



Insulin Dependent Diabetes Trust

Parents' Bulletin May 2006



Welcome!

This is our first bulletin for parents of children and adolescents with diabetes and we hope that you find it interesting and useful. We also hope that it will be your Bulletin, for you to express your feelings, your concerns and your achievements or the achievements of your child. Even if you don't want to contribute, we can all learn from other people's experiences and we hope that the Bulletin will help you to feel that you are not alone but one of many parents who are doing their best to live with diabetes in the family. We are publishing the Bulletin in addition to our quarterly Newsletter because our children are special, their needs, the needs of their siblings and our needs are different from adults with diabetes. Not any less important - just different.

I am a parent - my daughter, Bev, was diagnosed with diabetes over thirty years ago, when she was 5 years old. She is now 35 but we never stop being a parent! Things were very different 30 years ago - no diabetes specialist nurses, glass syringes that we boiled up every week, no home blood glucose monitoring, just urine testing, a more strict diet and very few low calories drinks. Looking back, diabetes control was pretty much guess work! But there were advantages too - we had a book that listed the carbohydrate values of nearly every brand of food you could think of so counting carbohydrates was easy and there were many different brands and types of insulin so it was a matter of finding the one that suited best. Time was spent with us teaching us about their action times, how to adjust carbs or insulin dose to achieve better control and avoid hypos. We learnt the hard way, by trial and error, not something I would advocate but perhaps some of the things we learnt by experience, we could never be taught. We hope that these experiences can be shared in future issues of the

Bulletin to help you.

Undoubtedly things have moved on, and for the better, but some things don't change - the feelings we have when our child is diagnosed, the anger, the denial and the sense of grief, the worries we have for their future and the need to do our best for them. No matter how many improvements are made in the treatment of diabetes, generations of parents of children with diabetes have the common bond of experiencing these feelings and emotions. We love and care deeply for our children and so they are the most natural feelings in the world.

We are here for you so please feel free to contact us at any time. You can talk to Jenny or Bev:

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How my family deals with diabetes

For this article we thank Marie Coles who describes herself as 'an anxious mum trying to retain sense of humour and sanity'.

In October 2004, our third child Lauren [who was 14 months old at the time] was diagnosed with Type 1 diabetes. She'd had a particularly nasty virus at 8 months old and, although no one can be absolutely sure, we feel this was the start of the onset of her diabetes. Lauren was a much longed for third child and when she was born my husband said she was „the icing on the cake'. Life was idyllic for us until diabetes struck.

Initially, my husband and I were very united, calm and positive about events. As the weeks past, the extent of living with a diabetic toddler started to unfold. Eighteen months on, everyday is still a new challenge and with our daughter's changing needs, we guess it will probably always be this way.

We're fortunate that our daughter has quite a placid nature and most tantrums can be attributed to hypos or hypers – she almost has a split personality and can change very quickly. Her older brothers aged 11 and 7 have been brilliant. Of course, at first, everyone forgot from time to time that Lauren was diabetic and often walked into the lounge munching on a biscuit or chocolate bar – only to be asked to go and eat it elsewhere! We're fortunate in some ways that Lauren was so young as she can't reach the food cupboards or open the fridge. Hopefully, by the time she can do these things, her routine will be well established.

We had a rough start with Lauren's diabetes and transferred hospitals six weeks in. This turned out to be the best move possible. The diabetic team, although over-stretched are extremely knowledgeable and compassionate. With the first hospital, we were going to have to wait 2 months to be seen by the consultant and home visits were not on the agenda. When we switched hospitals, with our doctor's support, we had a consultant appointment within a week and the diabetic nurse came out weekly to begin with until we gained confidence. What a difference all that made. Eighteen months on, they continue to show great interest in Lauren and the whole family and are always at the end of the line, should we have any concerns.

Lauren's medical care is of paramount importance to us but we do feel that resources to help the whole family live emotionally with diabetes are somewhat limited. Until I discovered IDDT I felt quite isolated. I had given up work [something I wouldn't otherwise have considered] and my husband ran away a little to his work to escape the daily grind of testing, injections, food routine and dealing with many, many hypos. Through IDDT, I realised my feelings of isolation and desolation at times were completely normal. I would say my husband and I felt

bereft about the whole situation but were able to comfort each other, each dealing with our own grief.

Eighteen months on, we cope with the routine with most of the diabetic care falling on to my shoulders. Lauren is now at playgroup and I'm presently staying for medical reasons but keeping a good distance from Lauren so she can develop normally. Emotionally, it has put a strain on the family and especially our marriage as we have no family who will take Lauren, even for one hour. This means that we haven't enjoyed time alone for some considerable time and this will not change in the foreseeable future.

Night time hypos are a problem for us and so consequently my sleep is deprived most nights to check blood sugars and take corrective action when necessary.

We hadn't realised, and probably still don't, the enormous extent to which living with diabetes would affect our whole household. Our social life now revolves around taking Lauren's brothers to clubs – mainly football and cubs – and we generally find, if these things affect eating or insulin times, one of us will stay with Lauren whilst the other looks after the boys. Lauren's siblings are generally very helpful and look out for Lauren but I know there are times when they too get fed up with the fairly tight eating routine we keep.

On the plus side, Lauren's HbA1cs aren't too bad – the best being 7.1% and the worst being 8.5%. Giving blood her is a trial at the moment for her and something I dread. We enjoy being a family and spending family time together. We probably eat better because of Lauren's condition, we fit exercise into our lives and the boys too benefit from extra snack times. Lauren brings lots of joy into our lives and we're extremely grateful that we are only coping with diabetes and not diabetes on top of something else. We're acutely aware that there are lots of families much worse off than ourselves.

Our dream is to raise three happy and healthy children who will live life to the full and grow into happy, healthy and responsible citizens.

Our dream echoes that of probably every parent in the land. On my part, I don't know what I did with my time before diabetes came into our life and it would be nice to have a day off every now and then but then Lauren will feel like this as she gets older. We need to be positive about Lauren's diabetes care now so she'll grow up. Hopefully not knowing any different and taking it all in her stride.

Bits and pieces

Making sure your child receives the specialist care they need

There are 20,000 children and adolescents under the age of 15 with Type 1 diabetes but a Diabetes UK survey of 150 local health authorities [2005] found that only 25% of them had made diabetes in children a priority. In addition, many were not offering counselling and nurses were over-stretched. However, nearly all of them had introduced diabetes training for staff.

Dr Sue Roberts, National Clinical Director for Diabetes said that the government recognised more needed to be done but improvements would take time. They also take money! Primary Care Trusts [PCTs] are in charge of commissioning services at local level and many of the decisions about priorities and funding are made at local level. If you feel that the services you and your child receive are not good enough, then write to the Primary Care Trust in your area to try to make sure that the care of children with diabetes is not put on the back burner.

Are annual eye examination necessary in children?

Diabetes can cause damage to the eyes and in many countries an annual eye examination is currently recommended for children and adolescents with Type 1 diabetes. However, a study carried in Sydney, Australia suggests that screenings at least two years apart are safe in most cases. The findings suggest that retinal screening at two-year intervals is suitable for most adolescents with diabetes, and longer intervals appear safe for younger children. Diabetes Care,

March 2005.

The rising incidence in childhood type 1 diabetes

The incidence of childhood Type 1 diabetes has increased worldwide during the second half of the 20th century, with an especially rapid rise in those diagnosed younger than 5 years old. Research published in The Lancet [Vol 343 Nov 6, 2004] suggests that the rise is too great for the cause to be family history. It is thought to be because some people are susceptible to something in the environment which is conducive to the development of diabetes.

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Hypoglycaemia - definitions and treatment

In this Bulletin we are looking at the factual aspects of hypoglycaemia but we will revisit hypoglycaemia again as it is a complex issue with social aspects as well as factual ones.

What is hypoglycaemia?

In people without diabetes the level of glucose in the blood is controlled by insulin produced by the beta cells in the pancreas. In people with Type 1 diabetes, the body does not produce its own insulin and the blood glucose levels rise too high [hyperglycaemia] and so injections of insulin are given to prevent this. If the blood glucose levels drop below normal, whatever the cause, then this is called hypoglycaemia [a hypo].

Defining hypoglycaemia is important

Are you asked at the diabetes clinic how many hypos your child has had? It used to happen to me quite frequently and I never quite knew what the answer was! Did the doctor mean just going low before a meal which strictly speaking is hypoglycaemia or did he/she mean having a more severe hypo that required more help than simply having a sugary drink? The number of hypos provides a true picture of diabetic control and insulin doses and/or regimes may be adjusted

on the basis on number of hypos as well as the number of high blood sugars. So it is important that everyone is using the same definition when talking about the number of hypos - if you are not sure, then ask. 'Good' diabetes control is the avoidance of lows just as much as the avoidance of highs.

Definitions

Normal blood glucose levels in non-diabetic people range between 4 and 7mmols/l. Hypoglycaemia is usually said to occur at 3.8mmols/l and so the recommended lower level is 4mmols/l – hence the recommendation to people with diabetes that “4 is the Floor”.

Note: Some publications say that hypoglycaemia does not occur until blood glucose levels are below 3.5 or even 3.0mmols/l. However, there is research that shows that the ability to function may be impaired by blood glucose levels of 3.8mmols/l and lower.

Hypos are generally defined as follows:

Mild: a hypo that is easily treated by the patient by the intake of a sugary drink or food, which should then be followed with some longer-acting carbohydrate eg a sandwich to prevent another hypo.

Moderate: one where someone else, spouse, friend or parent, has to intervene and give the sugary food/drink because the person with diabetes is confused or even losing consciousness.

Severe: one that usually means unconsciousness and maybe accompanied by a convulsion/seizure.

Treating severe hypos

If your child is unable or unwilling to eat or drink then GlucoGel can be given. It is a sugary gel that can be squeezed into the mouth around the cheeks and gums but it MUST NOT be given if the person is unconscious or unable to swallow because they could choke. [It is available on a GP prescription.] If mild and moderate hypos remain untreated and unconsciousness occurs, then this has to be treated either with intravenous glucose carried out by a doctor or it can be treated with Glucagon and many families carry it in case these situations arise. It is injected and releases glucose from the stores

in the liver. It works within a few minutes and then food/drink should be given. Glucagon can make children vomit and it can result in quite severe headaches and so it is often advised that parents try half the quantity to see if that is sufficient for your child to regain consciousness.

Research - an interesting study carried out in Brisbane, Australia investigated the use of small doses of glucagon using an insulin syringe in mild or impending hypos in children with Type 1 diabetes who refused food or were unable to take food due to gastroenteritis. Over a two year period in 25 children, subcutaneous injections of glucagon using insulin syringes were given at doses of two 'units' (20 mug) in children 2 years of age or younger, and one unit per year of age up to a maximum of 15 units (150 mug) for older children, with an additional doubled dose given if the blood glucose had not increased in 20 min.

Over a 2-year period, 25 children were treated with mini-dose glucagon on a total of 38 occasions. Additional doses were required for recurring hypoglycaemia on 20 (53%) occasions. The child could be managed at home on 32 (84%) of these 38 occasions, with only 6 (16%) children needing hospital treatment.

The researchers concluded that small doses of glucagon given with an insulin syringe is a simple, practical and effective home treatment of mild or impending hypoglycaemia due to gastroenteritis or food refusal.

Will this be the way forward in the future?

A Touch of Humour!

You know you're the parent of a child with diabetes when you have no problem asking your child if they are "high" in a middle of a public place. From childrenwithdiabetes.com

Hypoglycaemia - it's the biggest worry!

Yes, we worry about our children's future and the risk of complications but the biggest day to day worry is hypoglycaemia and the avoidance of it. It's the biggest worry for adults with diabetes too! It's not just where or when the hypo occurs, how bad it is or whether or not help from another person may be needed but also will I look foolish in front of friends or colleagues. Those of us without diabetes cannot possibly imagine what this feels like or what it feels like to be hypo and to be out of control of our actions.

Nobody likes night hypos!

A study published in the October 2005 issue of the Journal of Pediatrics has shown that children and adolescents with Type 1 diabetes are more likely to have low blood sugars in the night on days when they have taken exercise than on days when they have been more sedentary.

In the study diabetic children and adolescents were monitored on sedentary and active days and the researchers found that the risk of night-time hypos was much greater on exercise days.

- 42% of the 11 to 17year olds had night hypos after exercising in the late afternoon compared to 16% on exercise free days.
- Some children had night hypos on the sedentary days as well but this risk was greater in those who were active in their normal daily lives. This could be because regular exercise makes their bodies more sensitive to insulin.
- In nearly all the children and adolescents blood sugars dropped during exercise.

The message here is that the effect of exercise on blood sugars is not just at the time of the exercise but can be delayed for several hours so can result in a night hypo. So going to bed with an apparently normal blood sugar after an 'exercise day' may result in a night hypo. The researchers' advice is that their study shows the importance of adjusting the regime on exercise days and that it is important to

discuss with the doctor or diabetes nurse how to adjust insulin doses and evening snacks on particularly active days.

Research - an interesting UK study carried out a 12month survey on surveyed 243 people aged between 20 and 69 recorded the number of hypos and their severity. Over the 12month period, the results showed that there was a total of 1,955 mild hypos [self-treated] and 238 severe hypos [required help from another. Of the 238 severe hypos, 62% occurred at home, 15% at work and 23% not in the home or at work. 52% of all severe hypos occurred during sleep. It would be interesting to see if the figures differ for children and adolescents with diabetes.

Testing Medicines for children

A European Commission report on paediatric medicines states that 90% of medicines used on newborn babies and 50% of all medicines given to children of all ages have not been properly tested but there's no need to panic. The EU Commission is trying to set up common EU procedures for testing and approving medicines for use in children and incentives to encourage manufacturers to develop or adapt medicines specifically for children.

The House of Lords EU sub-committee on social policy and consumer affairs supports this move and the UK government has given the go ahead to accept the basic frame work proposed by the Commission. The conclusions of the report by the Lords sub-committee include:

- Too many children's prescriptions and over-the-counter drugs have not been properly tested on children prior to launch.
- Children are not simply small adults and their medication should not be treated as if they were. There is an urgent need to take action at a European level to promote and govern clinical trials of medicines on children.

- Guidelines covering medical trials must take into account the vulnerability of children, with consideration given to ethical issues around consent to trials by children, the effects of different drugs on children of different ages and access to research databases.
- Medical products should be properly labelled to indicate their suitability for children
- It is unclear how well the incentives designed to stimulate the development of drugs for children will work. The Government must press the Commission to carry out a full economic review of the incentive arrangements after a few years of operation.

We must welcome this move as it is for the benefits of our children and if you want to help to make sure that these improvements actually come about, write to your MEP.

The full report can be found at:
www.publications.parliament.uk/pa/ld/ldeucom.htm

Through the eyes of a child

By Bev Freeman

I am 35 years old, I have a beautiful six year old daughter and a wonderful partner who is supportive and understanding. I have a full time job where I regularly drive to London to meet MP's, I sit on various committees, I go out with friends, I drink, and eat foods from all over the world and I have had diabetes for 31 years. To all around me I appear to have a normal life which is the way I like it. In reality I have a normal life with diabetes. But the word normal is a difficult word to define because what is *normal*?

One thing that used to annoy me as a child was continually being told by well-meaning people that '*you can do anything anyone else can do*'. To a child this is the most ridiculous statement in the world. Let me explain why. As a child, I knew I could ride my bike, go to parties

and play out with my friends because I did all these things all the time. What I could not do was get out of bed, have my breakfast and then go to school without doing a test and then an injection. So in my little head I could not do what everyone else did!

Children really do understand more than you think if you are honest and explain things at a child's level. For example, *'Of course you will be able to still ride your bike with your friends but you will just have to take some sweets with you incase you feel wobbly'* and even, *'Of course you will be able to swim in the Olympics, you will just have to take good care of your diabetes by doing blood tests.'* I don't believe this is too much for the child to take on board. If they are old enough to ask the questions, they are old enough to hear the answer. The answer does not have to be harsh but true.

The downside to this is that your child may feel at times in their lives, that they can never get away from diabetes. From what I remember as a child these feelings did not happen very often but when they did, there was not a lot anyone could say that would console me. Nothing makes diabetes go away - not even your mum taking you on an all expenses paid shopping trip.

As a parent, when these situations occur, all you can do is listen let your child get angry, cry, moan and be there for them. If they feel like I did, never tell them that there is always someone one worse off than them because they simple do not care and do not need to be made to feel guilty about their feelings on top of everything else.

One thing I always remember that made me feel better was when my Mum and Dad put on a special meal for me. They said I could eat exactly what I wanted and said I could choose a starter, a main course and a pudding. This felt like a dream come true. But Mum and Dad had a cunning plan! They realized that there was only so much food one child could eat. So I wrote out my menu prawn cocktail to start with (no carbohydrate), burger and chips (carbs to count) and treacle pudding to polish it off. The idea was that it gave me back an element of control and by designing my own menu, Mum could work out what

she had to do to deal with this meal. Realistically the only thing that was difficult was the treacle pudding but by the time I had finished my large portion of prawn cocktail and my burger and chips there was no room for much treacle pudding. I never realized my Mum and Dad were so devious.

At the end of the day life with diabetes was not that bad. It had it's ups and downs but I really have very few bad memories of my childhood and the realistic approach to diabetes made a lot more sense than hiding things that I simply knew were not true.

Tips on Sports Day

By Bev Freeman who was diagnosed when she was 5 years old and is now 35 years old

It's that time of year again when the blossom is out and sports day is only a few weeks away. As a child I remember it is an afternoon out of the classroom full of fun with healthy competition between friends. I didn't give my poor mum a second thought about her worrying if I was going to go hypo on the sports field but then, as a child, nor should I have. It may seem a daunting day for parents especially if you are not attending and nothing in the world will stop you worrying.

Here are a few tips that my mum and I used to make life easier for both of us as I was growing up:

- Discreetly talk to one teacher that you trust and you know understands your child. If you speak to lots of teachers, they may over react and fuss around your child - this will do your child no good at all! By choosing wisely that teacher will be able to cope IF the worst should happen [a hypo].
- On the day of the great event, give extra slow acting carbohydrate at either breakfast or lunch depending on whether sports day is in

the morning or the afternoon. Give the teacher and/or your child something fast-acting too in case it's needed - good things to have are the all singing all dancing energy drinks and these are also cool in the playground.

- Long distant events, such as cross country, are a bit more difficult to deal with especially for the first time. Long distant events will take more of their energy and may leave their blood sugars lower for other events that are just as important but they can be managed. I used to take fast acting sugar just before the event and when I had finished, whether I needed it or not, for two reasons - I felt more secure that I would not go hypo and because sometimes prevention is better than cure.

I understand that parents would find it easier of their child carried out frequent blood testing, especially on sports day. But it is important to remember that sports day is supposed to be a fun day and one that your child will remember with warmth and for this, your child should feel comfortable and relaxed.

Some children like to do blood tests on sports day to make them feel more confident that they are not going to go hypo, and some will not go near a blood monitor at school because it makes them feel self-conscious or different from their friends. You know your child and whatever your child chooses to do, is workable.

If your child does not want to blood test on sports day, which is totally understandable, remember they will already have had extra carbohydrate, a teacher that understands and perhaps some good friends that know what to do. Of course do not under estimate your own child and their own common sense in knowing how they feel and what to do and an energy drink or their favourite sweets in their pocket, because it is sports day and sports day should be special.

Our ways of dealing with sports day may not be the answer to all your problems but it may help and each year you will develop your own techniques that suit you and your child.

Inhaled insulin - we can't avoid discussing it!

The interim report from the National Institute for Clinical Excellence [NICE] that recommended inhaled insulin, Exubera, is not funded by the NHS has caused quite a fuss, hitting headlines in the newspapers and it was even raised in Prime Minister's Question Time! The Chairman of the All Party Diabetes Group asked the Prime Minister to look again at the NICE decision and on this occasion, Tony Blair's answer seemed sensible. He agreed to pass the remarks back to NICE but said: *'It is important to remember that that body ends up making clinical decisions. I am not qualified to do that and neither is he.'*

The Times made political mischief on their front page by linking the NICE decision to shortages of funds within the NHS. It was sad to see in the Letters column the next day, an angry father writing to ask members of NICE if they had tried chasing a 4year old around struggling to inject him. Sad because my sympathies are with this father but also sad because he has been misled by all the newspaper hype about inhaled insulin. For months newspapers have raised hopes for inhaled insulin, no doubt fuelled by press releases from manufacturers, with claims that it is the greatest breakthrough since insulin was discovered. It is a huge breakthrough in that it is the first time that insulin has been administered in any other way than by injection. No doubt the future will see it developed further so that our children will benefit just as children have benefited from the development of home blood glucose monitoring in the 1980s.

Let us look at some facts:

1. Inhaled insulin was licensed in the EU and the US earlier this year but ONLY for use in ADULTS, not in children. Trials have only been carried out in adults with Type 1 and Type 2 diabetes and NOT in children, so there is no evidence of safety and efficacy in children.
2. The amount to be inhaled is in 3 units, so small dose adjustments

of 1 or 2 units cannot be done.

3. The inhaler is not small like an asthma inhaler, but opens up to about 9 or 10 inches, there are 5 steps to prime it and there is no way that it could be used discreetly in public, as is the case with injections! The long-term safety is unknown and there are concerns about possible lung damage and the effects on the development of insulin antibodies.
4. Injections of long-acting insulin are still necessary and trials have only been carried out using long-acting 'human' insulin and NOT with analogue insulins which are now widely prescribed, so again the safety is unknown if Lantus or Levemir are used.
5. Even in adults, the trials have not shown any benefit in terms of diabetic control as measured by HbA1c. It is not suitable for people with underlying lung disease, those with asthma or smokers.
6. The benefits appear to be patient preference, but some of the evidence for this was gathered from people with Type 2 diabetes who don't inject insulin, so they can hardly make a comparison from experience. NICE concluded that the evidence on quality of life and patient preferences was insufficient.

Then there is the cost! It will cost an extra £500 per patient per year with little evidence of benefit and concerns over long-term safety. IF it was licensed for children, would you take the risks with your child's future health? This seems fairly negative but this could be just the beginning of developments in different ways of administering insulin.

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

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From Your Editor – Jenny Hirst

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