



Insulin Dependent Diabetes Trust

Parents Bulletin

February 2007

The incidence of childhood diabetes throughout the world is increasing. A study published in Diabetic Medicine [August 2006] showed that during the years 1990-1994 this increase was 2.4% and during the years 1995-1999 it was slightly higher at 3.4%. The trends estimated for continents showed increases of 4.0% in Asia, 3.2% in Europe and 5.3% in North America but in Central America and the West Indies the trend was a decrease of 3.6%. The researchers pointed out that this rising incidence of Type 1 diabetes globally suggests the need for continuous monitoring of incidence in order to plan services or assess prevention strategies.

It may seem that there is great emphasis on Type 2 diabetes in children and adolescents - a condition that has appeared only over recent years with the increase in obesity and reduced exercise. While it is vital to address Type 2 diabetes in youngsters and develop strategies for prevention, it is equally important that those with Type 1 diabetes are not forgotten either in research agendas or improving services for children and adolescents with Type 1 diabetes.

The global rise in Type 1 diabetes in children is an enormous problem for families in developing countries and sadly many children with diabetes die soon after diagnosis while others have poor control and develop early complications. One of the main reasons for this is not a global lack of insulin but a lack of *affordable* insulin. In some countries, the cost of insulin for one child is more than the family income. This has been made worse by the introduction of the more expensive 'human' and analogue insulins by the pharmaceutical companies and their discontinuation of cheaper and equally effective animal insulins. While in the developed world we may debate the differences between animal and synthetic insulins, people with diabetes in developing countries do not have this luxury - they need is affordable insulin to keep them alive.

With the help of our members and many health professionals in diabetes clinics around the UK, IDDT tries to help. We are the UK arm of *Insulin for Life*, an Australian organisation, and we collect unwanted, in-date insulin, test strips and other diabetes supplies to distribute to countries in need. One of our main projects is Helping poor countries, a diabetes clinic for children and young people with diabetes in India run by Dr Sharad Pendsey and his wife. We send unwanted insulin and other supplies and many of our members sponsor children at the Dream Trust. Just as little as £2.00 a month helps to keep these children alive.

We would like to express our thanks to our members who are helping these needy children. If you have any unwanted insulin in your fridge or are interested in sponsoring a child with diabetes, please contact Bev Freeman at IDDT for further information.

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

Tel 01604 622837, e-mail enquiries@iddtinternational.org

Or write to us at IDDT, PO Box 294, Northampton NN1 4XS

Parents and Teenagers that have grown up with diabetes

By Beverley Freeman who has had Type 1 diabetes for 31 years and was diagnosed when she was five years old.

All parents of a child with diabetes are special types of carers. They deal with a whole bundle of different situations ranging from hypos to injections and the future health of their children. And this does not even begin to cover the emotional feelings parents and teenagers go through when living with diabetes.

Perhaps one of the biggest emotional problems you as a parent may have to deal with is never quiet understanding how your child actually feels and this becomes more apparent with the onset of puberty. For example, you can listen and sympathise with your teenager but it is impossible to truly experience what it is like to have hypos, experience the fears your teenager may have and the confidence loss whenever they have a hypo in public.

Damage limitation!

Arguably one of the best things you can hope for is damage limitation. Try listening to your child's feelings which may be ones of isolation from family and friends, while still allowing them freedom and independence to air their resentment and anger. This anger and resentment may well be directed at the person nearest to them, you, but do not see it as your fault. Your child having diabetes is something that was and always will be out of your control. For many parents, especially mums, feelings of guilt are very common, often quite irrational and exceptionally hard to control but they are a waste of energy. Use all your energy to remain strong and show you care. Even when your teenager is blaming you for everything try to remain strong and supportive in front of them. They could simply be looking for the reassurance that you still love them even though they feel their diabetes makes the whole families life hell.

Try not to bring diabetes into every family row, even if it may be the cause, as this will illustrate that you think of your teenager as an individual not just as a child with diabetes. For example, when they are late home, instead of saying to your teenager, '*You could have been hypo in a ditch somewhere*' say '*Why are you late anything could have happened to you*'. This is what you would say to a teenager without diabetes. Teenagers with and without diabetes will always test the boundaries.

Unless you yourself have grown up with diabetes you cannot be expected to know the difficulties or the conflicts and worries your teenager with diabetes may have. You and your child probably have little or no experience to guide you through this emotional roller coaster but this may help - as long as you care and do your best everything will work out and they will still love you at the end of this growing up stage.

Finding their adult identity

Entering the teenage experience is hard for every parent. A teenager begins to develop an adult identity, essential for them to have equal standing with other adults within society. This is where problems may occur as their struggle for independence is extremely fragile and is easily knocked. It is often why teenagers need to defend their integrity with such strength or power. A teenager with diabetes is also trying to form some sort of independence surrounding their diabetes and strongly believes that the way they are doing things is right for them. As a parent you have the natural urge to protect them and when you see them making mistakes you want to stop them continuing on this path of possible self-destruction. So you are dealing with two extremely strong and complicated emotions neither one of which is wrong.

To make things even more difficult when a teenager is struggling to gain independence they often swap between behaving like a child and being a grown up. As a parent it can be helpful to remember that a teenager has the chance to revisit areas that have not been completed during earlier phases of development. This maybe more apparent with teenagers with diabetes because they have had to grow up more quickly and have taken on more responsibility than the average child. Missing out on some of the carefree aspects of

childhood perhaps leads to them having a greater urge to revisit a carefree time they feel they missed.

Puberty is the final run through

Many parents look at this growing up stage with dread. But if you try to see puberty as a the final run through of the childhood and adolescent years before embarking upon adulthood, your view may be more positive and strengthen the belief that there is light at the end of that teenage tunnel.

In all the stages of bringing up children you are working towards the main goal that your child grows up, leaves home and most importantly is able to take care of themselves and their diabetes.

Maybe this is time to reflect on your own experiences of learning to live with diabetes and remember that you learned to live with it in your child - it did not come automatically. Your teenager is no different. They need to learn how to go out with friends, eat what their friends eat and learn to adjust their insulin according to the situation they are in. The earlier they learn to do this the better chance they have of dealing with a social life and their diabetes.

This is where it becomes really difficult for parents. There is a balancing act of being aware that your teenager needs to develop their independence but recognising that you may need to step in when your teenage feels the pressure of too much responsibility and also try not to criticise when they do make mistakes. Sometimes it can help if you can remember your own experiences in life and when things went wrong for you. The last thing you needed was someone telling you where you went wrong in even a minimally critical tone - this only fuels arguments and resentment.

The trick is to reach an understanding and balance with your teenager that is flexible and not based on principles only. Sit down with your teenager and find out what would make them feel more independent and together work out how you can both live with this.

An example of this could be to explain that you trust your teenager to eat the right things when they go to a friends house and they must make sure they let you know when they are going and that they get home at the time they said they would. This sort of compromise gives your teenager freedom and stops you worrying that something has happened to them.

We're here.....

There is no denying that this is a difficult and complicated stage of childhood but do remember we have people here who have been through it and are happy to listen and share their experience of how they managed to come out of it with their sanity! Just call IDDT on 01604 622837 or e-mail enquiries@iddtinternational.org

I will leave you with this quote from Ackerman:

'Teenagers are impossible to raise but it doesn't matter as long as parents do not stop trying'. In the next Parents Bulletin we will discuss kids that have develop diabetes during their teens.

Trials with Lantus in pre-school children

Researchers in Wisconsin carried out a study in pre-school children with Type 1 diabetes using a flexible multi-dose daily regime of pre-meal Humalog and bedtime Lantus [glargine].

35 children with an average age of 4.8 years were monitored for two years. They all received multiple injections for one year before being changed to the flexible multi-dose regime with Lantus and Humalog. The results showed that overall blood glucose control as measured by HbA1cs improved and there was a reduction in the overall rate of severe hypoglycaemia. However, this improvement only applied to children of normal weight and there was no improvement in children who were overweight. The researchers words were

"Excess body weight status appeared to preclude a desirable therapeutic response in the group of patients". [Pediatrics, May 2005]

Notes from the UK Specific Product Characteristics documents accessed December 2006:

- **Lantus** is not licensed for use in children under 6 years old
- **Humalog** - 'may be used in children when as advantage is expected'.
- **Levemir** - '6month trials have taken place in children between the ages of 6 and 17 but it has not been studied in children under 6 years'.
- **NovoRapid** - 'no studies have been performed in children under the age of 2 years. NovoRapid can be used in children when a rapid onset of action might be beneficial.'

Coeliac Disease Triples Risk of Diabetes

In December 2006, Diabetes Care published two studies about coeliac disease and Type 1 diabetes in children. Coeliac disease is caused by allergy to gluten, found mainly in wheat. It can cause intestinal cramping, pain, bloating, diarrhoea and weight loss.

The first study showed that children with coeliac disease have a threefold higher likelihood of a subsequent diagnosis of Type diabetes than the general population. Some children develop Type 1 diabetes before the diagnosis of coeliac disease but the researchers believe that coeliac disease without symptoms [therefore not diagnosed] was present for several years.

The researchers The second study found that children with coeliac disease had a high risk of being diagnosed with Type 1 diabetes before their 20th birthday. The researchers suggest that the association between coeliac disease and diabetes could be due to autoantibodies produced after the first exposure to gluten in the diet or due to a common genetic susceptibility. There was no evidence that an earlier introduction of a gluten-free diet offers any protection against Type 1 diabetes. The researchers recommend that if blood glucose tests or urine tests were not carried out when coeliac disease was diagnosed, then they should be checked.

Coeliac UK - Coeliac UK's recently revamped website is very informative. It provides a monthly update on available gluten-free foods and it has started to give listings of gluten-free places to eat. Visit www.coeliac.co.uk

Something we don't usually talk about - genital Itching

Genital itching, caused by fungal infections or yeast infections, mainly occurs in women and teenage girls but it can appear in children with diabetes. This happens because of a change in the genital environment. In the case of children with diabetes an excess of sugar in the urine can feed the yeast, found in the genital area, to cause an infection known as genital candidiasis or thrush.

The symptoms are intense itching, there may be a white flaky discharge and it may well be painful going to the toilet. The itching can be so intense that the child may have trouble concentrating at school and feel uncomfortably conscious of the itching they are experiencing. For this reason, it is important that the infection is cleared up as quickly as possible. It is also important that they know how to deal with the infection by themselves, as they get older.

For instant relief from the itching of thrush a bath with no soap or bubbles is a good place to start. If the child is experiencing a period of high blood sugars, for whatever reason, regular baths are very important. They wash away the excess sugar that has been left by urine and minimise the time the sugar has to feed the yeast that can cause the infection in the first place.

If the infection has taken hold a trip to the doctor is the best course of action. Typical treatments are antifungal drugs but your GP will explain the treatment options for children. The Fungal Research Trust recommends that individuals with recurrent thrush include yogurt in their diet and ask their GP to recommend a special diet. They also recommend loose fitting underwear and not to wear tights.

Can you count carbohydrates?

These days we hear the word carbohydrates bandied around so often that we assume we know what they are and how they work, but do we really know enough about carbohydrates?

How Carbohydrates Work

Carbohydrates are found in foods such as bread, potatoes, pasta and cereals in the form of sugars and starches. Carbohydrates provide our bodies with energy for our everyday activities as well as sports and other energetic activities.

When carbohydrates are eaten the body normally converts them into glucose which is then carried all around the body in the blood to provide energy wherever it is needed. Any excess glucose is stored in the liver. Glucose is fast acting and is always present in the blood. Blood glucose levels can be measured and people without diabetes always have blood glucose levels within a certain measurements [4 to 7mmols/l].

When people without diabetes eat carbohydrates, cells in the pancreas produce insulin to control the glucose level in the blood. The pancreas produces the right amount of insulin for the amount of carbohydrate eaten in order to keep the blood sugar levels within the normal limits.

What happens in people with Type 1 diabetes?

When people with Type 1 diabetes eat carbohydrates the situation is different because insulin is not produced in response to the carbohydrates eaten, so the blood glucose levels rise out of control. The body begins to counteract the excess of glucose by peeing a lot more than usual to get rid of this excess glucose.

Without insulin, the body is unable to convert the glucose into energy so it becomes short of energy and begins to burn fats to provide energy. This causes weight loss and upsets the body's metabolism [ketoacidosis] which in turn can lead to coma. Immediate treatment is necessary at this stage. Many children with Type 1 diabetes are diagnosed at this stage. So in Type 1 diabetes insulin treatment is essential to enable the carbohydrates eaten to be converted to into the energy the body needs for all its activities.

So just to recap: when carbohydrates are eaten by someone without diabetes, the body produces the correct amount of insulin for the amount eaten. But in people with Type 1 diabetes, insulin has to be injected to try to match the amount of carbohydrate eaten. This leaves the question of whether or not you can realistically match insulin dose to carbohydrate intake. The answer is we can try and this is a lot easier if you know the amount of carbohydrates in the food being eaten.

Remember!

The more carbohydrates that are eaten, then a larger dose of insulin is required to maintain 'good' blood glucose levels. It also follows that, with larger the doses of insulin, the greater is the risk of hypos and/or more severe hypos.

Insulin & Carbohydrates

There are very few guide books to show you how much carbohydrates are in the various foods we eat! Here is a simple chart to give you a demonstration of how every day carbohydrates are measured. Then we will discuss how Dr Katherine Morrison, a mother of a teenage boy with diabetes, calculates her sons insulin, to his carbohydrate intake.

The following is a list of foods compiled by the British Medical Association in one portion amounts where one portion = 10grams of carbohydrate

Fruit & Veg

One slice of melon or pineapple.

One medium sized banana, apple or orange.

Two small plum or tangerine.

One handful of grapes, cherries or berries.

Half to one tablespoon of dried fruits.

One small glass of pure unsweetened fruit juice.

Milk & Dairy Foods

One medium glass, 200ml or a third of a pint of all milks.

One small pot, 150 grams or 5.5 oz of plain or flavoured yoghurt with low fat and low sugar.

The size of two small matchboxes, 80 grams or 3oz of cream cheese.

One small pot, 100grams or 3.5oz of cottage cheese

One small pot, 150 grams or 5.5oz of fromage frais.

Meats & Fish

Two grilled sausages

Three fish fingers

Miscellaneous

Five tablespoons or 200grams of baked beans in tomato sauce.

Two tablespoons of nuts

Two tablespoons of peanut butter

Four tablespoons of red kidney beans, butter beans or chick peas.

Katherine & Steven's Experiences

Through experimenting and using Dr Richard Bernstein methods of counting carbohydrates Dr Katharine Morrison has found a method for her son of counting to match his insulin dose.

Her son Steven is a teenager and uses Levemir as his basal/ long acting insulin and when he eats his high protein foods (because high protein foods such as eggs, fish, meat and dairy products, slow down the action of the carbohydrates) he uses Actrapid.

Katharine has read Dr Richard Bernstein's book and he suggests that 12g of slow acting carbohydrate is the most that can be eaten at each meal but she realised this would be far too restrictive for her son [and most people!]. Using Bernstein's method of counting carbs Katharine experimented and found that carbohydrate to insulin ratios seem to work out reasonably steady up to 30g of carbohydrates. However after that blood sugars after meals tend to be much higher than expected and she found that after 30gms of carbohydrate she needed to add an extra 0.5 units of short acting insulin for every 10g of carbohydrate up to 60g. After 60g results are getting a bit unpredictable and really by the time you have eaten 80g of carbohydrate results become increasingly unpredictable. Katherine recommends never going over the 80g in one meal.

This suggests that a controlled carb [and not high carb], high protein diet is the most ideal for people with diabetes as it enables you to measure your carbs against your insulin intake up to 80g.

THE ARTIFICIAL PANCREAS - PROGRESS FOR Type 1 DIABETES

Scientists in Cambridge are developing a device being called an artificial pancreas. It uses an existing type of glucose sensor and an insulin pump and the researchers have found a way that enables the two to communicate with each other. So the system will be able to measure blood glucose levels every minute, transmit the information to a hand held computer which will then calculate the amount of insulin needed. The insulin pump then delivers the required dose of insulin. The artificial pancreas looks like a pager and can be clipped to a belt. Trials in youngsters are set to begin in January 2007 at Addenbrooke's Hospital.

It is estimated that with the present insulin injection regimes blood glucose levels are normal for only about 30% of the day. However, it is hoped that with the artificial pancreas, this will rise to 75% of the day so reducing the risk of long-term complications and reduce the numbers of hypos on a daily basis.

If this proves to be successful in achieving good control, then it really will be a positive step forward for everyone with Type 1 diabetes. The research is funded by the Juvenile Diabetes Research Foundation [JDRF].

Recommend a School

One of IDDT's main aims is to not only to support families with diabetes but also to create a better understanding of diabetes within the community. To do this we would like your help by you recommending schools in your area. We will then send them a free Teacher's Pack. This pack will help create a better understanding of diabetes and the needs of children with it. It also helps to build communications between parents of children with diabetes and teachers.

All the schools in your area will have a child with diabetes at some point and they may need help and information but do not know where to go. IDDT want to be there for all schools and provide them with free information on diabetes on a yearly basis. If you feel you can help, please give IDDT the names and addresses of as many schools as you can and help us to support children with diabetes. **Please send the information to Bev Freeman, IDDT, PO Box 294, Northampton NN1 4XS or email enquiries@iddtinternational.org**

