hospital in an emergency. In some instances, parents have taken their child to the doctors because they are not well but Type 1 diabetes is not diagnosed. In reality there are only about 23,000 children who are 15 and under with Type 1 diabetes, so perhaps it doesn't spring immediately to the doctor's mind to check for diabetes, at least not until the classic symptoms of thirst, weight loss and peeing a lot occur. But this needs to change for the safety of children.



If your child is diagnosed in emergency, it is a frightening experience and one that most of us don't forget.

We soon learn that they have ketoacidosis, often known as DKA. This is a serious condition caused by lack of insulin which results in the body fat being used up to provide energy but at the same time dangerous ketones and acids are also formed. The lack of insulin causes very high blood sugar levels and this in turn produces ketones in the urine, vomiting, drowsiness, heavy laboured breathing and breath smelling of acetone [pear drops].

According to research published in the BMJ [Feb 2011] 2000 children a year are diagnosed with Type 1 diabetes and one in four experience ketoacidosis before being correctly diagnosed with Type 1 diabetes.

The research also showed that:

- 30% of newly diagnosed children have had at least one related medical visit before diagnosis which suggests that doctors are missing the condition.
- 35% of children under five have DKA at diagnosis.
- Early symptoms such as excessive thirst, recent onset of bed wetting are frequently not picked up as signs of diabetes.

The study authors suggest that it is reasonable to assume that an earlier diagnosis would lead to a lower risk of DKA but they also make the point that there is still an unanswered question of whether this is due to delayed diagnosis and treatment or whether it reflects a more aggressive form of Type 1 diabetes.

Dr Rowan Hillson and NHS Diabetes are heading a team that is working on ways of raising awareness of Type 1 diabetes to prevent delayed or misdiagnosis and to prevent children from the dangers of DKA. [BMJ, 7 July 2011]

Children with Type 1 diabetes watching TV

A study carried out in Germany in 296 children, teenagers and young adults who had Type 1 diabetes for an average of 6.1 years, has shown that those who spend hours in front of a TV or computer screen each

day have poorer blood glucose control. However, the findings do not prove that the amount of screen time itself worsens diabetes control.



At first sight this may seem unsurprising although interestingly, the study showed that duration of diabetes, family income and daily screen viewing were risk factors for poor control in this age group but the amount of physical activity was not.

- On average they spent 2.9 hours per day looking at screens and 5.1 hours per week on physical activity.
- Among the 296 youngsters, those who spent 4 or more hours per day in front of a screen had higher HbA1cs.
- On average HbA1cs were 9.3% versus 8.5% among those who spent less time in front of a screen.

It is not known why screen time was connected to blood glucose control, indeed it may not be connected at all, but one theory is that the youngsters who spend more time on front of a TV or computer may have more snacks than those who spend less time in front of a screen. [Diabetes Care, September 16, 2011].

A letter from a Mum...

"My 8 year old son was diagnosed only a week ago, and as you know, our lives got totally turned upside down. Myself and my husband have been bombarded with info, helpful, but all mainly focused on the medical aspects, diet etc. My friend gave me one of your leaflets, and as I read it my eyes filled up. Finally someone understood the emotional trauma that we were facing. The fear, anxiety, and deep sense of sadness.

Everyone uses phrases such as 'he can still live a normal life', 'he'll be ok', and some look at your anguish as though you're over reacting, or attention seeking. I realise that it is early days and we WILL adapt to our 'new' way of life, but it can by no means be put in the category of 'normal', certainly not by my little boy, who undergoes injections at least 3 times a day, counts carbs on food labels, and gets upset that he can't grab a packet of sweets any time he wishes.

I want to thank you all so much for providing such invaluable information from a parent's perspective. It is both reassuring, and informative, from a totally not bias point of view, and gave me a lot of 'food for thought'."

I have not printed this letter to sing IDDT's praises but to highlight yet again the need for greater understanding and empathy with how parents feel when their child is diagnosed with Type 1 diabetes.

My daughter was diagnosed with Type 1 diabetes 36 years, and yes, many things have improved in that time, blood glucose testing was the change that made the biggest difference to our lives. However, this letter reminded me that no matter what improvements have been made to the management of diabetes, the same phrases are still being used, presumably in an attempt to offer comfort and reassurance.

I am not being negative or depressing about life with diabetes, but it certainly isn't 'normal'. At diagnosis, 'normal' to us means the life we and our children had before diagnosis. As our mum explains in her letter, however hard you try, this doesn't happen. We get used to life with diabetes and it becomes our normal but this takes time.

We have to be allowed time to grieve for the loss of the life our child had without diabetes, time to get used to our new life, time to come to terms with our sadness and our fears, not mention all the new information we have to absorb.

Thirty six years on, I can say that we develop our own 'normal' lives, as do our children with diabetes. Yes, they can do all of the things that

children without diabetes do – but always providing they take their diabetes into account.

So a plea to any healthcare professionals reading this – at diagnosis, please don't tell us our children can lead a 'normal life' as it really doesn't feel like that.

Has your child been brave or achieved something for the first time?

IDDT Certificate

If you would like to show how proud you are of your child, then apply for an IDDT Certificate for them. It could be doing their first injection or going to a school disco and managing the extra exercise and excitement.

Hall of Fame

Maybe you would like your child to join our Hall of Fame on our website – take a look at some of our Hall of Fame members by visiting: http://www.iddtinternational.org/?page_id=1819

For a certificate or to be on our Hall of Fame, contact bev@iddtinternational.org

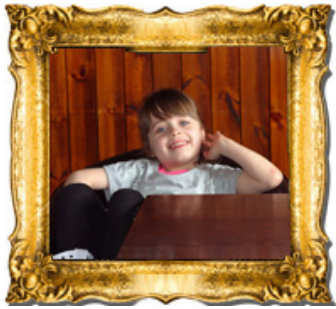
Here are a few members of our Hall of Fame:



Matthew

Matthew Rooney aged 8 has Type 1 diabetes. He and his Year 3 classmates walked for a week wearing IDDT pedometers and T-shirts. Thank you to Matthew, his friends and of course, the teachers who helped him to organise the event. The class walked a

fantastic 545,000 steps for IDDT in their walking week.



Elisia

Elisia was diagnosed in October of last year aged 4. Elisia has dealt with her Type 1 diabetes fantastically, she been truly amazing. Both Elisia and her mum have learned to count carbohydrates and then inject right amount of insulin before each of her meals. Elisia's outlook has been inspirational to her mum and those around

her. Here at IDDT, we like to say a huge well done to Elisia and the whole family.



Beatrice

Beatrice is 12 years old and we would like to say a big well done to Beatrice as she has just completed her animas pump training. Beatrice is especially brave as she is needle phobic, so she deserves a huge well done. During her training Beatrice fainted but despite this, she completed the day and was able to put the needle in herself.

Mum, Caroline, and brother, William are so proud of her and have both been brilliant at supporting her every step of the way.

IDDT News

Year 6 Lesson Plan



Further development of IDDT's Lesson Plans

In our May Parents Bulletin, we reported on how we are trying to educate children in schools about diabetes – helping them to understand what it is like to live with diabetes and the differences between Type 1 diabetes and Type 2 diabetes.

We have been doing this through our

Lesson Plans for primary schools so teachers can use them in their PSHE lessons. We feel this is an ideal place to raise awareness and promote a better understanding of diabetes.

We have now expanded the Lesson Plans to include a fully mapped series of lessons for Key Stages 2 and 3. This is available on our website as is a staffroom poster highlighting how children may behave if they are having a hypo.

In November, we sent the details to 1,700 primary schools to encourage them to help children to be more aware of diabetes and the needs of children with it. As parents, you can help too by letting your child's teacher know about the Lesson Plans and other resources we have available to them. The details can be found on our website:

http://www.iddtinternational.org/?page_id=2052



IDDT's new free leaflet, 'Your Diabetes – Know Your Rights'

We still do not know exactly how the NHS will be run or how we, as patients or family carers, will be able to ensure that we receive the high quality care that we have been promised, and to which we are entitled. We do know that there are going to be changes. We also know that there are going to be cuts in expenditure, some of which are already being made. For all of us, as patients or family carers, the health and wellbeing of our

families are our priority. We want diabetes and any other conditions, managed to the high standard we need and deserve and this leaflet will help to achieve that.

It puts together a range of information which includes knowing your rights as a patient, the standards of care you should expect, what to do if things go wrong and how to effectively manage your appointments or consultations.

Also included is chart to remind you of the key tests which should be carried out at your child's clinic visits. Some of the 9 tests will not be necessary for children but the chart will enable you to keep a record of which tests are carried out by putting the date in the box for each test. If any of the essential ones are not carried out, you can then ask why not.

The leaflet can be obtained by emailing bev@iddtinternational.org or simply telephone IDDT on 01604 622837



A huge thank you for buying IDDT Christmas Cards.

This year has seen our biggest ever sale of Christmas cards and we very much appreciate your help in raising funds for IDDT. This helps us to continue to supply our publications free of charge so that no one is denied information on the grounds of cost. So many thanks to everyone who has supported us in this way.

If you would like to join IDDT, or know of someone who would, please fill in the form (block letters) and return it to:

IDDT

PO Box 294
Northampton
NN1 4XS

Name: _____

Address: _____

Postcode: _____

Tel No: _____

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From Your Editor – Bev Freeman

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Insulin Dependent Diabetes Trust

PO Box 294
Northampton
NN1 4XS

tel: 01604 622837

fax: 01604 622838

e-mail: enquiries@iddtinternational.org

website: www.iddtinternational.org