



Insulin Dependent Diabetes Trust

July 2005 Newsletter



Is IDDT The “Naughty Child” Of Diabetes Organisations?

The simple answer to this is probably yes, judging by the statements that some of our members report to us! Sometimes it does us good to examine exactly what we do, not to defend ourselves against criticism, but to ensure that we are on the right path.

IDDT describes itself as **“the charity listening to people with diabetes and their families and supporting their needs”**. Listening is the key to all our aims and activities. We formed in 1994 simply because no one else was listening to the needs of people unable to tolerate synthetic GM insulins.

Listening defined our goals of trying to ensure that people with diabetes

had an informed choice of treatment and that animal insulins remain available for the people who need them. It enabled us to know that GM insulins are not bad per se and they suit the majority of people but listening also enabled us to know that they caused some people very real adverse effects not caused by ‘not looking after their diabetes properly’ or ‘being a bit neurotic’!

IDDT is probably the ‘non compliant’ patient organisation of diabetes because we don’t want insulin treatment to be based on assumptions of superiority of GM insulins over animal insulins but on evidence of superiority from independent, high quality research that also takes into account patient experiences. Yes, we have asked what may be uncomfortable questions in some quarters, such as do we really know how many people could be better if they were using animal insulin, but there is nothing wrong with asking questions!

Listening has enabled us to know that we are correct in fighting for the continued availability of animal insulin. The evidence from people who change to animal insulin is sufficient for us to know this - they feel better, they are better and their blood glucose control is better and easier. Here is an e-mail received in April 2005:

“Thanks to you, I have started using the animal insulin for the past two weeks and the results are amazing. The improvement is more than I ever expected.

On the human Insulin, I felt perpetually unwell, feeling nauseous on rising which went on through most of the day. Always feeling tired. Feeling dizzy in the mornings; erratic blood sugars.

Since taking the animal insulin, which is surprisingly easy to adapt to, my blood sugar is more controlled, my appetite is better and I wake up more refreshed and without the nausea. I also have more energy, which is noticeable to my family. Amazing.”

Trying to achieve this goal of continued availability of animal insulin has led us down many paths and confirmed the beliefs that drive us forward.

IDDT believes in showing care and understanding for the needs of people who live with diabetes - many people feel unable to discuss their concerns and fears with doctors, nurses and sometimes even with their partners leading to a feeling of isolation. Those of us involved in IDDT either have diabetes or relatives with it and so we understand many of the difficulties of living with diabetes and this helps to make people feel less alone.

IDDT believes that patients should have an informed choice of treatment - not unreasonable and is government policy after all!

IDDT believes that choice is not choice unless it is informed and that people should be involved in decisions about their treatment - people should be given information on medicines including risks and

benefits of them all otherwise their choice is not informed. Evidence suggests that people have better outcomes when they are involved in decision making about their treatment options and that 40-50% of people are not being involved as much as they want to be. www.medicines-partnership.org

IDDT believes in the provision of independent information and that we should not accept funds from the pharmaceutical industry - information must be from independent sources uninfluenced by industry and by those who may already be influenced by industry. We are uninfluenced and independent and realistic enough to know that industry is not altruistic and does not give away funds/gifts without some expectations of a return. Patents' organisations are a subtle way for industry to reach patients as drugs are not allowed to be advertised to them directly.

IDDT believes in encouraging people not to merely accept the information they are given by health professionals but to ask questions - this is not non-compliance or threatening to health professionals but part of decision-making.

IDDT believes in helping people with diabetes in poor countries. We realise that we are very lucky compared to many people in developing countries who die for lack of affordable insulin, a situation made worse by the major pharmaceutical companies globally systematically discontinuing the less expensive and therefore more affordable animal insulins for GM insulins

These beliefs are not rocket science. They are also held by many professional and patient organisations, some even by government, but for some reason when they involve animal insulin, they become unacceptable to our critics!

But principles and beliefs cannot just be dismissed because they don't conform to the popular view, especially when this popular view is not supported by good quality evidence! People with diabetes, including those who use or want to use animal insulin, are as capable

as anyone else of making informed choices about their treatment and they most certainly should be involved in decision making because this is what they do every single day!

There are 30,000 people in the UK and goodness knows how many others in countries around the world who need animal insulin and their needs will not be dismissed by IDDT because we care. If raising uncomfortable issues, questioning current thinking and encouraging people to be more involved in their own care make IDDT the “naughty child” of diabetes organisations, so be it!

Health, Education, Awareness And Research Trust [Heart] In India

HEART is a programme in India run by Mr V Ravi Shankhar with personal friends some of whom are doctors. They fund it themselves and with a little money they collect from friends. Several members of Mr Shankhar’s family and some of his friends have diabetes and as he says, he is fortunate in that he has a job that enables him to look after his family but there are many people in India who are not so fortunate.

The aims of HEART are:

1. To make people in villages more aware of diabetes
2. To help to educate rural people about the risk factors associated with diabetes
3. To screen people for diabetes through free blood testing programmes and give them advice from doctors
4. To try to help people to control their diabetes through awareness and educational programmes
5. To find people in the villages with Type 1 and 2 diabetes who are blind and to help them to improve the standard of their treatment according to their abilities

6. To run free awareness and educational programmes every month in villages
7. To aim for the eradication of diabetes.

HEART aims to carry out these aims by selecting villages for mass screening for diabetes and through patient interaction groups with visiting doctors who provide awareness and education: by selecting a member of each family who has diabetes and encouraging them to educate the rest of the family. As the programme develops HEART aims to give information about diets and eyes from a visiting specialists.

Progress so far??..

HEART has carried out this programme in three villages. The villages are selected on the basis that there is no hospital, no doctor and no pharmacy. The people of these villages are very poor but both the men and women work very hard and for this reason, they believe that diabetes will not affect them. But this is not so. In earlier times many of the village people were healthy because they ate natural foods but now the lack of rainfall, lack of cultivation and changes in their food style have left them much less healthy. Nevertheless it is very hard to get the co-operation of the villagers to attend health and education programmes.

Just one example of the work that HEART carries out is their recent visit to a village ‘Nanthi Rettiahypatti’ where blood glucose screening was carried out on 100 people. The situation in the village is as follows:

- There is no doctor, no pharmacy or ‘medical’ shop in the village and in emergency people have to get into the nearest town
- People have no idea about diabetes or its risks of complications
- Most people are illiterate
- Until HEART arrived in the village no one has talked to them about diabetes.

IDDT wishes the HEART programme every success and congratulates Mr Ravi Shankhar and his friends on their excellent work to help poor

people with diabetes.

Just to remind you: If you would like to help to sponsor a child with diabetes living in India, then please contact Bev Freeman, at IDDT, PO Box 294,

Northampton NN1 4XS, tel 01604 622837 or e-mail bev@iddtinternational.org

For as little as £2.00 a month you can help to make a difference.

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Health Committee Report

The Influence Of The pharmaceutical Industry

The Health Select Committee Inquiry received evidence from a very wide range of people concerned with every aspect of health and produced a very comprehensive report with 48 recommendations for change. [Your Co-Chairman, Jenny Hirst and Dr Matthew Kiln gave written evidence and Jenny gave oral evidence]. IDDT members will wholeheartedly welcome many of these recommendations!

The Chairman of the Committee said:

“The pharmaceutical industry is extremely powerful and influences healthcare at every level. The lives of millions of people have been improved by the medicines the industry has produced but we have developed an over-reliance on medicines and they have been over-prescribed and patients have suffered as a result.

Like any industry, drug companies need effective discipline and regulation, and these have been lacking.

The industry, the regulator, doctors and other prescribers must take their share of the blame. Our recommendations reflect the need for

tighter controls over drug company activities, improved medicines regulation and more effective monitoring of drug safety and efficacy.

Above all, greater transparency is required. Both the pharmaceutical industry and the regulator have already taken steps in this direction. Further change is needed to ensure the best medicines reach patients.”

Here are some of the key conclusions and recommendations of the Report:

1. People are being prescribed too many drugs, before the full consequences of adverse side effects are known.
2. The regulator of the pharmaceutical industry has been insufficiently rigorous about its public health responsibilities.
3. Much excellent clinical research takes place, but the current system of clinical testing provides ample opportunity for bias. Too many of these problems appear to persist unnoticed or unacknowledged by the organisations that are central to the co-ordination, conduct and review of the clinical trials. ?..The regulator must check that research is designed to provide objective evidence of a drug’s safety and efficacy at the time of licensing.
4. Tighter controls on the promotion of new drugs should be introduced until more is known of their potential side effects.
5. Limits should be set as to the quantity of promotional materials prescribers receive, particularly in the first 6months after launch. Stricter controls are needed in respect of drug company representatives’ promotional material to junior doctors and nurses or pharmacists with new prescribing powers as they are less experienced and ill-equipped to cope effectively with the material. Consideration should be given to limiting those who can prescribe a new drug in the 2years following launch.

6. Post-marketing surveillance in the UK is inadequate. This has several causes: lack of investigation of a drug's benefits and harms in real life situations and institutional indifference to the experience and reports of medicines users.
7. The Medicines and Health products Regulatory Authority [MHRA, that licences and monitors drugs] lacks the discipline and leadership needed to protect patients' health needs and an urgent review of the regulatory body should take place especially focussing on the need for greater independence from Government and from the pharmaceutical industry, the need for policies of greater transparency and accountability, scrutiny of the regulatory standards underpinning new drug review and the reporting and evaluation of adverse drug reactions.
8. A register should be maintained detailing all substantial gifts, hospitality and honoraria received by healthcare professionals. The register should be available for public inspection.
9. Measures to limit the influence of industry on patient groups are needed. Patient groups should declare all significant funding and gifts in kind and the Government should seek to make changes to charity law to ensure this.
10. The Government should fund: a multi-disciplinary investigation of existing medicines, combinations of medicines and medicines use where there is a reluctance of the industry to fund such research; research into the adverse health effects of medicalisation; and trials of non-drug approaches to treatment.
11. The Committee recommends that the NHS adopt a policy regarding the role of drug treatment in relation to non-dug treatment, emphasising the role of both approaches.
12. The responsibility for representing the interests of the pharmaceutical industry should move into the remit of the Dept of Trade and Industry [DTI] to enable the Dept of Health concentrate

solely medicines regulation and the promotion of health.

IDDT comments??.

We make no apology for taking up so much space in covering this Report. Its recommendations are key to seeing improvements in protecting the health of the public. The suggested shift of the pharmaceutical industry to the DTI can only be supported. The MHRA which is the regulator of drugs is presently funded by industry fees which in itself seems to be a conflict of interest!

We have already seen some changes as a result of the Report, such as patients being able to report adverse drug reactions and access the database of adverse drug reactions. How much of the Report will be put into action remains to be seen. In the meantime, it is a very useful document for our lobbying campaign as it offers possible explanations of why the problems with GM insulins have been ignored and why they are widely prescribed without evidence of benefit.

IDDT has been slightly demonised for criticising the system for licensing, monitoring and prescribing drugs, especially new ones, but we can now feel confident that we are not alone in this. Perhaps the conclusions that most reflect the feelings of many IDDT members who have adverse effects to GM insulins are:

- **Drugs are being prescribed before the full consequences of adverse effects are known.**
- **Post-marketing surveillance of drugs is inadequate. This has several causes: lack of investigation of a drugs benefits and harms in real life situations and institutional indifference to the experience and reports of medicines users.**

From our experiences with GM insulins, need we say more?

IDDT Goes To Westminster

Meeting with Lord Warner

With the help and support of Earl Howe, IDDT is to have a 45minute meeting with Lord Warner in June. Lord Warner has dealt with most of our lobbying as he has had responsibility within the Dept of Health for drugs and everything associated with supply and licensing. [The meeting is after the print deadline but we will let you know the outcome.]

Post election - where do we go from here?

Make no mistake, we intend to carry on with our campaign! We have to have guarantees that animal insulin will remain available for the people that need it now and as an alternative for people who are still finding that they have adverse reactions to GM insulins. The supply problems as a result of manufacturing difficulties at Wockhardt UK [CP] have served to demonstrate the vulnerability of people using animal insulin and have proved that we have to have better guarantees of supplies both now and in the future.

However, the election has brought in a lot of new MPs who will be unaware of our situation and who need time to 'find their feet'. In mid July the House goes into summer recess, so we believe that the most effective way of going forward with our campaign, will be to start again in October when the MPs are all back in the House of Commons.

Before this next stage in our campaign, we will be writing to all our members who have made tremendous efforts in the campaign so far. If anyone else would like to join us, please do get in touch with Jenny Hirst, tel 01604 622837, e-mail jenny@iddtinternational.org or at IDDT, PO Box 294, Northampton NN1 4XS

Some reshuffling at the Dept of Health

Secretary of State for Health - Patricia Hewitt MP

Minister of State - Rosie Winterton MP

Minister of State for Health - Lord Warner

Minister of State for Health - Jane Kennedy

Parliamentary Secretary - Caroline Flint

Parliamentary Secretary - Liam Byrne

So if you are in the constituency of any of these MPs, they should be particularly interested in our case!

IDDT and the EU Commission

Sabine Hancl lives in Germany, is a member of IDDT and cannot tolerate GM insulins. She feared that animal insulins would be discontinued in Germany so she drew up a petition requesting that they take action to ensure that animal insulins remain available in the European Union. Her MEP presented the petition to the EU Commission in 2003 and in February 2005, nearly 2 years later, the Commission responded but less than a month later, Sabine's fears became reality and all animal insulins in Germany were discontinued.

The Commission response to the Petition:

It appears that the Commission is unable to take action to ensure the continued availability of animal insulin as the responsibility rests with the governments of each EU country. It states:

“Under Article 152 of the Treaty any form of health care delivery is the remit of the Member States. This includes also the national provisions for the availability of insulin formulations from animal origin in addition to the dominating genetically engineered formulations of human insulin for individual treatment”.

It seems therefore that this says that each Member State [country] has the responsibility to supply animal insulin as well as GM insulins. This is good news! We now need an agreement that this will actually happen and so we will be raising it at our meeting with Lord Warner. What a shame it took 2 years to make this statement by which time Germany, and many other countries, had already lost their supplies but needless to say Sabine is not giving up - she is taking this to the German government.

UK MEP helps too:

Thanks to the help of Mr John Bowis MEP, we have established that people in Germany can import animal insulins from the UK and Switzerland but the difficulty is that they have to pay the full price. He has also established that the Netherlands, Slovenia and Eire also have a system for personal importation of animal insulin. One of the main difficulties is in making this information available to the animal insulin users and we hope that doctors and national Diabetes Associations will see it as their duty to inform people rather than forcing them to use GM insulins which cause them adverse reactions. Personal importation may well apply in other EU so it is worth exploring by those who have no access to animal insulin.

Note: People in Australia, Canada and the US can also import the animal insulins that are no longer available in their own countries.

Croatia: We would like to congratulate and thank Tatijana Malacko for his almost one man battle in Croatia to raise awareness of the adverse effects that GM insulins can have for some people. His articles in the press have resulted in some aggressive responses but he keeps going!

Possible Overdose Fault With OptiPen Pro-1

Although not reaching the press until April 2005, the Medicines and Healthcare products Regulatory Agency issued an alert in January 2005 about possible problems with the Aventis OptiPen Pro-1, the pen used with Lantus and Insuman insulins. The MHRA are of the view that the problem is so rare that the OptiPen has not been recalled but when the problem does occur, due to internal damage during assembly, the dosage button could fail to engage at the end of an injection. This could lead to people thinking the injection has failed and they could then give another dose resulting a double dose.

A spokesperson for Sanofi-Aventis, the manufacturers of Lantus and

the OptiPen, told the press that there have been no reported faults in the UK but they have received 398 in total.

Note: The AutoPen 24 3ml is an alternative pen that can be used with Lantus and from Autumn 2005 the OptiClik will be available.

IDDT Makes Formal Complaint About Advert

In the November/December issue of Balance, Diabetes UK's magazine for people with diabetes, there was an advert for the Roche Accu-Chek D-TRONplus insulin pump referring to its use with "with its 3.0ml Humalog pre-filled pen cartridges".

Insulin pumps are medical devices and can be advertised to the public but insulin is a prescription only medicine and cannot be advertised directly to the public.

IDDT made a formal complaint to the Association of British Pharmaceutical Industries [ABPI] Code of Practice Authority on two counts:

1. That the advert subtly was advertising Humalog, a prescription only medicine
2. That the advert was misleading because it implied that only Humalog can be used in the pump.

Both are important but the latter is particularly important as people have already contacted IDDT because they have received misleading information about which insulins can be used in pumps [especially when it comes to pork insulin]!

The complaint was investigated and it appears that the Balance advert was the first in the UK. Roche, based in Switzerland, stated that they did not intend to promote a particular brand of insulin to the public

and that other short-acting insulins can be used. Lilly stated that at European level they were aware of the advertisement but they had no involvement in its development or subsequent use and they did not pre-approve the advert. They also stated that they have no agreement with Roche regarding the promotion of pumps and Humalog in the UK or worldwide.

The findings:

The Panel ruled a breach of Clause 20.2 of the Code for the following reasons:

- Roche, based in Switzerland, submitted that at European level Lilly was aware of the advertisement and that Lilly had allowed Roche to use its trademarks and the visual of the pre-filled cartridge. Based on this information, the Panel found that Lilly in Europe had allowed Roche to use its Humalog brand name in an advert in a UK publication and under the Code, Lilly UK was responsible.
- The Panel decided that the advertisement was not for Humalog per se and so Lilly had not breached the Code but they did rule that the advert was misleading as it implied that only Humalog insulin could be used in the pump and the Code had been breached.

Roche apologised and stated that they will not use the advertisement again in the UK and its European office has been asked to recognise the sensitivities of member states.

Lilly appealed against the decision:

The Appeal Board noted that there had been no general agreement with Roche for the use of the Lilly trademark in any other country than Switzerland. They decided that there was no evidence that Lilly Europe or Lilly UK gave consent or were aware of the use of Lilly's trademarks in the advertisement and therefore overturned the original decision and ruled no breach of the Code.

Just a note???.

Interesting that TV drugs adverts in the US are being curbed

Readers may remember that IDDT supported the campaign to prevent

the EU approving direct-to-consumer-advertising [DTCA] of drugs eg TV and newspapers advertising of drugs. One of the arguments in favour of DTCA was that it provided the public with more information about medicines and often the US was cited as a good example of TV advertising helping to 'educate and inform' the public. But one of the major problems with TV advertising is now being accepted - that the adverse effects of the drugs are played down.

The arthritis painkillers such as Vioxx, subsequently withdrawn for causing serious side effects in large numbers of people, was one of the many drugs advertised on US TV but its subsequent withdrawal has added to public scepticism and greater scrutiny of the ads and many drug manufacturers are taking a step back from TV advertising. Among the companies withdrawing their TV ads are Johnson & Johnson and TAP Pharmaceuticals who have pulled a \$100million TV campaign for one of their drugs to 'focus on print ads that more easily explain the potential side effects and health risks'.

In addition, the Food and Drugs Administration [FDA] shows signs of watching TV ads more closely for misleading and faulty ads. They have asked the manufacturers of erectile dysfunction drug, Levitra, to remove their TV ads because they did not contain certain safety information and made misleading claims about how Levitra compares to other similar drugs. The same has applied to the ads for Viagra.

The EU Commission voted overwhelmingly against advertising of drugs to the public and it is good to see that campaigners in the US are slowly curbing the activities of the pharmaceutical industry and the public is becoming much more aware of the risks, as well as the benefits, of drugs.



At Last A Talking Blood Glucose Meter!

In April 2005 a new talking meter was launched for visually impaired

and blind people. IDDT and other organisations have been lobbying government and manufacturers to try to make sure that this very vulnerable group of people are able to reliably measure their blood sugars, maintain good control and just as importantly, their independence.

The SensoCard Plus meter is the size of a credit card and costs £149.00 and from 1st June 2005, the test strips should be available free on NHS prescription. Prior to June they are available from the company, CDx Ltd, for £23.50.

The important meter details are:

- Results in less than 5 seconds
- Memory stores the last 150 results with built in 7-14-28 day period average calculation
- Only small blood sample required
- Easy to operate - automatic operation on strip insertion

IDDT member, Alison Blackburn who is registered blind has tested the meter says:

“The meter is fantastic. Without it, I would have been really stuck on a solo trip to Japan and China. This meter will, quite literally, be a lifesaver for blind and visually impaired people.”

To order or for further information about the SensoCard Plus meter contact:

Cunningham Diagnostics Ltd, Stansfield Business Centre, Sunderland SR2 8BL

Tel 0191 564 2036

e-mail bcdx@aol.com

website www.cdx.uk.com

The Unwelcome Stranger - Part II

Learning to adapt to Chronic Illness

by Anne St Aubin Roberts

In the last IDDT newsletter, I introduced the concept of illness as the Unwelcome Stranger in our bodies. I described a process of co-counselling which can be used to learn more about our unique reaction to an illness. This process involves **thinking reflectively, using imagery, listening to the body, and monitoring dreams**. A series of questions can be posed as a focus. In the last article I suggested questions which can help us understand the effects of a diagnosis and illness. I now move on to suggested questions which can help someone learn how to manage their illness in a highly personalised way. Again, I use examples from my own work around diabetes, and initial difficulties with the insulin I was prescribed. The questions I suggest are:

1. Is the Stranger telling me something? Can we communicate? What can I learn from the Stranger?
2. How does my body respond to technology and treatment and how do I feel about this?
3. In what ways can I heal myself or find healing in others?

Having a conversation with the Stranger - Listening to the Body

Life in the 21st Century is busy, busy, busy. We end up doing so much, we lose sight of being. Our bodies talk to us all the time: to let us know we're hungry, we're tired, we need to pee, we need a hug. Too often we just don't stop and listen. Simply taking notice of our bodily sensations and acting on them means we're starting to communicate with our Strangers. Taking it a step further, simply ask, at least once a day, 'What do I really need now?' Sometimes a Stranger sees more clearly! The Stranger will even holler if you're in danger when you sleep, if you learn to listen to dreams.

Despite everything bad that happened in my first year with diabetes, at

least I knew I'd never again go 48 hours without eating, or try to drive 600 miles in a day. How healthy was that? Did I have no respect for my body? When, feeling slightly daft, I imagined talking to my Stranger, I got the message 'you're like an analogue person, only a poor copy of what you were'. How rude! But it certainly got me thinking about analogue insulins?.. Tuning into what I really needed meant I learned to ask for more help and accept people's love and care, instead of being fiercely independent. It led me to a wonderful aromatherapist and healer. And the dreams! I thought it was good when I trained my brain to wake me up if I dreamt of cake shops (hypo!), but one night I ignored the sticky bun dream - so, at 2.1 mmol/l, I dreamt of my diabetologist putting 'diabetic suppositories' on the gear stick of my car. Telling me to get my arse in gear!

The questions posed here also ask if we can talk back to our Strangers. The answer is that we can, and we can directly affect our body's reaction to illness or stress. Perhaps the most useful example I can give is techniques to enable someone to deal effectively with an authority figure - like the doctor who won't believe our story about a bad reaction to recommended treatment; or the head-teacher who won't take appropriate action when our child is having a hypo.

When we are placed in an anxiety-provoking situation, adrenaline causes a reaction in our bodies, to enable us to flee, fight or freeze. This can be counter-productive! We don't want our blood pressure to rise when we see a doctor, who may then insist on even more tablets. We don't want to become aggressive and hostile, if it means the doctor will become defensive and less able to listen. And we certainly don't want to become like a frightened child when we step into the head-teacher's office, if we need to persuade a school to take a constructive stance to our child's difficulties. Simple relaxation techniques like deep, slow, breathing, can minimise the adrenaline rush. We can use an inner strong voice to tell our bodies to maintain a confident posture, a steady voice, and a firm demeanour. Experiment with what works for you!

Technology and Treatment

Any of the above techniques can be used to think about how you feel about tests, drugs, treatments, or the experience of being a patient. I was so ill I was offered an insulin pump. My nurse was flabbergasted when I started choking and said without thinking 'it would be a fate worse than death'. I went home and wrote that phrase in the middle of a piece of paper and got out my coloured pens. I also came up with an image - my treatment regime was a fascist dictator with obsessive compulsive disorder! I was already at the end of my tether with 5-6 insulin injections a day, at least that many finger pricks, plus the tyranny of DAFNE. I knew I couldn't cope with any more technology and calculations for a while. Funnily enough, when I had dreams about a toxic placenta, mutating into a zombie, and a pharmacist trying to kill me, I started to wonder about the insulin again??? I was at least able to let my diabetes team know that a pump was not an option for me - at least not at that time. Another patient was delighted to have my place on the pump waiting list, and I gained the time I needed to find out what was really going on.

It's really important to learn to trust that your body's inner knowing. Professionals may have one kind of expertise (about an illness and treatments from a general and broad perspective), but the patient is the expert on their own experience of the illness. Let's all make the most of the National Service Framework on Diabetes, which encourages us to become empowered and have an equal voice in treatment decisions.

Healing

Learning to live with the Unwelcome Stranger is just one framework that can bring healing. Try working with your Inner Healer in other ways. I offer several suggestions: imagine sitting in a healing sanctuary and being brought what you really need; then go out there and get it. Focus on a traditional symbol of healing, like a rose, a grail, or being surrounded by healing light. Try something new and positive for your body: walking in nature, exercising, complimentary therapies, or a different and exciting meal. Most of all: speak to others, and ask for help. If you find something that works, share your experience

with others who might benefit - through the newsletter, through local support groups, by becoming an Expert Patient and working with your local Primary Care Trust.

I sent out a cry for help to all my friends: 'This feels so wrong! Can anyone out there suggest something?' One friend telephoned to say she'd read an article by Matt Kiln on pork insulin. My Unwelcome Stranger had been trying to tell me for months that the insulin didn't suit me - I just didn't realise there was an alternative. The pork insulin worked right away: my life may have changed dramatically, but I now feel my Self, a living soul, and it feels as if nothing could be more precious.

The word 'heal' means 'to make whole'. When I could do little else but read, I found the following quote in a book³:

'Healing is not the same as curing, after all; healing does not mean going back to the way things were before??Healing uses what is present to move us more deeply to Soul Awareness, and in some cases, physical 'improvement'.'

Healing comes in many forms. Amazingly, this living soul has learned to view the Stranger as a friend who speaks the truth, and would be welcome in my home any time.

Thus the Stranger is a metaphor for a patient's experience of his or her body's reaction to illness and treatment. Using simple reflective techniques, working alone or with a friend, can be a highly positive way of finding the most healthy path in life with the Stranger at one's side.

Ref 1 Still Here. Ram Dass. Hodder & Stoughton, 2000

Insulin Update

Update on the use of analogues in children

The European Commission has extended the marketing authorisation for Novo Nordisk's long-acting insulin analogue Levemir to include children and adolescents between the ages of 6 and 17years old. Extended authorisation has also been received for their short-acting analogue, NovoRapid, to include children of 2 to 6years old.

Reminder - Novo Nordisk synthetic GM human insulin discontinuations - the following insulins will not be available after February 2006 [see article below from The Times]

- In the Novolet - Actrapid, Insulatard, Mixtard10,20,30,40 and 50.
- Monotard 10ml vials
- Insulatard Flexpen

More information from Novo Nordisk Customer Care on Tel 0845 600 5055

Reminder - Eli Lilly HumaJect S and HumaJect M3 not available after June 2006

Both of these insulins will still be available in alternative delivery systems.

More information from Customer Care Tel 01256 315999

Hypurin insulins availability

Hopefully the supply problems for the Hypurin pork and beef insulins have now sorted themselves out. If you are having supply problems then ring CP/Wockhardt Customer Services on 01978 661261.

Important!

The Times news item on the withdrawal of 'human' Actrapid, 14 May 2005

In October 2004 Novo Nordisk announced that some of their 'human' insulins would not be available after February 2006. On May 14th

The Times carried a news item stating that Human Actrapid would be withdrawn in less than 5 months - making the date more like October/November 2005 and not the 18months notice that Novo Nordisk has guaranteed in the UK. True or not the article is worrying - here it is:

“A common insulin treatment used by thousands of diabetics is to be withdrawn in less than 5months, threatening disruption to diabetes services.

Patients on Actrapid, a fast-acting insulin, will be forced to stop their medication or revert to antiquated regimens using bottles and syringes as a result of the sudden announcement. The medicine has shown its efficacy in clinical tests and treatments for more than 20years, but The Times learnt that Novo Nordisk, the Danish pharmaceutical giant, will cease providing Actrapid disposable injection pens and insulin cartridges imminently. The company intends to focus on newer and more profitable insulin products.

Viggo Birch, the Chief Executive of Novo Nordisk’s UK business, said: “We wish to move towards newer insulins that are better supported by hard evidence and we wish to rationalise our portfolio.”

IDDT immediately sent a letter to the editor to point out the dangers of the stating that people will be forced to ‘stop their medication’. Insulin treatment cannot be stopped because blood glucose levels will rise out of control resulting in hospitalisation and possible death. We also pointed out:

- it is untrue that people will be forced to use bottles and syringes - an equivalent pork insulin is available in pen injection devices from a different manufacturer and it has a long safety history with few adverse effects, unlike its GM successors.
- insulin analogues have no information about long-term safety and we questioned that they are better supported by hard evidence. The independent Cochrane Review showed short-acting analogues gave only minimal clinical benefit for a minority of patients. But at the same time we had to mention the statement from Viggo

Birch that analogues are ‘supported by better hard evidence’ as it implies that the ‘human’ insulins were not! But then some of us knew this all the time!

- young children could be forced to use NovoRapid, the short-acting insulin analogue, and yet it only received approval for use in very young children in April 2005! There is no post-marketing surveillance available, no evidence of long-term safety and little experience of its effects in the wider population of young children destined to a lifetime of insulin treatment.

This is the power of industry removing choices from patients that could adversely affect their health, and making decisions that will increase NHS costs but their profits. No one has to succumb to the pressure to change to these new insulin analogues, you can use pork insulin in pen injection devices.

Just a note! We failed to comment on ‘patients will have to revert to antiquated regimens using bottles and syringes’ - marketing language, if ever you heard it! Pens and syringes are only devices and have no effect on the regime used! You can use the ‘modern’ regimen of multi-daily injections or any regime you like with a syringe and bottle! The big old glass syringes that had to be boiled once a week disappeared years ago and modern little syringes are hardly antiquated - they are tiny and discreet and some people actually prefer them to the huge 3ml pens!

Details of Novo Nordisk’s announcement of the withdrawal of some ‘human’ insulins were in IDDT’s January 2005 Newsletter available on our website www.iddtinternational.org . If you need a paper copy, call IDDT on 01604 622837.

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Does ‘Brittle’ Diabetes Exist?

Brittle diabetes is a term used to describe blood sugars that yo-yo

unexpectedly between high and low. This certainly happens to people but there are opposing views about whether or not this should be called brittle diabetes. There are some people who believe that brittle diabetes does not exist and it is just a convenient term used by healthcare professionals when they can find no easy answer as to why blood sugars are so erratic. Having a 'diagnosis' or an explanation for their erratic blood sugars often helps people with diabetes, giving them a sense of relief and something to blame. But at the same time, it can mean that having been classified as 'brittle', people and healthcare professionals can stop looking for causes or solutions for their erratic blood sugars.

Diabetes management is not an exact science and in an article in Diabetes Self-Management, The Myth of Brittle Diabetes, [July 2003], Gary Scheiner suggests that there are usually logical explanations for the variations in blood sugars and if you look hard enough, you can nearly always find them. Finding the explanation is the most important step towards finding a solution.

Keeping records

Keeping good records is how weather forecasters predict the weather and where detectives find clues to solve crimes and in the same way, keeping detailed written records can reveal blood glucose patterns. The records should include insulin and/or oral medication doses, carbohydrate intake at meals and snacks, exercise both formal and daily activities such as shopping or gardening. If several days records can be kept on one page, it is easier to look for trends or patterns in blood sugars.

Gary Scheiner reveals some interesting cases of patterns being picked up from detailed record-keeping:

- a fan of horror films found that he had very high blood sugars after watching scary films and they were even higher if he ate popcorn.
- A young boy found that he had high blood sugars in competitive sports followed by hypos the next morning
- A woman found that her blood sugars were high the week before

her menstrual period and dropped immediately after her period started.

All these people had been told they had brittle diabetes and without examining their very detailed records, they would have gone through life believing this and not taking steps to prevent the yo-yoing blood sugars.

Causes of variability in blood sugars

There is an almost unlimited list of possibilities from - chemical, physical and metaphysical but here are some of the most common causes:

Insulin - each type of insulin has a different activity profile. The onset of action [the time for it to start working] the duration of action and the peak of action [when it is working hardest] are different for each type of insulin. They can also be different for the same type of insulin but made by different companies. Ideally you should be using the insulin with the activity profile that most matches your lifestyle ie your meals and activity patterns. In the days when there were many more insulins with different activity profiles than are available today, at diagnosis the first questions to be asked were about eating habits, meal times, exercise patterns and lifestyle. Then people were given the type of insulin that was the nearest match to this whereas nowadays, there is a much greater tendency for the 'one size fits all' approach and when a new insulin comes out, then large numbers of people are transferred to it.

It is worth noting that in some people synthetic GM insulins are more aggressive and shorter acting than animal insulins and short-acting insulin analogues may stop working before the long-acting starts and this can lead to wide variations in blood sugars.

Not mixing up the insulin type - many of the insulin bottles and cartridges look alike and it is important to not mix them up. The appearance of the insulin used to help but not so much now that the long-acting insulin analogues are clear like the short-acting ones. If

there is a chance that you might mix them up or you have difficulty because you are visually impaired, then put a tape or big mark on the packs or vials.

Injection sites - where you inject also affects blood sugars as insulin is absorbed at different rates from different injection sites. It is absorbed most quickly from the stomach and slowest from the buttocks. It is important to rotate injection sites so that lumps of fat under the skin do not form as injecting into these lumps slows down the absorption of insulin.

While it is important to rotate injection sites, to try to keep stable blood sugars it is important to always do the same site at the same time each day but rotate within that site. For example if you inject in the legs in the morning, always inject in the legs in the morning and if you inject in the stomach at lunchtime, always do it there at lunchtime. This way the absorption rate will be similar everyday for each injection and lead to less variable blood sugars.

Inaccurate doses - this can lead to variations in blood sugars especially when using a syringe, air bubbles being the greatest culprit. A pen is thought to be more accurate although there is a degree of tolerance for variation in dose delivery by pens.

Expiry dates - if insulin is stored correctly in the fridge it will not lose any potency but in-use insulin kept at room temperature should be discarded after 28 days. Exposure of insulin to light, heat, extreme cold or being shaken a lot will make it less potent and this will affect blood sugars. Mixing insulins - if you mix two insulins in the same syringe, you should always draw up the clear, short-acting insulin first so that it is not contaminated with the long-acting which would delay its onset of action. [Note that Lantus [glargine] should never be mixed with another insulin.]

Rolling long-acting, cloudy insulins - is necessary so that the crystals that make it cloudy are evenly spread throughout the insulin. The vial or cartridge should be rolled between the fingers at least 10

times before injecting.

Pumps - insulin in a pump and tubing can lose its potency over time and its effectiveness deteriorates the longer you use your infusion set. The infusion set should be changed every 2-3 days and the insulin cartridge at least once a week. You should also check for kinks in the tubing and leaks between the pump and the tubing.

Carbohydrates - matching food to how much insulin is available is the key to blood glucose control and keeping records of what you eat can help to detect reasons for unexpected highs or lows. There are various ways of dealing with food intake:

- Some people adjust their insulin at each meal based on the amount of carbohydrate they eat or how active they plan to be.
- Some people count the grams of carbohydrate and roughly eat the same amount of carbohydrate for the same meals and snacks everyday. With the exception of fibre, most carbohydrates raise the blood sugars quite quickly and by about the same amount, so counting the carbs and trying to keep the total amount the same for each meal from day to day helps to keep blood sugars more stable.
- Low carb diets cause great debate. Low carb diets require smaller doses of insulin and smaller doses means that hypos are less likely to occur and if they do, they are likely to be less severe.

Fats and fibre - tend to slow down the digestion of carbohydrates so even meals that contain low-fibre carbs will lead to a quicker rise in blood sugars than those that are higher in fats or fibre. High fat meals may lead to blood sugar rises several hours later.

Eating out - meals at friends, restaurants or take-aways often contain more fat and carbs and are often bigger portions than you would eat at home, so to avoid high blood sugars you may need to take more insulin.

Alcohol - despite some alcoholic drinks containing carbohydrates,

they can have a blood glucose lowering effect for 24 hours or more afterwards by suppressing the release of glucose from the liver. So alcohol can cause hypos and/or delayed hypos. People with diabetes should not drink alcohol on an empty stomach or immediately after exercise and it is preferable to drink with a meal or eat carbohydrate nibbles while drinking.

Exercise - glucose is used for energy during exercise. Exercise also makes insulin work more efficiently and this is the reason why exercise can lead to hypos if extra carbs [or a lower insulin dose] are not taken before physical activity. But sometimes things do not seem to fit into this pattern. Long intense exercise can cause delayed-onset hypoglycaemia which can continue to lower blood sugars for up to 24 hours later. This is because the body has to replace the glucose stores in the muscles with glucose from the blood so the long-acting insulin dose may need to be reduced or more carbs consumed. High intensity or competitive exercise, such as weight lifting or sprinting, often cause the body to produce adrenaline which makes the blood sugars rise and if there is not much insulin in the system before the activity, then ketones can be produced.

So as exercise can have both short and long lasting effects on blood sugars varying the time you take exercise can lead to yo yoing blood sugars so it is better to try to exercise at the same time each day. The golden rule with all types of exercise is to monitor blood glucose levels frequently and to know what happen to you when you exercise.

Illness - any sort of illness or infection can cause the stress hormones to be released and this will raise blood sugars, sometimes before you are aware of an infection. It is advisable not to exercise with an infection, even a cold.

Hormones - if everything else is being done correctly and blood sugars are still erratic, then hormones could be to blame.

- Short-term emotional stress eg having an argument, increases the levels of stress hormones and in turn, these increase the heart

rate, blood pressure and blood sugars. Chronic stress eg marital difficulties or demanding job, can have the same effect but over a long time.

- During growth up to the age of about 20 insulin needs go up due to growth hormones and sex hormone production and erratic hormone production during this time can lead to erratic blood sugars.
- During the menstrual cycle the body produces hormones that can affect blood glucose levels. This varies in individual women but many women find that blood sugars rise just before menstruation and then return to normal or lower than normal immediately after menstruation begins. For some women the stress and carbohydrate cravings also affect their blood sugars at this time.
- Night time production of hormones is a common cause of the 'dawn phenomenon', high sugars in the morning. Night time production of hormones causes the liver to increase glucose production which is matched by insulin production in people without diabetes but people with diabetes cannot do this, so the result is high sugars in the morning.
- The other reason for morning highs can be a hypo in the night that stimulates the stress hormones to produce glucose from the liver. This is known as the rebound effect and can result in high sugars several hours later when you get up.

Progression of diabetes - however expert in self-management, the longer the duration of diabetes the harder it can be to achieve 'good' control. The body changes and lifestyle changes and so it may be necessary to make continued adjustments to insulin, diet and exercise.

Inaccurate monitoring - if monitoring technique is incorrect then this can lead to apparent fluctuations in blood sugars. For example, some strips require a certain amount of blood on them and if there is not sufficient, then the reading will be artificially low. This is less likely to occur with the strips that 'suck in' the blood. It is also important to check the coding of the meter - if it is not coded to match the strips, then the readings will be inaccurate. Out of date strips or ones that have been exposed to heat or humidity [those left in the car!] can also

give false readings.

So does brittle diabetes exist or is there just a lot of option to explore?

There are certainly many options to be explored but two things are clear - regular blood testing is essential and then detailed written record keeping can help you to identify patterns in your blood glucose levels and perhaps find out why you were high or low at particular times. If you are unsure of how to adjust your insulin, how to handle diet, how to deal with exercise, then discuss these and other issues with your doctor, diabetes specialist nurse or dietitian.

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Can You Help?

Sponsored bike ride in aid of IDDT in memory of friends Tim Seager and Shengul Keskin

Neil Tamlyn and Elliot Roberts will be undertaking a sponsored bicycle ride to raise money for IDDT. They aim to complete a 1000 mile route from Sunninghill, Berkshire to the south west of France in August 2005. At 100 miles a day, they plan to complete this task within 10 days.

Neil and Elliott say:

“Our reason for sponsoring this very worthwhile cause follows the sad loss of Shengul Keskin, due to complications arising from diabetes. After her death her fiancé, Tim Seager, became actively involved in researching and learning more about Diabetes; the Insulin Dependant Diabetes Trust were extremely helpful and supportive of him. Very sadly, Tim has since passed away and we have decided to carry on Tim’s support and interest in the IDDT by performing this sponsored event, in memory of both Tim and Shengul.

We would like to invite you to sponsor us in this challenge [forms available from IDDT] or to ask you to make a donation in memory of

our friends, Tim and Shengul.

We would especially like to thank Action Bikes of Maidenhead for helping us kit up for the event and on behalf of the IDDT and the friends and family of Tim and Shengul, to thank you for any support you may be able to offer.”

Please make cheques payable to ‘IDDT’ and send to: IDDT, PO Box 294, Northampton NN1 4XS

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Interesting Websites

- The connection between salt/sodium and obesity in vulnerable groups is examined on a website www.wildeaboutsteroids.co.uk and is well worth visiting. It suggests that there are groups of people who are sensitive to salt and therefore suffer from excess water retention that in turn can lead to obesity. We have all watched the advice about daily consumption of salt vary over the years and the website suggests that obesity reduction by reducing the sodium/salt in our diets is a very unresearched area despite obesity having such a dramatic effect on public health. Well worth a look!
- A whole host of information about the problems with GM human insulin and GM insulin analogues on this website - www.humaninsulin.org.uk

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Parents’ Part

- **Parents and Teachers Packs are available from IDDT**

In April 2005, IDDT had a pullout supplement in a magazine for head teachers called ‘Headteachers Update’ that goes to 26,000

primary schools. This was in response to the needs that parents have expressed to IDDT - the lack of information and therefore understanding that some teachers have about diabetes and especially about the treatment of hypos at school. The centre pages of the pullout supplement are a poster showing the effects of hypos on children and how to deal with them. We also included a flyer for parents, not just for parents of children with diabetes but parents of their friends too. We have received positive feedback from headteachers with the comment "Just what we have needed!"

IDDT has developed two new information packs:

"Introducing IDDT to Parents" containing information about diabetes in children, the feelings and difficulties that parents experience and a card for parents to give to the school about their child and the hypo warning signs that are specific to their child.

"Introducing Teachers to Children with Diabetes" containing information about diabetes, hypos, school trips, sports activities and how they can help to make life easier for children with diabetes in school.

The Packs are available free from IDDT at IDDT, PO Box 294, Northampton NN1 4XS, tel 01604 622837 or e-mail kids@iddtinternational.org

Research of interest to parents

Diabetes UK survey of 12,000 children and young people with Type 1 diabetes

This survey showed that four in five children with diabetes are not achieving recommended blood glucose levels but also that a third had fewer tests from doctors than they needed.

Teenage diets and the risk of Type 1 diabetes - researchers in Iceland investigated the relationship between food and the incidence of Type 1 diabetes in 4,701 adolescents from eleven European countries. The results were unexpected. Those eating diets that were

high in total fat, in saturated fatty acids or in fruit and vegetables were associated with an increased incidence in Type 1 diabetes. When fruit and vegetable intake was measured separately, no relation to the incidence of Type 1 diabetes was seen. There was also no association between a high sugar diet and the development of Type 1 diabetes. In view of the health benefits of fruit and vegetables, the researchers conclude that further investigations are necessary to find out why fruit and vegetables are implicated. [Annals of Nutrition and Metab, Nov/Dec 2003]

Poor control in adolescents and young adults

Researchers in the UK studied 397 young adults aged 16 to 25 with Type 1 diabetes and found that their average HbA1cs were high, 9.5%, 34 had hypertension and 10 had microalbuminuria [protein in the urine]. The researchers suggest that the causes are inadequate blood glucose monitoring, poor clinic attendance and inadequate screening for complications. They also suggest that limited funding of clinics added to the problem as many did not have access to dietary or psychological services. Clinics that offered young adults evening appointments and reminded them by letter or phone, had the highest attendance rates suggesting that young adults have difficulty conforming to traditional clinics. [BMJ August 2, 2003]

How teenagers deal with stress may affect their diabetes control

According to a new study published in Diabetes Care, how teenagers cope with problems may help to determine how well they manage their diabetes. The study surveyed 103 teenagers with Type 1 diabetes asking how they typically cope with problems and then looked at the relationship between coping styles and their HbA1cs [the test that reflects average blood sugar levels over the last 6 weeks]. In general those with more positive, practical responses to life's difficulties showed better blood sugar control - they faced a problem and resolved to do something about it. However, those who said they dealt with stress by getting angry or by giving up showed poorer blood sugar control. The author recommends that counselling focussed on teenagers coping styles should be part of routine diabetes care.

Eating disorders in pre-teens and teenagers

One Canadian study carried out in 9-14year old girls with Type 1diabetes has shown that eating disorders, though usually mild, were more common in girls with diabetes than girls without diabetes in the same age group. [Diab Care 27;1654-59, 2004]

Another study carried out in Australia looked at eating disorders in 251 male and female adolescents with Type 1 diabetes showed that 11.5% of the girls and only 1% of the boys had eating disorders. This study also showed that girls with eating disorders and diabetes had a significantly higher body mass index than those without eating problems. [Wein Klin Wochensher 2004 Apr 30116 (7-8) 230-4] Both studies recommend that screening and prevention programmes are required.

Summer Heat

Blood glucose levels can be affected by the weather - extreme temperatures, either high or low, can cause some people to have more hypos. Summer is here and forecasters are predicting with higher than average temperatures for July and August. Heatwaves can lead to dehydration, heat exhaustion or heat stroke so as well watching blood sugars more carefully, the Chief Medical Officer has set out measures so people can protect their health in a heatwave.

Plan your day so that you stay out of the heat

- Avoid going out between 11.00am and 3.00pm, the hottest part of the day
- If you go out, stay in the shade, wear a hat and light loose clothes
- Carry water and drink plenty of fluids
- Take cool showers or baths - splash yourself with cold water, especially the face and back of the neck
- Eat as normal, eat more cold food such as salad and fruit

- Note: people over 75 are amongst the people most at risk during heatwaves.

From Our Correspondents

Chronic pain with no specific cause and no successful treatment

Dear Jenny

I am a 49-year-old type 1 diabetic and I have a 20-year history of chronic pain and despite visiting numerous doctors and health professionals, to date, no one has been unable to identify the specific cause or provide a successful treatment. My problems started around the time I was diagnosed as a diabetic. The source area of discomfort is in the joint at the very top of my right leg, although until the last couple of years, it was in my coccyx. If I sit down, even for just a few minutes, I have referred pain in my spine, neck or shoulders that often lasts for several days or more. The pain moves around my torso but never completely disappears. I am interested in hearing from other diabetics who may have the same or similar symptoms to see if this is a common situation with a view to sharing information and possibly forming a support and self-help group.

Paul Mason

Note: If you would like to contact Paul you can do so by e-mail paul_mason17@btinternet.com or by writing to him through IDDT. PO Box 294, Northampton NN1 4XS

Surprising advantage of pork insulin - improved digestion

Dear Jenny

I found the information you sent me very useful and spoke to my GP (who was all in favour of my asking to change insulins). He wrote to my Diabetic consultant who asked me to contact the Diabetes nurse,

who would advise me which insulins and amounts I should start on. I started my new regime two days before Christmas (rather stupid I know), but having made the decision, I just wanted to get on with it. I coped much better over the holiday period than I had for the past several years, but constantly adjusted my insulin. It took about three months to get it to a state that I was happy with. Needless to say, I'm on nothing like the dosage first suggested.

My hypo warnings appeared to be better, but I still have a sudden hypo which necessitates drinking a half bottle (small) of Lucozade to start with so that it works quickly, followed by more carbohydrate which lasts longer. However, I'm pleased to report that my yo-yoing blood sugar levels are much more even - a real bonus. Because of my other ailments, I'm not very active and it only takes a small amount of extra exercise to affect the levels, but at least the hypos occur at more or less the same time. Forewarned is forearmed!

An added bonus of changing to porcine insulin has been better digestion. This was a really pleasant surprise. My husband and I tried to think back to when my digestion started to go wrong and it could well have been a little while after I changed to the GM insulins. I have been taking Omeprazole for years, but also managed to get through a bottle of Gaviscon every couple of weeks. Now, even after being on the porcine insulin for only two days and it being Christmas with all the rich food, I didn't need any Gaviscon at all!

Thank you so much for your help and support, giving me the confidence to challenge my treatment. I found your newsletter a very interesting read. Carry on the good work.

Mrs B.V.
South East

Jenny's comment: I'd be interested to hear from anyone else who had digestive problems when using GM insulins that have improved since changing to pork insulin. Just give me a call on 01604 622837 or e-mail jenny@iddtinternational.org

The confidence to pursue a change of insulin with my doctor

Dear Jenny,

I would like to let you know how IDDT has helped me in the short time since I was diagnosed with Type 2 diabetes in April 2004 and I started taking insulin in conjunction with Glyclazide in July. In just a few weeks I began to feel even more tired, lethargic, unable to concentrate with persistent headaches and painful neck ache. The most extreme symptom was what I can only describe as 'glue' head. I returned repeatedly to see the diabetic specialist nurse at my local Health Centre. She was/is extremely kind but didn't respond to my concerns about the additional symptoms I was experiencing and was focussed on my blood glucose levels.

Initially I was taking GM Insulatard which did not prove effective and so was changed to NovoMix 30 [analogue insulin]. As I increased the number of units, so the symptoms worsened and when I reduced the dosage, some of the symptoms decreased. I visited my GP who thought I was suffering from depression and wanted to prescribe antidepressants. I disagreed with him and asked to try animal insulin first. He reluctantly agreed and I now take Hypurin Porcine 30/70 mix.

Within a month most of the symptoms have gone and the neck ache is improving all the time. If a friend had not sent me a newspaper cutting from the Sunday Telegraph [Nov 2004] I would not have known about IDDT and the alternatives to synthetic GM insulins and certainly would not have had the confidence to pursue the change with my GP.

Ms W.P.
South

Useful information for parents about Disability Living Allowance [DLA]

Dear Jenny,

Further to your information in the April 2005 Newsletter about DLA, I thought perhaps other parents who are receiving DLA for their

children with diabetes should know that when they reach the age of 16, the money has to be paid into a bank account in their own name and no longer to the parents. I was unaware of this until I received an unexpected a visit from someone from the DLA especially to tell me that I had to open a bank account for my daughter so that once she was 16, the money could be paid to her.

Mrs K.J.
South

Carbohydrates again

Dear Jenny,

I was so pleased that the Newsletters seem to agree with my views on the over-consumption of carbohydrates. Since dramatically cutting down my carbs, I have been slimmer, healthier and more energetic. I cannot understand why such emphasis is placed on the importance of high carbohydrate in an insulin diabetic's diet. Less carbohydrate = less insulin = less weight gain = better health and more energy. Please keep up the fight to make people aware of this.

M.P. Received by e-mail

Glucosamine works for me

Dear Jenny

Thank you for your interesting Newsletters and for fighting for animal insulin to remain available for those of us that need it. I live in Australia and so have to import it from the UK. When my doctor gave me GM insulin, I had an immediate allergic reaction and so pork insulin is essential for me.

In addition to having diabetes, I also have very bad arthritis and I have taken pain killers for many years so I wondered about taking Glucosamine. My diabetes specialist told me not to take it but my GP said I could try it to see what happened. It has suited me very well and a lot of my pain has gone and I can now stand more upright, so

I no longer take painkillers but very surprisingly, my blood sugars are more stable now that they have been for a very long time. While it might not suit everyone, my GP says it obviously suits me and rather than making my diabetes control worse, it seems to have made it better!

Mrs C.B.
Australia

Jenny's comment: I checked the information about diabetes and Glucosamine with the manufacturers: Glucosamine sulfate may increase the risk of developing insulin resistance and could decrease the metabolic actions of insulin. Although glucosamine and chondroitin sulfate are biochemically classed as carbohydrates, the body is not able to break them down into glucose, so these compounds do not raise blood sugar by providing an additional source of glucose. However, many factors can affect insulin secretion and blood glucose levels in diabetic patients, and it is recommended that people with diabetes check their blood glucose levels frequently when starting glucosamine.



Diabetic ketoacidosis

We tend read and talk about hypoglycaemia much more than hyperglycaemia [high blood glucose levels]. Maybe this is because hypoglycaemia or the fear of it, is ever present and hypos and loss of warnings of them can also affect our ability to drive or renew our driving licence. But we should not forget that hyperglycaemia that leads to diabetic ketoacidosis, DKA, can be dangerous and if left untreated, can be fatal.

The process leading to DKA

Insulin controls the levels of glucose in the blood and DKA can occur if you don't have enough insulin to meet your body's needs □ this is

what happens at diagnosis of Type 1 diabetes. There is insufficient insulin in the body and so the blood glucose levels rise, the excess glucose is passed away in the urine and in order to deal with this, extra fluid is taken from the tissues. If this is not replaced, then you become dehydrated. At the same time, your body begins to burn fat and protein from the muscle tissue as a source of energy. The source for this would normally be carbohydrate which has been converted to glucose but because of the body's shortage of insulin, your cells cannot access the glucose in the blood so the body resorts to burning fat and one of the by-products of this process is ketones. Ketones build up and your blood becomes acidic and one of the tell tail signs of this is your breath smelling of pear drops. [People with Type 1 diabetes may well recognise all this happening to them when they were first diagnosed.]

As DKA progresses you become more dehydrated and your blood becomes acidic from the ketones and your body starts to 'rearrange' its own chemistry by moving electrolytes around. You retain sodium and lose potassium and this is when it becomes dangerous as your blood becomes too toxic for your organs. If your brain is not getting either glucose or electrolytes, then there is a risk of coma.

Signs of DKA

When DKA first starts you may feel sick, very thirsty and tired and this usually occurs over hours or days. After this stage you become confused and short of breath and if blood glucose levels are not reduced and fluids not replaced, then you could well need an IV drip. Untreated DKA can result in coma and death.

Risks of DKA

People with Type 1 diabetes are at far greater risk of DKA than those with Type 2 diabetes because in Type 2 there are usually small amounts of insulin produced which help to lower high blood sugars during illness. DKA is rare in people with Type 2 diabetes.

The most likely time for DKA to occur is during illness. Very often people aren't eating, so they take less insulin but actually in cases of

illness, very often the blood sugars rise and so you may need more insulin, not less! So when you are ill, it is advisable to test your blood sugars every 2 to 4 hours when you are unwell. The risk of DKA also increases when you are injured or have an infection.

This is because during illness, injury or infection the body releases stress hormones and these counteract the action of insulin, so blood sugars will rise. Although emotional stress can cause blood sugars to rise, it is unlikely to cause DKA.

There are other practical causes of DKA - your insulin has gone bad or if you use a pump, it is blocked so that your body isn't getting the insulin it needs.

Testing for ketones

Urine ketone testing kits are available and years ago, we were all supplied with these as part of our treatment. This seems to have stopped in many areas but it does not mean that diabetic ketoacidosis is any less important and if DKA is caught early enough, then hospitalisation can be prevented.

Treatment

- Moderate or high ketones require immediate treatment, usually your doctor will advise extra insulin. You also need to drink extra fluids to help to rehydrate your body but what you drink depends on your blood glucose levels and whether you need extra insulin.
- If you are vomiting and can't keep fluids down, you should get help immediately.
- You should not exercise if you have DKA because this will cause more fat-burning of the muscle tissue and so more ketones. Even if you have taken extra insulin, the exercise may cancel out its effects.
- If you end up in hospital, then you'll probably be put on a drip of fluids and insulin.

DKA can be dangerous, and it is just one more reason for knowing

what your blood sugars are doing especially at particularly difficult times.

Remember!

Patients Can Now Report Adverse Drug Reactions!

IDDT will be reminding you of this regularly because a more effective system for monitoring suspected adverse drug will result in greater safety for patients. You have the opportunity to report any suspected adverse reactions, so do use it. Remember adverse drug reactions can occur immediately or days, weeks or even years after taking a medication and you only have to suspect, not prove, that adverse effects are as a result of a medication.

In May 2005, we received answers from the Dept of Health to our questions about the new system:

- the same weight will be given to adverse reaction reports from patients as to those from doctors and other healthcare professionals and they will be recorded on the same database.
- the present methods of reporting are pilot schemes which will be evaluated and a permanent system for patient reporting will be in place in 2006
- the information presently on the Yellow Card Scheme website is from the period 1963 to January 2004 and 'over the next few weeks' this information will be updated to provide more up to date data.

Here's how to report any suspected adverse reactions:

- **If you have access to the internet:**

Go to www.yellowcard.gov.uk and CLICK on submit a Yellow Card report

- **If you prefer to use a paper Yellow Card reporting form:**

telephone the MHRA on 0207 084 2000 or e-mail patientreporting@mhra.gsi.gov.uk and ask for a form to be sent through the post.

Arthritis Drugs And Diabetes

Most people cannot have failed to read about the withdrawal of Vioxx, which was the most widely used painkiller for arthritis sufferers. It belongs to the class of drugs known as Cox-2 inhibitors and they were aggressively marketed because they avoided the gastrointestinal effects of the non-steroidal anti-inflammatory drugs [NSAIDs] such as ibuprofen. Vioxx was withdrawn by the manufacturers in September 2004 after research showed that patients using it had twice the relative risk of heart attack and stroke compared to those taking a dummy pill [placebo]. This also raised questions about other drugs in this class such as Celebrex and Bextra and there is a strong view that the risks of Cox-2 inhibitors outweigh the benefits to people with arthritis especially as there are safer drugs for patients to use. When drugs come in for criticism and litigation for damages totalling billions of dollars, as in this case, there is a long story which we will not go into here.

People with diabetes are already at greater risk of heart attack and they may also have arthritis, so how does this controversy affect them?

While pointing out that clear guidance is lacking, an article in DOC News of the American Diabetes Association, April 2005, makes the following points:

- Experts say that Cox-2 inhibitors are being taken by people that don't need them. This is either because they don't suffer the gastrointestinal effects of NSAIDs or because they also take

aspirin to reduce the risk of heart attack. Aspirin eliminates any protective effect on the gastrointestinal tract that Cox-2 may have.

- Many people with diabetes over the age of 50 take aspirin anyway and so the beneficial effects of Cox 2 inhibitors are lost.
- Since these drugs relieve pain and do not alter the course of the disease, they should only be taken if they relieve the pain from arthritis.
- Cox-2 inhibitors may pose an extra risk to people with diabetes as they tend to raise blood pressure and increase clotting [Arch of Intern Med.165:161-268,2005] so people using them should have their blood pressure closely monitored.
- As people with diabetes are already at greater risk of heart attack, there is a view that Cox-2 inhibitors pose an additional risk and therefore it may be wise to choose a drug with a lower risk.

Golden rule: if you are taking this class of drug, then talk to your doctor.

Medical Device Problems

April 12th 2005 - LifeScan issue an urgent medical device correction

This affects: **OneTouch® Ultra®, OneTouch® FastTake®, InDuo®, EuroFlash®, SmartScan®, and PocketScan® Meters**

1. **CERTAIN** OneTouch Ultra Systems and all OneTouch FastTake, EuroFlash, SmartScan, PocketScan and InDuo Systems are designed to show results in two different units of measure. When setting the time and date on these meters, it is possible for you to accidentally change the unit of measure. You may misunderstand your blood glucose results if your meter is set to the wrong unit of measure. Your meter's unit of measure should be set to "mmol/L," as shown on the meter display under the test result.

2. For **ALL** OneTouch Ultra, OneTouch FastTake, EuroFlash, SmartScan, PocketScan and InDuo Systems, an event such as dropping the meter while in use can, on very rare occasions, cause a brief power loss. As a result, the meter may unexpectedly change the unit of measure and/or the code number. Each time you test make sure your meter's unit of measure is set to "mmol/L," and that the code number on the meter's display matches the code number on the test strip vial. This very rare power loss may also affect the meter's 14- and/or 30-day averages. If your averages are not what you expect, you should not rely on them.

How to Check Your Meter's Unit of Measure

Each time you turn on your meter, the unit of measure will appear on the display with the symbol. The unit of measure will also appear under every test result.

If your meter is set to the right unit of measure, "mmol/L" will appear on the display. Your test result **will** include a decimal point. Do **NOT** change this setting - this is the right unit of measure for your country.

If your meter is set to the other unit of measure, "mg/dL" will appear on the display. The test result **will not** include a decimal point. Unless your doctor has told you to use this unit of measure, do not test your blood glucose. Contact LifeScan immediately for assistance.

What to do

In countries where "mmol/L" is the standard unit of measure, LifeScan has chosen to replace, free of charge, all OneTouch FastTake, EuroFlash, SmartScan, PocketScan and InDuo Systems, as well as those OneTouch Ultra Systems that allow users to change the unit of measure. All users of these products should contact LifeScan for instructions: LifeScan UK, 50-100 Holmers Farm Way, High Wycombe, Bucks HP12 4DPCustomer Care Freephone: UK 0800 121200 www.LifeScanEurope.com/uk/

Note: A similar warning has been issued to people in countries where mg/dL is the unit of measure

Another Nail In The Coffin For HRT?

Hormone replacement therapy [HRT] was designed to help menopausal symptoms in women but later it was thought that it had a preventative effect against cardiovascular problems such as heart attack and stroke. Readers will no doubt remember that studies have shown just the opposite - that HRT can increase the risk of cardiovascular disease and also breast cancer. The British Medical Journal [BMJ, 2005;330:342-4] has published a review of 28 separate studies involving nearly 40,000 women which looked at the association between stroke and HRT. The review found that the risk of stroke increased by nearly 30% among women taking HRT and that women using HRT were more likely to suffer more severe strokes with a greater risk of death or disability.

Snippets...

Breaking bad news - a study has shown that female doctors are better than male doctors at breaking bad news to patients. Male doctors were more likely to deliver bad news in an abrupt manner. It has always been suspected that women doctors have a more empathetic approach which is better suited to this sort of consultation while men are more likely to stick to the facts. The researchers suggest that perhaps a little more training in this area would be a good idea.

Electronic eye - Japanese scientists say that they have built an electronic eye that could help blind people to get around safely. The device would be mounted in glasses and consists of a smart camera-computer combination which detects and measures such things as traffic light colours and the width of the road. A voice speech system relays the information to the wearer.

White bread, foods high in starch may increase the risk of Type 2 diabetes - research published in Diabetes Care [November 2004]

suggests that eating starchy foods such as white bread may increase the risk of developing type 2 diabetes. The researchers investigated whether the glycaemic index of a food would influence a person's risk of developing type 2 diabetes. The glycaemic index is a measurement of a carbohydrate's effect on blood glucose levels eg a carbohydrate that breaks down quickly, such as white bread, has a high glycaemic index while a carbohydrate that breaks down slowly, such as brown rice, has a low glycaemic index.

Type 2 diabetes in children underestimated

Researchers believe that a suggestion that there are only 100 children with Type 2 diabetes caused by obesity, is a vast underestimation and the true figure is more likely to be several hundred. A study has shown that there are 22 children with Type 2 diabetes in east London alone. All but one of the children in the study come from a black or minority group who are five times more likely to develop Type 2 diabetes.

Danger of country music - researchers have shown that US cities where the radio plays higher than average amounts of country music also have higher than average suicide rates! Only the white populations were affected as they are the ones who listen to it and suicide rates in the African-American people were no higher than in cities where something else is broadcast. [BMJ,2004;329:817]

News From The Pharmaceutical Industry

Inhaled insulin

The newspapers have heralded inhaled insulin as being available within a year when in reality, the only news is that researchers believe that it will be! It has yet to receive a marketing license in either the US or the EU. The media coverage also fails to say that there are still long-term safety concerns about possible lung damage. The results of a trial in people with Type 2 diabetes on tablets has shown that inhaled insulin gave better blood glucose results than just increasing the tablets. [Surely insulin given by injection would do that too?] A study in people

with Type 1 diabetes using inhaled insulin for four years has shown it to be effective with no serious side effects but 4years is far from a lifetime. The American Diabetes Association magazine comments that people with diabetes are likely to take insulin for decades and these relatively short studies do not demonstrate its long-term safety and effectiveness, especially as there are still concerns about the risks of long-term lung damage.

The first non-injectable insulin!

Canadian company, GenereX Biotechnology have stolen a march on the large pharmaceutical companies and received approval from the Ministry of Public Health in Ecuador for an oral insulin spray called Oral-lyn for use in both Type 1 and Type 2 diabetes. Oral-lyn is delivered into the mouth by a device like a regular asthma inhaler from where it is readily absorbed into the bloodstream with no lung deposits. This actual news received far less media hype! Further trials are expected to take place in Canada and Europe later this year.

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Please Come And Join Us!

IDDT's Annual Conference "Your Voice Counts"

Our Conference is being held on Saturday, October 15th 2005 at the Paragon Hotel, Birmingham. It is a jam-packed day with opportunities to listen and learn, to join discussion groups about different aspects of diabetes and to chat to other people who live with diabetes.

It is also your opportunity to show your support for IDDT, so do come and join us. The programme and application forms are available from Bev Freeman, tel 01604 622837, e-mail bev@iddtinternational.org or by writing to IDDT, PO Box 294, Northampton NN1 4XS

Insulin Dependent Diabetes Trust

PO Box 294
Northampton
NN1 4XS

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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