



Insulin Dependent Diabetes Trust

Parents' Bulletin August 2006



Welcome!

This is our second bulletin for parents of children and adolescents with diabetes and as it is holiday time, we hope that you find the time to read it! For families with a newly diagnosed child or teenager, holidays and summer itself brings new experiences for families. It can be the discovery that hot weather may cause more frequent hypos and insulin doses may have to be reduced or the sheer excitement of going on holiday can lower blood glucose levels, especially in younger children. While this can be a hard learning curve, it is what living with diabetes is all about - learning how to handle the various situations that occur in day to day life. So next summer you will be pre-warned about the effects of hot weather on your child's diabetes.

Something else that we have rarely had to think about in the UK

is temperatures above 30 degrees but this summer we have! So it is worth remembering that the advised temperature for keeping insulin is usually 'below 30 degrees'. Insulin does not go off at high temperatures but it can become less potent and this means that it is less effective. So if you suspect that this has happened because blood sugars have gone up for no accountable reason, it is worth starting a new cartridge or vial.

We hope that this will be your Bulletin, and we will be able to exchange experiences. We'd love to hear from you but if you don't want to contribute, we would welcome your views on topics that should be included in future issues. We hope that the Bulletin will give you food for thought and perhaps look at some of the issues that are learnt by experience and cannot be taught in a textbook.

IDDT's Annual Conference takes place in Birmingham on Saturday

October 14th. It is an informal day and a good opportunity to meet with other people in a similar situation with sessions especially for parents and family carers. We hope that you will come and join us and if you would like an application form, just give Bev a ring on 01604 622837.

The Bulletin is published in addition to our quarterly Newsletter because our children are special, their needs, the needs of their siblings and our needs as parents are different from adults with diabetes.



The use of insulin in children and adolescents

Updated July 2006

Insulin was first used to treat diabetes in the 1920s, the first insulin used being beef insulin [extracted from the pancreases of cattle] and in the 1970s highly purified pork insulin [from the pancreases of pigs] first came on the market. So both have a long history of safety. Synthetic genetically modified human insulin [made from bacteria by DNA technology] was introduced in the 1982 and widely used as first line treatment by the end of that decade. From 1998 insulin analogues were introduced and they are made by a further genetic modification of human insulin.

The vast majority of people use synthetic insulins without any difficulties but a significant number of people experience adverse effects when using human and analogue insulins and need natural animal insulin.

Some of the newer insulins have had no or only limited testing in children and this information is in the Specific Product Characteristics document for the various insulins. Below is a list of some of them but first you should know what some of the phrases actually mean!

- *'Safety and efficacy have not been demonstrated'* - means no trials have taken place to provide evidence of safety and efficacy.

- *'No studies have been performed'* - means that no trials have taken place to provide evidence of safety and efficacy.

Hypurin Porcine Neutral, Hypurin Porcine Isophane, Pork Actrapid*, Pork Insulatard*, Human Actrapid and Human Insulatard

The treatment of insulin dependent diabetes mellitus.

Note: no warnings against use in children and adolescent.
*Discontinued at the end of 2007

Humalog [Lispro]

Should only be used in children in preference to soluble insulin when a fast action insulin might be beneficial eg timing of injection in relation to meals.

Humalog Mix 25

Administration in children below 12 years of age should be considered only in cases of an expected benefit when compared to soluble insulin.

NovoRapid [Aspart] and NovoMix 30

No studies have been performed in children under the age of 2 years. NovoRapid can be used in children in preference to soluble human insulin when a rapid onset of action might be beneficial.

Apidra [Glulisine]

There is no adequate clinical information on the use of Apidra in children and adolescents.

Lantus [Glargine]

Safety and efficacy have been established in adolescents and children of 6 years and above. Safety and efficacy have not been demonstrated in children below 6 years. However, the PIL says there is limited experience with the use in children and the Drugs and Therapeutics Bulletin [Vol 42, No 10, 10/04] says that its efficacy and safety has only been established when given at night.

Levemir [Determir]

The efficacy and safety have not been studied in children below

6 years. Efficacy and safety were demonstrated in children and adolescents aged 6-17 years in studies up to 6 months.

How will your child react to diabetes

This article does not hold all the answers of how to help your child with diabetes, but it may help you on your way to making your own decisions about how you help your child cope.

How your child reacts to the diagnosis of diabetes can depend on their age and their temperament. How you as a parent react will probably also depend on your temperament but you are entering unknown territory and unaware of the emotional roller coaster that may lie ahead.

Raising children is mostly repetition of how you were brought up yourself as this is the main source of your knowledge. However, according to Marianne Helgesson, a Swedish Lecturer on psychology and diabetes, if your child has a chronic illness there is usually a lack of role model to aspire to and this can make parents feel alone and insecure.

The balance between dependency and responsibility is difficult and can feel almost impossible at times for both parent and child. It can leave the parent asking the question, *'how much help should I give my child without being over protective'*. And it can leave the child asking, *'how much help should I ask for'* without losing their well deserved independence, regardless of age. This will be an on going situation throughout the growing up years and will continually change and be re-modeled the older your child becomes. Each family is different and will reach different compromises that suit their particular lifestyle.

Infants

With all infants (0 to 18months) it is important that parents put aside

their own needs in order to look after their little ones. Infants are unable to look after themselves and need mum or dad to answer all their needs.

If your child is diagnosed at this time it can bring a huge amount of stress to the whole family and feelings of helplessness for everyone. Understandably you could find the situation difficult to handle. Your confidence may feel crushed, making you feel tense and uncertain towards your child, you may find it hard to make your child feel secure and confident.

But it will be OK and everything will be fine. When dealing with your child try to put your own insecurities aside and be strong and positive for your child - this is the best thing you can do for them. But when your child is not around, there is nothing wrong with all your fears, anger and insecurities being expressed to a supportive partner or a good friend.

It is impossible to explain to infants why they have to do blood tests and injections and go through the pain surrounding them but they will understand when they are older. It is important to remember that you are doing the best thing any parent can do for their child by blood testing and giving them their life saving insulin.

Infants can't express their feelings which may be pain, anger and fear, so try to concentrate on getting the injection and blood test out of the way confidently and quickly. Comfort your child for as long as they need it. Then feel free to go into the kitchen and comfort yourself.

Toddlers

The next age group that we are going to try to look at is the toddlers (1 ½ - 3 years). According to R. Hanas MD, PhD, all toddlers regress and become more attached again to their mothers. So if your child is diagnosed at this age, do not be alarmed if you feel their behaviour becomes more infant-like than it was before.

As with infants, your toddler will also find it almost impossible to

understand their diabetes and what is happening to them but what sets toddlers apart from infants is the 'obstinate stage', better known as the terrible twos. All toddlers test their parents' limitations and so setting boundaries of what is allowed and what isn't is important.

During this time your toddler may display times of aggression and frustration. The positive to this is that it helps your child stand up for themselves, to compromise and to learn when to stop. Most parents find this stage difficult without the added limitations that diabetes places on a child such as injections times and meal times. Parents often say to us that they want to compensate the child because of the limitations they feel diabetes puts on their child. Some parents try letting their child decide on other issues, in the hope of restoring the child's ability to choose and become independent.

Unfortunately, as Hanas points out, in letting the child decide about everything else in their lives, the parent is showing pity and this can lead to the child being unable to set themselves limits later on in life. The child may then become insecure and disorderly. However, if the parents struggle to deal with the aggressiveness, the child may turn inward and become insecure and passive with low feelings of self-confidence. The child may feel that everyday requirements add extra pressure to their parents leaving the child feeling demanding. The child may then try to draw as little attention to themselves as possible.

As with infants, try your best to put your emotions to one side and look at the diabetes as a different issue to your toddler's needs, almost as a separate entity. When dealing with injections, blood testing and even hypos, where possible, place you and your toddler in an environment where you both feel safe and secure. It is important to give plenty of comfort and let them understand that you know how they feel.

Parents

Alleviating your stress and re-building your self-confidence and ability to cope can only be seen as a positive thing for your toddler's well-being. Do not feel guilty about having quality time with a supportive spouse or supportive friend and remember the blood tests and

injections you do for your toddler are totally in their best interest.

Parents need understanding too and they also need encouragement because a child with diabetes needs as natural an upbringing as possible, just as much as any other child. If you need some support and encouragement, give us a call we all know what it is like and are happy to listen.

Article by Bev Freeman who has had diabetes for 31 years and has a 7 year old daughter.



Five portions a day, but what is a portion?

Scientific studies have shown that people who eat a lot of fruit and vegetables may have a lower risk of getting illnesses, such as heart disease and some cancers. For this reason, health authorities recommend that you eat at least five portions of fruit and vegetables every day - and it doesn't matter whether they're fresh, tinned, frozen, cooked, juiced or dried. But what is meant by a portion? Here are a few examples:

- One piece of medium-sized fruit - eg, an apple, peach, banana or orange.
- One slice of large fruit, such as melon, mango or pineapple.
- One handful of grapes or two handfuls of cherries or berry fruits.
- One tablespoon of dried fruit.
- A glass (roughly 100ml) of fruit or vegetable juice.
- A small tin (roughly 200g) of fruit.
- A side salad.
- A serving (roughly 100g) of vegetables - eg, frozen or mushy peas, boiled carrots or stir-fried broccoli.
- The vegetables served in a portion of vegetable curry, lasagne, stir-fry or casserole.

Junk food banned in school meals!

Last year the government promised £280million to improve school meals after Jamie Oliver's campaign. Now the government has announced new nutritional guidelines for school meals in England from September which will ban meals high in salt and fat. The new rules will:

- ban low-quality meat products, fizzy drinks, crisps and chocolate from school meals and ban confectionery, fizzy drinks, crisps and chocolate from school vending machines,
- ensure a minimum of two portions of fruit and veg with each meal
- restrict deep-fried items to only two a week
- set tough nutritional standards for school meals to be introduced from 2008 in primary schools and 2009 in secondary schools and these will stipulate vitamin and mineral content.

While this is bound to be healthier for all children, it also means that temptation is removed for children with diabetes and they will not feel different from their friends because they too will be having healthy foods and drink.

Note: The Scottish Executive is also planning to ban junk food, Wales is planning 'to take junk food out of our schools' and Northern Ireland has put out proposals for public consultation.

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Back to School

The new school year is upon us and for some children with diabetes, this may mean the first time at school and the first time as parents, someone else is looking after your child all day. Starting school is a big step anyway - as big for Mums as it is for children! But if your child has diabetes there is an extra worry. Will the teachers make sure that

your child has a snack at the right time, will they recognise a hypo if it happens and a million more concerns...

For children who have had diabetes a while, the new school year means a change of teachers - just when you have got the confidence to know that the last one understood your child and his or her needs!

As parents obviously it is important to discuss with new teachers your child's needs but it is also important not to overload them with lots of information - something we parents often tend to do because of our own worries. To help with this we have put together a Parents **Information Pack** which among other things contains an information card to give to the teacher. You can fill in the details about your child's diabetes: your contact details and your child's hypo symptoms, likely times that hypos may occur, emergency food/drink, dietary details. This way, you know that the teacher and the school have the information written down in case it is needed. Hopefully it will also give the teacher confidence to look after your child.

Teachers are in a difficult position and cannot be expected to understand the details of all medical conditions that can occur in children in their class but at the same time they do take responsibility for them. Diabetes is especially difficult for them because as we know, no two people and no two children with diabetes are the same. To help teachers and schools we have put together a **Teachers Information Pack** and we have already supplied many of these to primary schools directly but it is also intended for parents to take to the school to help in their discussions about their child's diabetes with the teachers. The Teachers Pack contains the following leaflets and information:

- Diagnosis and its impact
- Effective liaison with schools
- Sports activities in children and adolescents
- Learning with diabetes: A colour supplement about hypoglycaemia which opens into a poster describing the various symptoms of hypoglycaemia for the staff room notice board.
- Introducing IDDT to Parents.

It may be advisable to give the teacher several copies of the Pack so that other members of staff and the head teacher also have the information. If you would like one or more copies of the Parents Information Pack and/or the Teachers Information Pack, then please do get in touch: Tel 01604 622837, write to IDDT, PO Box 294, Northampton NN1 4XS or e-mail enquiries@iddtinternational.org

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Common Infections May Be A Trigger for Diabetes in Children

A major study published in July 2006 has added weight to the theory that environmental factors such as common infections may be a trigger for diabetes in children and young adults. The study analysed information on the times and places where over 4,000 people aged 0-29 years old with Type 1 diabetes were diagnosed over a 25-year period. A pattern emerged with 'clusters' of cases found at different geographical locations and time intervals for 10-19 year olds.

- 6 to 7% more cases of Type 1 diabetes were found in 10-19 year olds in the clusters than would have been expected by chance.
- Clusters were more likely to occur in girls and young women with 7-14% more cases found in 10-19 year old girls than expected.

This pattern, called 'space-time clustering', is typical of conditions triggered by infections but conditions caused by more constant environmental factors produce clusters of cases in one place over a much longer time period.

These results should help towards understanding more about the causes of Type 1 diabetes but much more research is necessary to identify which infections may be responsible. The researchers believe that Type 1 diabetes is likely to be caused by a combination of factors. It has been suggested that infections are linked to the development of Type 1 diabetes in children who are genetically susceptible to certain

environmental triggers but as the number of cases is rising by 3% each year, this is too high to be caused by genetic factors alone. Ref: 'Space-time clustering analyses of Type one diabetes among 0-29 year olds in Yorkshire, UK.' McNally, R.J.Q et al, Diabetologia (2006) 49: 900-904.

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New Research looks at the quality of life of siblings

A chronic illness in a child is very upsetting and as IDDT frequently says, diabetes in one member of the family affects all the other family members too. I am sure that as parents we worry about the effects of the siblings - the healthy brothers and sisters and how much their life is affected. Some recent research carried out in Germany may put our minds at rest!

Questionnaires were sent to 72 children with Type 1 diabetes, 71 siblings and 63 children from families without a child with diabetes. The results showed that generally there was a great similarity in quality of life between healthy siblings of a child with diabetes compared to those in families without a diabetic child. The differences in quality of life that did occur depended on age and gender of the children and related to specific concerns of the sibling relationship, such as 'worried about the sibling' and 'looked after the sibling'. So the results from this study suggest that the health related quality of life of healthy siblings of children with diabetes only differ insignificantly from brothers and sister of 'healthy' families.

Dtsch Med Wochenschr. 2006 May 19;131(20):1143-8. Note: it is interesting that a study looking at the past history of infections in Chinese children also concluded that infections played a significant role in the subsequent development of Type 1 diabetes.

Bits and pieces

Piglet implants in children with diabetes

A team of international scientists in Mexico are claiming success in treating children with diabetes by implanting cells taken from newborn pigs. The use of animal organs or tissue to treat human disease is known as xenotransplantation and is controversial because it raises ethical issues as well as the possibilities that viruses from pigs could be introduced into people.

Cells responsible for producing insulin were taken from 10 piglets to provide enough cells for one child. The cells were then packed into metal tubes which were implanted into the child's abdomen. The tubes were used to 'hide' the cells from the children's immune system otherwise they would have been destroyed by the natural action of the immune system. A total of 23 children between the ages of 11 and 17 were given the cells and the results were that 8 of the first 12 children showed marked improvements and 7 out of 11 of the second groups needed fewer injections and 2 needed none at all. Five years later and WITHOUT the use of immunosuppressant drugs, the researchers are still able to detect insulin producing cells in the metal tubes. The researchers suggest that fears that deadly viruses could pass from pigs to humans may be unfounded.

Mixing insulin analogues in the same syringe is OK for children with diabetes

In the UK and throughout Europe, there is a very high use of pens for injections but in the US it is only the minority who use them [about 13% of those who inject insulin]. When insulin analogues were introduced the advice was that rapid-acting and long-acting insulin analogues should not be mixed in the same syringe. So for those using multiple daily injections, this meant an increase in the number of injections compared to human and animal insulins that could be used in the same syringe. However recent research [Journal of Pediatrics, April 2006] has shown that insulin analogues can be mixed in the same syringe as both high and low blood sugars occurred with the same frequency whether the insulin analogues were injected together or in

separate syringes. The researchers state, "The findings are especially encouraging to those patients who wish to minimize the number of total daily injections because of needle fear, forgetting injections, or other injection-related issues."

Just a thought - while pens have many advantages especially when out and about during the day, they do mean more injections per day if long and short-acting insulins are used. Some people do their evening injection [and their breakfast injection with a syringe if they are using longer-acting insulins twice daily] and draw up both insulins in the same syringe so that they only have to have one injection instead of two with pens.

Variant gene linked to Type 1 diabetes

Researchers have identified a variation in a gene that is associated with Type 1 diabetes. The new discovery lends support to the idea that an abnormal response to a viral infection knocks out insulin-producing cells.

The researchers discovered the IFIH1 variant after conducting a genome-wide search for genetic variants possibly linked to type 1 diabetes. The impact of the variant on diabetes risk was confirmed in a study of more than 10,000 individuals and an analysis of nearly 1800 affected families. The researchers describe these statistics as 'compelling' and justify further research to see if functional changes in the gene brought about by the variation could lead to Type 1 diabetes. Nature Genetics, May 16, 2006.

Don't forget! If you'd like a chat or we can help in any way, give Bev or Jenny a call on 01604 622827 or if it's easier, e-mail enquiries@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

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Northampton
NN1 4XS

Name: _____

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Postcode: _____

Tel No: _____

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From Your Editor – Jenny Hirst

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