



Parents' Bulletin

August 2010

Back To School

Whether children are starting a new school or a new school year with different teachers and different children, it can be a daunting time. Here at IDDT we know we cannot totally remove your worries but we can help. We have three different ways of helping your child's school and their class mates to understand a little bit more about diabetes.

Teachers Information Pack – this contains Understanding your Diabetes, Introducing Teachers to Children with Diabetes, 2 informative posters about how to deal with hypoglycaemia for the staff room, a care plan for you to fill in and give to the school and a publication list for further information.

Lesson Plan – this contains 5 lesson plans that the school can use to

help everyone (pupils and staff) learn more about diabetes as part of the school's PSHE program.

Powerpoint Presentation – this can be downloaded onto a memory stick straight from our website. It can be used to accompany the lesson plan as an assembly presentation or a tool to simply teach the school staff more about diabetes. It is a question and answer presentation so everyone can get involved.

Last school year we had over 500 requests from schools in the UK for IDDT Lesson Plans, 'About Diabetes'. We see this as a very positive and encouraging response.

The more people understand about diabetes, the easier the lives of children with diabetes will become.

My Involvement With Diabetes

Jenny Hirst, Co-Chair of IDDT

When I was asked to write about why I am involved in diabetes and why I helped to form IDDT, I thought the answer to both questions was the same – my daughter was diagnosed with Type 1 diabetes when she was just 5 years old. So I was involved in diabetes, like it or not! That was 35 years ago now, so while I am not involved in the day to day management of her diabetes and haven't been for a long time, I am called upon for the odd night hypo or to drive her to hospital appointments when she has drops in her eyes and can't drive herself. Before you think that this doesn't sound much of an involvement and seems pretty superficial, but it's not just because I am still her Mum and I still worry about her just as much as I ever did. If I see her drinking Lucozade, I learned a long time ago not to ask her if she's hypo, but I still automatically think it! If I see her giving a couple of units of insulin at an unusual time, I don't ask if she's high, but I still automatically think it!

As she grew into a teenager I had to learn to 'let go', something that is far easier said than done. Having managed her diabetes when she was little, I gradually handed over to her, this was not too difficult but the hard part were the teenage years, sometimes watching her make mistakes, doing some of the things that all teenagers do, or want to do, and trying to hit a balance between being there for her but not interfering. We got there, so I did let go. As she became an adult, I have watched her make choices about her life and how she manages her diabetes and I try to respect those choices – it is her life after all. I'm pleased that she often talks things through with me, to help her think things through or perhaps for me to point out choices that she may not have thought of.

'Letting go' does not mean that I have stopped worrying about her or her future health, I don't think that will ever go away but what it means to me, is that I try to not interfere in her diabetes or the way she manages it. She is 40, so it really is her business – I wouldn't have

liked my mother interfering in my life and my decisions when I was 40!

Why did I help to form IDDT?

Soon after my daughter was diagnosed, I became involved in our local Parents Group – initially just a small group. We learned a lot from each other – the sadnesses and the successes of our children but most of all we shared our feelings and sometimes, our frustrations. Sometimes our local paediatrician came too, not to teach us, but he listened to us and showed respect for our views and experiences – things that most of us would not have expressed in a clinic situation. The respect he showed us, made us all feel better.

Eventually I became a Trustee of the British Diabetic Association, now Diabetes UK. Part of my role was to represent the views and experiences of the patient groups throughout the UK, the services they received and how they thought that the organisation could help to improve their lives.

However, when the first adverse reactions to GMhuman insulin were reported by people with diabetes, I was surprised and dismayed that so little effective action was taken by the organisation which was supposed to listen and represent them. With threats that the animal insulins were likely to be withdrawn from the market, this significant minority of people who had serious adverse effects, not least the loss of hypo warnings, inactivity was not an option for me or Dr Matt Kiln – a GP who had had diabetes since he was a boy and suffered adverse reactions to human insulin.

So IDDT was formed with clear and specific aims:

[i] to ensure that animal insulins remain available for the people that need them – achieved so far.

[ii] To try to seek recognition amongst health professionals that some people simply cannot tolerate GM human insulins – sadly with only limited success even after 16 years.

[iii] To listen to people with diabetes and try support and represent their needs – we try.

[iv] To try to ensure that people with diabetes have an informed choice of treatment and information about the risks and benefits of the choices open to them – we try our best.

[v] Not to accept pharmaceutical industry funding so that IDDT is and is seen to be, independent and uninfluenced by funding sources – a basic principle which will not change.

Over 16 years, IDDT has grown and developed but in response to the expressed wishes and needs of the people who contact us – parents of children with diabetes and adults of all ages. Our strengths are that all the Trustees live with diabetes either themselves or as family members, so we know that life is not always easy, we know that sometimes it is just good to talk and be listened to.

Who Wants A Pump?

By Jane Essex

These days, the answer to that question is more people than ever before and in this article I am going to look at some of the medical reasons for the growth in use. I have to confess here that I didn't want my first pump, but I got one anyway, at a time when there were three patients with a pump at the hospital and seventeen rats. Happily, even with the very primitive pump I was given in 1982 it still transformed my control, and I am delighted that it is now available to many more people (and no more rats!). However, its increased availability and a growing population of enthusiastic pump users, does mean that it risks being seen as some sort of 'miracle' management tool. So in this article I would like to think about what a pump can realistically be expected to achieve, and who might expect to benefit from pump use.

When a child has diabetes, the adults caring for them face an additional dilemma, as to whether the child genuinely shares their interest in using a pump and can appreciate what it entails. Whilst pumps can achieve very good blood

glucose control, it requires a high level of education and motivation, combined with constant vigilance for any technical problems that may arise. The potential benefits of pump use are particularly attractive to parents and carers who are looking to the very long-term well-being of their child. Amongst the gains can be:

- Improved blood glucose control and general stability. This is especially true for people who have struggled to get good control because their hour-by-hour insulin needs vary dramatically over shorter time periods than those over which an injection would last.
- Fewer (but not a total prevention of) 'hypos'.
- Increased flexibility, of the sort many of us only see in the adverts for blood glucose meters and the like. This is achieved by being able instantly to re-set the rate of insulin infusion when unexpected situations call for a different dose.
- Reduced number of injections, since the needle used to insert the giving sets may only have to be inserted once every three days.

If one or more of these benefits is particularly relevant to your child, pump use may be a useful option to try. It is important to remember that the criteria by which adults have reached the conclusion that a pump may be a useful tool may not be shared by the child who will become the pump user. You also need to bear in mind that these benefits are not 'cost free'; the drawbacks of pump use include:

- A more visible manifestation of a 'hidden disability'.
- Some people find it inconvenient being attached to a plastic box full time. (Try taping a yoyo string to your abdomen to see how this might feel.)
- You have to be able to carbohydrate count to use a pump effectively, so you may need to attend a carbohydrate counting course first.
- You have to be prepared to do a minimum of four blood glucose measurements a day; because the pump only delivers fast-acting insulin you can get into serious difficulty if the insulin is not infused regularly, for instance if the giving set gets blocked.
- Because you can't stay well for many hours if the pump goes wrong for any reason, so you have to be willing to revert to injections at

any time if there is a mechanical failure of the pump. For something that can offer more flexibility, it is a system that requires a lot of planning!

- Needles may be longer and a little less comfortable to use.
- Close collaboration with clinic staff will be needed to get the best results from a pump, so it will be of limited use, and may even be distinctly disappointing, if you don't spend time reviewing your management with clinical staff.
- Most pumps don't respond directly to blood glucose levels; the pump has to be operated by a person who still has to make ongoing judgements about the dose of insulin to give.

The relative importance of the different pluses and minuses of pump use, will vary from person to person, and it is vital for the pump user to have 'ownership' of the decision to use a pump as far as they are able to form an informed judgement.

Bear in mind too, that a pump may be helpful at some points in your child's life and not others; you are always at liberty to disconnect it and revert to injections when it suits. Just to cloud the decision further, you may also need to consider whether other strategies might offer the same benefits with fewer disadvantages. Alternatives to pump use could include:

- Reducing hypos by running blood sugar levels slightly higher. (This will also help remove the roller coaster of posthypo hyperglycaemia.)
- Experimenting with different insulins, combinations of insulins and injection sites.

If after trying these alternatives the problems with control still exist, then a pump may be helpful for your child. In my next article, I will consider the process of getting a pump.

The Emotional And Physical Aspects Of Hypoglycaemia

Talking about both the physical and emotional side of anything to do with diabetes is hard for us all, whether we are the person with diabetes or the person that has to deal with diabetes. Perhaps one of the most difficult situations to deal with is hypos.

As a parent without diabetes it is impossible to know what a hypo feels like and all parents can do is listen to explanations of hypos in order to learn the warning signs of an impending hypo. With respect, the person with diabetes also does not understand the fears and emotions experienced by the person that has dealt with the hypo. Both situations are hard and difficult for the other person to understand. At times both parties can be left feeling isolated, guilty, misunderstood and in my case as a person with diabetes, embarrassed and ashamed.

This article is very much written from the heart and may contain, what some might see as, distressing information but also some reassuring information that aims to bridge the gap of understanding.

In all my 35 years of living with diabetes I have never read a description of a hypo that makes me feel that someone actually knows how it feels physically or emotionally when I am hypo. I would never wish diabetes on anyone, but sometimes I do wish that people around me knew how it felt so they then know how to deal with me in a hypo. I want people to realise how out of control my emotions are and although this is still me standing here in a hypo, this is not what I actually am. Physically and emotionally, I am not me while my blood sugars are low.

The list below shows the symptoms of a hypo which can be resolve with the in take of fast acting carbohydrate but there is more to a hypo than this. All involved in hypos can be left with fears, embarrassment anger and guilt.



Body

Bodily symptoms of hypoglycaemia (autonomic and adrenergic symptoms) are the result of both adrenaline secretions and the autonomic nervous system. They usually start when the blood glucose concentration dips to below 3.5 – 4 mmol/l.

- Irritability
- Hunger, feeling nauseous
- Trembling
- Anxiety
- Heart palpitations
- Throbbing pulse in the chest and abdomen.
- Numbness in the lips, fingers and tongue.
- Looking pale
- Cold sweats

Brain

The blood glucose concentration at which the brain begins to show symptoms of dysfunction (neuroglycopenic symptoms) is lower than that of bodily symptoms and largely independent of recent blood glucose levels.

- Weak and dizzy
- Difficulty concentrating
- Blurred vision
- Disturbed colour vision (especially red-green)
- Difficulty hearing
- Feeling warm or hot
- Headache
- Drowsiness
- Odd behaviour, poor judgement
- Confusion
- Problems with short term memory
- Unsteady walking and lack of co-ordination
- Lapses in consciousness
- Seizures

My explanation of how a hypo feels

Like most other people with diabetes, my hypos vary and my symptoms vary. Mild hypos are relatively easy to deal with but moderate or severe hypos are a different matter. Here is my explanation of my experiences of hypos and how I feel.

Tired

I feel so tired I want to do nothing but sit. My body has no energy, even breathing feels like such an effort and walking to the fridge to get some food seems not only the most complicated of tasks but also takes an unbelievable amount of effort.

Bad tempered

Just like PMT, I will become unreasonable, verbally aggressive and I think the whole world is laughing at me and I want to fight against them all. After the hypo I am left feeling embarrassed about what I have done and feel I have to compensate for my bad behaviour. The people who deal with the hypo have been left hurt by my actions and I can see how hurt and upset they are by it..... I feel terrible. I try my best to console myself that I really do not have control over these actions and what I say is not actually the reality of how I feel, but the guilt is hard to deal with. My mum and I (the one who dealt with these situations when I was younger) always had a good talk about these things and she continually told me that she knew it was the hypo and not me, but I still felt that what I had done had caused a lot of damage and that if I was capable of this in a hypo, was I capable of this in real life? My mum and I spoke about what had happened and even when I was very young, both of us felt guilt about what happened but we did understand each other.

Confusion

I become very light headed, giggly and strangely silly. I am unable to make any sort of decision and even though I know I'm hypo I cannot connect that I need some food. When people ask me if I am ok, I will just say yes. If people ask me what I need to bring me round, I cannot make that sort of decision, I just need someone to give me something sweet and tell me to eat it or drink it.

Unaware Hypo

I first began having unaware hypos when I was 12 years old, a year after I was moved on to synthetic human insulin. Out of all the hypos types I have I find these ones are the scariest. They are not scary because of my recollection of what has happened but the exact opposite. One

minute I would be fully conscious and the next I would be coming round with people standing around me, usually in a different room or different place altogether. I would have no idea how I got there and no idea what I had done. I could not understand why the people helping me looked so petrified and I could not answer questions as to what had happened and what I had done. It is like complete amnesia, a part of my life that I was not in control of and I can never recall or explain what had happened...horrible. Fortunately for me, I moved off synthetic human insulin several years later and back on to animal insulin and I have not had an unaware hypo since.

If there is a positive to hypos it is that it certainly gets rid of fickle and fair weather friends. The general public react differently to hypos, some good, some not so good. Regardless of what others think, I spend my time looking after my own feelings and my family's feelings about hypos and not worrying too much about other people's reactions and opinions. I let new friends and old make up their own mind and if they choose to judge me on the hypos that happen to me then so be it, but I know who I am.

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Free Leaflets available from IDDT.

IDDT has a number of FREE Leaflets and other publications to help you manage your diabetes

For further information please:

E-mail bev@iddtinternational.org,

Visit our new website www.iddtinternational.org or

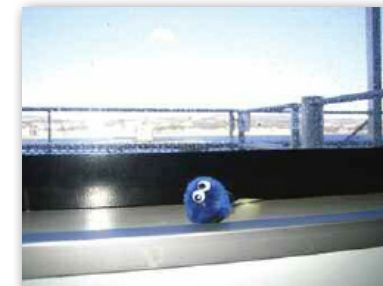
Call Bev on 01604 622837.



Where is Wilbert this summer?



Wilbert and Claud in Cyprus



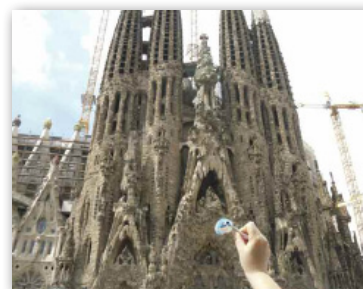
Life on the ocean wave



Lauren takes Wilbert to meet a new friend in Australia



Wilbert relaxing on the beach in Spain with Hannah



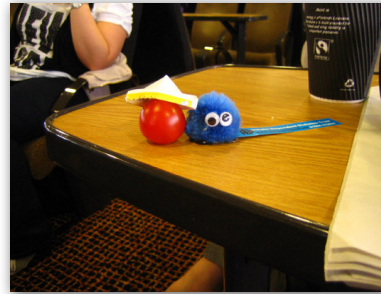
Wilbert climbs the Gaudi Cathedral in Barcelona



Wilbert decided he should have tried his sunglasses on before he went on holiday



Wilbert visits Mexico



Wilbert goes on holiday with his friend Tom



Wilbert meets a buoy in Crete

Making Things That Are Good For Us More Appealing

Supermarkets and confectionary companies go a long way, and spend lot of money on making food look better than it actually tastes. They spend time on choosing the right colours that will appeal to us, slogans that deceive us into buying food that sparkles and promote characters that make our children believe that sweets taste great. There is no doubt that most children love sweets and chocolate, but are they made more appealing by how they are presented to our children?

Can we beat the supermarkets and confectionary companies at their own game by making fruit look more appealing to our children. In

tests, when offered the same amount and types of fruit, children ate far more fruit if it was made fun and attractive, according to the journal, 'Appetite'.

The researchers, who studied nearly 100 pupils in the Netherlands and Belgium, say parents and schools should follow this example. However, they said food presentations needed to remain innovative.

In the study of children, aged four to seven, apples, strawberries and seedless grapes were put on offer, but presented in different ways. Given the choice, the children plumped for these fruits more readily when they were made into a hedgehog - skewered with colourful cocktail sticks that were pierced into a watermelon.

The same cubed fruits did little to appeal to children when they were simply offered on a white dish.

Children ate nearly twice as much of the "fun" fruit, even though they said they understood that both fruit options - hedgehog and plain dish - should taste the same. The researchers suggest supermarkets could also capitalise on the findings to make fruit more appealing for children and their parents. They suggest that attractive packaging and "perhaps adding a little toy to the packaging, like the one that comes with a Happy Meal, could make this kind of snack even more appealing". However, the researchers warn that "fun" fruit presentations might soon lose their appeal with children if they were used too many times, saying, "It is probably necessary for parents and food producers to remain innovative".

Dr Laura Wyness of the British Nutrition Foundation said: "It is advisable to try to make food as appetising as possible. How food looks probably does have quite an influence, especially for kids who are getting used to different types of food. Another technique is to try to hide vegetables and fruits in other foods like sauces. And for parents who do not have the time to make elaborate fruit faces and flowers from carrots and radishes, there are simpler ways to make foods interesting, such as cutting it into triangles, squares or strips. "

Getting children to choose fruit rather than sweets is never going to be easy but these suggestions may be worth a try.

Discontinuation of human Mixtard 30

On June 23rd 2010, Novo Nordisk announced the withdrawal of human Mixtard 30 by December 31st 2010. This will affect around 90,000 people who will have to change to a different insulin.

Mixtard 30 is human premixed insulin 30% of which is short-acting insulin and 70% is intermediate-acting, isophane insulin.

Humulin M3 is the nearest equivalent insulin to Mixtard 30. It is made by Eli Lilly and is also human premixed insulin made up of 30% short-acting insulin and 70% intermediate-acting, isophane insulin.

The only pre-mixed insulin that will be available from Novo Nordisk is NovoMix 30, an analogue premixed insulin 30% of rapid-acting NovoRapid [aspart] insulin and 70% protamine insulin aspart. This is not the same, nor even similar because NovoMix 30 has a very different peak and duration of action to Mixtard 30.

So if your child is forced to change from Mixtard 30, then the nearest equivalent insulin is Humulin M3. You may be advised to change to Novo Nordisk's only other premixed insulin, NovoMix30, so you should discuss your options with your usual diabetes team and if you want the nearest equivalent insulin, then ask to change to Humulin M3.

Notice Board



'Wilbert's Party In The Park' 26th June 2011

At Wicksteed Park in Kettering, Northants we are holding our very first 'Party In The Park.' As well as the rides already at Wicksteed Park, we will be having fun and games for the whole family. There will be live music, Parents vs Children's events, a Famous Faces Tombola, where you can win signed photo of some of your favourite celebrities and most importantly the chance to meet Wilbert and other families. Go on, come along it's going to be great. Ticket request forms will be out soon.



IDDT's Annual Conference 9th October 2010

'Trust Me, I'm The Patient'

Whether you are the person with diabetes, a carer of someone with diabetes or a parent of a child with diabetes, there is something for everyone.



A Listening Ear

IDDT would like to introduce Viv Bradford. Viv is a mum and her son has diabetes. Viv and her son went through a very hard time with their school. Although we know schools are trying hard to understand diabetes, there can sometimes still be misunderstandings about diabetes. Viv has volunteered to listen and support anyone who needs help with their child's school. All you have to do is drop her an e mail through Bev, at [IDDT bev@iddtinternational.org](mailto:bev@iddtinternational.org)

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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