

Insulin Dependent Diabetes Trust

Parents Bulletin

February 2008

EASTER TIPS

For parents of young children, Easter can be difficult time. The shops start selling Easter eggs almost as soon as Christmas is over and seemed even worse this year because Easter is so early. Of course, shops are deliberately putting temptation in our way and it is very hard to resist. Whatever age we are and whether or not we have diabetes, chocolate eggs always looks really good. Children with diabetes are no exception to this and so for families, Easter raises a few more questions and more thought on how to handle it. No one way is right for everybody but we all have one thing in common – central to what we do is what is best for our children, those with diabetes and those without diabetes.

Can we, and should we, deny our children Easter eggs?

If we deny our child with diabetes an Easter egg, then it is hardly fair to give Easter eggs to the other children in the family! Equally, it is hardly fair on the other children to not have an Easter egg because their brother or sister has diabetes. In fact, to do so would be the best way to build up resentment between siblings!

Is an Easter egg going to be harmful?

- Just weigh an Easter egg and you may well be surprised at how little chocolate they actually contain – it's not very much.
- Yes, chocolate contains fast acting glucose that will raise blood sugars and it contains fat. But how harmful is one Easter egg going to be compared to the feelings children with diabetes will have if they don't have one like everyone else?
- You probably would not let your child without diabetes eat a whole egg in a day but a bit each day, so limiting how much your child with diabetes eats in a day is no different.
- On Easter Day have an Easter egg hunt in the garden or the local park so that the children are running around and can eat some chocolate to avoid low blood sugars.
- Encourage them to eat some of their egg after healthy meals rich in vegetables as this will slow down the action sugar in the chocolate. Also their meal will fill them up so they want to eat so much!
- If blood sugars are high, go for a good walk or cycle ride.
- Be prepared for your child to 'cheat' a bit and don't be too cross if they do sneak a bit of extra chocolate – they are only human! If they do, it might be the opportunity to explain that you do understand the temptation but it is much better if they tell you they have 'cheated' so that you can make the necessary adjustments to either their meals or their insulin.

Sweet reasonableness!

- Don't buy a huge chocolate egg, perhaps buy them something else as well. When my daughter was young, Easter bunny came to our house and left both her and her brother an Easter egg each, new felt tips and colouring books.

- Avoid the eggs that have sweets inside.
- If your child is saving up for something special, ask if they would rather have money instead of an Easter egg. My granddaughter without diabetes is saving for her own laptop and she has already asked for money rather than Easter eggs!
- Discourage grandparents, uncles and aunts from buying eggs and ask them to give the children little presents instead. If your children do receive a lot of eggs, suggest melting them down and making them into cornflake cakes – they count for far less in terms of carbohydrates and children will enjoy making them.

Finally – relax and enjoy the day!

Take a Breath

There is an ancient Greek myth about a man called Sisyphus who had to roll a rock up a hill and then watch it roll back down again. He was cursed with this affliction for eternity. Sometimes this is what diabetes care can feel like.

As a parent of a child with diabetes you feel that the management of this condition makes a real difference to your child future and that responsibility is a heavy burden. There is never a gold star for you for good performance. At no point can you turn away and put the diabetes to bed, thinking to yourself that was a job well done. Diabetes will always come back and bite you on the bum when you are least expecting it. Often no matter how hard you try, the task never appears to have been done well or to have been completed, there is always something more that needs doing.

Today's parents can be ground down by the endless blood tests and multiple daily injections. The emphasis on multiple daily injections has never been greater. In years gone by injections at school was unheard of. My peer group and I did not have to inject at school and we had decent HbA1cs and are still here fit and healthy to tell the tale. The new multiple injections regimes are putting more pressure on parents along with the impossible goal of achieving perfect blood sugar readings all the time.

When you feel this pressure about to burst, don't panic as James Hirsch points out in his very good book, *Cheating Destiny*, '*diabetes has ups and downs and they're not your fault. When you have a good day, take credit. When you do have a bad day, blame the disease. Be realistic not a perfectionist.*'

Panic and guilt stem from your feelings that because your child's diabetes isn't perfect, they are doomed to imminent complications and an unfulfilled life. Try your best to keep in mind that occasional high blood sugars don't cause complications or devastate lives. Complications are a result of years of unchecked hyperglycemia.

Try to take the strain off yourself and your child by simply doing the best you can. There is not always an answer to why blood sugars rise and fall - it can vary no matter what you do and there is no rule you can rely on to work every time. Continuing to feel like you have failed every time your child's reading is not what you wanted can lead to panic and a sense of futility and this can cause apathy for both you and your child.

Dr Susan Guzman from the Behavioural Diabetes Institute in America believes your goals should be achievable. Perfection is not achievable for anyone and trying to achieve it can be lethal - not the odd high blood sugar reading.

Perfectionism leads to inevitable defeat and the possible long-term abandonment of effort by you and your child. This does not mean you are lax, it just means that your goals should be attainable and not out of reach. Balance the benefits of good control with the demands of real life. Set you and your child (depending on their age) small specific and achievable goals that you can both meet.

Above all don't lose heart. Life is not perfect as we know and you can only do your best. Give it your best shot and give us a ring here at IDDT (01604 622837) if you feel you have had enough. Good enough has kept me healthy, happy and sane for 32yrs of diabetes!

The General Medical Council advises doctors to listen to children

The General Medical Council [GMC] has issued new guidance to doctors after a consultation found that children do not always feel their doctors listen to them or take them seriously.

A three month consultation was carried out with 350 children and young people and 600 doctors, parents and organisations. The key recommendations are:

- **Children should be involved directly in discussions about their care and their views should be taken seriously.**
- **Children should be given appropriate information about their condition and treatment.**
- **They should be given the same rights of confidentiality as adults although the guidelines do say that doctors have a duty to inform others if there is any indication of serious harm.**
- **It should be made clear to children and young people that they can access health services without their parents present if this is what they want.**
- **A reinforcement of the position that under 16 year olds should have confidential access to sexual health and contraception services.**
- **Cultural or religious beliefs or values should be taken into account when assessing what is in the child's best interests.**

We know that adults often feel that their doctors don't listen and these GMC recommendations show that children and young people recognise the importance of doctors listening to patients and paying attention to their views and experiences. There are messages for us as parents here too – we also have to recognise that our children may want to talk to their doctor without us being present. It's called letting go!

Children 'must not wait for loo'

An estimated 82,000 children develop urinary tract infections [UTIs] each year and it is a condition that can lead to severe kidney damage. Children with diabetes are no exception to this and indeed, may be more prone to UTIs.

Signs that a child may have a UTI include:

- there was a significantly increased relative risk of Type 1 diabetes in the relatives of people with Type 2 diabetes and vice versa.
- The relative risks of Type 2 diabetes were significantly increased in first-, second- and third-degree relatives with Type 2 diabetes.
- Children of fathers with Type 1 diabetes were more likely develop Type 1 than children of diabetic mothers.

The researchers conclude that there is a genetic contribution to both Type 1 and Type 2 diabetes and that there could be a connection between both diabetes Type 1 and Type 2 diabetes. [Exp Clin Endocrinol Diabetes. 2007 Nov;115(10):634-40]

New type of diabetes

A report by researchers in the UK says that the increase in incidence of Type 1 diabetes, especially in children under 5 years can be put down to changes in environmental factors rather than to an effect of genetic factors. [Pediatr Diabetes. 2007 Dec;8 Suppl 9:88-95] The increase in Type 2 diabetes in children and adolescents is thought to be due to increasing sedentary lifestyle and obesity. However, there is an increase in children with a mixture of the two types of diabetes – those who are obese with signs of insulin resistance but who also have autoimmune antibodies to beta cells, as happens in Type 1 diabetes. The researchers suggest that the current classification of diabetes should be revised to take into account this new form of diabetes called 'double diabetes' or 'hybrid diabetes'.

Is the month of birth important?

A study carried out in Israel investigated whether children with Type 1 diabetes with signs of pronounced beta cell autoimmunity show a different pattern of month of birth compared with children with Type 1 diabetes and low beta cell autoimmunity and the general population. The results confirmed past observations that support the hypothesis that the autoimmune process leading to childhood Type 1 diabetes is partly triggered in the perinatal period by viral infections in genetically susceptible individuals. [Pediatr Diabetes. 2007 Nov 23]

Are you aware of some common problems in children with diabetes?

Dry eye syndrome in children with Type 1 diabetes

This condition is just as it sounds – dry eyes which result in eye discomfort. This study compared the signs and symptoms in 104 children with Type 1 diabetes with 104 similar children without diabetes.

- 15.4% of children with diabetes complained of symptoms of dry eyes but only 1.9% of the non-diabetic children complained of symptoms.
- Dry eye signs were detected in 7.7% of children with diabetes but in only 0.96% of the non-diabetic children.
- 7.7% of the children with diabetes had definite diagnosis dry eye syndrome and 0.96% had probable diagnosis but this did not apply to the children without diabetes.
- The tear break up time was significantly lower in children with diabetes.

The researchers concluded that symptoms, signs and definite diagnosis of dry eye syndrome are higher and tear secretion and tear film stability are lower in children with diabetes compared to children without diabetes. Duration of diabetes appeared to be the only thing that affected tear secretion and tear stability. [Eur J Ophthalmol. 2007 Nov-Dec;17(6):873-8]

Skin Disorders Common in Young People with Type 1 Diabetes

A recent study has shown that about two thirds of children and young people with Type 1 diabetes may have skin disorders. These usually develop after diabetes but they may also be the first sign of diabetes or may even be there before

diagnosis. The researchers compared the presence and frequency of skin disorders in 212 children and young people with Type 1 diabetes between the ages of 2 and 22 with 196 similar non-diabetic youngsters.

The results showed that 67% of those with diabetes had at least one skin disorder compared with 26% of those without diabetes. Active skin conditions that were thought to be associated with diabetes were present in 38% and these were:

- **Ichthyosis** - dry patches of scaly skin, in 22% of those with diabetes compared to 3% in those without.
- **Rubeosis** - abnormal growth of blood vessels causing red discolouration, in 7.1% in those with diabetes with none in those without diabetes
- **Fungal infections** in 4.7% of those with diabetes and 1.5% in those without diabetes.
- **Skin reactions to insulin** – the frequency was fairly low at 2.7%.

The researchers recommend that as the frequency and variety of skin disorders in children and young people with Type 1 diabetes is quite high a dermatologist should be included in the group of doctors who treat this age group. [Diabetes Care, August 2007]

Another gene for Type 1 diabetes in children

Research in the US and Canada has identified another gene variant that raises a child's risk of Type 1 diabetes. This adds a new gene and new knowledge to the four genes already identified. As the project continues, the researchers expect to identify additional genes (perhaps as many as 15 or 20) which are thought to interact with each other in the disease.

This recent gene discovery is most active almost exclusively in the immune cells. Although much research remains to be done, better understanding of the disease process may guide doctors to new and improved therapies. [Nature, July 2007]

What NHS Direct has to offer? Telephone 0845 4647

NHS Direct has become a household name and is now in its seventh year of providing telephone and web-based healthcare. NHS Direct was inspired by the idea of 'giving people the confidence to look after their own health' (David Edmonds, Chair of NHS Direct 2008) and has 37 centers across the country to support this belief. Many but not all of the 37 NHS Direct Centers offer a variety of additional services to support or take the strain off their local NHS partners ie our local GP surgery's and hospitals.

IDDT is often called by NHS Direct to answer questions about diabetes and the different types and availability of animal insulin. We are very happy to do this as it gives us the ability to educate the healthcare professionals that work for NHS Direct. But these calls always make me wonder as a patient or carer what can we get from NHS Direct and does it make our lives easier?

NHS Direct Services

This is the well-known service of supporting the GP's out of hours service and dental service by initially assessing patients when they call. However, it has expanded into other areas:

- **Booking appointments** - NHS Direct now has the ability to give a patient the opportunity to choose the place, date and time for their first consultant outpatient's appointment. Unfortunately, my years experience of dealing with hospital appointments in varying hospital leaves me with no doubt that after booking the initial appointment with NHS Direct, you will be told the original appointment has been cancelled and a new appointment is in the post! Sorry to be so pessimistic.
- **Supporting people with long-term conditions** – this interested me. NHS Direct suggests it provides support to people with long-term conditions, such as diabetes and heart disease, to help manage their condition at home. The potential here is huge and could possibly put IDDT out of business! If people use this service many of the day to day questions that occur for people with diabetes and carers could be answered. It would also be possible to ask the questions you forgot to ask at your check up and have the answer straight away. The support and education that could be provided through this service is endless. I really do hope this is the case as this is the kind of support people are asking for every day at IDDT.
- **Pre-op assessments** - if you or your any of your family are going into hospital for an operation, NHS Direct is working with some hospitals to provide a telephone assessment of patients in preparation for their operation. What this preparation entails is extremely unclear. I can only assume this cannot be a medical assessment such as taking a very important blood pressure reading as this would be impossible. However, it could be advising on what you will need in hospital, how long you will be expected to spend there and advice on cleanliness within the hospital you are visiting. According to NHS Direct they can also provide aftercare and support but again there is little indication of what this actually involves.
- **Information on local and national health issues** - in the cases of health care scares such as bird 'flu and heat waves NHS Direct can provide advice and information. NHS Direct states that 'trained health professionals are on hand to provide assurance and advice, 24 hours a day'
- **Telephone-based hearing assessments** - NHS carries these out for a number of NHS clinics to check whether patients' hearing aids are properly fitted, working correctly and comfortable. This saves patients having to make additional trips to the clinic. Logic tells me that unless there is a problem you would not be phoning NHS Direct, so I can only assume that if there are any problems with a hearing aid that NHS Direct's healthcare professionals will be able to put basic problems right otherwise the appointment seem a bit pointless.

NHS Direct Website and Digital TV services

If you check out the NHS Direct website you will find it is easy to negotiate and once you have found diabetes in the Health Encyclopedia, the site will give basic information varying from symptoms to causes. It gives basic background knowledge, which would be extremely useful to the newly diagnosed or for a grandparent who wants to find out more about diabetes.

The site did fuel one of my pet hates by giving information on Type 1 diabetes and Type 2 diabetes on the same pages. I personally believe that Type 1 and Type 2 are completely different conditions and information on these two conditions should be given separately. I believe this should occur in order to remove the stigma often attached to diabetes - that all people have diabetes because they have eaten too much food. As we know this certainly is not the case with anyone with type 1 diabetes.

If you do have a more complicated question such as what is a safe blood sugar reading or that you cannot reduce your child's blood sugar level, you are better to ring NHS Direct on 0845 4647. After your details have been taken you will be referred to a triage nurse. This nurse will give you advice on the best course of action in the same way your GP surgery nurse. I spoke to a nurse at NHS Direct for research on this article and she was extremely pleasant and understanding, non-patronising, happy to listen and once again new the basic facts. This was very similar to phoning the GP surgery except you do not have to wait to be called back and you can get a quick, straight forward response to a straight forward question.

This article is based on my experience of investigating NHS Direct and my over all view is that it was extremely easy to use, helpful, comprehensive and did not leave me feeling frustrated and annoyed. It revitalised my faith in the NHS which I have to say like most people is wearing a little thin. NHS Direct 'does what it says on the tin' and deals very well with simple medical problems. I guess this is ok because if you had a big serious problem, you would call an ambulance or go straight to A&E. It would be interesting to hear your opinions of NHS Direct, so let me know them by writing to me at IDDT, PO Box 294, Northampton NN1 4XS or e-mailing me at bev@iddtinternational.org

NHS Direct is to become a Foundation Trust and you, the user, will soon be able to have your say on how health in the community should be run. If you would like to become a public member of the NHS Direct Trust or have any question please call 0845 600 1866.

IDDT is trying to reach schools and teachers to help them to understand the needs of children with diabetes at school.

As many of our readers know, IDDT has free Parents' Information Pack and Teachers' Information Pack which we hope will help to make life at school as easy as possible for children with diabetes. We can send you both Packs so that you can the Teachers' Pack to your child's teacher.

In addition we advertise the availability of the Teachers' Pack in journals for teachers and schools and we have already sent out hundreds of Packs. This year we are having a stand at the Education Conference at the NEC.

So we hope that you can see that we are trying to help and support you by informing teachers about the needs of children with diabetes when they are at school.

Both Packs are available free of charge, so if you would like them, please give IDDT a call on 01604 622837, e-mail bev@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS