



Insulin Dependent Diabetes Trust

April 2011 Newsletter



The Demise Of Mixtard 30 Brought Back Memories

Yes, the discontinuation of Mixtard 30 did bring back memories of the introduction of human insulin. People with diabetes have been remembering the difficult time they had when they were forced to change from the animal insulin that had suited them for years, to the new genetically engineered so-called 'human' insulin. For many people, the main difference was loss of hypo warnings on 'human' insulin when they previously had full hypo warnings with animal insulin. Perhaps the biggest insult of all was that these people were not believed, yet their experiences provided valuable post-marketing information that could have been so useful – if they had been listened to! When we hear of children who have never had hypo warning signs which cannot be due to the length of time they have had diabetes, we

have to wonder if this is the result of treatment with human insulins. This question should not be ignored because the consequences of no hypo warnings will seriously affect these children – if only that come 17, they will not be able to drive a car like their peers.

In an article in the British Medical Journal about the withdrawal of Mixtard 30 in favour of insulin analogues, Cohen and Carter point that the evidence of benefit of insulin analogues for the majority of people is simply not there and the evidence of their long-term safety and efficacy is yet to be established. Yet patients have had to go through unnecessary changes of treatment at a large cost to the NHS as a result of 'commercial decisions'. [BMJ2010;341.15 Dec 2010]

This article was followed by a letter to the BMJ by Dr Robert Tattersall reminding us that this was not the first time we had seen this situation. The discontinuation of animal insulin and introduction of human insulin

in the 1980s was similar – human insulin was never shown to be better than animal insulin, yet over 80% of people with diabetes were changed to it, “driven by propaganda and bribery” and misleading adverts. [BMJ 2011; 2011; 342. 25 Jan 2011] There were promises that human insulin would be cheaper, that it was more pure and less immunogenic but they never did prove to be true.

Novo Nordisk has declared their intention to discontinue all human insulins in favour of insulin analogues, so at some point we can expect similar situations again.

Yes, the story of human insulin is an old story that maybe only some of us remember, but it should be not be forgotten - it serves as a lesson for the future. Unless action is taken, this will be a future where the power of the pharmaceutical industry is likely to dictate treatment, based on their commercial decisions and not necessarily what is best for patients or for the NHS which will have to meet even higher costs for little or no benefits.

Mixtard 30, Actraphane - Where's The Logic?

The withdrawal of Mixtard 30 by Novo Nordisk at the end of 2011 caused the predicted disruption and upset for many people and increased the workload of health professionals throughout the UK. The press quotes that as many 60 to 70% of people have been transferred to Humulin M3, the nearest 30/70 pre-mix insulin made by Eli Lilly, so that is good. For many people the change has been fairly smooth, accepting that any change of insulin means more testing and more anxiety until everything settles down. But for others the change has been difficult and several months later, there are people still struggling to find an insulin that gives them the same control they had with Mixtard 30 and worse still, does not cause adverse effects and allergic reactions.

However, again as predicted, the most vulnerable group – those with visual impairment and manual dexterity problems – are the ones who are really suffering. They cannot manage to inject with a pen so Mixtard 30 in the Innolet injection device enabled them to maintain their health, independence and quality of life by being able to self-inject. But not anymore - thanks to Novo Nordisk's commercial decision the Innolet has been removed, so this vulnerable group need assistance as they are no longer able to self-inject.

Information from the MHRA

The Medicines Health products Regulatory Authority [MHRA] informed Co-Chair, Jenny Hirst, that Actraphane, a pre-mix 30/70 human insulin made by Novo Nordisk, is licensed in the UK.

- **Actraphane is a licensed product in the UK [MHRA to IDDT, 17.12.10]**
- **As a licensed product in the UK it can be prescribed by a doctor. A product prescribed can be sourced by a pharmacy through their wholesalers or by contacting the company directly. [MHRA to IDDT, 21.12.10]**

As this information came from the government organisation responsible for the licensing of medicines, in all good faith we passed on this information. Why would we doubt the MHRA?

IDDT also wrote to the Secretary of State for Health, Mr Andrew Lansley, expressing our concern that this information had not been provided in the first instance, especially for those who need the Innolet. Some 6 weeks later we received a response during which time, doctors and health professionals trying to prescribe and obtain Actraphane for their patients discovered they could not do so.

Why can we not access Actraphane in the UK when we are in the EU? Here's what Earl Howe told IDDT:

1. Actraphane has a central marketing authorisation which means it is authorised to be marketed in ALL EU member states but which countries market it is determined by the authorisation holder –

Novo Nordisk.

2. As Actraphane is a licensed medicine in the EU it cannot be imported for patients in the UK using the unlicensed import procedures [known as the named patient basis] because it is licensed!
3. Actraphane cannot be imported using parallel importation because this requires the involvement of Novo Nordisk, approval from the European Medicines Agency [EMA] and a wholesale dealer with a licence to carry this out. And from March 2011, Novo Nordisk are only supplying their products through one wholesaler, so ruling out all competition.
4. If it is available outside the EU [and it is, albeit with yet another name] then it could be imported as an unlicensed product from a country outside the EU, although this carries added responsibilities and risks, such as maintaining it at the correct temperature during the process.

Where's the logic?

If all this sounds confusing, irrational or illogical to you, you are not alone! Actraphane has a licence in the EU, so we can't have it in the UK even though it is available in Germany and Italy. But if it didn't have a licence we could! Yet regulators are prepared to access it as an unlicensed medicine from countries outside the EU on a named patient basis with the added risks of this process.

It is clear that the regulations favour pharmaceutical companies and not patients:

- as holders of the marketing authorisation, companies have control over where a medicine is sold even when it is licensed,
- the control for allowing parallel importation rests with the companies and the wholesale dealers are controlled by them.

So where do patients' needs come into all this? They actually don't.

IDDT's actions

It is hard to argue with a system which seems so illogical but we have

tried by responding to the Earl Howe's letter, yet again pointing out that some people with diabetes need Actraphane because it is near or identical to Mixtard 30. We have emphasised that the most vulnerable group need it in the Innolet to maintain their independence, while at the same time reducing NHS costs through frequent visits from nurses to carry out injections. We have requested that the importation of Actraphane on a personal need basis [named patient basis] be treated as an exceptional case. We are also taking the matter up in the EU Parliament and may well be asking for the help of MEPs.

Are we just being difficult?

No we are not! Not only is this an important issue in itself, but Novo Nordisk have said that it is their intention to discontinue all human insulin, so this will go on happening and will affect even more people. As a charity that cares about the needs of all people with diabetes, we cannot sit idly by and accept their reduced quality of life and health status, when the insulin they need is actually available but inaccessible due to regulations that defy logic.

Note: If you would like to see the correspondence from the Ministers and IDDT's responses, please visit the Latest News section on the Homepage of our website: www.iddtinternational.org



Press Don't Panic

'Press Don't Panic' is a small, highly visible, clearly medical, audio device which communicates vital information in a medical emergency – at the press of a button. It can be worn on outer clothing or as a pendant. It allows the wearer to record a personal message containing emergency procedure and/or essential medical information in any language. This message can then be played back at the press of a button by the wearer or by those offering assistance whenever the wearer requires it. Those assisting will then know what to do and

who to contact. It has been designed to primarily help people with conditions such as diabetes, epilepsy, allergies, or asthma who may require assistance when they are out and about.

‘Press Don’t Panic’ sells at £34.99. To purchase or for information go to www.pressdontpanic.com or telephone 01721 730511 or 07710012114

For The Ladies

Hypoglycaemia and the menstrual cycle

It is well recognised that many women with Type 1 diabetes have erratic blood glucose levels before and/or during their monthly periods. The variability of the glucose levels may be the same each month in individual women but it is different from person to person. So some women may go high 3 days before their periods are due, while other may go high just on the day they start and some have more hypos. Sometimes it is possible to take this variability into account before the blood glucose levels rise or fall, but some women simply ride it out. This variability can be even harder to manage for women whose periods are not regular.

Recent research has shown that when estimating the risk of hypoglycaemia in women with Type 1 diabetes, certain risk factors are dependent on the regularity of the menstrual cycle. The study looked at the 24-hour glucose levels using a long-term glucose monitoring system in 155 women with Type 1 diabetes. One group had regular periods [Group 1] and the other irregular periods [Group 2].

- In both groups if less than 50% of the day the glucose levels were normal and high, there were increased risks of hypoglycaemic reactions regardless of the regularity of the menstrual cycle.
- The opposite was true for HbA_{1c} levels as a risk factor for hypoglycaemic reactions, these were dependent on the regularity

of the menstrual cycle.

- In Group 1, those with regular menstrual cycles, an HbA_{1c} of 7% or less was a risk factor for hypos but in Group 2, those with irregular menstrual cycles, an HbA_{1c} of less than 6% was a risk factor for hypos.

How this translates into real life, not sure but it is interesting and may help to explain some of the ‘unexplained’ hypos. [Int Conf Adv Tech Treat Diab, Feb 16-19, London]

Pregnancy and Type 1 diabetes

Reducing the risk of severe hypoglycaemia during pregnancy

It is important for pregnant women with Type 1 diabetes to tightly control their blood glucose levels because of hormonal changes which can put the baby at risk of complications. Most pregnant women with Type 1 diabetes aim for and often meet blood glucose levels close to normal but this has high risks of severe hypos which can lead to serious health problems and occasional mortality of the baby.

An article in a recent edition of ‘Diabetic Hypoglycaemia’ [a journal edited by Professor Brian Frier] concludes that episodes of severe hypoglycaemia may be reduced in pregnant women with Type 1 diabetes if they undergo:

- pre-conception counselling on the risks of developing severe hypoglycaemia
- training on hypo awareness
- treatment with insulin analogues and/or insulin pump with continuous glucose monitoring and hypoglycaemia alarms.
- The accompanying editorial by Professor Simon Heller also points out that:
- pregnant women who start on intensive glucose control before or during pregnancy should be advised of the importance of testing before driving and
- they should ensure their partners are educated on how to give glucagon if there is a severe hypo.

The artificial pancreas can help pregnant women with Type 1 diabetes

Researchers at Cambridge University have found that using the artificial pancreas device can help pregnant women with Type 1 diabetes to control their blood glucose levels. Although this was a small trial, it is important and suggests that pregnant women with Type 1 diabetes spend an average of 10 hours a day with glucose levels outside the recommended target levels. The researchers recommend that larger studies are needed to ensure these findings are accurate.

The artificial pancreas is being developed and combines a continuous glucose monitor and insulin pump to test glucose levels and then deliver the right amount of insulin. This mimics the way the pancreas works to control blood glucose levels.

Pregnancy and diabetes national guidance

In February this year the Royal College of Midwives and NHS Diabetes published joint guidance for managing pregnant women with diabetes. Called “Lead Midwife in Diabetes: Standards, Role and Competencies”, it sets out standards for the role and practice of midwives who lead in the care of pregnant women with diabetes and those who develop diabetes during pregnancy. The document points out that the care of pregnant women with diabetes, including gestational diabetes, should be provided by a multidisciplinary team at the same time and same setting. As a minimum this should include an obstetrician, diabetes physician, diabetes specialist nurse, diabetes midwife and dietitian. To view the document, go to www.diabetes.nhs.uk/document.php?o=2008



Holidays

Travelling with an insulin pump – full body imaging

The last time IDDT discussed removing insulin pumps when having an X-ray, CT scan MRI or any other type of radiation therapy, several people responded by saying this was unnecessary but the reality is that most manufacturers advise that pumps and remote controls

should be taken off.

A debate has now arisen in the US over the Transportation Security Administration’s [TSA] new screening methods before boarding a plane. The new scanners are not simple X-ray machines but a full body imaging system. This means that if you are wearing an insulin pump and can’t go through the scanner, then you are subject to a ‘patdown’ which some people maintain is not a gentle one and is intrusive.

Reports suggest that the TSA is reluctant to discuss the new screening procedures in detail but they do say that travellers with diabetes and a pump can have a private screening if necessary.

The OmniPod perhaps causes the most difficulty because its pods attach to the skin and they are not easily removed for the scan. Medtronic’s MiniMed pumps cause less of a problem because they can easily be detached from the cannula which remains inserted in the skin. Medtronic advise that you remove your insulin pump, Guardian monitor, sensor, transmitter, meter and remote before going through the scanner or alternatively ask for a patdown instead.

There are differing views from pumpers but one quote was that if this is the way security is going, then it has to be accepted for the safety of all.

IDDT’s Holiday Pack

With holidays approaching, you may be travelling abroad for the first time with diabetes, or you may just like some helpful tips about travelling and holidays. IDDT has a Holiday Information Pack.

If you would like one, call IDDT on 01604 622837, e-mail enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS



Proposed Changes To The Driving Licence Standards For Vision, Diabetes And Epilepsy

As we have reported, a new EU directive on driving came out in August 2009 and yet the Department of Transport has not issued a consultation document on changing UK law, despite several Parliamentary Questions about the delay. Well at last it has! The consultation runs from Feb 3rd to April 28th 2011

The consultation document says that where EU minimum standards offer an opportunity to relax a standard, a greater number of people may apply for a licence but where there is a need to tighten a standard, some applicants and existing drivers may be prevented from holding a licence BUT they anticipate that the number of drivers affected is likely to be small.

Diabetes

The Directive recognises two groups of drivers

- Group 1, vehicle categories A and B – 2 or 3 wheel vehicles, cars and light vans up to 3.5 tonnes.
- Group 2, vehicle categories C and D [and C1 and D1] – medium and large lorries and buses.

Group 1 drivers

Recurrent Severe Hypoglycaemia

- Severe hypoglycaemia is defined as “the need for assistance of another person”.
- Recurrent hypoglycaemia is defined as “second severe hypoglycaemia during a period of 12 months”
- It is also noted that severe hypoglycaemia can result from medications other than insulin.

The UK present regulations – drivers who have had frequent hypos must cease driving and licences may be refused or revoked for such

applicants if they are considered ‘a source of danger to the public’. If control is re-established, a licence can be issued or renewed.

The new EU rules – drivers experiencing recurrent severe hypos shall not be issued with a licence. This is more clear cut than previously because recurrent hypoglycaemia has been defined as 2 episodes in 12 months.

Proposed UK changes – the UK is obliged to adopt this more strict standard which may prevent some new applicants and existing drivers from holding a licence but as now, if control is re-established, a licence can be issued or renewed.

Impaired Awareness Of Hypoglycaemia

- This is defined as an inability to detect the onset of hypoglycaemia due to a total absence of warning symptoms.

The UK present regulations – drivers with impaired awareness are required to cease driving, until awareness has been regained.

The new EU rules – as presently for the UK. In practice this will prevent some people driving.

Proposed UK changes – the UK is obliged to adopt this standard. As with recurrent hypoglycaemia, existing UK guidance must now be interpreted more strictly.

Severe Hypoglycaemia

The UK present regulations – drivers should report any significant change. This would give rise to a reassessment of the licence and in particular, frequent hypos likely to impair driving will lead to a licence being revoked.

The new EU rules – a severe hypo during waking hours, even unrelated to driving, should be reported and lead to reassessment.

Proposed UK changes – to make the regulations clearer that a severe hypo even when not driving, will lead to a reassessment.

Group 2 drivers

The UK present regulations – drivers treated with insulin are considered in exceptional cases for eligibility to drive only Category

C1 vehicles [between 3.5 and 7.5 tonnes]. The driver must be over 18 and all cases are subject to annual review. Drivers treated with insulin cannot be considered for licensing in any other Group 2 vehicle.

The new EU rules – drivers with diabetes that carries a risk of hypoglycaemia [whether treated with insulin or tablets] may apply to drive all Group 2 vehicles providing certain criteria are met:

- No severe hypos in the previous 12 months.
- Full hypo awareness.
- Show adequate control of the condition by regular blood glucose testing, at least twice a day and at times relevant to driving.
- The driver must show an understanding of the risks of hypoglycaemia.
- There are no other debarring complications of diabetes.

Proposed UK changes – adoption of this EU standard subject to the opinion of an expert diabetologist annually. This is generally a relaxation of the present standards in the UK and allows drivers with diabetes the same opportunities as other drivers with diabetes when applying for a licence. For diabetes treated with medication [other than insulin] which carries a risk of causing hypoglycaemia, it is recommended that a doctor's report is accepted.

Vision

Group 1 drivers

Field Of Vision

This is defined as the area which can be seen without shifting the gaze.

The UK present regulations – driving licences are not issued or renewed if the horizontal field of vision is less than 120°.

The new EU rules – the horizontal field of vision should be at least 120°, the extension should be at least 50° left and right and 20° up and down and there should be no defects present within a radius of the central 20°.

Proposed UK changes – that the EU standard be implemented whenever a full visual examination is carried out but the DVLA will continue to allow limited exceptions as at present. The exceptions

are when there is a horizontal field defect, but this is on an individual basis and subject to strict criteria.

Visual Acuity

The UK present regulations – for the 'number plate' test a visual acuity of Snellen 6/10 must be achieved with binocular vision.

The new EU rules – the EU level of acuity is slightly lower at Snellen 6/12 with binocular vision.

Proposed UK changes – to relax the UK regulations to the EU standards. Where there has been a recent substantial or total loss of vision in one eye, there should be an adaptation period which can vary according to individual circumstances.

Group 2 Drivers

There are proposed changes to the vision requirements for drivers of Group 2 vehicles which generally are a relaxation of the present rules.

Remember, these proposals have not yet come into force. If you want to offer comments to the DVLA, you can do so as follows:

Online visit:

<http://www.dft.gov.uk/dvla/consultations/currentconsultations.aspx>

You can request a form from: Mr Mark Davies, Annex III, Medical Standards, DVLA, Corporate Affairs Directorate, D16, Longview Road, Swansea SA16 7JL

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Department Of Health News

Scotland to get free prescriptions

From April 1st 2011 all prescriptions in Scotland will be free. This follows a gradual reduction in charges over the last few years. Wales and Northern Ireland have already scrapped prescription charges, but patients in England still pay £7.20 per item.

Change4Life – the Great Swapathon

In January, Health Secretary Andrew Lansley announced that families will get more help this year to eat more healthily through the Change4Life scheme, called 'the Great Swapathon'. In this £250 million scheme, the Government will give families 5 million £50 healthy lifestyle voucher books as well as tips and advice to help them get healthy. By urging families to swap at least one unhealthy habit for a healthier one, the Government aims to deliver one million 'lifestyle swaps' in England.

Families will be able to access:

- A £50 book of vouchers for money off healthier foods and activities
- Recipes for healthier alternatives to favourite snacks
- Recipes for family options for each mealtime
- Nutritional and activity advice.

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How to access the vouchers

- Four million £50 voucher books will be available through the News of the World Sunday Newspapers and ASDA stores.
- One million vouchers will be available through Change4Life supporters in the community.

Further information is available at www.nhs.uk/change4life

Footnote - Andrew Lansley sees this initiative as a new partnership between Government, industry and the media and is quoted as saying, "The healthy option isn't always the cheapest option so it's a really important step to be able to offer £50 off healthier foods, drinks and activities. ASDA is even offering 20% off dining room furniture to encourage families to sit round a table together for meals."!!!!

Government takes steps to reduce salt

Andrew Lansley has written to all members of the Food Network, which includes the major food companies and take-aways, asking for a written commitment to put calories on menus, ban trans-fats and cut salt. The scheme is voluntary as the Government wants to avoid regulating the food industry in the belief that voluntary changes would

be faster and less costly to the taxpayer than regulation.

Under the plan, all food outlets and staff canteens would sign up to put calorie labels on their menus from this September. The aim is to cut the average salt intake for an adult from the current average of 8.6g to 6g a day. For example, by 2012, 100g of sausages would have 1.13g of salt, 100g of tomato ketchup would have 1.83g of salt and 100g of pasta sauce (excluding pesto) would have 0.83g of salt. A 100g slice of average pizza would have 1g of salt. According to the scheme, businesses would 'once and for all' remove trans-fats from their products by the end of 2011.

The Food Standards Agency maintains that cutting salt intake to 6g a day could prevent an average of 20,200 premature deaths a year.

NICE to continue to develop public health advice

Many changes are taking place in the NHS but the Department of Health has confirmed that NICE will continue to develop independent public health advice which contributes to the promotion of health and the prevention of ill health. Much of the NICE public health work programme will continue although some topics will be removed and some put on hold whilst they are considered further by Ministers. Among others, the following guidance is currently being developed by NICE:

- Type 2 diabetes - preventing pre-diabetes among adults in high-risk groups
- Type 2 diabetes - preventing the progression from pre-diabetes among adults in high risk groups.

After consultation, generic substitution is not to be introduced

After public consultation, the Government has changed its mind about introducing generic substitution of medicines. Generic substitution is where the cheapest non-brand named drug replaces the more expensive version that has been prescribed. The public consultation responses showed:

- There was strong perception that generic substitution posed a

threat to patient safety and these concerns would come to the fore and increase the workload of health professionals.

- The cost effectiveness of generic substitution is inconclusive
So in view of these findings the Department of Health will not be going any further with implementing generic substitution but will look at other ways of using generic medicines that are more acceptable to patients.

NICE draft guidance has not recommended Lucentis for treating diabetic macular oedema

NICE final guidance has yet to be issued but in the draft guidance Lucentis [ranibizumab] is not recommended for the treatment of diabetic macular oedema. This is a condition where there is a build up of fluid and swelling in the macula, the central part of the retina which can lead to severe visual impairment or blindness.

The current treatment is laser coagulation. Although Lucentis has been shown to be an effective treatment for diabetic macular oedema, NICE has not approved Lucentis on the basis of the economic analysis from the manufacturer – it costs £742.17 per injection. Treatment is given monthly and continued until a patient achieves maximum vision (visual acuity) which is stable over three consecutive monthly assessments. The Appraisal Committee recommended that Lucentis treatment is not an effective use of NHS money.

Shortly after publishing this draft guidance, the manufacturers of Lucentis reported positive results from a 2 year study. Patients who received the drug experienced a 'rapid and sustained improvement in vision compared to those who received a placebo injection'. After 2 years greater numbers of people could read at least 15 additional letters on the eye chart. NICE final guidance will be issued later in the year.

Patient Experiences

“You’ve had your allocation”

One of our members asked us to publish his recent experience at the hands of his GP practice as a warning to others, although when you have read it, you will surely not believe that this can happen – but it might.

Roger has had Type 1 diabetes for 60 years and is a retired pharmacologist, so knowledgeable about drugs and the way they work. In January he had a ‘flu jab since when his blood glucose levels have fluctuated so he used more insulin than usual. Towards the end of February, he went to his surgery for a repeat prescription but when the receptionist checked the computer, she said he couldn’t have any more insulin because **“You have had your allocation”**. Naturally Roger explained why he needed more insulin and that the daily dose required can vary and the serious harm that can occur if he did not take insulin, but all he got was **“You have had your allocation”**. For Little Britain fans, it really was a case of “Computer says no”.

I think we are all aware that computers keep a track on the medication we use or the number of blood glucose test strips we use but insulin has to be taken as needed!

Who is to blame for this apparent level of ignorance? Whatever the explanation, this is an unacceptable situation and one which could have caused serious harm. Surely this can’t happen anywhere else but with cut backs, who knows? IDDT’s advice is that people must stand up for their needs, insist on seeing the practice manager or the doctor and if all this fails complain to the local Primary Care Trust [PCT], while there still is one.

Unfounded opinions offered as supposed facts

After falling and damaging my ankle and ribs recently one evening, I was asked to go to my local hospital, which is almost like a cottage hospital from the fifties, the next morning for X-rays to identify potential fractures or otherwise.



This I did and on arrival at 9.00 am my wife selected a wheelchair and wheeled me into A & E where I was met by a middle aged nurse who asked why I was there. I explained and also pointed out that I had Type 1 diabetes. She asked what insulins I took and she wrote them down. One of the insulins I take is Hypurin Porcine and she immediately retorted quite indignantly “That’s an animal based insulin! We no longer advise patients to take animal insulins, they are not being prescribed any longer and you ought to go to your GP and get changed to another type of insulin which will be much better for you”. I just ignored her ignorance rather than get involved in a disagreement as I was a bit “off sorts and distressed”, whereas I would have told her what I thought of her opinions in normal circumstances.

While there will always be wrongly opinionated people when talking of health issues, we deserve to be offered solid advice and not subjected to unfounded “opinions offered as supposed facts” which are not only incorrect but if acted on by a patient could very easily prove detrimental to the management of diabetic control.

No matter with whoever or whenever I consult in the health service I always find it best to listen to what is said, take time to digest it and if in doubt, seek an alternative opinion. Better safe than sorry as they say.

Nigel J Frostwick, Aberdeenshire.

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Sex And Older People – Can We Discuss It?

According to a study of nearly 2,000 people aged between 57 and 85, many middle-aged and older adults with diabetes are sexually active. [Diabetes Care, Sept 2010] Almost 70% of partnered men with diabetes and 62% of partnered women with diabetes are engaged in

sexual activity 2 or 3 times a month, which is similar to those without diabetes in the same age group. However, having diabetes did have its effects with many people with diabetes in this age group having sexual problems that are not being addressed. For both men and women the problems were reduced sexual drive and orgasm difficulties.

The study lead highlighted that both patients and doctors need to know that most middle aged and older adults with partners are still sexually active despite their diabetes. The information was gathered from a survey of nearly 2,000 people in the US and involved an interview at home, a questionnaire, details of the medication people were taking and a blood test. Using the HbA_{1c} test:

- 47% of men had diabetes - about 25% diagnosed and 22% not yet diagnosed.
- Nearly 40% of women had diabetes – 20.5% diagnosed and 19% undiagnosed.
- Nearly half of women in this age group do not have a partner and women with diabetes are far less likely to have a partner than women without diabetes. Those who have a partner were more likely to avoid sex because of a problem and were far less likely to discuss a sexual problem with their doctors – only 19% of women with diabetes had discussed sexual problems with a doctor compared to 47% of men.
- Men were more likely than women to express a lack of interest in sex and erectile dysfunction difficulties.

The researchers concluded that sexual problems are common in people with diabetes and a failure to recognise and address sexual issues among middle aged and older adults with diabetes may impair quality of life and the ability to adapt to living with the condition.

It is clear that many people are not discussing these problems with their doctors. This is understandable and not an easy thing to do, so let us hope that doctors and health professionals read this research and tactfully start discussions with their patients.

While talking about sex and diabetes

It is often assumed that sexual dysfunction is a male problem but women with diabetes can also experience sexual problems. This is often related to uncontrolled blood sugar levels in both men and women. Women are not good at discussing these things with their doctors and maybe doctors aren't too good at discussing them with their women patients but this is the way to get help.

IDDT has a free leaflet, 'Sexual Dysfunction in Men and Women'. For a copy just call 01604 622837, e-mail enquiries@iddtinternational.org or write to: IDDT, PO Box 294, Northampton NN1 4XS

Report – 100,000 People With Diabetes Misdiagnosed

A report by the Royal College of General Practitioners and NHS Diabetes [March 2011] showed that 50,000 people have been told they have diabetes when they did not and another 50,000 have been told they have Type 1 diabetes when they actually have Type 2 diabetes, or vice versa.

The researchers at Leicester University examined the records of patients from five GP practices in Surrey who had been diagnosed as having diabetes. The report says that the errors in diagnosis were due to:

- mistakes by medical staff when entering information about patients,
- a lack of understanding of the condition by doctors and other health professionals,
- the sharp rise in excessive weight has made it harder to differentiate between Type 1 and Type 2 diabetes,
- but the most widespread error was a misunderstanding by health professionals and changing a patient's diagnosis from Type 2 to Type 1 diabetes when those with Type 2 diabetes started insulin treatment,
- rarer forms of diabetes, such as maturity onset diabetes of the

young, are often misdiagnosed as Type 1 diabetes which leads to patients, many of whom are children, being treated with insulin when tablets would help them achieve better blood glucose control.

Some of the consequences for patients

- Some people are receiving poorer quality of care because they are not on the Quality and Outcomes Framework (QOF) register, the NHS-wide system under which GPs receive payments for conducting key checkups and treating patients with certain conditions.
- There could be an impact on patient care because the guidelines for the use of insulin in Type 2 are very different from those in Type 1 diabetes.
- Misdiagnosis can have practical effects, such as problems with getting insurance – a misdiagnosis of Type 1 can have serious consequences for obtaining insurance.

What is the NHS going to do?

The NHS has pledged to improve the diagnosis of diabetes. New guidelines and audit tools have been developed which will help GPs to diagnose diabetes correctly. The Care Services Minister advised that if any patients have concerns about their diagnosis, they should discuss this with their GP.

IDDT's experience

IDDT can confirm from the calls we receive from members and the public that it is very common for people with Type 2 diabetes who go on to insulin, to be told that they now have Type 1 diabetes. The opposite situation is also true – one of our members who has had Type 1 diabetes for 60 years is regularly told that he has Type 2 and so only needs enough blood glucose test strips to test 2 or 3 times a week. Many people are also now telling us that they don't know what type of diabetes they have because they used to be one type and now they have been told they are another! We also hear from people who have been diagnosed with Type 2 diabetes when their blood glucose levels are within the normal range – they may well have pre-diabetes but not necessarily diabetes.

If you are concerned, do go to your GP and discuss your concerns.

Are You Having A Clear Out This Spring?

Viral infections linked to Type 1 diabetes

There have been indications for many years that viral infections could play a role in the development of Type 1 diabetes. A review of existing studies found that people with Type 1 diabetes are around nine times more likely to have had enterovirus than those without diabetes and three times the risk in children with autoimmunity. [BMJ, Feb 4, 2011] Enterovirus is a collection of viruses which can cause a range of symptoms including fever, cold, rash, sickness and diarrhoea.

The researchers say that this cannot prove that enterovirus infection causes Type 1 diabetes but the results provide “additional support to the direct evidence of enterovirus infection in pancreatic tissue of those with Type 1 diabetes”. Type 1 diabetes is thought to be caused by a complex relationship between genetic factors, the immune system and the environment but genetics alone cannot explain the worldwide rise in the numbers of people with Type 1 diabetes.

Why do some people escape complications?

For many years research has been carried out to find out why people with diabetes develop complications but at last researchers have turned the question on its head – why do some people with diabetes not develop diabetes complications?

Many people who live with diabetes have been asking the question this way round for many years as many of us know people who have had diabetes for 50 years or more and they have very few complications.

According to the researchers, 10 to 15% of people with diabetes never do develop complications, so what protects them? This study, called the PROLONG study, is starting in Sweden with a pilot study of

patients who have had diabetes over 30 years. Thirty years has been chosen because people who have not developed complications after 30 years are unlikely to do so later in life. At a later stage, people will be recruited from across Sweden and they will be compared to people who have only had diabetes 15 years but have developed severe complications.

There are approximately 12,000 people in Sweden who have had diabetes for more than 30 years and of these, 1,600 have had it for over 50 years, two thirds of whom do not have complications.

The study will ask questions about lifestyle, about diseases they or their relatives may have as well as various blood tests including genetic tests. Let us hope that it also looks at which type of insulin people have used over the years...

New Units For Reporting HbA_{1c} – And The Point Is?

**By David Levy MD FRCP, Consultant Physician,
Whipps Cross University Hospital, LONDON E11 1NR**

HbA_{1c}, the indicator of long-term blood glucose control, has been reported in percentages (%) since it first came into clinical use in the early 1980s, and we have used the current DCCT version of the measurement for more than 20 years. After this length of time, most of us have grown used to the numbers, usually between 6% and 12%: the higher the number, the higher the average glucose levels over the preceding 6-12 weeks. HbA_{1c} broadly correlates with the risk of developing complications, and most Type 1 patients know that target HbA_{1c} is around 7%, a level at which there is a low risk of developing long-term complications. The Diabetes Control and Complications Trial (DCCT) established this important number in 1993, and our current HbA_{1c} measurement, developed during this

long study, is therefore referred to as the DCCT. Very importantly, we also have a good 'feel' for changes in the numbers, so that consistent changes of more than about 10%, for example, from 8% to 7% would be an encouraging sign that glucose control is heading in the right direction. Worldwide, laboratories use the same DCCT standard, so a DCCT-aligned HbA_{1c} in Mumbai will be the same as one measured in Manchester. We have an excellent national quality control system that ensures consistency across the UK. But all biological numbers must be taken with a pinch of salt. So any HbA_{1c} measurement carries an error of about 10% either way, very similar to the error in finger-prick blood glucose measurements.

Although clinicians and patients seem to be happy with the DCCT measurement – there haven't been street riots demanding a change – the people in charge of supervising HbA_{1c} standardisation have been complaining for many years that they don't like it. They sit on one of those important world committees, in this case the International Federation of Clinical Chemistry (IFCC) – an abbreviation we must get used to, because the IFCC has told us that from June 2011 we must use their units, and their units alone, not the DCCT, for HbA_{1c}. The change is profound: to move from DCCT percentages to IFCC units, that is, mmol/mol. You can't do the conversion in your head, so you will need a table (see below) or online converter, eg www.diabetes.org.uk/Professionals/Publications-reports-and-resources/Tools/Changes-to-HbA1c-values/

The arithmetic also works out in quite an inelegant way – for example: 7% converts to 53 mmol/mol, 8% to 64 mmol/mol – so 1% of DCCT is equivalent to 11 (not 10) units in the IFCC.

There are good scientific reasons for a universal standard for HbA_{1c}, but nevertheless many national organisations, including Diabetes UK, have agreed with the IFCC's over-hasty timetable, seemingly accepting without question that we can all become fluent in thinking in these new numbers with just the two years' notice they issued in 2009. But the scientific stuff can be overstated – there is a widespread belief, even among doctors, that once we have standardised to reporting

the IFCC numbers, the instruments in our hospital laboratories will be measuring the 'real' amount of HbA_{1c}, and therefore the results will be more accurate. This is completely wrong. There will be only a handful of laboratories worldwide with the complicated and expensive equipment needed to measure 'real' HbA_{1c}. In all other labs we will be using the same equipment as we are now, but using a different conversion factor – actually a 'fudge' factor – built into the software to convert to the IFCC number. In other words, the measurement won't change – it's just the numbers reported that will be different. So why not continue to provide us with the familiar information as well? It would cost nothing.

The IFCC has given a barrage of reasons why the world must declare compliance by 1st June 2011. One of the least convincing is the following: by chance, DCCT HbA_{1c} measurements are numerically similar to blood glucose measurements in mmol/L – blood glucose usually ranges between 5 and 20 mmol/L, so it can be confusing when discussing both these measurements with patients. However, the rest of the world uses mg/dL for glucose measurements, which usually vary between 40 and 300 in diabetes, so the confusion exists only in the UK, Scandinavia and the Netherlands, Australia and New Zealand, countries which together contain only a small proportion of the world diabetes population. Actually, since the IFCC measurements will usually be between about 42 mmol/mol (= 6%) and 108 (=12%), we seem to be transferring the potential confusion to the rest of the world. Nor will this change be the end: amazingly, once we've not got used to the current change, the IFCC proposes yet another, which will reduce all IFCC measurements by a further 20%. Apparently expecting us to accommodate to these changes without some detriment to patient management (simply explaining the change to every patient would take clinical teams hundreds of hours) suggests that most of the IFCC don't spend too much of their time in diabetes clinics. The list of members of the Working Group on Standardisation of HbA_{1c} supports this cynicism.

My own hospital laboratory has readily agreed to continue reporting DCCT results as long as patients and clinicians request them,

regardless of the demands of the IFCC. Strangely, our transatlantic colleagues may determine the fate of the whole enterprise. For decades the Americans have resisted with grim determination any attempts to introduce SI units such as mmol/L (they universally use mg/dL for blood glucose and most other measurements as well), and they have no plans to implement the IFCC programme for HbA_{1c}. In other words, they have studiously ignored the world guidance. You may take a political view of this: I couldn't possibly comment. Actually, the Americans have proposed two good and practical ideas, unfortunately supported by neither Europe nor Oceania. First, they have abbreviated HbA_{1c} to A1c, which is much easier to write, print and say, and second, and more important, they advocate staying with DCCT measurements (which after all originated in the USA) but attaching to it an 'estimated average glucose' (eAG) number which would give the average real blood glucose measurements to be expected for any given HbA_{1c} – for example the eAG for an HbA_{1c} of 7% is 8.6 mmol/L. Unfortunately this valuable idea has been ignored by the IFCC, and discounted as scientifically unsound by some national organisations.

The wider concern is that this episode, and there are others that I don't have space to mention, means that Europe and America may continue to disagree over an increasing number of important diabetes matters, a process that has now gone on for years without even professionals being aware of it. However, diabetes is too important a world problem to allow even more transatlantic antagonisms to develop. Patient organisations and ordinary clinicians must now be allowed a meaningful say, and not leave our specialty to be managed by committees whose decisions, though probably well-meant, may increase international tensions, with unpredictable consequences for patients. On this particular question (though not others) and though my reasons for dissent are different from those of my American colleagues, I am completely with them on their approach to the HbA_{1c} problem. Diabetes UK could enhance its reputation by declaring, in patients' (and clinicians') interests, an immediate and indefinite moratorium on the shift to IFCC units in the UK. Let IDDT know what you think.

Table showing the current DCCT measurements, the proposed new IFCC measurements, and the average blood glucose measurements you can expect to be associated with each particular level of HbA_{1c}

HbA _{1c} (DCCT) Current measurement (%)	HbA _{1c} (IFCC) Measurement from June 2011 (mmol/mol)	Average blood glucose level for this HbA _{1c} , mmol/L
6	42	7.0 (range 5.5-8.5)
7	53	8.6 (range 6.8-10.3)
8	64	10.2 (range 8.1-12.1)
9	75	11.8 (range 9.4-13.9)
10	86	13.4 (range 10.7-15.7)
11	97	14.9 (range 12.0-17.5)
12	108	16.5 (range 13.3-19.3)
13	119	18.6 (range 14.6-21.1)

Dr Levy has recently written a small book entitled 'Type 1 Diabetes'. It is primarily aimed at health professionals but Dr Levy believes that many IDDT members will also find it useful and informative. The details are as follows:

Type 1 Diabetes by David Levy, OUP, January 2011. ISBN: 978-0199553211

Click here to find out more about the book on Amazon.co.uk



Seasonal Variations In HbA_{1c}s In Children

Research has been carried out to find out if HbA_{1c} levels vary with weather conditions. HbA_{1c} levels were measured over more than 3

years in children and young people under the age of 18 who had had Type 1 diabetes for more than a year. The results were correlated with weather conditions – ambient temperature, hours of sunshine and solar irradiance. A total of 3,935 HbA_{1c} measurements were taken in 589 children 7 and over and 88 children under 7 years old.

Results

- The lowest HbA_{1c}s were in late summer and the highest were in the winter months with the differences being consistently more than 0.44%.
- There was a pattern over 12 months which mirrored changes in the ambient temperature.
- There was a relationship between HbA_{1c}s, ambient temperature, hours of sunshine and solar irradiance present in the children 7 and over but not in those under 7 years old.

The importance of these findings

- The researchers suggest that these seasonal variations in HbA_{1c} levels in schoolchildren with Type 1 diabetes are significant and should be considered in patient education and diabetes management.
- Potentially they could affect the results of clinical trials where HbA_{1c} levels are used as a primary outcome. For example, if comparing two treatments where the primary outcome is a comparison of HbA_{1c} results, then if these vary with seasons, the study would have to take this into account for the results to be accurate and reliable.
- If HbA_{1c}s are used for diagnosis of Type 1 diabetes as is being suggested in the US, then his seasonal variation could need to be taken into account.

[Diabetologia DOI: 10.1007/s00125-010-2013-4]

Living With Someone With Diabetes

The effect on spouses and partners

It is well recognised that parents of children with diabetes often have symptoms of stress, anxiety, frustration and sadness, especially mothers, because of the responsibility and worries of looking after their child with diabetes. Adults with diabetes can also suffer with these anxieties but so too can spouses and partners who often support their partners with diabetes.

Research has looked at whether there is a difference between the feelings of partners and those of the person with diabetes. Interestingly, the distress that spouses/partners feel is similar to that felt by patients and could contribute to their own depressive symptoms, such as irritability or sadness. However, these depressive symptoms come from their own anxieties about living with diabetes or caring for someone with the condition and are not necessarily because the other person is struggling.

In addition, when male patients were concerned about the management of their diabetes, their depressive symptoms were greater than those for female patients with similar levels of concern, but there was not the same pattern of distress between their respective spouses. The researchers comment that this is surprising because it could be assumed that the spouse would be as worried or that wives might worry more.

Actions

- The researchers suggest that because the distress is not always linked to the feelings of their partner, more attention needs to be paid to the spouse as well as the patient to provide better care for patients and spouses as individuals and as a unit.
- Many people reported some depressive symptoms and some reported levels that could indicate a risk for clinical depression, so it is important that the triggers for this are recognised and if necessary, treatment given.

[Family Relations Journal, Dec 2010]

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The effect on children whose parents have Type 1 diabetes – an important but rarely mentioned group

Many years ago, I can remember a meeting where a dad with Type 1 diabetes who expressed his concerns about being hypo in front of his children. He hated the thought of being out of control of his actions in front of them and worried that they would lose their respect for him.

But there is another perspective to this that doesn't seem to have been addressed – the effects living with a parent with Type 1 can have on children, especially those in a one parent family situation. Children with two parents may find hypos a bit scary but they do have the parent without diabetes to talk to. But like spouses, partners or parents, children in one parent families may have to deal with day or night hypos, decide on whether or not to call 999 or another member of the family. They may feel that they have to keep a watchful eye out for an unheralded hypo, especially where their parent has reduced hypo warnings. The responsibility is a lot for children and teenagers and sometimes it may feel too much. Sometimes they may simply be fed up of the stuff associated with diabetes being around their home – the blood testing and injection kit being around acts as a reminder of the more difficult times.

They may also feel isolated by their situation with no one to talk to because they don't want to talk to their parent for fear of upsetting them and their friends don't, and can't be expected to understand. If their friends visit the house, to them the parent with diabetes looks and acts like any other parent – it is the invisibility of Type 1 diabetes. This is a group of children and young people who may need support and help, not all the time but sometimes when life gets tough for them.

As a society we are aware of children who are classed as 'young carers' for parents with physical disabilities but no one seems to have given thought to the needs of children whose parents have diabetes. Perhaps we should?

One suggestion from a child in this position is that a 'pen' friend / 'e-mail pen friend' in a similar situation would be good to talk to. Do

you have any thoughts on how we can help these children? If you grew up with a parent with diabetes what might have helped you? If you have Type 1 diabetes, do you feel there are ways in which your children could be helped?

We'd love to hear your thoughts, so please contact Jenny on 01604 622837, e-mail jenny@iddtinternational.org or write to Jenny Hirst, IDDT, PO Box 291, Northampton NN1 4XS

..... **Diabetes And Eating Disorders**

The number of people estimated to have eating disorders seems a little unclear but it has increased considerably over the last 30 years or so. Eating disorders are known to be more common in young women but men can have eating disorders too and they can develop at any age in men and women.

Research has shown that teenage girls and young women with Type 1 diabetes are two and a half times more at risk of developing the eating disorders, anorexia or bulimia than those without diabetes. There is a wide range of eating disorders but research suggests that as many as 15% to 40% of 15 to 30 year olds regularly omit or manipulate their insulin injections to lose weight. A commonly used term for this manipulation or omission of insulin is Diabulimia. Eating disorders and diabetes are both complicated conditions when they occur on their own but together the results can be very serious.

Men can have eating disorders

Although not widely recognised, men get eating disorders too. Again the figures are not really known but it is thought that between 10% and 25% of eating disorders are in men. Figures from the NHS Information Centre suggest that 6.4% [2.7 million] men show signs of some sort of eating disorder. Males of any age can develop eating disorders but they are most likely to begin between the ages of 14 and 25 although it is not unusual to have an eating disorder in middle age.

Recent research in Sweden has shown that young adolescent boys with Type 1 diabetes have a higher drive to be thin than their peers without diabetes.

Risk factors

Many of the risk factors for developing eating disorders are similar in men and women. Certain eating disorders are a coping mechanism or an underlying expression of emotional stress. One of the most powerful triggers for eating disorders in both sexes is dieting and as many as 70% of the general population of young people will diet at some time in their young lives. But for young people with Type 1 part of their everyday lives is having to think about food and their diet, so perhaps it is not surprising that if dieting is a trigger, eating disorders in people with Type 1 diabetes are likely to be common.

What are the consequences of eating disorders and Type 1 diabetes?

The short-term consequences are severe dehydration, muscle loss, diabetic ketoacidosis which can quickly escalate to high cholesterol, skin and yeast infections and disruption of the menstrual cycle. The long-term consequences are even more serious with a hastening of the complications of diabetes – retinopathy, neuropathy, gastroparesis, thickening of the artery walls, a type of liver disease, stroke and even death.

The services for people with Type 1 diabetes and eating disorders

Despite how common insulin manipulation or omission appears to be, it can be difficult to diagnose and there are no NHS guidelines on how to treat or deal with these issues. The services vary and in some parts of the country there are no facilities at all for people with diabetes and eating disorders.

A new organisation has formed in the UK called 'Diabetics with Eating Disorders' [DWED] and they can be contacted as follows:

e-mail info@dwed.org.uk or on their hotline, Monday to Friday after 7.00pm on 02028 808 3832 or visit their website www.dwed.org.uk

Other useful sites are: www.nationaleatingdisorders.org and for eating disorders in men: www.mengetedstoo.co.uk

Pharmaceutical Industry News

Profits up for Novo Nordisk

In February 2011, Novo Nordisk announced that their net profit for 2010 climbed 34% to 14.40 kroner [2.66 billion US dollars] with sales up by 19% to 60.78 billion kroner. The insulin analogues, Levemir and NovoRapid, contributed 26.6 billion kroner to this, an increase of 24%, with human insulins up by 5%. Profits from insulin sales are always significantly higher than other products - but not profitable enough to stop them withdrawing insulins and ignoring the needs of the very people who provide their profits!

One supplier of Novo Nordisk insulins is associated with risks

Novo Nordisk has recently appointed a single wholesaler to distribute its products in the UK so tightening its control over the supply chain. The sole wholesaler for Novo Nordisk products [except NovoSeven] is Alliance Health who will buy the products directly from Novo Nordisk and distribute them. Novo Nordisk's decision has been criticised by the body representing pharmacies on the basis that [i] it will further reduce competition in the wholesale market and [ii] there are risks of reduced availability of medicines when adverse events occur, such as the bad spell of weather last winter. The British Association of Pharmaceutical Wholesalers is calling on government to introduce a legal duty of care compelling wholesalers and manufacturers to supply enough drugs to match market demand.

Novo Nordisk subpoenaed over marketing practices

In the US Novo Nordisk has received a subpoena from the US Attorney for Massachusetts instructing the company to hand over documents relating to an investigation of potential criminal offences in its marketing and promotion of NovoLog [NovoRapid] and Levemir and Victoza. Last year in the UK Novo Nordisk was criticised by the

Prescription Medicines Code of Practice for promoting Victoza before it was approved and for misrepresenting the drug's risk-benefit ratio. Complaints were also made about the adverts for Levemir which implied that it caused weight loss, when it only causes slightly less weight gain than other insulins – not the same thing!

Novo Nordisk investing in oral insulin

Novo Nordisk and Emisphere Technologies have entered into an agreement to develop and commercialise oral formulations of Novo Nordisk's insulins using Emisphere's Eligen Technology. This technology makes it possible to take by mouth a molecule without it being altered chemically or biologically.

German Sanofi-aventis plant receive warning

Sterility problems - Sanofi-aventis has received a warning letter from the US Food and Drugs Administration [FDA] for failure to establish or follow "appropriate written procedures to prevent microbiological contamination of drug products purporting to be sterile". Inspections in September 2010 identified shortcomings at the German plant and although Sanofi responded, the FDA still had concerns and in February 2011 sent the warning letter. Sterility testing of the analogue insulin, Apidra is at the centre of some of the FDA's concerns.

Adverse event reporting - Sanofi-aventis also received a warning letter from the FDA in January 2011 for failing to comply with post-marketing adverse reaction reports. Drug companies are supposed to pass on any adverse reaction reports they receive to the FDA within 15 days of the reports being received. Since receiving 483 reports in May 2010, Sanofi-aventis have only forwarded three responses to the FDA who believes that the corrective actions are inadequate.

From Our Own Correspondents

30 years and so much information I didn't know

Dear Jenny,

I am sending you this e-mail to say thank you for the newsletters. They have so much information that I didn't know. I have been diabetic going on for thirty one years and apart from my annual visits to the hospital, I don't hear anything from them. Up to now I am still on Mixtard 30 but only have enough for a few months. Thank you for informing me about Actraphane. I was also interested about the fact that pork insulin is available. Since going on to human insulin my hypo awareness is very poor but if switching to pork could help me feeling hypos coming on more, I would like to go back on it. I am also very scared of having night time hypos so thank you very much for all the information.

H.D
By e-mail

The switch from Mixtard 30 – NovoMix 30 just made things worse

Dear Jenny,

Many thanks for the Newsletter which both myself and my husband found very interesting. We have been affected by human Mixtard 30 being withdrawn. We assumed that our consultant had suggested the correct course of action by changing him to NovoMix 30. NovoMix 30 made things a lot worse as well as having no control of blood sugar levels no matter how much insulin he took, or not! He also had injection site problems. Six months later he is now on Humulin M3 and what a change, he is lively and has more energy than for sometime, in fact he is a different man!

The consultant and diabetic nurses were not very helpful until they were told that he wanted to change insulins. I do not know if the differences in my husband have been noted by other Mixtard 30 users but NovoMix 30 certainly made things worse.

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I look forward to the next newsletter and will leave this one at the hospital for other people to see and I am already telling people just how great your organisation is. If I get a place on this year's 'Great North Run' I will ask for sponsorship for IDDT.

Many thanks once again.

M.M.
By e-mail

Keeping us all informed

Dear Jenny,

I became a diabetic in 1957 when I was 10, so I have seen many changes. As you can imagine, and thank goodness I keep in reasonably good health with few complications.

Thank you for your letter sent 14th January – "Mixtard 30 has gone". Although I don't use this insulin, I would just like to say thanks for all the work you do to keep us all informed, and for fighting on our behalf. It is appreciated. Keep up the good work.

J.K.
By e-mail

A policy change in the NHS

Dear Jenny,

Thanks for the item on the "dead in bed" issue, I would think all diabetics, however old, are all too aware of this. I have found myself at the bottom of the stairs surrounded by ambulance staff and family, having gone hypo during the night and I have no wish to do this again.

My worry is that there is very little concern about our ultimate care. With the best will in the world I have found little in the response from diabetic carers that helps me in any way. Since I have found that my only effective way to get my insulin to work is to walk every day immediately after breakfast, sometimes 3 miles sometimes up to 12,

I know that I am unlikely to see any change. I have absolutely no sensations of the extremes of sugar levels from 1.2 - 20 and more. This is probably to be expected after 30 years on human Actrapid. Indeed, when I do get warnings of lows it can be very touch and go to stop myself going into a coma. Add to this the fact I now work for myself and not driving, I could be walking anywhere around the towns locally carrying heavy tools etc.

My doctors will not allow me to have my preferred Porcine Insulin but instead have told me to use shorter needs (no difference), change my sites (no difference), not to pinch up (no difference), leave the needle in after I have injected for some seconds (still no difference) as well as some bizarre advice on changing my lifestyle and going on a one day refresher course! For a short time I used Humalog which I found gave me such graphic nightmares I never slept.

I think there should be a policy change in the NHS that says the cheapest insulin should be tried first, so for anyone who finds bovine or porcine works okay for them, the NHS need not pay the huge increase in costs associated with the analogues and human varieties. The NHS could then use the saved money to give us all sensible priced blood test machines.

By the way, why is it that no one has reverse engineered the test strips and produced them at a tenth of the current exorbitant price? When I first started testing it was going to be so cheap. Seems now that the device manufacturers see this as a cash cow the NHS and the rest of us have to suffer.

Dave Tutt

Animal insulin not available in my country

Dear Jenny,

Having read John Bruton's letter in your January 2011 Newsletter (Back to my old self), I know exactly what he is talking about.

Having been treated with animal insulins from 1950, I was the epitome of good health and control. I lived out in the bush, many miles away from civilisation for ten years performing bush surveys and walking many miles through the bush every day, sure I had problems, however they were very few and far between.

I have run riot on almost all the new insulins released from the 1980s - the human insulins then the analogue insulins in 1990s. "You know these are new insulins and are so very efficient and good for diabetic control....."

Since then my mental health - memory, cognisance, short temper, total lack of energy, tiredness, lack of motivation and general mental ambience has deteriorated alarmingly. I feel like a total moron unable to socialise, concentrate, focus, read books and unable to carry out a normal conversation.

The doctors of course think that I am deranged and a total fool, when attempting to inform them of my concerns. "It's neurotransmitters you know, especially at your age" (a young 60 years). Unfortunately those who know so much more than those of us with diabetes, refuse to allow the importation of animal derived insulins into our country. I am at a total loss. I would do all in my power to return to using animal insulins and good mental health. Instead of giving up, the obvious recourse is to take up the good fight and kick some butt.

By e-mail
New Zealand

Beef Lente solved my night hypo problems!

Dear Jenny,

As you know, I have serious adverse effects when using synthetic human insulin and I have been using Hypurin Bovine Neutral and Hypurin Bovine Isophane twice daily. Over the last few months I have been having bad night hypos but at last I have sorted out this problem.

I have changed from Hypurin Bovine Isophane to Hypurin Bovine Lente for my long acting insulin and still inject this twice daily with Neutral. The result has been fantastic. Dr. Bernstein suggested that some people create antibodies to the zinc in Isophane so that it does not work and then releases it in one go, hence the comas. I have been free from night hypos and I am waking up with blood glucose levels between 4 and 6 and I am no longer considering an insulin pump!

I imagine that some of your readers might make some use of this information.

Mrs H.S.
Midlands

Has it occurred to anyone?

Dear Jenny,

I read with interest the newsletter regarding people with Type 2 and their high HbA_{1c}s. Has it occurred to anyone that perhaps limiting their tests strips and no education on carb counting or control might be to blame?

S. A.
By e-mail

Tell us what we can eat!

Dear Jenny,

Having had Type 1 diabetes for 52 years, I have been interrogated about what I eat and advised what to do and what not to do. I often feel preached at about my weight but I have now started to wonder if sometimes some of them should take a look in the mirror and practice what they preach!

Secondly, I would like to ask why it is that they are all so negative and tell us what we should not eat but very rarely do they give us good alternatives that we can eat. The effect of constantly being told what

NOT to eat can be very demoralising and depressing for many of us which only makes living with diabetes worse than it already is.

Thanks for a great magazine.

R.L.
Suffolk

- Light therapy which involves sitting for 30 to 60 minutes about a metre away from a bright light source has been shown to reduce depressive symptoms. It can take several weeks before benefits are seen but if there is no response after 6 weeks, you should seek further advice.
- Your doctor may advise antidepressants if there is a lack of response to light therapy.

We are now coming to the longer days but if you suffer from SAD you can make plans for future winter seasons to try to reduce symptoms.

The Importance Of Light

All too often we take daylight or sunlight for granted but it has some important effects for many of us.

It's been a long winter – SAD

Seasonal affective disorder, [SAD] is a mood disorder with depressive episodes that occurs with seasonal light variation. It is thought to be under-diagnosed but affects about 7% of the UK population. It affects women more than men and often first occurs in people in their thirties. SAD is caused by lower levels of exposure to light during the short days of the winter months with January and February being the worst months. It often begins in September and ends in April – so if you are a sufferer, it should be ending about now!

Severe forms of SAD can be serious, disabling and can affect relationships and quality of life. A less severe form is often described as 'winter blues' and although the symptoms are more mild, it still can be a debilitating condition and this mild form is thought to affect about 17% of the population.

Management of SAD

- Getting a higher exposure to daylight is effective. Work in bright conditions and increase time outside and get plenty of exercise.
- Healthy eating and relaxation techniques may help. Seek the support of friends and family.

Light and Vitamin D levels

A report in the Daily Mail [Jan31st, 2011] suggests that the experts' advice to use high factor sun protection lotion and avoid exposure to sun between 10.00am and 2.00pm to avoid skin cancer is wrong. The Mail looked at five volunteers who had their Vitamin D levels measured and found that the results were 'shocking'. Well, yes there has been a turnaround in the advice but we must not forget that the article only quoted 5 people.

Facts: Cancer Research UK has changed their message this year but they still advise caution. "Never be red at the end of the day" is their message but they add that 10 to 15 minutes of midday sun exposure without wearing suntan lotion is actually beneficial.

The advice from Professor Mike Kelly, director of the centre for public health excellence at NICE has stated: "There is nothing wrong with short periods of exposure to sunshine, and it may in fact be beneficial. But prolonged exposure and sunburn can have dangerous consequences – a third of all cancers are from skin cancer."

Reason for the change: there has been a resurgence of Vitamin D deficiency resulting in the childhood bone disease, rickets, where the bones are soft. Vitamin D is essential for the absorption of calcium and maintaining strong bones and teeth and is also important for the functioning of the immune system. Research suggests that 1 in 1000 children have rickets with up to 70% of those under 16 being deficient in Vitamin D. Rickets was common a century or longer ago when

diets were poor and many cities were covered in smog the limited the exposure to sunlight but it largely disappeared in the 1940s.

Experts also warn that a lifetime of covering up from the sun also means that adults are at risk as Vitamin D deficiency in adults has also been linked to cardiovascular disease and several cancers as well as bone softening. It has also been suggested that low levels of Vitamin D can be a risk for the development of Type 2 diabetes. However, a recent study suggests that Vitamin D deficiency does not put older women at a greater risk of Type 2 diabetes. [Diabetes Care, Feb 2011]. Having said this, it was an observational study which means that the study doesn't disprove a role for vitamin D in diabetes risk, randomised controlled trials are needed to do this.

Why we need sunlight: although Vitamin D can be obtained from eating oily fish, eggs and liver, about 80% of Vitamin D the body needs is obtained by a chemical process that happens when sunlight is absorbed by the skin.

If you already have Vitamin D deficiency: the amount of sunlight needed to put this right would be harmful and put you at risk of sun-related skin damage. The best way to put the levels right again is with prescription-only supplements and with the correct dose, levels should be corrected in about 3 months, although any symptoms may happen within a month.

Insulin for Life

You may or may not be aware that IDDT acts as the UK arm of an organisation called Insulin for Life. On behalf of the Insulin for Life campaign, IDDT collects unwanted, unopened and in-date insulin and other diabetes supplies and distributes them to clinics in developing countries, where children die for lack of affordable insulin. In developing countries the cost of insulin for one person can be as much as 50% of a family's income, meaning that poor families find it extremely difficult to commit this amount of their income to the treatment of just one child.

In 2010 IDDT collected and distributed over 9000 pens, cartridges and vials of insulin to those who so desperately need them. All this unwanted insulin came to a total value of over £60,000. This is a cost paid for by the NHS as this would have gone to waste were it not for the Insulin for Life campaign and the kind actions of those who make the effort to send us their unwanted insulin and diabetes supplies.

For more information about how we help developing countries visit http://www.iddtinternational.org/?page_id=1747 or contact IDDT, Tel 01604 622837 or e-mail martin@iddtinternational.org

The sad thing is, this is only the tip of the iceberg, there is far more insulin simply being thrown away that could be used to help save lives.

There are three ways in which YOU can help.

- Perhaps you have recently changed your insulin or equipment and now have supplies that you no longer need – then send them direct to us, IDDT, PO Box 294, Northampton NN1 4XS. We will ensure that they are sent to those that need them.
- Ask for one of our “Look in Your Fridge” posters to give to your doctor and/or nurse and ask them to send us any unwanted insulin that they have.
- Consider sponsoring one of the many children whose diabetes is cared for by the Dream Trust in India. It costs as little as £2 a month to sponsor a child. For more information on the Dream Trust visit www.dreamtrust.org or contact IDDT for more information.

Old Chestnuts Worth Remembering!

Testing

Hopefully most people who self-monitor their blood glucose will have been warned about washing your hands to ensure your finger tips are free from sugary, sticky things before testing so that you don't

get falsely high readings. After treating a hypo it is easy for whatever was eaten or drunk to remain on the fingers and the next test actually measure this as well as the blood sugar!

New research on non-diabetic people examined whether hand contamination with fruit can cause false readings. [Diabetes Care, Jan 2011] Blood samples were taken and tested after peeling oranges, grapes or kiwi fruit without the hands being washed or rubbed with an alcohol swab and compared to those who did clean their hands.

People who washed their hands in water after peeling fruit had similar blood glucose levels to control subjects who didn't peel fruit. However, glucose levels were significantly higher after peeling fruit followed by no washing, even when the fingers were cleaned with an alcohol swab before testing.

Messages from the study

- Always wash your hands in soap and water and dry them before testing.
- If it is not always possible to wash your hands, then it is acceptable to wipe away the first drop of blood and test a second drop, rather than not test.
- Firmly squeezing the finger to obtain blood can affect the results and should be avoided.

And of course, if you have meter test results that seem to disagree with how you are feeling, then repeat the test.

Reassurance about animal insulin

Several people have contacted IDDT as a result of reading a letter in Diabetes UK's magazine, Balance [Issue 1, 2011] which referred to the 'potential termination of animal insulin.' It would have been helpful if Balance had included an editor's note to reassure people that Wockhardt UK is continuing to produce both pork and beef insulin in the UK and that the company has stated that there no plans to discontinue doing so.

Last year IDDT also received reassurances from the National Director for Diabetes that there are no plans to discontinue animal insulin.

Useful Bits And Pieces

Have you received an opened pack of insulin and re-labelled?

Have you received your insulin from the pharmacy and it has been labelled in a foreign language and opened with a notification inside saying 'CARTON HAS BEEN OPENED'? Understandably this can cause concern and fears that the insulin may have been tampered with but it is parallel distribution of medicines where medicines are licensed through the EU Centralised Authorisation procedure and allowed to be distributed to other member states.

Any company who does this has to register with the European Medicines Agency [EMA] which checks the licences are in place and that the correct translations for the label and product information are in place in the language of the member state to which it is being sent. The carton has been opened to add this information.

The EMA also check for products such as insulin, that the correct temperatures have been maintained while the insulin was being distributed. If you are unhappy about receiving insulin that has been distributed this way, you are entitled to ask your pharmacy for insulin that has been produced specifically for the UK market.

Difficulty seeing the numbers on your mobile phone?

The RNIB supply mobile phones that make this easier but some of them do tend to be expensive. If you wish to contact the RNIB, their Helpline number is 0303 123 9999. However, if you want a small but simple phone with big comfortable keys and large digits with an SOS button on the back, it is worth looking into Aspect Two. The price we recently had quoted was £29.99 for further information ring 0844 863 0064 or go online to www.aspect-two.com

Difficulty exercising? A tip from one of our members

One of our members with Type 2 diabetes aged 73 has to use a wheelchair. He knows that exercise is important for his diabetes and general health but this is difficult when he is wheelchair bound. So he has chosen not to have an automated wheelchair but a manual one – an NHS one with tyres that don't puncture and weighing 63pounds. This is how he gets his exercise – well done John – perhaps others have not thought about this!

Being Underweight

The emphasis these days always seem to be on being overweight but some people are actually underweight, particularly after an illness or being in hospital. The most common classification for being underweight is to calculate your Body Mass Index [BMI] which measures your weight in relation to your height. There are often BMI charts around at your doctor's surgery or pharmacy or if you have internet access just google BMI calculator and there are plenty of sites that calculate it for you automatically.

The World Health Organisation definitions relating to BMI are as follows:

BMI	Meaning
Below 18.5	Underweight
18.5 to 24.9	Health weight
25 and over	Above ideal weight

Ideas for gaining weight but talk to your health professional or dietitian first

- Have small meals more frequently – often easier than three large meals and helps to increase the appetite.

- Use full fat dairy products.
- Serve vegetables with butter or cheese.
- Add cream or milk to mashed potatoes or soups.
- Add unsaturated fats to food eg nuts, seeds, spreads and oils.
- Have nourishing milky drinks or smoothies.

Snippets

Improving the nation's health

The Daily Telegraph has reported that a Cabinet Office study suggests that stairs in public buildings should be adapted to play tunes as people stand on each step so making them fun to climb!

Warm houses may increase obesity and Type 2 diabetes

Research has shown that the increased use of central heating and air conditioning over the last decades could be contributing to the increase in obesity and Type 2 diabetes. It sounds unbelievable but as the temperature inside our houses increases, the energy used for the body to stay warm is reduced – the metabolic rate is slowed. So reducing the temperature in the house makes the body work harder to stay warm which in turn helps to burn fat. Obesity Rev 2011

Diet drinks may not be what we think

Exchanging sugary drinks for diet ones seems a good option for people who want to lose weight to avoid the risks of Type 2 diabetes and heart disease. However, recent research has shown that diet drinks can actually increase these risks. The reason is unknown but one suggestion is that the artificial sweetener in diet drinks leave us craving for more sugar and high calorie foods. An alternative suggestion if you like fizzy drinks is adding lemon or lime juice to sparkling water.

Hangover cure

Not that we are recommending anyone to drink so that they have a

hangover but recent research suggests that the best way to cure a hangover is to drink coffee and take aspirin because they block the action of acetate which causes headaches associated with alcohol. But remember alcohol lowers blood sugars for up to 24 hours afterwards.

Herbal Medicines

A safety concern of herbal medicine use is the risk of interactions with prescription drugs which can lead to toxicity or loss of efficacy of the prescription medicines. The UK regulatory body, the MHRA, has launched a scheme for the registration of herbal medicines which requires them to be produced under assurances of safety, quality and information for the patient. Companies selling existing herbal medicines that are unlicensed have until April 30th 2011 to register them with the MHRA.



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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