



Insulin Dependent Diabetes Trust

Parents' Bulletin May 2009



The Goodie Bags have been a great success!

We have sent out over 700 to children with diabetes and their brothers and sisters here are some of the comments from you.

Hi! We got Dylan's Goody Bag he was over the moon! It's so nice to get something fun specifically for his Diabetes, he uses the bag for his swimming kit at school and insists on taking his stress pig everywhere with him. He has taken his pencil case to school – he is very impressed it's made from recycled tyres!! So I just wanted to thank you for making Dylan so happy! Also all the info that was also sent is very interesting – Dylan is on morning and evening injections and has good HbA1C's and overall control. We have no desires to move to MDI unless his needs change and I was very happy to read the research that states MDI is actually no better at keeping blood

glucose levels stable than the regime he's on at the moment. So I was pleased to read that what I want for my son is ok!!

Kieran and his brothers have received their Goodie Bags. I hadn't told Kieran about it and he was so surprised and excited to receive them. It was really good to be able to give something special to him and his brothers. He is using his drink bottle at school and is really proud of it. Hats off to whoever thought of the Goodie Bags. Such a simple idea that has given so much pleasure.

We received your information pack this morning just before Polly went to school, and I must say she was DELIGHTED with her goodie bag, for two reasons. The first reason was that she had been sent a gift which very rarely happens as the postman only ever seems to deliver post for mum and dad! Secondly, her topic at school this term is recycling, so how pleased was she to be able to take to school a

pencil case made out of tyres, a pencil out of old newspapers and a ruler made out of recycled plastic!! Brilliant thank you.

I have been meaning to thank you for the receipt of the Diabetes 'Goodie Bags' you sent my children. They were very pleased with them and they use their new pencil cases for school. I am really glad that your organisation exists and helps people recognise that children with diabetes and also their siblings need support. It helped make my son realise there are a lot of other children who are in the same position as him. Thank you for also including my daughters as sometimes they take a back seat. I have started to read through some of the information you sent and I must say what I have read is very interesting. I look forward to receiving the next Parents Bulletin and Polly is already thinking of a name for the IDDT mascot.

The DAWN Youth Survey

In 2001, the Diabetes Attitudes, Wishes and Needs (DAWN) survey interviewed 5,400 adults with diabetes and 3,800 health professionals across 13 countries to see what the barriers to achieving positive outcomes were. When using the term positive outcomes the researchers meant the acceptance of diabetes as part of daily life and the reduction, as far as possible, of stress and anxiety. At the time of the study, it was realised that diabetes in young people was different to that in adults and that a separate study would be needed to identify and ultimately overcome the psychosocial barriers to optimal health and best quality of life for young people with diabetes and their families. This realisation gave rise to the DAWN youth survey.

There were 3 objectives of the survey:

- To gain an understanding of the challenges and issues facing children, adolescents and young adults living with diabetes, as well as the parents, carers and others with responsibility for

supporting them.

- To identify new avenues for improvement in the context of psychosocial support for children with diabetes.
- To stimulate new efforts to improve care for children, adolescents and young adults living with diabetes and their families.

The study found that there is a significant amount of unmet needs among young people, their parents, family and carers. Some of these needs could be met through the provision of additional resources to schools. Many people stated that they felt that the support they received at school was poorer than in other areas and that improvements could be made to the education of teachers, particularly on how to deal with hypos.

IDDT is very aware of the issues facing children and parents with the regard to the management of diabetes in schools and we hope that by providing children with our goodie bags we can give them an opportunity to raise awareness among teachers and their classmates about their condition. We are currently developing a range of other resources and tools that can be used by children, their parents and teachers to address the shortfalls that exist and to promote awareness and understanding of the condition. We were really pleased to hear that one young man, who had received his goodie bag, used it to go into his class and talk about his diabetes.

We also provide specially-tailored information packs to teachers so that they are able to educate themselves about diabetes and its management, should they have a child with diabetes in their class. What would be really good to see would be the adoption of the system used in Sweden. Swedish schools do not rely on nurses. Instead, the legal responsibility for overseeing self-care lies with the schools and so the teacher of a class that includes a child with a medical condition is required to know how to support that child in the same way as his or her parents.

Similarly, a child's needs for social and emotional support can be met by providing increased training and resources for healthcare

professionals. The healthcare professionals themselves said that they were not able to provide the levels of support required but would be happy to do so if the necessary resources were in place.

Regarding the UK government's position on the provision of support for children with diabetes in schools, two documents have been produced "*Managing Medicines in Schools and Early Years Settings*" and "*Including me: managing complex health needs in schools and early years settings*". These documents address what schools can do to support pupils with medical needs such as diabetes. They encourage schools and local authorities to develop policies on the management of pupils' medicines and on supporting pupils with medical needs, taking account of local resources and their various responsibilities.

We feel that simply encouraging the development of local policies is not enough. While these sources of guidance may give parents and teachers some idea of what they can expect, they give no guarantee that they will get it. Similarly they place no responsibility on schools to provide it.

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Welcome to Wilbert!

The name for the IDDT Mascot has been pulled out of a hat and the lucky winner is Paul O'Maolain. Paul, your ipod Shuffle is on its way to you.

IDDT would like to thank you all for your fabulous entries to the name our mascot competition. You all spent time thinking about your names and came up with some brilliant and imaginative ideas that you should all be very proud of. It was fantastic that so many schools got involved and we hope that these schools learned a little more about diabetes. Once again a big thanks to all of you for taking part. We wish we could give you all a prize for being so imaginative.

Stepping Out For IDDT

Over the past two years we have had a dedicated team of runners and supporters who have been working hard to raise awareness of diabetes and IDDT. This has helped thousands of people to receive the support and information they need to make living with diabetes a little easier. The information IDDT provides has been described as 'invaluable, easy to understand and life saving'. We want as many people as possible to receive this free information.

So this year we are stepping up our appeal. We are asking everyone to take a step to help someone with diabetes.

Everyone can do their bit to help and at the same time, take some exercise!. With our free Tshirt, every step you take could help someone with diabetes. If you are going for a run or simply walking to the shops or to school you can wear our T-shirts or an IDDT sticker to show people how to get in touch with IDDT.

To help you on your way we will also give you a free IDDT Pedometer which will show exactly how many steps you have taken. Each month you can e-mail IDDT at martin@iddtinternational.org and let us know how many steps you have taken to help people with diabetes. Each month the steps will be added up and posted on IDDT's Home Page so we can see how well we're all doing.

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Get your free pedometer from IDDT!

For your free Pedometer & T-shirt, please contact Martin on 01604 622837 or e-mail martin@iddtinternational.org

Self-confidence in Children with Diabetes

When I was diagnosed with diabetes at 5 years old I really had no idea of what lay ahead and in some ways it seemed like another adventure. It did not take long for the reality of diabetes to hit home. But like most children that are diagnosed at a young age, I took it all in my stride and carried on with being five.

At the ripe old age of 38, and working for IDDT, I am fully aware of the issues of confidence and low self-esteem that surround many people with diabetes. I also understand as I have experienced confidence issues of my own.

As a young child, I do not remember being particularly lacking in confidence but as I grew older I remember a definite slow change in my confidence. Looking back I now realise that I began to lose confidence when I started to become more in control of my own diabetes. I began to monitor my own blood sugar readings, speaking to my diabetes specialist about my diabetes control and having more control over what I ate. Until that point, my mum had been in charge of all these things and she also had to bear the brunt of not being able to reach some of the unrealistic targets that had been set. Each time I attended a hospital visit I felt my diabetes was scrutinised by my diabetes team. No matter how hard I tried I never got it quite right and no matter what I had been through e.g chicken pox or even a cold, my efforts never quite met the mark. Even at the age of seven I felt an amazing amount of pressure to get it right and felt that these unrealistic targets of perfect blood sugar readings never took into account that I wanted to do what other kids did, like go to parties and eat cake.

Club this together with the realisation that I could easily go hypo in any give situation and behave in a completely uncharacteristic way, this understandably led to a lack in confidence. Luckily myMum was at hand to counteract a lot of these feelings of failure and negative comparisons to this mythical person who had the most perfectly controlled diabetes who was capable of doing anything no matter

what life threw at them! My mum used a method that I now use with my own daughter, even though she does not have diabetes. Mum would listen to what I had to say and never pass judgment which made me feel secure and able to express my true feelings. This in turn helped my mum to deal with my feelings of insecurity.

Methods of dealing with confidence

- Give credit to your child when they achieve something, no matter how big or small. Make them feel proud of their achievements.
- Downplay situations that are unavoidable and targets that are unachievable. Depending on the age of your child use reward charts – you can use our stickers as the reward. Kids love stickers, even older ones. You can have as many stickers as you need and we can also give them certificates for anything you feel needs rewarding.
- When things go wrong like a hypos or hypers, discuss these situations at a level your child understands and why this may have happened and what your child felt may have caused it. This will give them a chance to ask themselves questions rather than be told the answer.
- Even though the solution to this problem may appear to be to not hand responsibility over to your child, it is important that they get used to dealing with their own diabetes as early as possible. It can become a learned behaviour to deal with their own diabetes rather than the learned behaviour of relying on Mum or Dad to deal with their diabetes. Relying on someone else to deal with your diabetes becomes very difficult habit to break and is riddled with emotional problems for both you and your child.

Hall Of Fame

Zoe, aged 3 years old, was diagnosed with diabetes over Christmas last year and had to spend Christmas Day in hospital, so this brave little girl needs a huge well done. She has amazed everyone with how well she has coped and how she has managed to do her own blood tests only 2 months after she was diagnosed. Zoe's older brother Sam has been a rock for his little sister and has been so patient and understanding of all the new stuff that have arisen over the last few months. Here at IDDT we would like to say how proud we are of both Zoe and Sam for how well they have coped and there is a bravery certificate on its way to both of them.



Alex lives in Russia and is five years old. Alex was diagnosed with diabetes in 2007. Alex's diagnosis has not slowed him down and he has a huge lust for life that keeps his mum on her toes. Well done Alex for dealing with your diabetes so well.



Here's a huge shout out to Steven (6 years old) who has had diabetes for 3 years and his little brother Charlie. Steven and Charlie have taken part in a 1000m Fun Run. The athletes taking part in the 2012 Olympic need to keep an eye out for these two as Steven completed his Fun Run in 6mins 49 seconds and Charlie finished in 13mins 2seconds. We wish Steven good luck in his up and coming football matches.



Toby Cotton is six and a half years old and was diagnosed in October 2008 and he has dealt with his diabetes remarkable well since then. He does his own blood tests and injections and has a brilliant understanding of his glucose control. He has also recently learned makaton (sign language) to help his 12 year old brother who has learning difficulties. Toby takes life in his stride and is a very kind and caring young man and we would like to let him know how proud we are of him, especially his mum Jane.



A big shout out to Pam from the Guy Culverwell Children's Trust. In February Pam completed a massive 19K sponsored swim in the Red Sea and raised a staggering £4400 to help support children with diabetes. Way to go Pam – we're all really proud of you!



Send us your photos!

Ask Dr Laurence - your questions answered

Question: I worry about the long-term complications for my little girl who is 6 years old, so we do try very hard to keep her blood glucose results in the right range but what are the longterm effects of hypos?

Answer: While it is important to warn people about long term complications, I always feel the distress for parents who worry about their children and it is difficult to strike a balance. These days, people with diabetes suffer fewer complications because of better

monitoring of kidneys and eyes etc. As far as hypos are concerned, the main problem is an acute one, ie recovery from the hypo. Long term hypoglycaemia can affect nerve function. Overall, one should maintain a sensible approach and keep the sugars as far as possible in the normal range. No-one with diabetes has perfect sugars.

Question: My son is now 16 and his friends have all started drinking but I worry about his diabetes. He won't really listen to me but what advice should I try to give him?

Answer: This is difficult. I often say to my teenage patients that someone with diabetes can lead a completely normal life apart from flying a Jumbo jet and overdoing the partying. It is not just the alcohol (and its carbohydrate content) but it is the lifestyle that goes with it. Drugs such as cocaine and ecstasy apart from being illegal, bring additional problems to control of diabetes. Teenagers and 20-somethings who drink heavily (and the weekends seem to start on Thursday nights) often lie in bed till after midday the next day. If this means skipping insulin and breakfast, it creates havoc with control. Moderate alcohol intake is not a problem. The occasional heavy session is regrettable but not disastrous. What must be avoided is the regular bingeing and all that goes with it.

Question: My daughter has only recently been diagnosed, she is 9, and I know this sounds silly but I worry about whether she will be able to have a baby, and whether I will be a grandma.

Answer: With all the improvements in management of diabetes, your daughter will be able to have as many children as she wants. Diabetes before and during pregnancy is well monitored and the complication rate is low. Worry about the future is a common issue in diabetes. If we look after the present with good control, healthy living, plenty of exercise and fluids, the future will look after itself.

Injections and needle sizes

Now we have small disposable syringes and of course, injection pens which most adults and children in the UK now use. We also have a choice of different needle lengths and widths [known as the gauge]. Your diabetes specialist nurse will discuss with you having the correct needle length which basically this is dictated by the thickness of the skin [the body mass index, BMI]. In other words, people with more fat require longer needles. However, the right injection technique [angled or vertical] is also important in thinking about the needle length.

There are three different lengths of needle:

1. 5mm x 31G [width of needle 0.25mm]
2. 8mm x 31G [width of needle 0.25mm]
3. 12.7mm x 29G [width of needle 0.33mm]

Where to inject when using a pen

- Insulin should always be injected subcutaneously – this means into the fatty tissue between the skin and the muscle. Insulin is best absorbed from here and has a longer effect. It is best to avoid injecting into the arms or calves because there is a risk of hitting muscle.
- Short-acting insulin should be injected into the tummy area [if your child is happy about this] because it is absorbed more quickly from here.
- Long-acting insulins should be injected into the upper thigh as it is absorbed more slowly from here. The injection site should be varied as injecting into the same site can result in hard lumps developing. As well as these being unsightly, the insulin will not be absorbed properly from these areas.

Injection technique

- It is easier to inject into the subcutaneous tissue by making a fold in the skin [pinching] and this also prevents injecting too deeply

and hitting the muscle.

- If you pinch the skin, then you can inject at either 45 degrees or vertically but the choice of needle length must match the thickness of the skin. This is what your diabetes nurse will discuss with you.
- If you do not want to pinch the skin, the needle should not be injected vertically but must be at an angle of 45 degrees and the needle should be short or medium length. If you inject at an angle less than this, then the insulin will only reach the dermis [first layer of the skin] and bruising may occur.

Tips

- Remember, count to 20 between injecting the insulin and before removing the needle so that the injected insulin does not leak out.
- Always remove the pen needle after injecting. If the needle is not removed this leaves an open passage to the insulin which can [i] leak out and [ii] air bubbles can enter the cartridge and with the next injection the full dose may not be given.

Injecting through clothes

Whether we as adults like it or not, some of our teenagers will inject through their clothes! The drawbacks of doing this are that it is difficult to pinch the skin through clothes, the fabric can remove the lubricant on the needle and can damage the needle tip both of which increase discomfort. It is also not possible to inspect the injection site for insulin leakage or damage.

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Letters Page

From Kelly O'Donoghue, Mum of two children with Type 1 diabetes
I thought I would send you our story, as there are not many families with a brother and sister with diabetes.

In April 2006 my daughter who was 11 months at the time became ill

in the space of a week, she had been waking in the morning soaked through her nappy. Myself and my husband blamed the nappies and kept changing brands through that week, She had been drinking quite a lot but as she was only 11 months she obviously could not tell us how thirsty she was.

At the end of the week she became very irritable, and I thought maybe she was having trouble with her teeth, she had no temperature and was eating loads, (obviously now know the reason for this). A day later she woke at 5.30am with very restrained breathing and I rushed her to the doctor. She sent me straight to the hospital. Within 5 minutes I had 6 doctors/nurses around the bed, within 10 minutes Cara was having part of her head shaved, as that was the only place they could locate a vein.

My husband arrived and we were both in shock, when we were told within 20 minutes that they thought she was diabetic. Cara was in the high dependency unit for one week, I slept in her room for the first 48 hours as she was so poorly.

We were then introduced to our diabetic nurse, Alison Sadler, who has since been a great guide for us as a family. Alison started the task of showing us how to inject, and what the future would now hold for us. We went home within a week, and our lives changed drastically.

In September 2006 as we were just settling into our new regime, our son Max who was then 3 years old complained of being thirsty, I looked at my husband and just said 'NO'. We used Cara's blood glucose monitor and tested him, it just read 'HI', he was then admitted to hospital and stayed there for a couple of days.

Max and Cara are both on insulin pumps now and have been since January and May 2008. The pump has made a big difference to their lifestyle, and I now weigh everything they eat, which can be difficult. They are both very healthy, Max is now 6 and plays ice hockey for the Peterborough Phantoms under 10's team, and Cara is now 3 and has just started gymnastics.

Yes, life has changed drastically, and there are sometimes days when I still cry about it, but there is nothing I can do to change this. I can only continue to educate my children to carry on being as sensible with food choices and medication as we all are now...

Thanks to Kelly for sharing her story with us and I am sure everyone wishes her and her family all the best for the future. Let us know your experiences that may well help others feel they are not on their own, just e-mail 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 – Jenny Hirst

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