



Parents' Bulletin

November 2010

Novo Nordisk withdrawal important insulin

Novo Nordisk is discontinuing Mixtard 30 in the UK for commercial reasons by December 2010. This is bad for patients, bad for healthcare professionals and bad for the NHS.

“I am 6 years old and have been using Mixtard 30 for 5 years since I was diagnosed at 15months. I have had no problems with this and sailed along good and why it is being discontinued is beyond my mum and dad??? Why change a good thing???” [A quote from the Drug and Therapeutics Bulletin petition]

“The decision to remove Mixtard 30 will cause huge disruption and anxiety for people with diabetes, not least because it might take months to switch successfully to another form of insulin.

And at a time of tight budgetary constraint, the added costs inherent in this move are an unwelcome blow for the NHS.” [Drug and Therapeutics Bulletin, Dr Ike Iheanacho]

Mixtard 30 is a pre-mix [biphasic] insulin used by about 90,000 people in England alone, many of whom are children or older people – the most vulnerable groups in the diabetic population. This discontinuation also means that the Innolet device will no longer be available, used by some children and especially by older people with visual impairment and/or manual dexterity problems. Many will lose their independence and have to rely on others to help them inject their insulin – this has far-reaching consequences.

It maybe be too late for Mixtard 30 but...

Novo Nordisk has stated it is their intention to discontinue ALL human insulins to have an ‘analogue insulin only portfolio’ - an amazing

decision given the lack of evidence that analogue insulins are neither safer nor more effective. As we all know, people with diabetes are different and a variety of insulins has to be available to suit all needs. Discontinuation of insulins means a reduction in treatment choices for children and adults with diabetes. We need to give the message to Novo Nordisk that commercial decisions such as this are unacceptable to people with diabetes and their families.

We need your help!

As an entirely voluntary and independently funded organisation, IDDT has no intention of merely accepting this decision or the way in which it was made. Even if you are not using Mixtard 30, please think about those who are and help us maintain the choice of insulin treatment. You can help - please sign the petition and give the message to Novo Nordisk that its commercial decisions are not acceptable. If you don't have internet access, ask someone who does to sign for you or go the local library and visit:

<http://www.thepetitionsite.com/1/withdrawal-of-mixtard-30-from-the-uk-market/>

Mixtard 30 - independent information about your choices

- **Mixtard is recommended by the National Institute for Health and Clinical Excellence [NICE] as a treatment of choice. Crucially, scientific evidence indicates that alternative analogue insulins, promoted by the company, such as NovoMix 30, are neither more effective nor safer.**
- **NICE also states that any decision to start a patient on insulin analogues to treat diabetes should be balanced carefully against the lack of long-term safety data and increased prescribing costs. [National Prescribing Centre Report, August 2010]**

The Secretary of State for Health, Andrew Lansley, has assured IDDT

that the information sent by Novo Nordisk to health professionals is 'non-promotional' and advises them of the alternatives, including insulins from other manufacturers.

Independent information is the best and the UK Medicines Information [UKMi] website provides this to health professionals and the public and can be accessed at <http://www.ukmi.nhs.uk/> Here is the relevant information taken directly from the website.

Choice of insulin preparation

When switching from Mixtard 30 to another biphasic [pre-mix] insulin, the options are to transfer to another human insulin preparation or to an insulin analogue preparation.

With all switches it is important that the patient be monitored carefully. The patient must be warned that the symptoms of hypoglycaemia may be different, or even absent, when changing from one insulin to another.

The preparations described below are those most similar to Mixtard 30 in terms of the proportion of short- and intermediate-acting insulin components they contain.

Switching to another biphasic human insulin

The advantages of switching from Mixtard 30 to another biphasic human insulin include the possibility of switching dose for dose, and the fact that the timing of insulin administration in relation to mealtimes is the same.

- Humulin M3 is near-identical to Mixtard 30; it contains 30% soluble insulin and 70% isophane insulin. When switching to Humulin M3, no change in dose is required for patients with adequate glucose control. Some health professionals advise a 10% reduction in dose if hypoglycaemia is a particular concern.
- Insuman Comb 25 contains the same constituents as Mixtard 30 and Humulin M3 but in a different ratio: 25% soluble insulin and 75% isophane insulin. It may be an option for some patients whose blood glucose is not optimally controlled on Mixtard 30.

Switching to a biphasic insulin analogue

Patients switching from Mixtard 30 to a premix analogue will require changes to their insulin dose and administration schedule. Although Novo Nordisk suggest that switching from Mixtard 30 to the company's biphasic insulin analogue, NovoMix 30, represents an 'upgrade' in treatment, evidence suggests that human insulin and insulin analogues are similarly effective in controlling Hb1Ac. Insulin analogues may, however, be useful for patients who are prone to hypoglycaemia at night.

- **NovoMix 30** contains 30% insulin aspart and 70% insulin aspart protamine.
- **Humalog Mix25** contains 25% insulin lispro and 75% insulin lispro protamine.

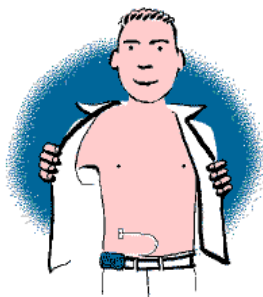
The timing of administration in relation to mealtimes is different to that of human insulins because of the more rapid effect of the short-acting insulin component. Patients switching from Mixtard 30 will need to adjust the timing of doses so that they are administered immediately before a meal. There is no direct dose conversion for patients switching from Mixtard 30 to a biphasic insulin analogue. It has been suggested that an initial dose 15-20% lower than the previous Mixtard 30 dose may be appropriate; the dose should then be titrated according to the patient's blood glucose control.

Living With A Pump

By Dr Jane Essex

Which pump?

Most of the pumps are fairly similar in terms of what they do, apart from the option of connecting to a particular indwelling Continuous Glucose Monitor. A key feature, especially for first time pump users, is the level of support available from different manufacturers. If your care team is very familiar with certain types of pump, you might want to use one of that type. There are minor differences in weight and carry cases,



which may be more important for the very fashion-conscious! It is recommended that you handle the different pumps on offer and get the chance to speak to other people about their pumps before making the final choice. You could be living with the decision for the next four years, so don't be rushed into it.

Making the connection

The giving set for the insulin is made of a reservoir of insulin which is emptied very slowly through a giving line, or long plastic tube. The tube connects with the subcutaneous cannula. The cannula may be inserted wrapped around a needle and then remains in place after the needle is extracted, or it can be a metal needle which is inserted and left in place. The tube or needle can be left in the same site for up to three days before it needs replacing. Most of the needles or tubes have a fitting that enables the pump and long tube carrying insulin to be detached and reattached easily, for instance when showering or swimming, without needing to insert a new set. The plastic lines carrying insulin from the pump, where it is stored in some way, vary in length and it is worth experimenting to see what length of line suits you. Generally you want as little as possible to avoid the perils of door knobs and other 'line snatchers'! When you get your pump, request a variety of giving sets and line lengths, and try them all out.

Cannula sites

The insulin giving set can be placed anywhere that is suitable for insulin injections. Bear in mind that everything you already know about different rates of insulin absorption from different sites will hold true, most noticeably for the boluses. The needles do not go very deep in adult terms but children may find 'adult deep' sets uncomfortable because they have less padding. The bottom is commonly used in very small children for this reason. Just like injections, the site of the giving set needs to be rotated to ensure that hard or pitted areas don't develop from overuse. If the cannula hits a small blood vessel there will be bleeding at the site, followed by clotting which can block the tube. You need to be vigilant for bleeding around the cannula, check the site regularly especially after exercise and be prepared to change the site if blood is visible.

Sites should be kept 'soap and water clean', the incidence of infections at the point of insertion are very low as long as the skin is kept reasonably clean. A common complaint is sticky marks when the set is removed; if it troubles you, a rub with Tea Tree oil is a popular solution, amongst others.

Choosing your insulin

Although analogue insulins are most commonly used in pumps, soluble human or animal insulins can be used successfully in pumps. Staff without experience of the more uncommon options may tell you it can't be done, but it can and you should feel at liberty to experiment until you find one that suits your child. Calculating functions, for example the 'Bolus Wizard' tend to be based on the assumption that you are using analogue so if you choose one of the other, more slowly absorbed and longer acting types of soluble insulin you will need to be suitably wary of 'automatic' options. Animal or human insulin delivered as part of the basal ('background') insulin will impact on blood sugars up to six hours later, not the four hours for analogue. Correspondingly you should be more cautious about repeated boluses because you will have more active insulin under your skin than you would with an analogue. Boluses behave broadly like your pre-meal bolus of whatever insulin type you used in the MDI regime, though absorption may be different as it is closer to the skin.

Whatever you decide to try in the pump, don't forget you will still need a complete set of insulins and syringes on 'stand by' in case you need to revert to injections because of a pump failure.

Wearing your pump on your sleeve

A common question is about where to put the pump. Anywhere you can secure it is possible. You will need to consider how much you wish to trade off visibility against accessibility and decide on an occasion-by-occasion basis. Most pumps come with a clip attachment which can be clipped to a waist band or collar; they also come with a case through which a belt can be run. Garments with pockets are valuable, dungarees and jogging bottoms are especially good on this feature. You can even buy iBoxers and put the pump in the fabric pouch where

the iPod is meant to go. Small bags with shoulder straps are a further option for pumpers on the go. For those events where the pump isn't wanted anywhere in site you can hide it under clothing by slipping it into a piece of sports bandage around the arm or leg; perfect for bridesmaids and page boys!

The Emotional And Physical Aspects Of Hypoglycaemia – a mum's perspective

In the August edition of the Parents Bulletin Bev Freeman wrote an article 'The emotional and physical aspects of hypoglycaemia'. She has asked me to respond to this as her mum and I might add, a very proud mum.

As well as explaining her experiences of hypos, Bev also touches on the feelings that she experiences afterwards – the guilt, the embarrassment and the loss of control. As Bev rightly points out, the parents don't know what it feels like to have diabetes, let alone have a hypo but we do have feelings – fears, responsibilities and guilt, is it something I have done, did she have enough carbohydrate at the last meal, could I have prevented it?

I would look back over the day and try to find a reason for the hypo and sometimes I found a possible explanation and sometimes I didn't – but that's diabetes.

And the night hypos are the worst especially on the rare occurrences that she had a seizure - you have to suddenly wake up and get into action. I managed it but always used to shake later when things had calmed down and yes, I confess to running her blood sugars a bit high for a few nights afterwards. This was for my peace of mind and to calm my fears of it happening again.

When Bev was hypo she could be aggressive and say some hurtful things and it took me quite a long time to realise that this was not Bev talking or behaving badly – it was her diabetes and this made it a lot easier. So I separated the two in my mind and also explained this to her brother who had to put up with the aggressive hypos too.

As her mum, I tried to hide my feelings and fears, they were mine and my responsibility and certainly not hers. I belonged to a Parents Self-help group and this helped because I discovered that other mums felt just the same, so if I felt an emotional mess sometimes, I found that they did too.

As Bev got older, we did discuss things and tried to understand each other. I do remember in her teens being a bit cross when she had some night hypos and I thought they could have been avoided if she had taken more care. I felt she was doing what she wanted and I was there just to pick up the pieces. I feel guilty about this afterwards, and still do, because she just wanted to be like her teenage friends. But none of us are perfect all the time!

Bev has now had diabetes 35 years and has been independent for a very long time, she's a mum herself and I know that this has given her a greater understanding of what it must have been like for me having a child with diabetes. So many years on, I try to support her and be at the end of a phone if she needs me – that's being a mum.

I remember years ago going to a meeting and heard a doctor telling us that diabetes does not cause hypos, it is the treatment of it that is the cause. So no one is to blame for hypos, we have not yet been provided with the tools to prevent them. This was backed by a recent article I read [ref 1] which said that despite hopes that the new insulin analogues and the use of insulin pump therapy would be a solution to the problem of hypoglycaemia, this has not been the case and neither have they provided the expected reduction in hypos. Statements like this still make me feel better, the hypos were not all my fault – I did my best with what we had, just as today's generation do their best with what's around today. So, yes life can be hard sometimes and hypos

will happen. But this is not our fault.

Ref 1 'Hypoglycaemia in Type 1 diabetes – a still unresolved problem in the era of analogs and pump therapy' [Diabetes Care 31:S140-S145, 2008]

Note: If you would like more information on hypoglycaemia, ask for our leaflet – call IDDT on 01604 622837 or e-mail enquiries@iddtinternational.org

Coeliac Disease And Diabetes

What is coeliac disease?

- It is a condition in which the lining of the small intestine is damaged by gluten. Gluten is a protein found in rye, wheat, barley and possibly oats.
- This damage causes foods to not be absorbed properly by the small intestine and so before diagnosis there is weight loss and possibly malnutrition.
- Treatment is a gluten free diet.
- It is prevalent in the UK although estimates of incidence vary from 1 in 1000 to 1 in 300 people.
- It can be diagnosed at any age but mostly it is finally diagnosed in adulthood between the ages of 30-45.
- Many other cases may remain undiagnosed or may be falsely diagnosed as irritable bowel syndrome and only a third of cases are ever diagnosed as coeliac disease and treated with a gluten free diet.
- Certain groups are at greater risk of developing coeliac disease – people with Type 1 diabetes, Downs syndrome, thyroid disease and osteoporosis.

Diabetes and coeliac disease

Both diabetes and coeliac disease are autoimmune diseases and

there are increasing amounts of research to show that there is a link between the two in adults, children and adolescents. Increasingly there are views that more attention should be given to this link and that tests for coeliac disease should be routinely carried out in both adults and children with diabetes.

Coeliac disease maybe the cause of vague abdominal symptoms and may cause hypoglycaemia due to impaired carbohydrate absorption in the gut.

The experiences of a family living with diabetes and coeliac disease

Veronica Readman, Trustee of IDDT

As a family we have learnt to cope with coeliac disease and diabetes, but it is not easy. As we know, children hate being different and some find living with coeliac disease more difficult than living with diabetes. Coeliac disease makes a child more obviously different from their friends and family and it can bring emotional and behavioural problems that can be difficult to deal with.

There can be arguments about which foods can and cannot be eaten. Always being different from their brothers, sisters and friends and going out for a MacDonalds or a pizza can turn into a nightmare when your child, yet again, cannot eat all the yummy things available.

This can result in bad behaviour, temper tantrums and refusal to eat at all which in turn, affects diabetic control. Yes, living with diabetes and coeliac disease does bring its stresses and strains to family life and these should not be underestimated.

All this sounds pretty horrendous and it can be overwhelming at the beginning but I know from experience, that once you have got used to the idea of your child having coeliac disease and diabetes, it is possible to survive!

Here are just a few tips we have learnt along the way:

Eating Out

This can seem like just another obstacle to overcome, but it can be so don't give up. Fast foods are enjoyed by children and we discovered that with a bit of forward planning they can still be part of our life.

Holidays



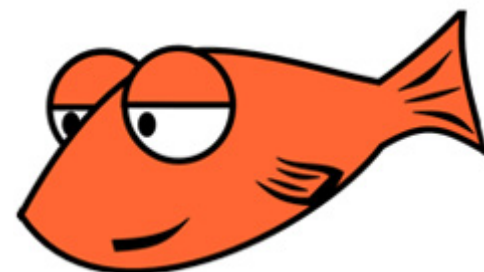
Pizzas – we've discovered that most pizza bars are happy to put a topping on a gluten-free pizza base so you can always make your own base and take it with you.



Pasta – you can take your own gluten-free pasta with you and ask to have it cooked.



Burgers – MacDonalds etc are always keen to oblige and will put a burger inside a gluten-free roll.



Fish - can be fried without batter. We always go armed with gluten-free bread and insulin wherever we go!

Again it is a matter of 'be prepared' and we've discovered that time spent on forward planning is well worth it, whether holidaying in this country or abroad. If you are going abroad it is worth taking all your gluten-free products with you. If flying we have found that airlines will provide a gluten-free diet if ordered 3-4 weeks in advance but, of course, there is never enough carbohydrate so we have to take extra.

School

School kitchens are usually very accommodating and are happy to provide a gluten-free diet but there may not be enough carbohydrate. I've found that catering staff are very willing to help once I have spent time with them explaining my son's needs, although it is often easier and a safer bet for younger children and the newly diagnosed to have packed lunches.

An expensive tip!

We've invested in an automatic bread maker and it makes delicious home made bread and prepares dough for pizzas, doughnuts, buns and pastry etc. It has brought a greater variety and freshness to the gluten-free diet and, even better, it has given my son a real interest in making his own recipes.

For our Coeliac & Diabetes leaflet simply email your request to: bev@iddtinternational.org or ring Bev on 01604 622837

carbohydrates and then injects relevant amount of insulin before each of her meals. Elisia's outlook has been inspirational to her mum and those around her. Here at IDDT, we would like to say a huge well done to Elisia and the whole family.



Helen has nominated her daughter, Emma's diabetes specialist team at Queen Alexandra Hospital in Portsmouth for the Hospital Team of the Year Award because of their fantastic support to Emma and all the children with diabetes in their area. The team go into schools, nurseries, child-minders to carry out vital training to help build understanding about diabetes training.

Helen says, 'I have had home visits from the nurses and PDSNs. We are lucky that we are able to access a psychologist and dietician too. They take the children away for weekends, they have run an education event, giving up their own time. Emma absolutely adores the team and there is much hugging at the clinics. They are just a lovely supportive team. Their prize was deserved because they just go the extra mile for you.' Well done to the team at Queen Alexandra Hospital well deserved.

Linzi has diabetes and her sister, Abbi (Yr 7) is learning All About Diabetes in her Enterprise class at school. Abbi is supporting her sister by showing her class even more about diabetes and encouraged the class to choose IDDT as their chosen Charity. Abbi has been excited about doing this project and has taken time out with her sister to test her own blood sugars.



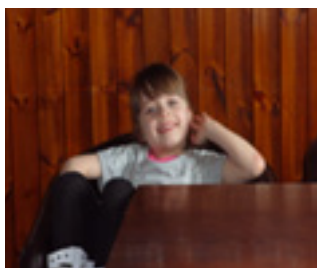
Linzi has also been working hard for IDDT and has managed to persuade her Headteacher to have a non-school uniform day and all the proceeds will be donated to IDDT's Children Department. Thank you to both Linzi and Abbi for being so dedicated to IDDT.



Hall of Fame



Elisia was diagnosed in October of last year aged 4. She turned 5yrs in February of this year. Elisia has dealt with her Type1 diabetes fantastically. She's been truly amazing. Both Elisa and her mum have learned to count



Medication or snack reminders

We are all only too aware of the needs of children at school and that with young children we have to rely on teachers remembering our child's particular needs - for instance, reminding a child with diabetes that they need a blood glucose test and/or a snack at 10.00 am. With the best will in the world, a teacher has 30 children in a class and may forget to remind your child that it is 10 o'clock. One way that can help this situation is using an alarm or warning. The following site has some medication reminders and one in particular looks as if it would be useful for someone with diabetes – the Medreminder 6.

http://medicalarm.co.uk/index.php?main_page=product_info&cPath=66&products_id=229

For further information, the contact details are:

MedicAlarm

The Old Barn

Court Farm

Overstone

Northamptonshire

NN6 0AP

Tel: +44(0)1604 646200

E-mail: sales@medicalarm.co.uk

Notice Board



Wilbert's Party in the Park, 26th June 2011 Wicksteed Park, Kettering, Northants

Wilbert will be appearing live with other friends including the Heart FM Honey's at our first Party in the Park. Everyone is invited to enjoy the fun and games and sing along to the live music. It is a chance for mums and dads to meet each other and all the children to make new friends and enjoy the fun. As well as Wicksteed's Theme Park there will be:

- Wilbert's autograph signing
- Parents VS Children's Sports Day
- Famous Faces Tombola (Chance to win signed photos and memorabilia from stars who support young people with diabetes)
- Live music
- Heart FM Honeys
- Put Dad in the Stocks
- Netball Training
- Football training

Places are limited, so for further details contact bev@iddtinternational.org or telephone Bev on 01604 622837

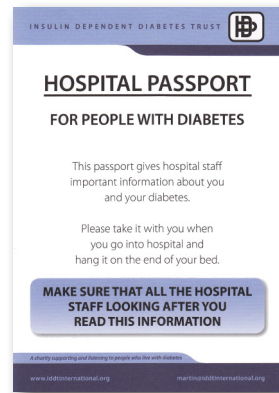


Keep us up to date so we can give you all the latest News

We recently e-mailed those of our members who have given us e-mail addresses, with the news about the withdrawal of Mixtard 30 and you would be amazed at how many e-mails bounced back! So if you have changed your e-mail address in the last year or two, please do let IDDT know – just send a quick e-mail to us to us using enquiries@iddtinternational.org

Hospital Passport

- At any given time 14% of the adult population in England who are being treated in hospital have diabetes.
- In 2009, of those treated with insulin more than 33% had medication errors on their charts.
- More than 25% of all patients experienced a hypo while in hospital with one in 30 requiring rescue with intravenous glucose or glucagon.
- A third of people who inject insulin have an error on their medical chart.



These are the figures for adults and of course, many of them will have Type 2 diabetes but nevertheless, these are pretty shocking statistics. IDDT also receives a considerable number of calls and letters from people who experience difficulties while in hospital. The reasons for the difficulties are numerous but often it can be the change in mealtimes, restricted access to their insulin and food, as well as the general stress of being unwell and away from family and friends.

IDDT felt that it was time to try to help and support both adults and children if they have to be admitted to hospital. So at our Annual Conference in October, we launched the 'Hospital Passport'. The Passports are intended to be put with the notes and provide hospital staff with vital information about the person's diabetes, how it is managed, their likes and dislikes or any allergies. All of this is essential information for hospital staff to help to treat the 'patient' immediately and effectively, minimising the risks of harm.

We are enclosing a Hospital Passport for you with this edition of the Parents Bulletin and hope that you will find it useful if your child is ever admitted to hospital.

The Passport is FREE and available to anyone with diabetes and also to health professionals to provide to their patients. Copies are available from IDDT by contacting martin@iddtinternational.org phone 01604 622837 or write to IDDT, PO Box 294, Northampton NN1 4XS.

If you would like to join IDDT, or know of someone who would, please fill in the form (block letters) and return it to:

IDDT

PO Box 294
Northampton
NN1 4XS

Name: _____

Address: _____

Postcode: _____

Tel No: _____

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From Your Editor – Bev Freeman

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