



Insulin Dependent Diabetes Trust

July 2009 Newsletter



The Number of Diabetes Prescriptions has Risen by 73%

A report from the NHS information centre has shown that the number of prescriptions for diabetes has increased by 73% from 2002 to 2008. This figure includes oral drugs, insulin and blood glucose monitors. Overall the total cost of the drugs rose 93% over the six years, from £76.7 million to £148.2 million.

In 5 years, the increase in Type 2 diabetes from 1.5 million to 2.25 million is bound to be a major factor in these rises. The National Audit Office suggests that 47% of Type 2 diabetes is caused by obesity, and these new figures serve to emphasise the need to really tackle the obesity problem. Perhaps we should ask the question, "does

the government recommendation of high carbohydrate / low fat diet really work?" Surely there is now sufficient evidence from research, to revisit this question? Some of us can remember the introduction of this diet in the 1980s. The intention was to reduce the risk of heart disease by lowering fats in the diet. As fats provide some of the energy we need, the thinking was that carbohydrates would have to be increased to provide the extra energy needed. But we can also recall that the obesity problems started soon after – the timing may be sheer coincidence, but surely it's worth a look?

But obesity is not the only cause of increased costs. People with Type 2 diabetes are now being prescribed tablets to control their blood glucose, to control blood pressure and cholesterol levels to reduce the risk of diabetes complications. In addition, there is a whole range of new drugs, which of course, are significantly more expensive than the older drugs but have yet to be proven to be more effective.

There is a real need to look at the costs of insulin for both Type 1 and Type 2 diabetes. Do we really need pre-loaded disposable insulin pens, when less expensive cartridges can be used with a non-disposable pen? It may seem small fry but small savings per person, mount up in the large numbers of people using insulin. In fact, if half the insulin-using population are using disposable pens and they each have 2 packs of 5 a month, the extra cost is £2.4 million per year!

Another hidden cost is pharmacists' dispensing fee for every item. Most people are issued with 28 day prescriptions, theoretically to stop the wastage of unused medicines. People using insulin don't waste their 'medicine' because they know that insulin is vital to their survival, so why not allow them a 3 month prescription to reduce dispensing fee costs by 66%? [Not to mention, improving the convenience for patients!]

As we know from NICE, from Cochrane Reviews and from IQWiG, the German equivalent to NICE, insulin analogues have yet to be proved beneficial for many people with both Type 1 and Type 2 diabetes. Yet they are widely prescribed despite them being significantly more expensive. A pack of 5 cartridges for long-acting human insulin [Humulin I] or long-acting animal insulin is £15 cheaper than a similar pack of long-acting analogue [Levemir]. The cost saving per person for a year of only 1 pack of cartridges per month would be £180 being prescribed. So if half the insulin users were prescribed human or animal insulins, instead of analogues, this would be £72 million! And this is only for one pack a month!!

No way would IDDT be even suggesting these cost savings if the evidence of benefit for people with requiring insulin was actually there, but it's not and the potential savings are staggering! Why aren't prescribers and PCTs looking at the evidence instead of automatically prescribing the latest, more expensive insulins that have no proven benefits for the majority?

NHS Round-Up

by Martin Hirst

Mice droppings!

In March, Michael Fabricant, Conservative MP for Lichfield, told the House of Commons that a large hospital in the West Midlands had "mice droppings" in an operating theatre and that he had been shown photos of "blood smeared in wards" by two hospital workers. He said that he could not name the hospital in order to protect the jobs of the two workers involved, one of whom is a consultant surgeon. Health Secretary, Alan Johnson said he was investigating the claims.

Three questions clearly arise from this. Firstly, how can such appalling standards of hygiene and cleanliness exist in a hospital when the NHS has spent so much time and money promoting the importance of infection control? Secondly, what sort of ethos exists within the NHS, when clinicians whose primary role is the safety of their patients, are afraid to blow the whistle on such poor standards, for fear of losing their jobs? Thirdly, if NHS staff are afraid to whistle blow, then how can we be assured that these standards of hygiene do not exist in other hospitals?

More people say that hospital wards and bathrooms are cleaner
A new survey by the Care Quality Commission [CQC] shows that in 2008 significantly more patients have rated hospital wards and bathrooms as 'very clean'. It also showed that doctors and nurses have been seen washing their hands between patients. However, the survey highlighted that the NHS must do more to improve the quality of hospital food and that patients should be sent copies of letters between hospitals and GPs. It also showed that performance remained 'weak' in key areas such as discontinuation of mixed-sex accommodation and help with eating. Patient involvement in decisions about care was also lacking.

NHS workers "feel overstretched"

In a possibly related vein, the worrying results of a Healthcare Commission poll of NHS staff were published recently. It showed that

nearly half of NHS staff feel so overstretched they fear they cannot do their jobs properly. A third said they did not feel valued and a quarter had experienced work-related stress. Nearly half said that they did not feel there were enough people to do the job. The poll is carried out every year and covers the full range of NHS staff from doctors and nurses to support staff. The findings are worrying in the light of the fact that inadequate staffing levels were the main reason highlighted in the report on Stafford Hospital's emergency care, where death rates were significantly above average.

Equally worrying is the fact that the survey has been published at a time when NHS staffing levels have hit an all time high, having risen by 25% in the last decade. Although the survey reveals that there has been a slight improvement since last year, the report also says that more work is needed. It probably comes as no surprise to find that the rise in the number of managers is outstripping that of many clinical staff. It seems that there should be a re-focusing of priorities – less on bureaucracy and more on improving standards of clinical care.

Budget cuts

In the April Budget the Chancellor of the Exchequer announced the Dept of Health's revenue budget adjustments from £104.6bn to £102.3bn but spending will be cut by 18% in the current review period 2007/8 to 2010/11. According Health Secretary, Alan Johnson:

"As well as providing health care and support to those that need it at this crucial time, the NHS is also well placed to help the country through the economic downturn as a major contributor to the overall economy and the country's largest employer."

NHS Constitution

There has been a blow to the impact the NHS constitution may have on health services. A proposed amendment to give the constitution legal standing has been defeated in the House of Lords by a majority of just four. The amendment would have allowed the health secretary to make regulations in relation to the constitution, thus making its principles enforceable in law.

Money to encourage new ideas for the NHS

A £220 million fund will be made available to encourage innovation within the NHS. England's 10 Strategic Health Authorities will each receive £2 million this year, and £5 million in each of the following four years to support frontline NHS staff in developing innovative ideas. The cash will be invested directly into a combination of projects on the ground and at regional level. It aims to speed up the time it takes for new solutions to reach patients and is intended to increase the quality of the care they receive.

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Europe Is Looking At Driving Regulations

A parliamentary question in March 2009 asked if the Secretary of State for Transport will bring forward proposals to provide that people with insulin-treated diabetes may drive heavy goods vehicles following the approval of a medical practitioner. The following answer was given:

"Drivers with diabetes treated by insulin, who have good diabetic control and who have no significant diabetic complications may apply for consideration of a category C1 licence (goods vehicles between 3.5 and 7.5 tonnes). Applications must also be supported by a report from a medical practitioner specialising in the management of diabetes. An amendment to the minimum health standard set out in the second European Commission directive is also currently progressing through the EC legislative process. The UK will then review its current medical standards and, in consultation with the expert members of the Secretary of State for Transport's honorary medical advisory panel on driving and diabetes, consider the implications of diabetes for driving and whether there should be a relaxation of the current standards. Legislation may then be amended to accommodate any changes."

As readers may know, the UK regulations for people with diabetes driving are tougher than in many other countries, so I don't think that we should hold our breath that they will be relaxed. Even if the EC

Directive relaxes the regulations, it does not automatically mean that the UK will follow suit.

Research News

Botox injections may ease the pain of neuropathy

One of the common complications of diabetes is neuropathy [nerve damage], particularly affecting the feet and it can be extremely painful. Treatment is difficult and what works for one person does not necessarily work for another. Doctors in Taiwan have shown that injecting Botox under the skin on the top of the foot can substantially reduce the pain. A local anaesthetic gel was applied and then the injections into the skin were given at 12 sites on top of the foot. Not only did the Botox significantly reduce pain within 12 weeks but patients reported sleeping much better after the treatment. Don't go trying it yet, as this is still in the experimental stage. We also have to know whether this is a one time treatment that will only last for 6 months, like cosmetic Botox injections and if so, will further Botox injections continue to be effective. [Neurology, May 2009]

Yet more on Avandia and Actos!

Avandia, already hit by safety concerns, and Actos both of which belong to the family of drugs known as glitazones have been shown to have a modest risk of increasing the risk of developing maculaoedema. This is where fluid accumulates in the area of the retina responsible for central vision. People taking glitazones were 160% more likely to develop maculaoedema. This is not the first study to suggest a link but it is the largest and involved 143,000 patients from 2002 to 2006.

The researchers recommend that ophthalmologists treating patients with diabetes-related macular oedema 'should consider the role of glitazone class of drugs'. [American Journal of Ophthalmology, April 2009]

Stem cell trial – no need for insulin injections

A small experimental trial of stem cell transplantation in people with Type 1 diabetes has freed a number of people from needing insulin. A small number of people were given stem cells made from their own bone marrow and they regained their ability to produce insulin. One person did not use insulin for 4 years, four people remained insulin-free for 3 years and three patients for 2 years, and four patients did not use insulin for more than a year after transplantation of the stem cells. C-peptide levels were measured to find out if the change in insulin production lasted over time. C-peptides are a marker that show how well the body is producing insulin. The researchers found levels increased up to 24 months after transplantation and were maintained until at least 36 months. Even in the group that had to restart insulin injections, C-peptide levels increased significantly and this lasted for 2 years.

In hoping for a cure, we must keep this study in perspective. It was experimental, carried out in only a small number of people, possible side effects are unknown and it may only work within 3 months of diagnosis, before the immune system has destroyed all the body's own insulin-producing cells – so further research is necessary.

Antibiotic use and childhood Type 1 diabetes

It has been thought for many years that there may be a connection between the use of antibiotics in early childhood and the development of Type 1 diabetes. A nationwide study was carried out in all children born between 1995 and 2003 in Denmark to compare the rates of Type 1 diabetes and antibiotic use. [American Journal of Epidemiology, on-line 24.3.09] Antibiotic use was classified according to class, number of uses and the age of the child when used. The results showed:

- The use of antibiotics was not associated with the risk of developing Type 1 diabetes, nor was there any association with any specific class of antibiotics.
- No specific age of use of antibiotics and no specific age of onset were associated with the risk of developing Type 1 diabetes.

So the researchers concluded that there is no link between the development of Type 1 diabetes and the use of antibiotics in Danish children – perhaps this is one theory that we can put to bed.

Causes of declining glycaemic control in adolescents

Blood glucose control in adolescents with Type 1 diabetes is known to be difficult especially in early to middle adolescence. Researchers carried out a study annually over 4 years which involved interviewing 70 girls and 62 boys with Type 1 diabetes [average age 12 years] to try to find the reasons for the changes in control as measured by the HbA1cs in the medical records. [Journal of Pediatric Psychology, 2009 34 (3): 254- 270] They found that:

- Glycaemic control got worse with age.
- Self-care [managing their diabetes control] got worse with increasing age and was linked to poorer control.
- Eating disturbances, depression and peer relations were also linked to poorer control.
- Good family relationships and parental support were related to better control in girls.

The researchers recommend that ‘future research should examine the mechanisms by which these relationships emerge’. For parents of children that have grown up with Type 1 diabetes through adolescence, these results are fairly unsurprising. Perhaps what is surprising is that so little seems to have been done over the years despite reports of the need for psychological help particularly for this age group. It also raises other questions about the clinical aspect of managing Type 1 diabetes in adolescents. If many of the causes of ‘poor’ control are psychological, does increasing the pressure to inject, test and control carbohydrates just make matters worse, not better? Another unanswered question...

Insulin link to Alzheimer’s disease

Previous studies into the relationship between insulin and brain function have shown that insulin is active in the brain and a recent study has looked at the effect of insulin on proteins, called ADDLs.

These proteins build up in the brains of people with Alzheimer’s.

The researchers took neurons from a part of the brain mainly concerned with memory and treated them with insulin and rosiglitazone [Avandia]. After doing this, they found that the cells were significantly less susceptible to damage when exposed to ADDLs. This suggests that insulin had a blocking effect on the ADDLs. There is scope here for investigations into new treatments for Alzheimer’s and links with diabetes.

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Retinopathy & Screening

Retinopathy is one one of the complications of diabetes which affects the eye and is still the leading cause of blindness in people of working age. The hard facts are that 50% of people with Type 1 diabetes and 30% of those with Type 2 diabetes will develop some form of retinopathy in their lifetime and need treatment to reduce the risk of vision loss. Pregnant women, children and adolescents are particularly vulnerable to retinopathy. It can also be caused by sudden and sharp tightening of blood sugars with insulin at diagnosis.

Good control of blood glucose and blood pressure greatly reduces the risk of retinopathy developing. Early detection of any changes in the retina and early laser treatment helps to stop the progression of retinopathy and helps to maintain sight. This is the reason that regular eye screening is so important for people with diabetes.

What is the retina?

It is the light sensitive layer that lines the interior of the eye and is made up of light sensitive cells called rods and cones. The rods are for seeing in dim light and the cones are for bright light. The cones are essential for seeing sharp images and for distinguishing colours. The macula is a spot on the retina that has the greatest concentration of cones and so it responsible for greatest acuity of vision such as

reading. The retina works in much the same way as a camera,

What is diabetic retinopathy?

Retinopathy is usually classified according to its severity and there are two classifications.

Background retinopathy – this is the first stage and is rare in people who have had diabetes less than 8 to 10 years. At this stage vision is normal and sight is not threatened. If there are changes to the retina such as small haemorrhages, fatty deposits [exudates] or abnormal blood vessels then this is a sign that retinopathy is worsening and your doctor should arrange more frequent follow ups.

Proliferative retinopathy – this is where the tiny blood vessels [capillaries] that supply the blood and nutrients to the retina become blocked. The retina becomes starved of nutrients and this causes new blood vessels to grow either in front of the retina on to the back of the vitreous [the jelly-like substance on the centre of the eye] or occasionally on the iris [the coloured part of the eye]. These new vessels are fragile and may bleed into the vitreous which can then affect sight and may cause floaters, dots of lines. If this is severe, then it may cause cloudy vision or loss of vision. However, this process can continue for years without causing visual symptoms or visual impairment which is why regular screening to detect any changes is so important.

Prevention and treatment of retinopathy

There is a difference between the prevention of retinopathy and the prevention of sight loss once retinopathy has developed. The best way to try to prevent it developing is tight control of blood glucose levels [as near normal HbA1cs as possible] and good control of blood pressure [lower than 130/80mm Hg] although these targets are not always achievable in everyone. Various drug treatments to prevent or stop the progression of retinopathy are being looked into but so far clinical trials have given disappointing results.

The purpose of retinopathy treatment is to prevent or reduce vision

loss once retinopathy has developed. Laser treatment is used for this purpose to seal the leaky blood vessels and reduce the risk of further retinopathy. After laser treatment, retinopathy can remain stable for many years, although this is not always the case. However, where laser treatment has been used it does damage that area of the retina and this can cause some visual field loss. Visual field tests are carried out to check the degree of loss and this is the reason the DVLA ask for visual field tests to be carried out in people who have had laser treatment.

Screening for retinopathy

The best way to try to stop the progression of retinopathy is early laser treatment and this is why screening everyone with diabetes once a year is so important. In 2003, the Government set national targets for eye screening of everyone with diabetes – 80% of people were supposed to be screened by 2007 and everyone with diabetes was supposed to be screened by 2008. The latest Department of Health figures show that around 700,000 people with diabetes in England are still not being screened.

- 28% of people aged 12 and over did not receive digital retinal screening between October 2007 and September 2008.
- 13 of the total of 152 Primary Care Trusts [PCTs] failed to screen half of their diabetic population.
- Almost 66% of PCTs are failing to meet the Government's 2003 target of screening 80% of the diabetic population by December 2007.

Clearly some areas are doing well while others need considerable improvement.

Here's an example of screening working

One of our members, David Mottershead who is part of the local Diabetes UK group, was invited to join the working group to establish the retinopathy screening scheme in his area. He has been involved in progressing the work and in April 2008 saw the scheme launched. David says:

"The screening service has progressed well and by October 2008 90% of people known to have diabetes had been invited to attend for their annual screening. A significant number have not attended. Patients who miss their appointments are sent two follow up letters and if they still do not attend, a letter is sent to the GP to advise him/her. By the end of March 2009, all patients registered will have been invited and will subsequently receive an annual recall."

Patient choice – David says that there have been some issues regarding patient choice of optometrist. Apparently all practices were invited to join the screening programme but not all wanted to do so. There are national standards to be an accredited screener which involve attending an approved course within 2 years of gaining a City and Guilds Certificate in Retinopathy Screening and agreeing to undertake to carry out 500 screenings per year. Optometrists not formally accredited can undertake screening but this is not recognised as being to the national standards.

Non-attenders – David is rightly concerned about the people who do not attend for screening. He says: *"As someone with significant damage to my eyes, I strongly recommend everyone to attend. Before you become aware of a problem yourself, progressive damage may well be occurring, damage that could at least be controlled or minimised with early treatment. This is particularly important if you are a driver where other people's lives are also at stake."*

David's message is one that IDDT wholeheartedly supports:

"Don't throw your vision away by not under taking a simple screening." We have another message too: If you have diabetes and have not been called for a retinopathy screening, request a screening and insist that you have your eyes properly checked.

Experience of Continuous Blood Glucose Meters

The short piece in the April newsletter about continuous blood glucose monitoring stated that '*.you can't go swimming or have a bath while wearing*' a sensor. A Mum wrote in to say that her son has used sensors continuously since May 2006 and he keeps the sensor on for swimming, showering and bathing and that it is absolutely ideal in these situations as his insulin pump can be placed beside the bath or on the side of the swimming pool where it keeps receiving a signal and updating us with the glucose levels. She added, *"This is particularly valuable with swimming because if the downward trend arrows appear we have been able to give some extra carbs to prevent a hypo occurring which is very reassuring indeed. We are thrilled with the results from using the sensors and actually find them to be very accurate once you understand when to calibrate. The timing is crucial but not at all difficult to get right."*

IDDT is delighted to hear that this family gets on so well with continuous glucose monitoring. However, as this is a Newsletter, we have to get the facts straight according to the manufacturers and the approval documents. All the manufacturers say the monitors are waterproof, but some say 'hot water not suggested' and for swimming some say 'up to 3 ft for 30 minutes'. Realistic Expectations and Practical Use of Continuous Glucose Monitoring for the Endocrinologist [Journal of Clinical Endocrinology & Metabolism, online April 21, 2009]. This is a recent review of the studies of continuous glucose monitoring and to quote its conclusion:

'Accuracy of this technology has improved in the short amount of time it has been available. Six-month data suggests patient selection is a key for success. Patients who do not understand or practise the basics of intensive insulin therapy have the greatest challenges. Those who do best watch the receiver frequently, continue with frequent home blood glucose monitoring, use the trending information to make insulin adjustments, and understand the limitations of the technology...'

Like home blood glucose monitoring and insulin pump therapy, this technology by itself is not a panacea for diabetes control. However, it further adds to our ability to improve the lives of people with diabetes. Long-term, the hope is this technology will pave the way for a ‘closed loop’ device.’

Even more recently published research [Diabetes Care, May 8, 2009] looked at adults and children who had well controlled Type 1 diabetes, HbA1cs of less than 7%. After 26 weeks, hypos were less in those using continuous monitoring than the group who were not but the difference was not statistically significant – one or more severe hypos occurring in 10% and 11% of both groups. There was a significant difference in average HbA1cs between the two groups favouring those using continuous monitoring. The researchers concluded that taking into account hypoglycaemia and HbA1cs, “the weight of evidence suggests that continuous monitoring is beneficial in those who have already achieved excellent control”. And a further randomised control trial involving 404 adults taking at least two injections a day also showed that these devices did not result in improved HbA1cs. [Diab Med, May 2009, 26, 540-547]

But looking ahead...

An article published in April 2009 [JAMA 2009;301:1525-7] suggests that in a few years, there could be an artificial pancreas that could transform diabetes care. The important step in developing such a device is to close the loop between the continuous glucose monitor and the insulin pump with a computer that calculates the amount of insulin to be delivered. Pre-clinical testing of such closed loop systems became more rapid last year with the approval of a computer simulation environment. This mimics a human metabolic system and reduces years of animal experiments to minutes in a laboratory. The article goes on to suggest that once there is an artificial pancreas, the nanotechnology of glucose responsive insulin will follow fairly soon.

Late news – the first stage is here, new insulin pump that stops insulin flow to prevent hypos.

Scientists have developed a new insulin pump that automatically stops the flow of insulin if blood glucose levels drop too low. The new device combines an insulin pump with continuous glucose monitoring. It reads the amount of glucose in the blood and the pump is then programmed to deliver the amount of insulin with a threshold below which blood sugars must not fall. If the glucose levels drop below this threshold, then the pump stops delivering insulin for up to 2 hours to prevent hypoglycaemia. This device, the Paradigm Veo made by Medtronic, is going to be available first in the UK and Ireland.

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Useful Sources Of Information

Introducing Glycosmedia

We thought it was about time we told you about Glycosmedia. Glycosmedia produce a regular e-newsletter that we have found of great use over the last few months. The team is dedicated to providing a free, editorially-independent, non-promotional newsletter to a global audience about news and developments in diabetes. Although the site is aimed primarily at health professionals, we are sure that many of you who enjoy reading our newsletter will find that Glycosmedia have much to offer.

The team work very hard to produce a newsletter that is very comprehensive, containing articles on issues such as research, lifestyle and healthcare that will be of interest to all people living with diabetes. You can subscribe free to the newsletter at: www.glycosmedia.com/index.htm

An organisation for pregnant women

Following the supplement with the April Newsletter about the struggles one expectant mum with Type 1 diabetes had to keep her healthy baby with her and not have the baby put in the special care unit, we received information about an organisation called AIMS.

AIMS works towards normal birth, provides independent support and information about maternity choices and provides information about current research on childbirth. If AIMS could be of help to you, their telephone helpline is 00870 765 1543, their website is www.aims.org.uk or you can write to: AIMS, 2 St Ann's Court. Grove Road, Surbiton, Surrey KT6 4BE.

Thinking About Your Thyroid

People with one autoimmune disease, such as Type 1 diabetes, are more susceptible to developing other autoimmune conditions and thyroid disease fits into this category. According to Diabetes Spectrum [15:140-142, 2002] 31.4% of people with Type 1 diabetes have thyroid disease and only 6.8% of people with Type 2 diabetes have it.

About the thyroid gland

The thyroid gland is situated in the lower part of the neck. It is part of the endocrine system and releases the thyroid hormone, thyroxine which controls how quickly the body burns energy. When there is too little thyroid hormone released, energy is burned at a slower rate - this is hypothyroidism or an underactive thyroid and tends to be more common than an overactive thyroid. When too much thyroxine is released, the body burns energy at a faster rate - this is called hyperthyroidism or an over-active thyroid.

Testing for thyroid disease

According to the American Thyroid Association people with diabetes should have their thyroid tested once a year. There are two hormones that should be measured:

1. The thyroid hormone, Thyroxine [T4]
2. The Thyroid Stimulating Hormone [TSH]. This is a hormone, produced by the pituitary gland, which controls thyroid function and is a more sensitive test. A low TSH indicates hyperthyroidism

and a high TSH indicates hypothyroidism.

There is also another test that is recommended and this is a test for Anti Thyroid Peroxidase Antibodies and this shows whether someone has a predisposition to thyroid dysfunction. If this test is positive, then it indicates that the thyroid should be watched more carefully and regular T4 and TSH tests carried out.

Pregnant women should have their thyroid tested because undiagnosed hypothyroidism can cause still birth, premature delivery and high blood pressure at the time of delivery. Tests should also be carried out after pregnancy as this is a common time for thyroid antibodies to damage the thyroid.

Symptoms of hypothyroidism - an under-active thyroid

- Fatigue
- Sluggishness
- Slow pulse
- Low blood pressure
- Depression
- Feeling cold when others don't
- Constipation
- Weight gain unrelated to an increase in appetite

Treatment

An under-active thyroid is treated with tablets of thyroxine to bring up the levels of thyroxine necessary to prevent the symptoms. Until the mid 20th century thyroxine was a natural product taken from the thyroid glands of pigs and this contained all the necessary hormones needed for full replacement therapy. Then the pharmaceutical industry developed a synthetic version but this only contained one hormone, T4.

For a significant minority of people, this synthetic product does not relieve their symptoms because they need the other hormones contained in the natural product. More and more people are changing

to the natural product. UK and European law recognises that the synthetic thyroxine may not be suitable for some patients. Although they are now unlicensed medicines in the UK [not in the US], the MHRA has confirmed that doctors can prescribe them safely and they can be imported.

Just a note: All this sounds just a little familiar to those people who cannot use synthetic insulins and are better suited to natural animal insulins. The similarity is even greater when we remember that unlike synthetic insulins, animal insulins also contain a minute amount of glucagon, the hormone that triggers warnings of hypoglycaemia and the most common adverse effect people have reported with synthetic insulins is loss of hypo warnings!

Symptoms of hyper thyroidism - an over-active thyroid

- Pounding heart
- Quick pulse
- Increased sweating
- Shortness of breath after exercise
- Weight loss despite normal or increased appetite
- Muscle weakness or tremors
- Diarrhoea
- Difficulty concentrating
- Thickening of the skin on the knees, elbows and shins
- Change in menstruation

Hyperthyroidism in particular also tends to give worsening blood sugars and increased insulin requirements.

Treatment

The treatment for an over-active thyroid depends on the condition itself and is more complex but here is a brief outline. Betablockers, often given to treat high blood pressure, may be prescribed to improve some of the symptoms [to improve palpitations, slow down the heart rate and improve tremor] but they do not cure the thyroid over-activity. Antithyroid drugs are effective in reducing the production of the thyroid

hormones and the dosage can be adjusted every 6 to 8 weeks to keep the thyroid hormone levels in the normal range. They are not a cure but provide a reduction in hormone levels. Radioiodine is a radioactive isotope of iodine that is taken up by the thyroid. In most people a small, single dose will gradually destroy the thyroid tissue. In many cases, this can result in an under-active thyroid which then has to be treated with thyroxine tablets.

Thyroiditis

Thyroiditis is inflammation of the thyroid gland. There are several types but the most common is Hashimoto's Thyroiditis [also called autoimmune or chronic lymphocytic thyroiditis]. The thyroid gland is always enlarged, although only one side may be enlarged enough to feel. The cells of the thyroid become inefficient in converting iodine into thyroid hormone and so compensate for this by enlarging. The net result of this is that the thyroid becomes under-active [hypothyroidism] and eventually the TSH levels become higher because the pituitary is trying to make the thyroid produce more thyroxine. This process can take weeks, months or years to develop.

Treatment

Treatment is thyroid hormone replacement [as with an underactive thyroid] to prevent or correct the under-active thyroid. In most cases the thyroid gland will decrease in size with this treatment.

Thyroid dysfunction in children and adolescents with Type 1 diabetes

A study published earlier this year, confirmed that autoimmune thyroiditis and thyroid dysfunction occurred 'frequently' in children and adolescents with Type 1 diabetes. Over 12 years, the researchers investigated 148 children and adolescents with Type 1 diabetes aged between 1 to 21 years.

- 15.5% developed autoimmune thyroiditis and this was significantly higher in girls. There was no difference in growth and metabolic control between those with and without thyroiditis.
- 8.1% developed hypothyroidism and there was no significant

difference between boys and girls but of those with raised thyroid antibodies, boys were more likely to develop an under-active thyroid.

The researchers recommend annual screening for thyroid antibodies in everyone with Type 1 diabetes. If you would like further information about thyroid disease, the following organisations may be useful:
British Thyroid Foundation, www.btf-thyroid.org
Tel 01423 709707
Website only: www.thyroid-disease.org.uk

European Parliament News

Petition 1086/2003: Diabetes patients and their need for animal insulin

Sabine Hancl from Germany put forward a petition to the European Parliament which called for action to be taken to ensure that animal insulin is available throughout Europe. The Commission's answer on February 20, 2009, was that no medicinal product may be placed on the market in a Member State unless a marketing authorisation has been issued by that Member State or by the Commission. Both can issue marketing authorisation for animal insulin, but only if an application is submitted by an applicant [the manufacturer].

In its conclusion, the Commission stated that only two countries, the UK and Switzerland, have marketing authorisation for animal insulins, but Community Pharmaceutical legislation allows Member States to make products available even in the absence of a marketing authorisation on the basis of "compassionate use". Member States may also place the particular product [in this case, animal insulin] on the market for justified public health reasons, when it is authorised by another Member State.

IDDT congratulates Sabine on her persistence with the Petition, which

has made it abundantly clear to people throughout the EU that if they need animal insulin then it can be obtained, even if it is not marketed in their own country.

At IDDT we know that people who need animal insulin do worry about continued availability and they may be reassured by an advert from the manufacturer, Wockhardt UK in the journal, Practical Diabetes International which says:

"Hypurin Insulin – your supply of porcine and bovine insulin remains safe in our hands."

European Directive: Application of Patients' Rights in Cross-Border Healthcare

In April 2009 the European Parliament voted this Directive past the first administration barrier towards becoming law. If or when it eventually becomes law, it will give EU citizens the right to seek medical care within other Member States than their own. Then:

- People with a rare disease will be given special priority.
- People needing medical care outside the hospital setting will not need to get prior authorisation.
- People seeking hospitalisation in another Member State will still need authorisation from their own country for costs to be covered.

We know that people have been going abroad for treatment but this has been based on precedents set by judgements made by the European Court of Justice [ECJ], rather than actual laws.

Important Warnings

After the April Newsletter went to print two alerts were issued by the Medicines and Healthcare products Regulatory Agency (MHRA).

Medical Device Alert - Autopen Classic [MDA/2009/019]

The ALERT warns of a manufacturing failure for the following lots of Owen Mumford Autopen(r) Classic (1 unit 3ml) insulin pens, supplied in the UK since February 2008. Product Code: AN3810

Affected Lots: CJF, DBR, DEX, DMP, DND, BRG and CCW

The lot number is stamped on the white collar on the lower part of the pen body and printed on the device packaging. Affected pens may fail to dispense insulin which could lead to underdosing and hypoglycaemia. Autopen Classic (1 unit 3ml) pens are the only devices affected. Your pharmacy will replace faulty pens.

Counterfeit Novofine(r) insul in pen needles [MHRA 27.03.09]

This ALERT warns that a small number of counterfeit NovoFine(r) needles for use with Novo Nordisk disposable and durable insulin pens are on the UK market. The needles are not made by Novo Nordisk and do not meet quality standards.

How to recognise the counterfeit needles:

- They are sized Fine 31g x 6mm and have the batch number 08J02S, expiry 08/2013.
- They lack a line underneath the CE number on each box containing a hundred individual needles.
- They have a transparent glue on the top where the cannula is glued to the hub of the needle (the glue on a Novo Nordisk NovoFine(r) needle is white/yellow)
- Needles may not fit well on the device and this may cause leakage of insulin.

If in doubt as to whether a product is counterfeit, contact your pharmacy or Novo Nordisk UK Customer Complaints on 0845 6005055.

Taking a look at HbA1cs

What is HbA1c?

Glucose is carried around the body in the blood to provide the source of energy we need for all activities. The glucose binds or sticks to a certain part of the haemoglobin in the red blood cells forming HbA1c. So the higher the glucose in the blood, the higher is the HbA1c. The glucose sticks to the haemoglobin for the lifespan of the red blood cells which is about 2 months. Therefore measuring the HbA1c gives a good idea of what the blood glucose levels have been over the last 6 to 8 weeks and is a percentage of the total haemoglobin.

From a patient's perspective the drawback to the HbA1c result is that it measures high blood sugars but does not reflect how many hypos there may have been. So your diabetes team may well congratulate you on having 'good control' because your HbA1c result is either normal or low, when in actual fact you could have been having lots of hypos - which is NOT good control!

The purpose of measuring the HbA1c

Two major studies, one for Type 1 diabetes [DCCT] and one for Type 2 diabetes [UKPDS] both showed that the risk of diabetic complications increased as HbA1cs increased. So the HbA1c is a measure of the risk of complications.

Changes in the reporting of HbA1c

Average blood glucose results - the UK's not going to use them

In IDDT's January 2008 Newsletter we informed you that it was likely that HbA1c results would be reported in new average glucose units [eAG]. This was following an international study comparing HbA1cs measurements in 700 volunteers of various ethnicities with Type 1 and Type 2 diabetes and HbA1cs in people without diabetes over a 4 month period. The researchers found a way of interpreting HbA1c results as an average blood glucose level [eAG]. The stated purpose was that we, as patients, would not be confused by the two different units of measurements - one for HbA1cs and one for finger-prick

blood glucose tests. The intention was that the eAG would be used as the standard measurement across the world. The US is on course to include estimated average glucose into the HbA1c reporting but some other countries, including the UK, have decided against doing this. So please ignore the article in the January 2008 Newsletter – average glucose levels are not going to be used in the UK!

New HbA1c units

For reasons we don't profess to understand, UK minds have changed and there is no longer mention of patient confusion. Instead, we are now going to have a totally different unit of measurements for the HbA1c, which will still not be the same as the unit for finger-prick tests.

The HbA1c will be reported in units of 'mmols per mol' or 'mmols/mol' and not as a percentage figure. If this new measurement looks familiar, it is because our home blood glucose test results are measured in 'mmols/L' [mmols per litre] which is NOT the same. This measurement is going to be international so that all laboratories will be using the same measurements.

The relationship between the old HbA1c and the new measurements will be:

Old HbA1c [%]	New HbA1c [mmol/mol]
6.0	42
6.5	48
7.0	53
7.5	59
8.0	64
9.0	75

- So if you are aiming for HbA1c targets of 6.5% and 7.5%, the new units will be 48mmol/mol and 59mmol/mol.
- Normal blood glucose [in someone without diabetes] is 4 – 6% but in the new units it will be 20 – 42mmol/mol.

When will the new units come into force?

From June 1st 2009 HbA1c results in the UK will be given in both percentage and mmol/mol to give everyone time to get used to the new units. From April 1st 2011, the results will be reported only in the new units, mmol/mol. Hopefully health professionals will discuss the new units with you over the next two years and IDDT will regularly remind you of the changes through the Newsletters and the website.

While talking about HbA1cs - let's take a look at targets

Diabetes UK has recently issued updated general targets for HbA1cs to below 6.5% [Diabetes Update, Fact sheet, Spring 2009]. Where someone is at risk of severe hypoglycaemia, then an HbA1c target of 7.5% is set. They go on to add that these targets are a guide in line with the recommendations of NICE [National Institute for Health and Clinical Excellence].

The target HbA1cs for other countries are as follows:

- American Diabetes Association - less than 7%
- Diabetes Australia and Diabetes New Zealand - equal to or less than 7%

It always seems odd that research to provide the evidence for recommendations is global, yet different countries have different recommendations. Why are the targets for the UK lower than other countries? We have no answers to these questions, but it leaves us wondering who is right?

To achieve these lower target HbA1cs, Diabetes UK has revised the recommended targets for home blood glucose monitoring to be the following:

- Children with Type 1 diabetes should aim for 4-8mmol/l before meals and less than 10mmol/l two hours after a meal.
- Adults with Type 1 diabetes should aim for 4-8mmol/l before meals and less than 9mmol/l two hours after a meal.
- Adults with Type 2 diabetes should aim for 4-7mmol/l before meals

and less than 8.5mmol/l two hours after a meal.

The previous targets were 4-6mmol/l before meals and no more than 10mmol/l two hours after a meal.

Are the HbA1c targets achievable?

There is no doubt that the emphasis has to be on avoidance of long-term complications but research is constantly showing that a high proportion of people are not achieving the existing targets, so why are they being lowered even further? Will even more people fail to achieve them?

It is well known that hypos and fear of hypos are one of the reasons people do not achieve targets – they run their blood sugars higher to avoid hypos. Last year Diabetes UK issued a press release to say that £15 million a year is being spent on A&E admissions of people with diabetes mainly because of hypoglycaemia. In addition, anecdotal evidence from paramedics suggests that they are being called out to more people in hypos. Could this be because people are aiming for low targets and therefore having more and/or more severe hypos?

Targets – one size doesn't fit all!

As we know, when blood glucose levels drop [hypoglycaemia] the hormone glucagon is released to try to raise blood glucose levels back to normal. The glucagon response is blunted or even absent in many people with Type 1 diabetes and research has shown that this is related to the length of time people have had diabetes. [West J Med. 1984 October; 141(4): 467-471]

The research showed that in people who had Type 1 diabetes for 10 years or less, the glucagon response was lower than in people without diabetes but it was still significantly higher than people who had diabetes for more than 10 years. The researchers concluded that in diabetes with a duration of more than 10 years not only were glucagon responses to hypoglycaemia severely impaired but the abrupt restoration of blood glucose levels was also impaired. They recommended that these findings should be taken into account when

establishing targets and regimes for tight control. In other words, 'one size does not fit all' when it comes to setting targets – individual circumstances should dictate the targets, for instance, duration of diabetes or whether people live alone.

Note from IDDT: not achieving targets can make us feel inadequate and depressed but it is worth remembering that we haven't been given the right tools.

- Injected insulins don't work like the body's natural production of insulin. The potency of insulin only has to be accurate to within 10% plus or minus of 100% potency.
- Industry accuracy standards for blood glucose meters are generally plus or minus 15% to 20% of the actual blood glucose level for each test. So a blood glucose meter reading of 10mmol/l could mean it is actually 12mmol/l or 8mmol/l, or a meter reading of 5mmol/l could actually be 6mmol/l or 4mmol/l [very close to being hypo].

With all these variables, it is hardly surprising that sometimes we get test results that don't seem to make sense and that achieving targets is difficult.

Then there are GP targets

There was a short article in the January 2009 Newsletter describing government targets and the quality and outcomes framework [QOF] where GPs have to achieve targets to receive financial rewards. These targets were HbA1cs of 7.5% and 10% or less but these have been replaced with 3 new HbA1c targets - below 7%, 8% or 9%. GPs will no longer receive QOF points towards their payments for any patient whose HbA1c is between 9 and 10%.

GP views - tougher HbA1c targets will neglect some patients with diabetes

Experts have varying views about these tougher targets with some saying that GPs will concentrate their efforts in the wrong place - on people with lower HbA1cs to bring them down to achieve their

QOF targets and neglect the patients most at high risk - those with high HbA1cs.

At the NHS Alliance Conference in May 2009, Dr David Jenner said that the new QOF targets are posing a threat to patients. The latest QOF reduces the lowest HbA1c target for Type 2 diabetes from 7.5% to 7.0% with 50% of people with Type 2 diabetes having to achieve 7%. More medications and/or insulin may well be given to achieve this, which Dr Jenner says can lead to hidden hypoglycaemia and in frail elderly people, to falls as well as heart risks associated with aggressive treatment.

NOTE: The new QOF targets are not in line with the NICE Guidance for Type 2 diabetes which says that the aim is for HbA1cs to be 6.5% with metformin and sulphonylureas and insulin or other drugs should only be added if the HbA1c is over 7.5%. So even the messages to our doctors are confused!

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Revisiting Blood Glucose Self-Monitoring In People With Type 2 Diabetes

There has been much debate about the value of home blood glucose monitoring in people with Type 2 diabetes who are not using insulin but are on diet and tablets, or diet alone. IDDT has always maintained that this should be dictated by individual choice and not by a blanket policy that all people with Type 2 should not be allowed test strips. Equally, we believe that people with Type 1 diabetes should not be refused the number of test strips they require. We are all different!

Some people with Type 2 diabetes on diet only test regularly because this not only tells them the effect different foods have on their blood sugars but also means that they can take some action. If sugars are high they can go for a long walk, dig the garden or reduce the amount

of carbohydrate they eat at the next meal. If people are taking tablets that can cause hypos [low blood sugars], then testing may well give them greater peace of mind. If people have never been taught what action to take as a result of testing, we can see that testing may well be an unnecessary expense and worry to the patient.

Use this information!

If you are having a problem obtaining test strips, a recently published Health Technology Assessment [Health Technol Assess 2009;13(15): 1-72] provides some useful and quotable information that may help you to obtain the strips you need. While the study concludes that there is no convincing evidence to support the routine use of self monitoring by non-insulin treated people with Type 2 diabetes, importantly, it also says:

- Our in-depth interviews suggest that some individuals may benefit from self-monitoring of blood glucose levels. However, with our present knowledge, we cannot clearly identify these patients, and clinical judgement is required to make this assessment in discussion with patients.
- Our trial cannot exclude the possibility that self monitoring may be helpful in non-insulin-treated type 2 diabetes patients with symptoms of hypoglycaemia; in those motivated to make alterations to behaviour that lead to consistent changes in blood glucose; and where there is strong patient preference.
- If HbA1c remains above 8%, then self-monitoring may provide motivation for medication adherence and lifestyle measures, as insulin therapy may be required in this group.

These are IDDT's points exactly - it should be down to individual choice and need.

Also use the latest NICE Guidelines for Type 2 diabetes [May 2009]. Further information to use is that provided in the latest NICE guidelines. One of the 'key priorities for implementation' is as follows:

"Offer self-monitoring of plasma glucose to a person newly

diagnosed with Type 2 diabetes only as an integral part of his or her self management education. Discuss its purpose and agree how it should be interpreted and acted upon.” If the word ‘only’ is confusing, it is worth noting that the first key priority NICE lists is: “Offer structured education to every person and/or their carer at and around the time of diagnosis”. So everyone with Type 2 diabetes should receive education and therefore, everyone should be offered blood glucose testing.

It is hard to see how anyone with Type 2 diabetes should be refused test strips but if you are, this is the ammunition to use!

Schools Bill to Help Children with Long-Term Conditions

The government has pledged to honour the Schools [Health Support] Bill which will ensure all children with long-term conditions receive the necessary level of support at school. Currently a lack of training and support for school staff means that the needs of children and young people with medical conditions such as Type 1 diabetes are not always met. The Bill aims to ensure:

- Schools are required to produce and implement medical conditions policies.
- School staff to receive appropriate support and training to support children with health conditions.
- NHS organisations, local authorities and primary care trusts help schools to fulfil their responsibilities.
- School inspections also look at how a school supports children with health conditions.
- Every child with a health condition has an individual healthcare plan.

It remains to be seen how this will work out in practice. Presumably in

situations where teachers are not prepared to undertake responsibility for testing and injecting, for which IDDT believes they should not be criticised, then the primary care trust and local authority will have to step in to provide suitably trained staff to do this. IDDT has already received a letter from a parent whose recently diagnosed son is having to stay at home because there is no healthcare plan in place!

Children with diabetes - is Norfolk taking the lead?

There are many issues that face children with diabetes and their parents and many of them are associated with school and understanding the needs. One issue that is causing concern to parents is if their young children are on 3 or 4 injections a day and have to test and inject at lunchtime. Some schools have someone who is prepared to take the responsibility for this but some parents have to go into the schools every lunchtime.

In April, Norfolk Health Overview and Scrutiny Committee, made up of 15 councillors from across the county, set up a working group to look into whether services for children with diabetes are good enough.

They are seeking the views and experiences of children and young people with diabetes in Norfolk and their families and carers especially on the following topics:

- The treatment and support offered at acute hospitals.
- The support offered by schools and the support available in the community.
- The effects of diabetes on family life.
- Improvements that could be made to existing arrangements and services.

Well done Norfolk!

By the way... According to the Royal College of Nursing (RCN), the number of school nurses in England working the equivalent of full-time needs to more than double, from 2,634 (2008 figures) to 6,000. So no wonder there are difficulties with support for children with diabetes and other chronic conditions.

No Proof that Long-Acting Insulin Analogues Outperform Human Insulin in Type 2 Diabetes

In March 2009, Germany's cost-effectiveness watchdog, IQWiG reported that it can find no proof that long-acting insulin analogues, Lantus and Levemir, are better than human insulin in long-term outcomes in people with Type 2 diabetes.

IQWiG mainly looked at long-term outcomes, such as diabetes complications. It examined 18 studies and also asked the manufacturers for additional information. Nine studies compared Lantus [glargine] with NPH insulin eg Insulatard, 6 compared Levemir [detemir] with NPH and 3 compared the analogues with each other.

Comparison of long-acting analogues with human NPH

IQWiG's statement said that although there was one five-year study on the use of Lantus, it offered little information in terms of diabetes complications and in terms of heart disease, the comparison with NPH insulin showed no difference.

It also said that although the FDA had suggested that Lantus could increase the risks of eye damage, there was no indication this was the case.

IQWiG failed to find any proof of advantages in shorter-term effects, although there were some indications that under certain circumstances, mild hypoglycaemia appears to occur less frequently with Levemir. The five-year-study shows some indication that serious hypoglycaemia occurs less frequently with Lantus than with NPH insulin.

Comparison of Lantus and Levemir

Neither of the two analogues performed clearly better. People taking Levemir on average gained less weight than those taking Lantus but the difference was only slight [0.9 and 1.3 kilos]. As the studies were

only 6 or 12 months long, it is not known whether this slight reduction in weight is maintained over time.

What do the NICE Guidelines say about long-acting analogues and Type 2?

Long-acting analogues are not recommended for routine use for Type 2 diabetes and should only be considered for people in certain categories:

- Those who need the assistance of carers for injections.
 - Those who have recurrent hypoglycaemia.
 - Those who would otherwise need twice daily injections in combination with oral anti-diabetic drugs [tablets].
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From Our Own Correspondents

Here is a selection from the many letters we have received and which the writers have kindly allowed us to reproduce:

The best doctor I have had doesn't judge

Dear Jenny,

In response to the recent letters in your magazine I would like to add my story to the pile.

I have been type 1 diabetic for 38 years. I also have renal failure and am on home dialysis. I too have had bad experiences in the diabetes clinic including one consultant telling me I would be dead by age 30 if my HbA1c didn't improve but even if it was 6, they wanted it lower, nothing was ever good enough. I have had several diabetes nurses demanding I take the new human type insulins. At one point, I was using more and more human insulin until I was having to have a whole pen full in one shot, yet my HbA1c was always too high. I saw the same diabetes consultant for around 10 years until she told me that

if I didn't take the human insulin, she wouldn't see me again in clinic. Needless to say I didn't go back. So I thought I would do without a diabetes consultant and go it alone.

As I have overnight dialysis my blood sugars are really high in the morning [25-30], it is due to the glucose content of the fluid. I used to be on Pork Mixtard, but when that wasn't produced anymore I phoned Jenny who advised me that Hypurin 30/70 pork insulin was available and that Hypurin Neutral may bring down my morning high sugars. This now works fine for me, despite a glitch when I first started taking it.

Then I started having trouble with my Graves disease which was previously treated by the diabetes consultant, damn, I'd have to go to the diabetes consultant! I arrived for my appointment in a defensive mood, I was convinced all diabetes consultants were the same! The new consultant remarked on how scared I looked!

I have been seeing this consultant for a year now and he is the best doctor I have ever had. He doesn't judge, he doesn't tell me what to do, he just asks about any problems I have (such as hypo's) and gives me advice on how best to deal with them. I mentioned to him that when I am an inpatient they tend to use Human Actrapid in a drip on me – this is fine while I am on the drip, but as soon as I come off it my blood sugar goes above 30 and takes 2 days to bring down to normal again. So he has advised the ward that when I am admitted for my kidney transplant they must use Hypurin Neutral in the drip and it has been confirmed that Hypurin Neutral can be used in the drip. So he really does listen and care! It has only taken 38 years to find him! My once out of control HbA1c now ranges from between 6.5 and 7.5 and the doctor even commented "why can't all my patients be like you?!" Finally!

Ms F.C.
By e-mail

Husband and wife perspective on stains

Dear Jenny

Having had Type 1 diabetes for 50 years my kidneys decided to give up nearly four years ago and consequently I was put on the kidney transplant list, had the chance of a transplant, which sadly failed from the outset and was removed after three days. I was taking statins prior to this at a dose of 10mg, on leaving hospital they upped it to 40 also I was put on omeprazole [antiacid tablets]. After several months of taking these, my liver function tests were deemed to be totally abnormally high - panic [on behalf of the doctors...] However, after I had done some research I discovered that both tablets were a bit iffy with regard to the liver and could "throw" test results. In the meantime, I was not happy about the statin and with a cholesterol level of 3.5 the doctors agreed that I could leave these off for a while. My wife noticed a difference in my moods the day after I stopped the statin - but couldn't believe that missing just one tablet could make such a difference. After a couple of weeks, and feeling much improved, I also asked the doctors why I was taking the antacids... to be told that these were prescribed for transplant patients and that it was not necessary for me to be taking them, so these were also stopped. Within four weeks I feel totally different and more like myself again - the first time in eight months.

Mr R.L
By e-mail

And from Mr R.L.'s wife

I have had my suspicions about the statins for a long while, and at one stage did say to the doctors that I didn't think they suited my husband as I often think that subtle differences in attitude aren't always noticed by the patient. The statins were changed to a different one, but while he was in hospital for the transplant "they" changed them back - I protested! I must admit I didn't really notice the great increase in strength but I really did not believe the difference that one tablet made. I decided to keep quiet about it for several days to make sure it was removing the statin that was making the difference. I am

seriously beginning to wonder how much research is done with these things and why they are handed out like "smarties" – though at times I do have my own ideas!

Mrs R.L.
By e-mail

Jenny's comment: This just shows the value of having a partner or family member.

Understanding your diabetes
Thank you for putting it into words
Dear Jenny,

Thank you for the new booklet and for putting it into words from a parent's perspective. There were many things in the book that could have been written by us, especially the diagnosis part. We were told to toilet train our son when I took him to the doctors and said he had wet the bed – even I knew it was a sign of diabetes. I'm not an assertive person but I was that day!

There are still so many questions I haven't got the answers to as the clinic is just so busy that you don't want to feel stupid asking what is taken for granted that you know. But I knew very little about diabetes until I was thrown in at the deep end, so I am glad that I have found IDDT.

A Mum

Mixing up rapid and longacting insulins
Dear Jenny,

There is a simple answer to the problem of rapid and long-acting insulins both being clear and the risk of the wrong type of insulin being used at the wrong time. It was much easier when the longer-acting insulin was milky. When I receive my new stock of insulin, I immediately mark the short-acting with brightly coloured adhesive tape thereby

distinguishing it from the long-acting one. Is it too simple a solution for the insulin manufacturers to label the insulins more prominently before they leave the factory?

Mr M.W.
West Midlands

If you have a view, write to Jenny Hirst, IDDT, PO Box 294, Northampton, NN1 4XS or e-mail jenny@iddtinternational.org

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IDDT Day Out With Diabetes 2009 'Understanding Your Diabetes'

IDDT is pleased to announce that we are holding another 'Day Out with Diabetes' on 10th October 2009 at The Paragon Hotel, Birmingham. This year we are trying to take a realistic look at living with diabetes.

As usual we have a range of speakers and discussion groups. These will include doctors and people living with diabetes giving frank and informative presentations about the realities of diabetes. For the first time, we will also have speakers talking about the positives and the negatives of insulin pumps. We will also have a lady who has fought to obtain a pump and continue to use animal insulin.

As usual, the discussion groups will allow everyone to have their say on a variety of subjects and they allow people to learn from others and voice opinions to people who want to listen. Come along for the day and learn something new or share your experiences with others. It really is a fantastic day out where everyone learns new things and meets new people. For a programme and booking form, call IDDT on 01604 622837 or e-mail bev@iddtinternational.org

Taking Statins

I apologise to readers for ‘going on’ about the cholesterol-lowering tablets, statins, but IDDT still receives a lot of calls with concerns about statins, their adverse effects and the need to take them. In April both The Times and The Daily Telegraph gave considerable coverage to the use of statins after scientists analysed 24 studies and concluded that the risk of stroke was reduced by lowering cholesterol levels.

Statins work by blocking the action of a liver enzyme that plays a key role in making cholesterol in the body. Taking a statin is expected to lower cholesterol levels by 20 to 30% and a slowing of the furring of the arteries – the cause of most strokes and heart attacks. Recent research also suggests other possible benefits of taking statins – a reduction in the risk of certain cancers, Alzheimer’s disease and blood clots.

The standard line from medical experts is ‘Statins are generally well tolerated but they can cause side effects.’ However, there are three things that concern people – firstly the adverse effects and the effect on their quality of life, secondly, concerns about their long-term effects and thirdly, it is not known whether there are any hidden adverse effects from long-term use of statins. Both The Times and Telegraph articles talk about the benefits and the call for even wider use of statins in the UK, but they also list the common adverse effects:

- Flatulence and upset stomach.
- Sleep disturbance.
- Aching muscles, which should be reported to your GP because in rare cases [1 in 50,000] it can lead to a serious condition called rhabdomyolysis.
- Long-term use can lead to inflammation of the liver.
- Some people, particularly the elderly, complain of mental fogging and poor memory.
- There is concern about long-term effects on the brain and recent research has suggested that their use may increase the risk of

Parkinson’s disease.

What are the influences on cholesterol levels?

- Hereditary factors can affect cholesterol levels so some families have naturally high cholesterol levels which have nothing to do with what you eat.
- Environmental factors affect cholesterol levels. Levels vary in different parts of the world – they are higher in northern European countries than southern European countries and much higher in Asia.
- Diet is a major influence on cholesterol levels and diets that are high in saturated fats raise cholesterol eg cakes and pastries. However, most of the cholesterol in the blood is made by the body rather than eaten in animal-based foods.
- Various health problems can cause high cholesterol levels, such as thyroid problems, kidney diseases, diabetes and alcohol abuse. Cholesterol levels also rise slightly with age.

What is a ‘normal’ cholesterol level?

In the UK 2 out of 3 adults have average cholesterol levels of 5 or above, 5.5 in men and 5.6 in women 5.6. These are averages so looking at the list of what affects cholesterol levels, does this mean that these averages are ‘normal’ for the UK? Until fairly recently we were advised to aim for cholesterol levels of 5 and as this was in line with the UK average levels, many of us interpreted this as the normal level. However, now we are advised to aim for less than 5, we are aiming for below the average [or what we thought was normal] which suggests that 66% of over 40s in the UK should be taking statins.

NHS Choices tells us that present Government advice is less than 5. The website www.netdoctor.co.uk defines the levels of total cholesterol as:

- Ideal level: less than 5 mmol/l.
- Mildly high: between 5 and 6.4mmol/l
- Moderately high: between 6.5 and 7.8mmol/l

- Very high: above 7.8mmol/l

Prescribing guidelines

Current Guidelines suggest that GPs should prescribe statins to people who have a 20% or more risk of having a heart attack or stroke over the next 10 years. This means that doctors use risk calculations when deciding who should be offered a statin rather than cholesterol levels per se. The consensus view seems to be that it is this group who should be aiming for total cholesterol levels of less than 5mmol/l - some people with diabetes will fit into this category.

The choice of whether or not to take statins still rests with the patient and here is an article by Louise Page who is trying to avoid taking statins.

I have over the last 12 weeks been working to lower my overall cholesterol, without taking statins. My cholesterol from one hospital test to another (over 3 months) has lowered by 27% - yes, that much, from 7.9 to 6.2. It's still not in the "perfect" zone but even so, such a reduction is pretty significant.

Having had Type 1 diabetes for 40 years, I have had a good low fat, high fibre diet for years as I was brought up with sensible eating rather than fads. However, my cholesterol has been creeping up over the years and it was time to sort it out. I have been on statins occasionally but have found that they didn't really help. I am also convinced that stress has a lot to do with it, I went travelling for a year a few years ago and my cholesterol came down, as did my HbA1c.

So, this is what I did...

Meat: I use soya mince instead of lean beef mince (for chilli etc) and have red meat maybe twice a month.

Sausages: I swapped meat sausages for soya ones and I eat chicken when not using soya mince or fish.

Breakfast: Porridge with oatmeal and fruit, using soya milk everyday.

Cooking oil: I use rapeseed oil and walnut oil instead of just olive oil.
Fish: I eat at least 5 portions of fish a week (tuna, mackerel, fish fingers).

Beans: I have introduced more beans into my diet (into chilies, casseroles etc) – baked, haricot, aduki and (frozen) soya beans.

Snacks: walnuts, cashews, roasted soya beans, marmite rice crackers

Hypo: I use apple juice, chocolate soya drink

Dairy: No cheese, sunflower spread, use 1% instead of 2% fat milk (for tea and other drinks). I eat soya yoghurt / soya cream.

Alcohol: One or two bottles of beer and maybe 3 glasses of wine a week

Exercise: Average half hour each day – nothing too excessive, walking, shopping, gardening.

I also make the effort to eat fruit and vegetables, maybe not the 5 a day, but as much as possible without going silly. I did all this quite gradually and I still have the odd treat. I have not taken one statin, although my GP was insistent that I MUST take statins and explained the usual consequences. I discussed what I'd done with my Consultant and although he would like me to be on a low statin, I want to see how far I can take this – hopefully to a lot lower. I still want to enjoy my food but not have to take statins.

I'm not saying this will work for everyone, as everyone is different, as we all know. However, I didn't expect to see such a difference over just 12 weeks. Ian, my husband has also taken on some of these changes, and he probably loves beans more than I so it's worked because we're not making two different meals. I'm the only one who will entertain soya sausages, Ian keeps to meat sausages but at least we are having 'bangers and mash' together.

Introducing Amanda Sugarman

Dear IDDT Members,

My name is Amanda Sugarman. I was chairperson for the Leeds branch of Diabetes UK for ten years and met and spoke with many people who lived with diabetes and encountered problems after changing to Human Insulin.

After speaking and liaising with many people, it brought to my attention that there was nowhere to go with feelings and emotions that people who live with diabetes sometimes experience in everyday life.

It also highlighted just how individual people who live with diabetes are.

I therefore decided to study to become a counsellor and after four years I am now qualified and have a diploma in counselling and I am a member of the British Association for Counsellors and Psychotherapists. I can now support people with diabetes and their families by offering empathic understanding in a safe and non judgemental caring environment.

I am currently working at the City Counselling Centre in Milton Keynes and would be able to offer low cost counselling at a time to suit you.

You can contact me by telephoning 07505 287734 or by e-mail at amandasugarman@btconnect.com

If You Are A Man With Type 1 Diabetes, Can You Help With Research?

Research is being carried out at Nottingham Trent University to investigate the experiences of men living with Type 1 diabetes. This

will include the relationship between men and their diabetes, the wider impact of living with diabetes and looking at partners' experiences of diabetes in their lives.

The study is divided into two parts, the first being interviews with men with Type 1 diabetes and the second interviews with heterosexual couples where the male partner has Type 1 diabetes.

The research is being carried out by Lesley O'Hara who has Type 1 diabetes herself and has already carried out a study into what it means to live with Type 1 diabetes.

If you are interested in taking part or would like more information and live in Nottinghamshire, please get in touch with Lesley by e-mail lesley.ohara@ntu.ac.uk or if you don't have e-mail access, call IDDT on 01604 622837.

Rise In Childhood Diabetes Hits The Headlines

If present trends continue, there will be a doubling of new cases of Type 1 diabetes in European children younger than 5 years old between 2005 and 2020 and the cases in those under 15 will rise by 70%. [The Lancet, Vol 373, June 13, 2009] The rapid changes in these numbers over a 20 year period cannot be put down to changes in susceptible genes, so there must be other factors involved. There are several hypotheses about environmental factors being involved in this rise.

In the absence of a cure or prevention of Type 1 diabetes, there are two things for sure that this study highlights – the need for greater emphasis, and funds, to be directed to research into the causes of Type 1 diabetes and the need to put in place high quality care to

cope with the increased numbers of children who will be diagnosed in future years.

Going Into Hospital & Worried About Infections?

It is not uncommon for people going into hospital for a planned operation to be more worried about the risk of picking up infections while they are in there than the actual operation. We hear about people taking their own cleaning materials into hospital with them!

The government has issued a new edict that all patients undergoing surgery will be tested for MRSA with skin swabs on the days leading up to the operation. Those who test positive will be provided with packs containing creams, shampoos and shower gels to remove the bacteria before surgery. If you are still concerned, you can buy a 'PatientPak' to take into hospital with you. The packs contain sanitising wipes, hand sanitising spray, fabric spray and hair and body wash all of which are antimicrobial. In addition there is lip balm, soap and nail brush, toothbrush and toothpaste and a pen – all to throw away when you leave hospital.

The PatientPak can be obtained from Tesco Pharmacy, Sainsbury's Pharmacy, Boots, Mothercare, Holland and Barratt and some independent pharmacies – the R.R.P. is £15.65.

Snippets...

Sisters make you happy

Research presented at the British Psychological Society's 2009 annual

meeting suggests that sisters can make their siblings and family members happy, while brothers are more likely to cause distress. 571 people between the ages of 17 and 25 had their psychological wellbeing tested. People who have at least one sister present while growing up tended to have more optimism, better social support, and more positive coping, compared with people who only had brothers. The author of the study said. "Emotional expression is fundamental to good psychological health and having sisters promotes this in families."

GP Review

An 18-month inquiry into the standard of general practice in the UK has been launched by the Kings Fund. This has come about after warnings that plans to improve healthcare are too heavily focussed on hospitals and not on the performance of GP practices which are responsible for 90% of patients' contacts with the NHS.

The economic recession hitting people with diabetes in the US

According to a recent Kaiser Daily Health Policy Report [April 2009], the recession is hitting people with diabetes in the US. They are increasingly cutting back on doctors' visits with some people never coming back. They are also cutting back on treatment and testing and therefore increasing the risks of long-term complications. They are also choosing cheaper insulin rather than the more expensive ones.

Over 130 billion dollars per year is spent just in America on diabetes. The average cost per patient with diabetes is \$13,000 – a huge amount compared to those without diabetes who spend an average of only \$2,500.

A first in the US - Supreme Court Judge has Type 1 diabetes

President Obama has nominated Sonia Sotomayor to be a Federal Judge on the US Supreme Court. Apparently, there has been a lot of hype and some controversy as she is the first Hispanic nominee and the first with Type 1 diabetes. She was born in 1954 and diagnosed with Type 1 diabetes at the age of 10. Perhaps from across the pond it is difficult for us to understand that either of these things should

cause controversy!

Recycle your mobile phones and inkjet cartridges

Thanks to go to you! So far you have raised £350 for IDDT simply by sending your unwanted mobile phones and inkjet cartridges to Recycle4charity. Just to remind you that instead of throwing away your unwanted phones or used inkjet cartridges, send them off in the envelope provided with this Newsletter and you will be helping IDDT. And don't forget to put your name and address on the back of the envelope to receive another envelope to carry on collecting.

Laughter is good for you

A study in the US has shown that laughter reduces cholesterol levels and reduces the risk of cardiovascular disease in high-risk people with diabetes, those with high cholesterol levels and high blood pressure. 20 people were divided into 2 groups and all took their standard medicines but in addition, one group viewed daily 30 minutes of self-selected humour. At the end of a year, 26% of the laughter group had higher levels of good cholesterol [HDL] compared to only 3% in the other group. Harmful C-reactive proteins decreased by 66% in the laughter group but only 26% in the non-laughter group. [Presented at American Physiological Society Convention 2009] So perhaps there is a message here for all of us – find something to laugh at everyday!

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Just A Reminder!

Short-acting human insulin is still available in pens

A recent call to IDDT made us realise that perhaps other people have experienced similar problems. The caller had been told that Human Actrapid made by Novo Nordisk is no longer available. This is not so, it is available but only in vials and not in cartridges for pens. So for people who prefer to stay with the insulin they are used to, they can use vials and inject with syringes. Human Actrapid is a soluble short-acting insulin, so another alternative is to change brands to either:

- Humulin S made by Eli Lilly. Humulin S is also a soluble shortacting insulin like Human Actrapid and is available in cartridges for use with HumanPen Luxura or
- Insuman Rapid made by Sanofi-aventis for use with the OptiPen Pro or in pre-loaded OptiSet pens. [Although this is called 'rapid', it is a short-acting soluble insulin and not a rapid-acting analogue insulin.]

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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