



Care, Compassion and Communication

As you will read in this Newsletter, IDDT receives many calls and emails from people who are distressed, worried or anxious and sometimes simply angry and frustrated as a result of their experiences with today's NHS. We have to be fair, there are other people who have good experiences at the hands of the NHS. However, we have to look at what has changed because we are aware that the calls and emails we have been receiving for the last 5 years or so, are very different from the ones we received in the previous 20 years. We are logging them anonymously, but we know they are from all areas of the country.

Unfortunately, I have had reason to spend a lot of time visiting a relative in hospital, and still doing so. Treatment has been between two hospitals, one described as one of the government's "super" hospitals with an 'excellent' CQC rating and a much older hospital with a CQC rating of 'in need for improvement'.

My observation? The 'excellent super' hospital could be criticised on so many levels and the move to the old 'in need of improving' hospital was a big improvement. I have had time to assess the differences between the two hospitals and I have concluded that the differences are that the staff in the older hospital showed **care, compassion and**

communication which were sadly lacking from the majority of the staff at the 'super' hospital. Looking at the reasons for the calls IDDT receives from members and non-members, it does seem that **care, compassion and communication** are what they are missing.

The definition of Care: to maintain, restore, or promote someone's physical, mental or emotional well-being especially when performed by trained and licensed professionals (as in medicine, dentistry, clinical psychology, and public health).

The definition of Compassion: the feeling that arises when you are confronted with another's suffering and feel motivated to relieve that suffering. In practice this means speaking with kindness, listening carefully without judgement, apologising when you have made a mistake, forgiving people for making mistakes and accepting people for who they are.

The definition of communication: this is a two-way process of sharing information in the form of thoughts, opinions and ideas between two or more people with the purpose of building an understanding.

Here are just a few of the calls IDDT receives all of which show a lack of care, compassion or communication or all three!

- *"Medication was increased, GP requested HbA1c test but receptionist refused to book one until it had been a year causing anxiety about possible side effects and lack of support from healthcare professionals."*

- *“Member with major learning difficulties was in hospital for removal of an abscess. Her blood sugars went high and she was put on metformin tablets despite not being able to swallow easily. She was refused liquid metformin but was put on insulin and now is fearful of hypos but received no support or understanding from healthcare professionals.”*
- *“My husband received a letter from his GP telling him his medication was being changed, without a review or discussion about adverse effects or benefits from the GP or pharmacist.”*
- *“I was diagnosed with Type 2 diabetes 6 years ago. I am now nearly 70 and although I have an eye check every 12 months, I was supposed to have had 6 monthly checks with a diabetic nurse but I have not seen anyone for 18 months.”*

I understand that the NHS is in difficulties and I equally understand that staff may be demoralised or burnt out as a result of Covid, waiting lists, the need to strike and staff shortages. However, **Care, Compassion and Communication** are essential

for the treatment, wellbeing and where appropriate, the recovery of people. To some extent, communication skills can be taught, while understanding the need is difficult to teach but care and compassion cannot be taught, people either have them or they don't.

My recent experiences of the 'excellent' hospital and the 'in need of improvement' hospital are that the staff of the latter showed all three towards both the patient and the family but only a handful of staff, of all levels, at the 'excellent' hospital showed them. The 'excellent' hospital may have more technology, more impressive buildings and gardens and even more tick boxes ticked, but these have little to do with patient care and treatment.

Are **Care, Compassion and Communication** what are lacking throughout sections of primary and secondary care, especially when compared to 10 years ago? Is this why IDDT is receiving so many calls from worried and anxious people who lack information, understanding and support?

Jenny Hirst, Co-chair

Diabetes patients to be offered artificial-pancreas technology

We discussed the details of this device in our previous Newsletter, so suffice to give the brief details that it continually monitors a person's blood glucose, then automatically adjusts the amount of insulin given to them through a pump.

This announcement hit headlines and the TV News bulletins on 1st April 2024 but it was actually announced in December 2023 when NICE approved it for use in the NHS.

The approval was for those with Type 1 in certain categories, including children and under-18s, pregnant women and those with an HbA1c reading of 58 mmol/mol (7.5%) or higher. It is expected that 150,000 people will be supplied with the device.

This latest news was actually giving the details of the roll out plans, which are:

- From 1st April, local NHS systems will start identifying eligible people with Type 1 diabetes who health chiefs believe could benefit from the artificial pancreas. Later during this month, the NHS will start contacting adults and children who could

benefit from the system.

- NHS England has published a 5-year implementation strategy, which sets out a timeline for how local systems will provide the artificial pancreas system for eligible patients.
- NHS bosses warn it could take five years for everyone eligible to have one. One of the reasons for this is that not only do patients have to be educated in the use of the artificial pancreas, but healthcare professionals also need education in its use and how to help their patients.
- Scotland is also offering the technology, and Wales and Northern Ireland could soon follow suit.

Let's look at the costs

According to NICE, in 2023 an average annual cost for the technology was £5,744, which was higher than NICE considered to be a cost-effective use of NHS resources, so what has changed? However, we can all do the sums:

- Supplying 150,000 people with Type 1 diabetes will cost £861,600,000 over 5 years which is £172,320,000 each year – yes these are the correct numbers of naughts!

- NHS England has provided local health systems with £2.5 million so they are ready to start identifying patients that can benefit.

IDDT's stance on this – is it fair?

Clearly it is great that people with Type 1 diabetes can have access to this latest technology, if this is what they want, and we welcome the news.

However, we are an organisation for people with Type 1 or Type 2 diabetes and one of the very common problems for people with Type 2 diabetes on medication that can cause hypoglycaemia, is that many cannot even obtain test strips for straight forward blood glucose meters on the NHS, not to mention flash glucose meters, such as the FreeStyle Libre.

There is a failure to realise that not only does testing help people with Type 2 to manage their diabetes, it also helps them to learn the effects of various foods on their glucose levels and reduces their anxieties – better for patients and cost effective for the NHS.

Clearly, we would not want to prevent access to the artificial pancreas for people with Type 1, but we have to ask for some fairness to enable people with Type 2 to have the means to test their glucose levels on the NHS, especially those on medication that can cause hypos!

People with Type 1 diabetes still have a choice!

To make this choice, they need to look at the benefits and the limitations of the artificial pancreas:

Benefits

- It may help people with Type 1 diabetes to reach their target blood glucose levels and improve their quality of life.
- Glucose levels will be monitored continuously.
- The computer programme improves blood glucose control by automatically adjusting

the amount of insulin it delivers to keep your blood glucose levels in range.

- The system helps to avoid hypoglycaemia and hyperglycaemia.
- Doctors can monitor insulin doses remotely and recommend dose adjustments for people who need closer supervision.

Also, parents or guardians can monitor glucose levels from their own smartphones throughout the day and night.

Limitations

- Artificial pancreas systems are not completely "hands off." The device has to be regularly maintained to be sure it is working properly.
- Mealtime carbohydrates have to be entered into the system every time you eat.
- The CGM and infusion pump catheter have to be checked to be sure they are in place and they have to be changed when needed
- Reboot or reconnect of the CGM, infusion pump and computer programme if there are problems.
- Manage high or low blood glucose levels if the system is not able to keep your levels in range.
- The adhesive patches used with these systems may cause skin redness or irritation and some medicines you take might also interfere with the glucose monitor.

And! Labour announces business partnership to provide Med-Tech for children with Type 1 diabetes

In April, the Labour Party announced that an incoming Labour Government will partner with Virgin Media O2, so that every child with child with Type 1 diabetes can benefit from the latest technology. The NHS will identify children who are not using modern glucose monitors and direct them to the charity, Supporting Diabetes, so they can be provided with a smartphone provided by Virgin Media O2.

Thank you to Melvyn!

Melvyn Heath has raised funds for IDDT in memory of his friend, Maurice Staples who passed away in February 2024. Maurice was a long-standing Type 1 member of IDDT living on Shetland.

Maurice and Melvyn had planned to go on a motorcycle tour of Italy, so Melvyn decided to raise money in Maurice's memory by touring Italy going between Park Runs in different locations with the plan of completing 15 park runs, including Rome. He left Shetland on 19th March with the plan of ending his journey with a Park Run in Shetland in April.

While on his trip, Melvyn sent IDDT this message: **"I've been bowled over by the**

welcome I'm receiving from the parkrun regulars and officials here, but that welcome hasn't been restricted to people connected with parkrun. Also I have been placed on the parkrun Italy cover photo for their Facebook page. See what I mean about the welcome?"

At the time of writing this Newsletter, Melvyn had raised over £1,500 and we are very grateful to him for helping IDDT, and people with diabetes in this way. So, Melvyn, congratulations on your achievements and many thanks for helping IDDT and people with diabetes!



Update from Ukraine

This year so far we have sent two consignments of insulin, tablets for Type 2 diabetes and other diabetes necessities to help people with diabetes in Ukraine and we are very grateful for all the help our members and others are giving.

Here is a comment from our contact in Ukraine:

“Together with InDependent Diabetes Trust we are able to help insulin dependent people in Ukraine who suffer due to invasion of Russian troops. Recently we delivered aid to Kherson city. We so much appreciate the help of the team of InDependent Diabetes Trust and everyone who makes donations - it is so important now!”

Here is a comment from just one of the people your donations have helped: “I am from Zaporizhia and I got the help I needed too. Big thank you to your team for such sincere help, for supporting our lives. May God protect you and give you strength and health.”

We are still collecting to help people with diabetes in Ukraine, so if you have any unwanted, in-date Type 2 tablets or insulin, please send them to IDDT, 210 Abington Avenue, Northampton NN1 4PR.



It might be obvious but - regular exercise is linked to better sleep

New research has shown that exercising twice a week is associated with fewer insomnia symptoms and better sleep duration. Exercising or being physically active was defined as an hour or more exercise twice a week. The study involved 4339 adults (48% men) aged 39 to 67 years from 21 centres in 9 countries and this was the third follow-up after 10 years.

Participants answered questions about physical activity, insomnia symptoms, sleep duration and daytime sleepiness.

Results

From the start of the study, after 10 years, 37% of participants were persistently inactive, 25% were persistently active, 20% became inactive and 18% became active. After adjusting for age, sex, body mass index, smoking history, and study centre,

- persistently active participants were less likely to report difficulties with sleep initiation, with short sleep duration of 6 hours and over per night and long sleep of 9 hours and over per night compared with persistently nonactive subjects.
- Those who were persistently active were 22% less likely to report any symptoms of insomnia, 40% less likely to report two symptoms, and 37% less likely to report three symptoms.
- Daytime sleepiness and difficulties maintaining sleep were found to be unrelated to physical activity status.

Conclusion

This study strongly indicates that consistent physical activity may be an important factor in having the best sleep duration and reducing symptoms of insomnia. (BMJ Open, March 2024)

Is napping associated with increased risk of diabetes?

Intentional napping is very common, particularly in countries such as China but there is limited information about its potential health effects. This study examined the possible relationship between napping and Type 2 diabetes. It involved 19,567 Chinese men and women aged 50 years or older who answered questionnaires which looked at self-reported levels of napping and their Type 2 diabetes was assessed.

- Participants reporting frequent naps (4-6 days/week and daily) were 42% to 52% more likely to have diabetes.
- The relationships remained essentially unchanged after adjustments were made for lifestyle and sleep habits, health status, adiposity, and metabolic markers. Removal of those with potential ill health and daytime sleepiness did not alter the observed associations.

Conclusions

The researchers concluded that napping is associated with raised rates of diabetes and impaired fasting glucose in this older Chinese sample suggesting that napping may increase the risk of Type 2 diabetes. (The Guangzhou Biobank Cohort Study)

In addition, two recent studies from Germany and the US suggested a higher prevalence of diabetes in those who reported napping. In these populations napping is not the norm and could be the result of underlying health problems, eg diabetes itself could induce tiredness and therefore may increase napping.

A further more recent study found that long versus short napping duration and morning versus afternoon/evening napping were associated with increased HbA1c levels suggesting that tips on napping should be take a nap of less than an hour and take a nap in the afternoon instead of in the morning.

A clearer picture of the health impact of napping might be seen with studying Western populations, where napping is more likely to be unplanned and initiated by sleepiness.

Note: IDDT has a free booklet, 'The importance of sleep'. If you would like a copy call IDDT on 01604 622837, email enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS.

The menopause and diabetes

Managing diabetes during the menopause can be difficult due to the effects of both conditions and it also affects women differently. Nevertheless, in order to live through this time of life, we need to understand what the menopause is and what to expect.

What is menopause?

Menopause is the general term that describes the end of a woman's menstrual cycle – the end of monthly periods which usually occurs around the age of 50. Periods usually come to a gradual halt, becoming less frequent and with longer intervals between each one before stopping altogether.

But for some women, the end of menstruation can be sudden. It is this period that is referred to when a woman is 'going through menopause'. For many women, the end of menstruation can lead to a number of physical and emotional symptoms, which can be detrimental to health. Levels of the female sex hormone oestrogen decrease, causing the ovaries to stop producing an egg each month. Reduced oestrogen can result in women experiencing hot flushes, night sweats, mood swings and vaginal dryness.

Menopause and diabetes

In addition to the above symptoms, changing hormone levels can also trigger rises and falls in blood sugar levels, which for women with diabetes can lead to problems and may pose a number of health risks. Menopause will not affect every woman in the same way, however, there are a number of common effects:

- **Fluctuating blood sugars** caused by changes in the levels of oestrogen and progesterone which are hormones that affect how your cells respond to insulin. This can lead to unexpected fluctuations in blood sugars which make it harder to keep diabetes well controlled.
- **Weight gain** is a common problem for some women going through the menopause and afterwards. This can increase the need for insulin or oral medication.

- **Infections** – diabetes increases the risk of urinary and vaginal infections but menopause increases these risks further due to less oestrogen in the body making ideal conditions for the development of urinary and vaginal bacteria and yeast infections to thrive.
- **Sleep problems** - hot flushes and night sweats after menopause can cause sleepless nights which in turn can have a negative impact on blood glucose control.
- **Sexual dysfunction** can also be a problem during the menopause. Over time, high blood sugars can damage the nerves of the vagina causing thinning and inflammation of the vaginal walls. This makes it more difficult for women to become aroused or achieve orgasm, often made worse by vaginal dryness, a common problem that can cause pain during sex.

Managing menopause and diabetes

Menopause does make it harder to keep blood sugars in control but there are several steps that can be taken to improve both. These include:

- Healthy lifestyle changes – healthy, balanced diet, avoid smoking, reduce alcohol and take exercise.
- Regular and more frequent blood glucose testing will help to see how blood sugars are affected by various menopausal symptoms.
- Seek help with menopause symptoms – your doctor can prescribe lubricant for vaginal dryness and pain, sleeping problems, weight gain or hot flushes. HRT is also an option for some women.
- Get assessed for heart disease risk as weight gain during the menopause for women with diabetes can increase the risk of heart disease, so your doctor should regularly check your blood pressure and cholesterol. Both are health factors important for controlling diabetes and heart disease risk, but can be affected by menopause.
- Protect your bones as diabetes can cause several bone problems, especially in women, which can increase during and after menopause. It is important to strengthen bones by taking calcium and vitamin D supplements and having your bone density measured.

Is the menopause over-medicalised?

The Lancet is publishing a series of papers which ask this question suggesting the present view of the menopause is that it is over medicalised instead of it being seen as an ordinary, healthy phase of women's lives. The article makes the following points that maybe we don't consider because these days, we tend to concentrate on the negative aspects of the menopause. The points made are:

- Women's experiences vary substantially and are influenced by psychological, social and contextual considerations, many of which are modifiable.
- Although the management of symptoms is important, the medicalised view of menopause can be disempowering for women, leading to overtreatment and overlooking potential positive effects, such as better mental health with age, and freedom from menstruation, menstrual disorders, and contraception.
- Even physical symptoms can be influenced by prevailing attitudes but psychological factors, including stress, negative beliefs about menopause, embarrassment about hot flushes, feeling out of control and concern about the reactions of other people, are associated with more problematic, negative menopause symptoms and attitudes that may be harmful to women.
- In many Asian cultures, ageing in women gives them respect and status, rather than stigma. Women tend to have worse experiences of menopause in countries where their value is marked by youth and reproductive capacity but ageing is associated with decline. If women fear menopause because they have been taught it's the end of their value to society, it may well adversely affect their physical and emotional response to it.

An important statement worth thinking about is that empowerment means approaching the menopause with confidence and an open mind, being informed, and knowing that there are evidence-based treatments if symptoms are difficult to manage.

IDDT has the following free booklets that may be useful during this time:

- Stress, Depression and Anxiety
- Diabetes – the importance of sleep
- Exercise and Diabetes
- Sexual dysfunction in men and women

If you would like any of these booklets, just contact IDDT: call 01604 622837, email: enquiries@iddtinternational.org or write to IDDT, PO Box 294, Northampton NN1 4XS

Useful practical information

This may help you – BT free priority fault repair

Under this scheme, BT show understanding of how importance a working landline and/or broadband service is for people who rely on them for mobility or health reasons. Under the scheme BT give priority over standard faults by dealing with them as a matter of urgency, every day of the year, including Christmas Day. Having said this, there are circumstances outside BT's control, such as bad weather, when engineers cannot carry out repairs eg to overhead cables. To make sure that the services reach the people who need it most, there is a rigid set of criteria.

Who can apply?

The free priority repair line and/or broadband is with BT repair scheme and your household must include someone at risk who meet the following criteria which are:

- Classified as disabled under the Equality Act 2010. You are considered disabled under this act if you have a physical or mental impairment that has a substantial and long-term negative effect on your ability to do normal daily activities.
- Incapacitated and therefore housebound, due to chronic long-term illness or disability which prevents you from leaving the house without the assistance of another.
- A severely sick child.

The scheme does not cover:

- Your line supplied by another service provider.
- You have a BT line and live in warden-controlled premises, residential nursing home, care home or similar type of property.
- Alarm monitoring stations, control rooms etc.

How to apply

If you have a printer, print off the form from the website bt.com/help/her-for-you, complete in black ink and capital letters. All applications must be countersigned by a doctor or hospital consultant, with a doctor's or hospital stamp included. The doctor also needs to confirm their General Medical Council (GMC) number. Send the form to: BT Plc, Po Box 334, Sheffield S98 1BT. If you don't have a printer, an application form can be obtained by calling: 0800 800 150.

Good News about the neuropad®

neuropad® is a patented 10-minute screening test for the early detection of diabetic foot syndrome. The test is completely painless and is an early warning system for your feet. Nerve damage to the feet is a common complication of diabetes but is often not noticed until it becomes quite advanced, neuropad® helps to solve this problem with a simple colour change test.

The good news!

For some years IDDT's website shop has sold neuropads for £14.99, and still does and this comprises of two test pads but the good news is that now neuropads are available free for people with diabetes on a GP prescription!



Here's how it works

Damage to the nerves in the feet can result in the sweat glands not producing enough moisture, leading to dry and cracked feet (called sudomotor dysfunction). A neuropad® is stuck to the sole of each foot like a small sticking plaster and left in place for 10 minutes. The pad is blue to start with and should turn pink in the presence of moisture from sweating to indicate a normal result. If the neuropad® test patch stays blue, or turns patchy blue/pink, this indicates that you may have diabetic peripheral neuropathy and your sweat glands are not working properly because there is not enough moisture to complete the colour change. In clinical trials, the sensitivity and specificity of neuropad® was comparable to well-established hospital-based tests.

Note: if you still prefer to buy one from IDDT: online at www.iddt.org/shop or phone IDDT on 01604 622837. We also supply a FREE booklet 'Looking After Your Feet' if you would like one, just ask.

Smart insulin pens

Smart insulin pens (also known as connected pens) came on the market in 2022 as development to help people with diabetes. They can show you:

- if you have missed an injection,
- how much insulin you've taken,
- the last time you injected.

The smart insulin pen can make life a little easier for people who use multiple daily injections. They can be used by people with any form of diabetes where the treatment is with insulin whether using finger-prick tests, blood glucose meters, continuous glucose monitoring or FreeStyle Libre. Smart insulin pens can also connect with certain apps that let you keep your insulin dosages and blood glucose data in one place. Therefore, you can look at the timing and dose of your insulin in relation to any food you've eaten or exercise you have carried out to check how it has affected you. The data can also tell you how much insulin is still working in your body which can help you make decisions for unplanned activity or unexpected sugar readings.

What is a smart pen?

Smart insulin pens are reusable that automatically record when insulin has been injected, including the amount and time of day. The devices have a dose memory display which shows the amount of time that has passed since the last dose, and they can also show when a dose has been missed. Once the smart insulin pen is connected to an integrated app, this information can be sent virtually to help people manage their insulin data more easily and in one place.

Which smart insulin pens are available?

There are two smart pens currently available on the NHS:

- the NovoPen 6®
- NovoPen Echo Plus®.

Both are reusable and compatible with 3ml Penfill cartridges of insulins made by Novo Nordisk. If you wish to use the smart pen like a standard insulin pen without the connectivity function, then you can discuss this with your healthcare provider.

Which apps can connect with smart insulin pens?

Providing your smartphone or tablet supports Near Field Communication (NFC) then Novo Nordisk's smart pens can be connected with the following apps:

- Mysugr
- FreeStyle LibreLink
- Glooko
- Novo's smart pens also connect with the Dexcom G6, G7, and Dexcom One (via Glooko).

The importance of breakfast

For many people, breakfast is the most neglected meal of the day, but if you have Type 2 diabetes, breakfast is a must, and it can have real benefits for your health. It helps control blood sugar for the rest of the day and sets the tone for how you'll feel throughout the day progresses. The key is to choose a nutritious breakfast that will keep you full and your blood sugar levels in a healthy range, which can vary depending on your age and health.

The American Diabetes Association (ADA) recommends: A diabetes-friendly breakfast is one that includes a combination of carbohydrates, protein, and healthy fats in the right proportions, which helps balance blood sugar. An example of simple diabetes-friendly breakfast is a plate of eggs and avocado on whole-grain toast. Being pressed for time is not a reason for skipping breakfast! However, an unbalanced breakfast, such as a sugary cereal with plant milk contains very little protein or fat and blood sugars will immediately begin to rise. Skipping meals can create blood sugar fluctuations and extreme hunger cravings, which then lead to overeating at meals and high blood sugars, skipping breakfast is no exception. This same advice applies if you at increased risk of Type 2 diabetes but don't actually have the condition.

A study published in the Journal of Nutrition in January 2019 found that adults who skipped breakfast had an increased risk of Type 2 diabetes. Risk factors for Type 2 diabetes and what is referred to as pre-diabetes include being older than 45, being overweight, having a family history of Type 2 diabetes (particularly a brother, sister, or parent), having had gestational diabetes, and being of ethnic origin.

Delaying progression of pre-symptomatic Type 1 diabetes can reduce the disease burden over a patient's lifetime

Screening children with first-degree relatives with Type 1 diabetes can identify those at an earlier stage of the condition which could reduce the severity of the disease, reduce cost of treatment and delay the onset of the complications caused by the disease.

Parents, siblings and children of patients with Type 1 diabetes are 15 times more likely to be diagnosed with the condition compared with the general population. According to the American Diabetes Association, there are 3 well-defined stages of pre-symptomatic Type 1 diabetes:

- stage 1, asymptomatic with normoglycaemia;
- stage 2, asymptomatic with progression to dysglycaemia (this is when blood sugars are too high or too low);
- stage 3, onset of clinical Type 1 diabetes characterised by symptoms of hyperglycaemia (high sugars).

The researchers screened first-degree relatives of people with Type 1 diabetes through autoantibody testing including insulin autoantibodies and the results showed:

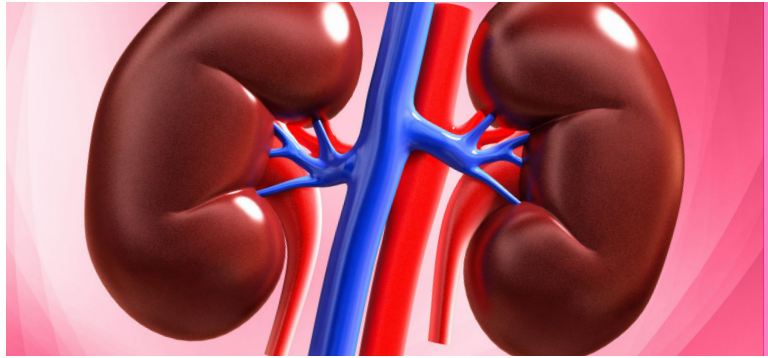
- People with 1 positive antibody result have a 14.5% chance of developing Type 1 diabetes within 10 years;
- People with 2 or more positive antibody results have a 70% chance of developing Type 1 diabetes within 10 years.

When did treatment start?

Treatment started while the patient is in stage 2 with teplizumab a recently approved antibody to treat pre-symptomatic Type 1 diabetes in adults and children aged 8 years or older.

In clinical trials, teplizumab delayed stage 3 development by 25 or more months. Teplizumab is administered via a daily intravenous infusion for 14 days, premedication is required and there are adverse effects. (Presented at the National Association of Pediatric Nurse Practitioners National Conference, March 2024)

Human patient receives first-ever pig kidney transplant



One of the complications of diabetes is kidney damage which can lead to kidney failure which is also common in people without diabetes but it is well known that there is a shortage of kidneys for transplantation.

For the first time, surgeons at Massachusetts General Hospital have successfully transplanted a genetically edited pig kidney into a man living with end-stage kidney disease. This procedure is called xenotransplantation and the intention is that it could offer hope to reduce the long organ donor waiting lists worldwide. The first recipient, Rick Slayman, 62, has Type 2 diabetes and hypertension and received a kidney from a human donor in 2018. This kidney showed signs of failure after 5 years, so he agreed to undergo the pig kidney transplant. Days after the four-hour surgery on March 16, however, Slayman's vital signs indicated that he was tolerating the transplanted organ well and was expected to be discharged soon after.

Researchers used CRISPR gene editing to help with potential barriers to cross-species transplantation. This involved deleting three pig genes and inserting seven human transgenes to mitigate chances of rejection. CRISPR was also used to deactivate retroviruses in the pig genome. In total, 69 genetic modifications were made to the pig which led to the procedure's success. The surgeons concluded that they will consider Mr Slayman's transplant a success if he no longer needs dialysis, and they hope it buys him a couple years of time to wait for another donated human kidney. Though if the procedure proves successful and leads to further clinical trials, it could benefit many more than just one patient. (March 2024)

Seeing the same GP improves patient health

According to researchers at Cambridge University and INSEAD business school, patients seeing the same doctor reduces the workload for family doctors. They also found that there was a range of benefits when patients have a long-term relationship with their doctor. They analysed more than 10 million GP consultations in 381 practices in England over a period of 11 years.

- Seeing the same doctor during GP visits (called continuity of care) meant people could wait on average 18% longer between visits, compared with patients who saw different doctors.
- People did not take up more GP time in each consultation and the findings were particularly strong for older patients, those with multiple chronic illnesses and people with mental health conditions.

The researchers said that, although it will not always be possible for people to see their regular GP, the findings translate to an estimated 5% reduction in consultations if all practices in England were providing the level of continuity of care of the best 10% of practices.

They commented: "Importantly, if patients receiving care from their regular doctors have longer intervals between consultations without

requiring longer consultations, then continuity of care can potentially allow physicians to expand their patient list without increasing their time commitment."

The published study made the following points:

- A physician can be considered more productive if they improve the quality of care provided without reducing the number of patients they serve per year or if they serve more patients without reducing quality of care.
- If physicians provide high-quality care to their regular patients, they are likely to keep them healthier, which reduces the demand for consultations and increases their capacity to serve more patients.
- Seeing the same doctor could have substantial benefits, equivalent to increasing the GP workforce by 5%. Getting it right first time will reduce future workloads by preventing revisits.
- The benefits of continuity of care are obvious from a relationship point of view. If you're a patient with complex health needs, you don't want to have to explain your whole health history at every appointment. If you have a regular doctor who's familiar with your history, it's a far more efficient use of time, for doctor and patient. This is particularly important for people with chronic and/or multiple health conditions. Clearly Type 1 and Type 2 diabetes fit into this category.

Rates of flash glucose monitoring or continuous glucose monitoring

As we know standard care for Type 1 diabetes involves regularly measuring blood glucose levels by self-monitoring, blood testing, or by using a continuous glucose monitor, real-time or intermittently scanned.

Data to the third quarter of 2022/23 shows that 73% of people with Type 1 diabetes were prescribed flash glucose monitoring.

As a result of the recent National Institute for Health and Care Excellence (NICE) guidance that also recommended that insulin dependent patients with Type 2 diabetes should benefit from flash or continuous glucose monitoring devices, so there are now signs of a growth in prescribing for people with Type 2 diabetes. (February 2024)

Disordered eating and Type 1 diabetes: unmet needs highlighted

People living with Type 1 diabetes are more likely to experience mental health challenges compared to those without diabetes. This includes disordered eating and eating disorders and those with Type 1 diabetes are 3-4 times more likely to experience these conditions.

Eating disorders include anorexia, bulimia, binge eating disorders, and insulin omission or restriction to lose weight (often called “diabulimia”). Eating disorders are serious in anyone but are particularly dangerous in people living with Type 1 diabetes. Insulin omission can cause hyperglycaemia or diabetic ketoacidosis (DKA) (very high blood glucose levels), which can be dangerous and in some cases can lead to severe diabetes related complications, coma, or death.

The following suggestions are thought to be possible reasons why people with Type 1 diabetes are more likely to develop eating disorders:

- The close relationship and strict monitoring of food, such as carbohydrate counting, can cause stress that may increase the tendency to develop eating disorders.
- There are often feelings of guilt and shame associated with living with a condition that requires careful self-management, and people living with Type 1 diabetes are further at greater risk of depression, anxiety and diabetes distress – a clinical condition that refers to the negative emotions that come with the burden of diabetes self-management.
- Starting or changing insulin treatment can result in weight gain which adds to the already existing problems.
- Although nearly 1 in 5 children with Type 1 diabetes show signs of disordered eating, the signs are often missed.

On January 23, 2024, a UK Parliamentary Inquiry report was issued on the risks of Type 1 diabetes eating disorders (T1DE).

The Parliamentary inquiry identified several systemic gaps and barriers that fail to provide effective support and care for people affected by T1DE (Type 1 diabetes specific eating disorders) which included:

- gaps in diagnostic criteria and terminology for T1DE,
- the effect of stigma,
- limited research and evidence in this area,
- lack of knowledge and training of healthcare professionals, and lack of funding and access to mental health providers and eating disorder support services.

There are clearly many areas that must be addressed to improve the experiences of people who are affected by T1DE. A clear finding from the report is a recommendation to introduce mental health checks along with the existing physical health checks, screening during annual diabetes care appointments, and a need for mental health providers to have training on diabetes and T1DE. People living with T1DE often receive mixed messages and advice from different care providers with conflicting care plans. This latter finding suggests a need for greater communication, collaboration, and integration of different health services within health systems.

What can we learn from this report?

- Greater investment in research in the area of Type 1 diabetes and disordered eating is needed to generate evidence-based best practices.
- Evidence needs to be integrated into practice – this means training healthcare teams to recognise early signs of T1DE and explore prevention initiatives.
- Greater collaboration and communication among healthcare providers and care teams to improve patient care.
- Increased funding in mental health is needed to allow people living with Type 1 diabetes the ability to have improved access to mental health treatment.

Have the 2019 health and social care commitments been met?

In 2019, the government made commitments on health and social care but at IDDT, we hear so many problems from people about the care they are, or perhaps more accurately, they are not receiving, it is important to ask to what extent these commitments have been met. Naturally this affects the general population and especially people with chronic conditions such as diabetes, who are in need of regular treatment. So this article takes a look at some of the commitments that affect us as people living with diabetes, just one of the chronic conditions that need regular healthcare.

Let's take a look at some of the promises...

The workforce

• 50,000 more full-time equivalent (FTE) nurses working in the NHS in England (includes nurses working in general practice)

In November 2023, according to the government this promise has been met as they cited the workforce data for August 2023 indicating that there were 51,245 additional nurses working in the NHS compared with September 2019 (the baseline on which the target was set).

Our Comments

Considering these included the years of Covid and that it takes 3 years followed by a working year to train a fully qualified nurse, we have to question these figures: does this include healthcare assistants and nursing associates who are not fully qualified nurses? How many of this number are from abroad and have cultural differences? How many are retirees who have returned to work, so have they had retraining to update their skills?

• 6,000 more FTE fully qualified GPs working in general practice by 2025

This promise has not been met as there are fewer full time equivalent (FTE) fully qualified GPs working in the NHS in January 2024 than there

were in December 2019, when the commitment was made.

Our Comments

We can only assume that this is the main reason that we cannot obtain GP appointments – there are simply not enough doctors.

• 26,000 more primary care professionals working in primary care by March 2024

According to government, this promise has been met. Figures for March 2023, show there are 29,103 more direct patient care staff than there were in March 2019, this includes pharmacists, dietitians, paramedics and physician associates.

Our Comments

- **Pharmacists:** In January 2024, pharmacists were on the UK Government's skilled worker shortage list. Labour market data indicates job pharmacy vacancies are set to grow by 6.9% by 2027 (4,700 jobs to be filled), compared to the UK workforce average of 6% growth. In the same period, 52.8% of the workforce is projected to retire, leaving 35,600 job vacancies.
- **Dietitians:** are currently listed as a shortage occupation with currently less than 10,000 registered dietitians. There are 400,000 people with diabetes alone but also children's health, cancer, renal issues and public health. Paramedics: currently, there are 2,954 vacancies across all ambulance services in England. For example, Yorkshire ambulance service has the highest vacancy rate with over 17% of positions unfilled, so a shortage of 1,157 staff.
- **Paramedics podiatrists:** there are currently just under 10,000 podiatrists registered with the Health and Care Professions Council and this number is due to decline. How many of these work in the NHS?
- **Physician associates:** now, in 2024, there are more than 4,000 Physician Associates working across general practice and primary care, with a view to increasing this number to 10,000 by 2036/37. Are we, as patients, going to be told that we are seeing a physician associate and not a General Medical Council registered doctor?

Performance

• Deliver 50 million extra general practice appointments a year by 2024–25 compared to October 2019.

According to NHS Digital information, this target has been met because in the year to January 2024, there were more than 50 million more appointments in general practice than in the year to October 2019.

Our Comments

Clearly this shows that the problems of shortage of GP appointments was present before 2019 and before Covid! We have to question what is meant by appointments? How many face to face appointments have there been compared to phone and online appointments?

• Bringing down operating waiting times, improving A&E performance and increase cancer survival rates

These targets have not been met as admitted by the Prime Minister:

Operating times – in September 2019, waiting times for primary surgical treatments such as general surgery (eg hip replacement surgery, transplants, tumour removal) was 6.5 weeks, but by January 2024 the average waiting time has risen to 12.4 weeks with many people reporting much longer times!

Improve A&E performance - this has not improved. The number of patients waiting less than four hours from arrival to admission, transfer or discharge has decreased from 85.2% in September 2019 to 70.9% in February 2024. On 1st April 2024, the Royal College of Emergency Medicine (RCEM) released their findings of analysing the progress of the implementation of the government's January 2023 Delivery Plan for the Recovery of Urgent and Emergency Care Services.

This promised to improve increasing capacity, discharge, expanding care outside hospital and making it easier to access the right care. According to the RCEM, in 2023 over 1.5 million patients waited 12 hours or more and 65% of those were awaiting admission, the significance of which is that there will be one additional death for every 72 patients who have an 8 to 12 hour wait to be admitted. The RCEM estimates that there were 14,000 associated deaths relating to waits of 12 hours or longer in 2023, more than 238 a week!

Then there's bed-blocking – recent figures show that a daily average of 13,690 patients remain in hospital after a decision to discharge them has been made, only 275 fewer than in January 2023.

Cancer survival rates – it is difficult to determine whether overall cancer survival rates have increased as NHS data breaks down differently into specific cancer type, sex, age and length of survival from one to five years. However, overall one-year survival rates for cancer in England increased from 65.6% in 2005 to 74.1% in 2019 and 74.6% in 2020.

Social care

• Urgently seek a cross-party consensus in order to legislate for long-term reform of social care

This promise has not been met. In September 2021, proposals for social care reform were announced by the government but in November 2022, the Chancellor announced the reforms would be delayed for two years to October 2025, with the funding instead allocated to deal with existing cost pressures and to 'allow local authorities to provide more care packages'. No plans have been announced for implementation changes until October 2025.

NHS estate to build 40 new hospitals across the country

This promise has not been met and although the deadline date is 2030, according to the original definition of 'new hospitals', there still will not be 40 'new hospitals' by 2030. Instead, the government now plans to build 32 'new hospitals' which are classed as complete rebuilds or completely new hospitals.

Finances

• £1 billion more funding every year for more social care staff and better infrastructure, technology and facilities

This promise has only partially been met. The government has stated that creating this Social Care Grant in 2020–21 fulfilled this manifesto commitment, as the grant provides at least £1 billion extra funding each year until 2024/25.

However, the Health and Social Care Committee's expert panel evaluation of the government's health and social care workforce commitments concluded that the government's progress on this commitment had been inadequate on all its benchmarks as the government's commitment is too vague on what it will deliver. The expert panel also argues that the £1 billion extra funding every year has not delivered what was pledged. In addition, following a sustained period of very high inflation, £1 billion does not go as far now as it would have when promised.

- **Increase spending on the NHS by £34 billion per year by the end of the parliament**

This has been met but not in real terms. The March 2020 NHS Funding Act enshrined in law the pledge to increase NHS spending to £34 billion more per year by 2023/24 than was spent in 2018/19.

The planned increases were in cash terms, but were not adjusted for inflation, which has been much higher than expected when the commitment was made in 2019.

There has been less progress on commitments with a deadline beyond the next general election such as building 40 new hospitals by 2030 and extending healthy life expectancy by five years by 2035.

The commitments with less-specific aims haven't been met either, such as seeking cross-party support for long-term social care reform or doubling dementia research funding.

Can we draw any conclusions?

It seems that at best, the government's progress on its 2019 manifesto commitments has been mixed.

Perhaps to us as patients, the most important commitment made by the government in 2019 was to cut waiting lists and Rishi Sunak has admitted that this has not been delivered.

UK's first registry of those at risk of Type 1 diabetes



New cases of Type 1 diabetes, especially in young children, are increasing every year and researchers from Oxford University are to set up the first UK registry for children and adults at risk of Type 1 diabetes. They will build a database and a website that people can use to join.

It will list those who test positive for diabetes autoantibodies, which is the most reliable indicator that a person is likely to develop the condition. The proteins appear when the insulin-producing beta cells in the pancreas are damaged. It is believed that half the people who have positive autoantibodies are no longer being followed up as they are not involved in research studies so there is limited understanding of living with being at risk.

The registry is expected to start later this year aims to:

- Tell people about new treatments and opportunities to take part in research to prevent Type 1 diabetes, such as testing immunotherapy treatments that could prevent or delay the condition.
- Better understand what it's like being at high risk of Type 1 diabetes and develop resources to support people, to avoid anxiety and worry.
- Provide guidance for doctors on how best to care and support people who are at risk. Collect data on how Type 1 diabetes develops and understand why people progress from being antibody positive and at risk of Type 1 to needing insulin.
- Understand whether being at risk causes people to attend their GP or A&E more often.

There are around 400,000 people with Type 1 diabetes in the UK, around 8% of all cases of diabetes, and including over 29,000 children and young people. The number of new cases of Type 1 diabetes, especially in young children, are increasing by about 4%four per cent every year. (March 2024)

Blood sugar lows and highs hamper brain function in people with Type 1 diabetes

Large swings in blood glucose tied to Type 1 diabetes may affect the brain's ability to quickly process information. This research also showed that some people are more severely affected by these changes, which includes older people and those with certain health conditions.

The study found that very low and very high glucose levels were associated with slower and less accurate cognitive processing speed – this is the ability to respond to and process information quickly.

The most dramatic effect was seen at low glucose levels. Optimal cognitive processing speed is important for a wide variety of everyday tasks and contexts, from driving and operating machinery to decision-making in fast-paced environments.

Previous studies have shown a connection between low blood glucose and cognitive function in a laboratory setting. As we can now use digital sensors that measure glucose every few minutes, this is the first study to look at the impact of glucose fluctuations on cognition in people going about their daily lives. The research team collected data on glucose levels every 5 minutes and cognitive performance 3 times a day in 200 US participants over 15 days.

Results

- Cognitive processing speed was worse when glucose was much lower or much higher than usual.
- Participants' sustained attention, an element of cognition that represents the ability to stay focused on a task over an extended time but found that it was not significantly impacted by glucose fluctuations.
- There were differences in the extent to which changes in glucose affected cognition and identified factors that could predict who might be more at risk of severe impacts. This was the case for older people and those with certain health conditions, such as diabetes-related eye damage, kidney and nerve damage, fatigue and sleep apnoea.
- Surprisingly, participants' peak cognitive performance coincided with glucose levels that were slightly above their normal range, though performance dropped off as glucose levels rose even further. This is an important finding because people with diabetes often report feeling better at a glucose level that is higher than what is considered healthy. It could be that the brain habituates to a glucose level that it is used to so, a next step in this research is to see whether the glucose level associated with peak performance drops into the normal range when the amount of time spent above range is reduced. (Digital Medicine, March 2024)

Ultimately, the researchers hope to find ways to help people with Type 1 diabetes function at their best cognitively. Given rising evidence that people with Type 1 diabetes may be more at risk for cognitive decline and dementia, this could also potentially have long-term health benefits. (Digital Medicine, March 2024)



People with Type 1 diabetes not achieving glycaemic targets despite new technology

This research looked for reasons why people with Type 1 diabetes continue to experience severe hypoglycaemia and impaired awareness in high numbers despite the use of modern technology such as continuous glucose monitors (CGM) and automated insulin delivery (AID). Although these technologies have improved diabetes management, reaching glycaemic targets remains a challenge for many people despite their best efforts. If this applies to you, then it may be reassuring to know that you are not alone.

The targets have been to maintain blood glucose levels as near as possible to those of people without diabetes. The study included 2074 people with Type 1 diabetes who completed an online survey on their glycaemic results, severe hypos, loss of hypo warnings as well as information of continuous glucose monitoring and insulin delivery methods.

Results

- 91.7% were using CGM and half of these included AID but only 57% of participants reported achieving glycaemic targets.
- Around 20% reported having at least one severe hypo in the previous year.
- 30.7% of participants reported impaired hypoglycaemia unawareness despite using CGM or AID.

Conclusion

Given that a high proportion of the study participants used modern technology, the researchers concluded that educational initiatives continue to be important for everyone with Type 1 diabetes as well as the development of new therapeutic options and strategies. (Diabetes Care, February 2024)

Comments: As someone who has been around in diabetes for the last 50 years, it does seem that the trend over the last few years has been towards technology but has this been at the expense of basic education about diabetes? An example of this is are people as aware of the messages their body gives, such as their hypo symptoms or how they feel when they are too high?

A couple of articles that surely must raise eyebrows!

Really? Diet and exercise in a pill!

In recent studies conducted at research centres across the US, mice have eaten more, fattened up, exercised only if they felt like it, and still managed to lose body fat, improve their blood lipids, increase muscle power, avoid blood sugar problems and boost heart function. They did this by being given mimetics, experimental drugs that "mimic" the effects of exercise and calorie reduction in the body without the need to break a sweat or eat less.

What have been described as "have your cake and eat it, too" drugs aren't on the market for human use, but are getting closer. Several companies have moved into human trials with encouraging results. The National Institutes of Health in the US and the pharma industry are taking notice and increasing research funding. At the earliest, one could be approved by the US Food and Drug Administration in 4-5 years. The drugs are mimetics which apparently could one day prevent and treat serious conditions such as age and disease-related muscle loss, diabetes, heart failure, and neurodegenerative disorders like Parkinson's disease and Alzheimer's disease.



Mimetics have the potential to help non-dieters avoid weight gain and allow dieters to build and/or preserve more calorie-burning muscle, important because losing weight can reduce muscle, especially with rapid loss. Clearly, they have an appeal to the pharmaceutical industry, because it will be another profit-making drug!

How these drugs work is complicated and maybe we don't need to know this, but we have to question if mimetics are an effective pharmaceutical way to replicate two of society's biggest lifestyle problems - diet and exercise? We also have to question what happens when these drugs become available to the general public, will diet and exercise no longer be part of treatment?

One of the researchers is quoted as saying: "Our environment is designed to keep people sitting down and consuming high-calorie foods. In the absence of people getting motivated to exercise, and there's no evidence the country is moving in that direction on its own, a pill is an important option to have." (Journal of Pharmacology and Experimental Therapeutics, March 2024) IDDT has to question whether it is better that people pop yet another pill or actually do what was proven to work in years gone by – a balanced, healthy diet and exercise? Yes, we know that lifestyle has changed and is much more sedentary but is a pill really the way to deal with it, especially when we know that all drugs have side effects?

For IDDT, it seems amazing - cow hacked with human DNA to produce human insulin!!!

A team of scientists from the US and Brazil have found a new way to produce insulin – a gene edited cow that produces insulin in its milk. Their aim was to find a way of produce affordable and accessible insulin for the many people around the world unable to afford it.

The researchers inserted a segment of human DNA coding for the precursor of active insulin called proinsulin into the cell nuclei of ten cow embryos. Of the ten embryos, one calf was born in Brazil and once matured, the cow was impregnated and stimulated to lactate using hormones.

The researchers were surprised to discover that not only did the cow produce proinsulin but even produced insulin in her milk! The goal was to produce proinsulin and then go on to process it to produce insulin but the cow basically processed it herself. The gene-edited cow produced the equivalent of a gram per litre which means each gram is equivalent to 28,818 units of insulin.

It seems ironic!

The reason IDDT formed was to fight the battle to maintain animal derived insulins for the people who had adverse effects to genetically modified so-called 'human' insulin. In the course of this, the arguments used against us included:

- 'animal insulin is dirty'- never true as animal insulin was highly purified from the 1970s,
- 'synthetic insulin will be cheaper and easily available to supply the global need'- never true because GM 'human' insulin never became cheaper,
- The risk of BSE being passed on to human beings!

Yet here we are, using animals to produce real human insulin and not GM insulin!

Shortage of Tresiba® FlexTouch® pens

Department of Health and Social Care (DHSC) has issued a medicine supply notification for Tresiba Flextouch 100units/ml solution for injection 3ml pre-filled pens

Date of issue 24th May 2023, now amended

- Tresiba® FlexTouch® (Insulin degludec) 100units/ml pens will be out of stock from August 2023 until December 2024.
- Tresiba Penfill® (Insulin degludec) 100units/ml solution for injection 3ml cartridges remain available and can support increased demand.

The shortage only affects people using prefilled pens. If this applies to you, you will need a new prescription to change to Tresiba 100units/ml cartridges and a reuseable pen, the NovoPen 6.

If you have not used a disposable pen before, you may need to be shown how to load and change an empty cartridge by your healthcare professional.

The NovoPen 6 comes in two different colours, so it is advisable to have different coloured pens for different insulins.

Note

NovoPen® 6 & NovoPen Echo® Plus are intended for patients who have been prescribed Tresiba® or Fiasp®. NovoPen® 6 offers a 60-unit maximum dose in 1-unit dose increments.

NovoPen Echo® Plus offers a 30-unit maximum dose in 0.5-unit dose increments.

Carers are an important aspect of healthcare management – Carers Leave Act 2023

There are many forms of carers – parents, guardians, friends and live-in support but their role and influence is often overlooked. There are 5.7 million carers across the UK today, but unfortunately many of these don't receive the right support for their own health and wellbeing. People with diabetes are no exception and can be in need of family carers.

The value of unpaid care in England and Wales is £162 billion, almost equivalent to a second NHS. The UK's health and social care system would collapse without unpaid carers but many carers face huge pressures caused by the current cost of living crisis which is causing additional anxiety.

Carers Act

- If you're over 18 and provide regular unpaid care for someone, you're entitled to a carer's assessment under the Care Act. This is an opportunity to discuss your needs with the local authority.
- Carers should also register as a carer with their GP to be included in conversations and decision making about the person they care for.
- If you spend at least 35 hours a week caring for someone with an illness or disability, you may be eligible for financial support via Carer's Allowance.

Carer's Leave Act 2023

On 6th April 2024 millions of people who have unpaid caring responsibilities and are in paid employment are being recognised in law and receive

the right to five days unpaid leave through the Carer's Leave Act 2023.

The regulations:

The legislation will cover employees in England, Wales and Scotland and include:

- to be entitled to the provision, employees need to be providing long term care
- the leave will be able to be taken in half or full days, up to and including taking a block of a whole week of leave at once.
- the notice period an employee needs to give to take the leave is twice the length of time that needs to be taken in advance of the earliest day of leave.
- an employee does not need to notify their employer in writing regarding their request to take Carer's Leave, although they can do so if they wish to.
- importantly, employees taking Carer's Leave will have the same employment protections as associated with other forms of family related leave. This includes protection from dismissal or detriment as a result of having taken the leave.

Information about receiving a carer's assessment, as well as Carer's Allowance and additional financial support is available on the Carers UK website: www.carersuk.org

Pharma News

MannKind Announces Enrolment Goal Completion of INHALE-1 Paediatric Diabetes Trial of Afrezza®

Afrezza is powdered ultra rapid-acting inhaled insulin. It achieves blood insulin concentrations within 12 minutes and produces maximal glucose lowering in about 45 minutes with a short duration of action (about 3 hours). It allows for early suppression of endogenous glucose production.

MannKind Corporation is an American company focused on the development of

inhaled therapeutic products for patients with endocrine and orphan lung diseases including inhaled insulin. In February, it announced that it has fully enrolled 305 patients living with Type 1 or Type 2 diabetes in its INHALE-1 study assessing efficacy and safety of inhaled insulin in the paediatric population.

Afrezza is not licensed in the UK but is available to adults with Type 1 diabetes in the US. The researchers believe that there is a need for insulin preparations such as this to be available to children and adolescents living with Type 1 diabetes so enabling them to have the same

choices as adults with Type 1.

INHALE-1 is a 26-week open-label, randomised clinical trial with a 26-week extension. The primary endpoint is change in HbA1c level after 26 weeks. Secondary endpoints include change in fasting plasma glucose after 26 weeks and rate of hypoglycaemic events. The multi-centre study evaluated Afrezza in combination with basal insulin vs. multiple daily injections (MDI) of insulin in children and adolescents aged 4-17 with Type 1 or Type 2 diabetes. The researchers expect to complete a primary endpoint analysis in the fourth quarter of 2024 for submission for approval in 2025. (Published: February 2024)

Novo Nordisk EU positive opinion on once-weekly insulin for Type 2 diabetes

Novo Nordisk has announced that the European Medicines Agency's Committee for Medicinal Products for Human Use (CHMP) has adopted a positive opinion and recommendations for marketing authorisation for Awiqli®. This is a once-weekly analogue basal insulin designed to cover the basal insulin requirements for a full week with a single injection.

Trials involving more than 4,000 adults with Type 1 or Type 2 diabetes. showed:

- Once-weekly basal insulin icodec achieved superior blood sugar reduction (measured by a change in HbA1c) and superior Time in Range (time spent within recommended blood sugar range), compared with daily basal insulin in people with Type 2 diabetes.
- In people with Type 2 diabetes who have not previously been treated with insulin, overall observed rates of clinically significant or severe hypoglycaemia were below one event per patient-year of exposure with both once-weekly basal insulin icodec and comparators.
- In people with Type 1 diabetes, once-weekly basal insulin icodec demonstrated non-inferiority in reducing HbA1c with a statistically significant higher estimated rate of severe or clinically significant hypoglycaemia compared with insulin degludec (Tresiba). Non-inferiority means 'no better or no worse' than the comparator.
- Across the programme, once-weekly basal insulin icodec appeared to have a safe and well-tolerated profile.

Novo Nordisk said:

"We believe that by reducing the number of basal insulin injections from seven to one per week, Awiqli® has the potential to have a significant impact and improve treatment for people living with diabetes.

We are committed to driving innovation in diabetes treatment, and Awiqli® has the potential to become the insulin of choice for people with Type 2 diabetes initiating insulin treatment."

Novo Nordisk expects to receive final marketing authorisation from the European Commission within approximately two months. (Company announcement, March 2024)

Eli Lilly to offer low-cost insulin in Minnesota settlement

Eli Lilly agreed to provide low-cost insulin to patients and donate free insulin to clinics, to settle a lawsuit by Minnesota, USA that accused the three largest insulin makers (Novo Nordisk, Sanofi and Lilly) of deceptively raising the price of the diabetes treatment.

The settlement calls for Lilly to offer patients in Minnesota who pay out-of-pocket, the ability to pay no more than \$35 a month for its insulin products. Patients with insurance can also choose not to use their coverage and pay the \$35 instead. The settlement will be in force for five years.

Minnesota said the three insulin manufacturers fraudulently set artificially high list prices for their products, while offering rebates to pharmacy benefit managers in exchange for them covering the drug on behalf of health plans. Lilly said last March it would slash insulin prices and make it available to many patients for \$25 or \$35, following pressure from President Joe Biden, lawmakers and advocacy groups over skyrocketing costs.

However, a survey released last July found that many patients were still being charged hundreds of dollars for their insulin. (7th February 2024)

Novo Nordisk to expand obesity drug manufacturing

In February 2024 Novo Nordisk announced that it has agreed to acquire three fill-finish sites from Novo Holdings A/S., a global contract development and manufacturing organisation.

The acquisition of the filling sites, for an upfront payment of 11 billion USD, enables an expansion of the manufacturing capacity at scale and speed which is expected to gradually increase Novo Nordisk's filling capacity from 2026 and onwards.

Holiday Tips

If you are going on holiday this summer, it may be the first time you have travelled since your diabetes was diagnosed. Whether you are staying in this country or going abroad, for people who live with diabetes, going on holiday means more planning and taking a bit more care when you are away.

IDDT has a booklet on Holiday Tips which contains information and useful tips for holidays whether at home or abroad. It covers things like:

- Travelling by air and jetlag
- Dealing with heat
- Medication safety
- Diabetic Holiday Foot Syndrome

If you would like a copy of this handy FREE booklet, then please contact IDDT using the details at the end of this newsletter. Alternatively, the Holiday Tips are also on our website: www.iddt.org

A little something from us...

If you are going away, you may find one of our **FREE Tote Bags** useful. Measuring 35cm x 40cm, made from environmental-friendly, unbleached cotton and displaying our logo, they are ideal for carrying beach towels, sun cream and other holiday essentials.

For your **FREE Tote Bag** simply contact us again using the details at the end of this newsletter.

IDDT Event 2024 – 'Living with Diabetes'



We are holding an Event for you again this year. It will be held at the Kettering Park Hotel on Saturday, 28th September 2024 and there is an event booking form accompanying this Newsletter.

The day will start with our Annual General Meeting and then it will be an interesting day with speakers and group discussions. The title is **'Living with Diabetes'** to reflect some of the issues that are important to people living with diabetes.

We are pleased to tell you that we are being joined as speakers by Professor Alan Sinclair, Dr Charles Fox and Abban Qayyum who along with Dr Mabel Blades and Mr Ken Heard will lead groups on topics of your choice. So, something for everyone and we hope that you and your family - the spouses, the partners and the parents of those with diabetes, will be able to join us at the event. Just complete the form and return it to IDDT. Remember, the date for your diary is 28th September 2024!

NICE

Fluocinolone acetonide intravitreal implant for treating chronic diabetic macular oedema

**Technology appraisal guidance:TA953:13
March 2024**

In people with diabetes, high blood sugar

levels can damage the tiny blood vessels at the back inner wall of the eye, the retina, or block those vessels completely.

This condition is diabetic retinopathy. Tiny bulges, called microaneurysms, form in the blood vessels, leaking fluid into the retina.

This fluid can cause swelling in a part of the retina called the macula, which is part of the retina for seeing fine things, such as small print.

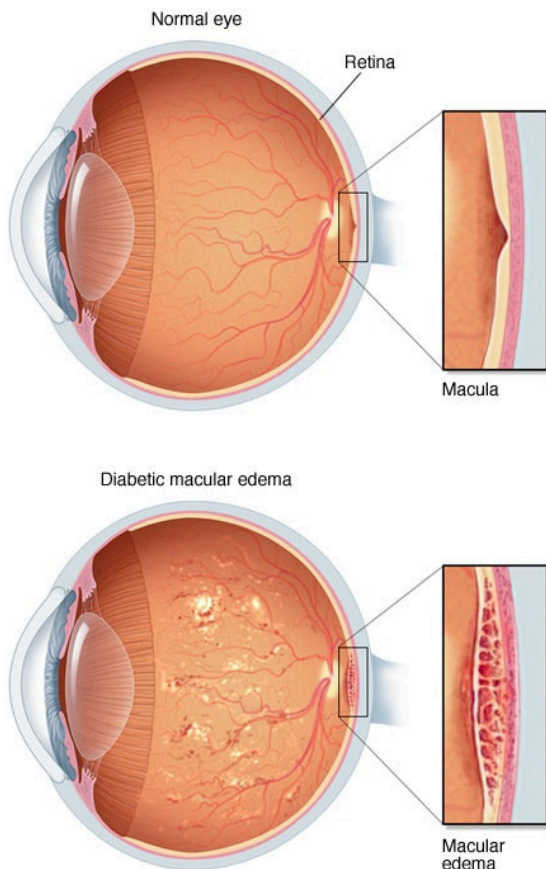
This is a serious eye problem called diabetic macular oedema. It can cause vision problems or blindness.

Recommendations

Fluocinolone acetonide intravitreal implant is recommended, within its marketing authorisation, as an option for treating visual impairment caused by chronic diabetic macular oedema that has not responded well enough to available treatments in adults. It is recommended only if the company provides it according to the [commercial arrangement](#).

The commercial arrangements are as follows:

There is a simple discount patient access scheme for fluocinolone acetonide intravitreal implant. NHS organisations can get details on the Commercial Access and Pricing (CAP) Portal. Non-NHS organisations can contact medicalinformation@alim-erasciences.com for details.



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Winners of the January 2024 draw are:

- 1st prize of **£478.56** goes to Ruth from Gloucester
- 2nd prize of **£358.92** goes to Anon. from Treharris
- 3rd prize of **£239.28** goes to Terry from Romford
- 4th prize of **£119.64** goes to Anon. from Halifax

Winners of the February 2024 draw are:

- 1st prize of **£476.16** goes to Frances from Chester
- 2nd prize of **£357.12** goes to Sandra from Kettering
- 3rd prize of **£238.08** goes to Anon from Southport
- 4th prize of **£119.04** goes to Anon from Worcester

Winners of the March 2024 draw are;

- 1st prize of **£477.12** goes to Anon from Thornton Heath
- 2nd prize of **£357.84** goes to Anon from Stratford on Avon
- 3rd prize of **£238.56** goes to Bethany from Doncaster
- 4th prize of **£119.28** goes to Janet from Biggar

Note: The winners of the draws for April, May and June 2024 will be announced in our September Newsletter and on our website.

A huge 'Thank You' to everyone who supports IDDT through the lottery. If you would like to join in for just £2.00 per month, then give us a call on 01604 622837 or email karl@iddtinternational.org

If we can be of help in any way, please contact:
InDependent Diabetes Trust (IDDT), PO Box 294,
Northampton NN1 4XS
Tel: 01604 622837 email: enquiries@iddtinternational.org
Or visit our website: www.iddt.org

From our own correspondents

Unbelievable! GP surgery: "We don't do eyes" Dear Jenny,

I wonder how many of your members have come across a new worrying trend of GP surgery's outsourcing services. Last week my 64 year old husband who has been Type 1 since he was 18 woke up and had no vision in his left eye which he described as trying to see through a thick fog. At spot on 8 am we both tried contacting our GP surgery and eventually after multiple calls, my husband spoke to someone taking triage calls who said "they didn't do eyes".

He told her it could be serious but all he got back was a text message to ring a call centre. I rang for him as he couldn't see the number and he was asked basic questions and told someone would call back within 10 hours and arrange for him to visit an optician. He had the same symptoms I'd had a few years ago when I had a bleed. I called the surgery back and told them I wasn't happy but they just didn't listen to our concerns.

In desperation, I called the eye clinic where he's been a patient ever since he had laser treatment 30 years ago. They wanted to know why it wasn't a GP referring him so I told them what they had said and they told me a nurse would call him back. She did within 15 minutes and arranged him an appointment the next day. He was told the sight loss was due to a build up of pressure, was given drops to use for a month and it was recommended that he has an eye injection in each eye. He was also told that an optician wouldn't have the equipment to pick the problem up. This seems to be a trend. I spoke to a friend who is with a different surgery and she said their's has the same system. Now call me old fashioned but what is the point of a GP if all they do is refer you to a call centre hundreds of miles away.

Please warn your members if they think there's a problem be pushy.

Mrs D.T.

The right path to follow!

Dear Jenny,
Thank you so much for all the booklets and all the information with them it's given us the right path to follow food wise with the meal planning and recipes, things don't feel so scary now, once again thank you.

By email

Multiple Daily Injections (MDI) with good success

Dear All,
I hope this information may be of use to yourselves and others with Type 1 diabetes, which I have had for 32 years. I am fortunate enough to use Abbott's flash glucose system to measure my glucose levels. I set myself the target figure of between 85% and 90% on the meter to start and was generally successful but it took some time to achieve. With the advent of the mark 2 FreeStyle Libre and the new alarm system, I increased my target to between 90% and 95%, thus giving even better control. My blood sugars have tended to fluctuate so the last 3 years, I have been using multiple daily injections (MDI) with a good success rate.

On this journey, I have found that even health-care professionals sometimes don't understand MDI. I was recently taken to Milton Keynes Hospital by ambulance for another reason and spent the day there. I received a copy of the report that they issued stating that I needed to see a diabetes specialist to stabilise my control! I sent them a copy of several weeks of my results, as they were mostly above target and never heard any more from them!

A friend of mine has been finger-pricking to test his blood glucose for many years until I finally persuaded him to insist his doctor to provide him with the FreeStyle Libre. The diabetes nurse he saw gave him this with a smartphone to read it and he was totally confused – not surprising as he is 85 years old. I emailed the manufacturers, Abbott, and asked them to send him a reader so he didn't have to use a smartphone. This they did and he is very happy now. I think smartphone is too complicated for many 85 year olds!

Mr P.R.

Whilst writing...

I have just renewed my membership and ordered some literature online. Whilst writing, please let me just add that I find your magazines to be absolutely outstanding and I read each one cover-to-cover!

The detailed subject articles are first class and I particularly like the research and health service updates - I find that health care professionals at clinics etc., are frequently unaware of items that you have covered. You might also be amused to learn that, during a recent hospital clinic (not for Diabetes), the Specialist Nurse mentioned that her 12 year old daughter was a recently diagnosed Type 1 and that her family were struggling with it.

At that point, the 'clinic' immediately reversed roles and as part of that 'consultation' I was able to strongly advocate the IDDT (she'd never heard of you of course)!

Mr C.R.
By email

She's happy with her IDDT Pack of Information!

Dear IDDT,
Thank you soooooo much for the fantastic pack soooooo informative

Helen

IDDT's comment – good to see we are getting things right!

Better medic/ patient conversation and cooperation

Dear Jenny,

As a Type 1 diabetic since 1960 I had a similar experience to Dominic Cooper who, in hospital found his diabetes care somewhat inflexible and with little willingness by staff to accept the patient view which long term diabetics have been living with for many years - including often been told by doctors that our experience is as valuable as their medical knowledge of this ancient disease.

In my case I had been retired for 17 years as a result of the human insulin I was prescribed. This was causing unexpected hypos leading to me immediately reverting to pork mixtard insulin. I was in 2020 admitted to two different mid-land hospitals for a heart operation. Following the successful operation I was again converted to human insulin - both Tresiba and Nova Rapid as was Dominic. This, despite my original reluctance to move from the long establish two daily injections to four, has given me much improved blood sugar control.

During my 3 weeks hospital stay I received good care from a specialist diabetes nurse who suggested my conversion to 4 injections per day and one other staff nurse whose knowledge was enhanced due to her husband also being Type 1 diabetic.

My main frustrations were the way that, although I was permitted to draw up my own insulin and inject it after checking, but it was kept in a locked drawer by my bed and I was not allowed to inject out of the Ward rotation of several diabetic patients even if my blood sugar was high and climbing (for example pre-breakfast). Injecting within 20 mins prior to a meal, as I had been taught when first diagnosed, appeared to have no consideration.

diagnosed, appeared to have no consideration. Again similar to Dominic, I found that, despite being labelled as suitable for diabetics, the pre-order hospital meals were mainly full of carbs and I often needed to leave food on the plate in order to keep my blood sugar in control!

Overall the message is better medic/ patient conversation and cooperation.

Mr K.R.
By email

Sharps boxes are full and its frustrating

Dear IDDT,
I am a carer of someone with diabetes with other conditions that require a carer and I organise repeat prescriptions, medications pick up and administering. Full sharps boxes are refused by the surgery, the issuing pharmacy and the hospital but nobody referred me to anywhere that would take them and the can'ts and don'ts have reduced me to anger, tears and frustration!

Internet searches eventually led me to putting in a postcode for an adjacent town and local authority to get a list of pharmacies that I can reach on the bus. (List does not include the pharmacy that dispenses the boxes!) I also emailed the surgery, which replied they will take full boxes.

I have taken the precaution of screenshotting the pharmacy list, and the surgery email reply, in case of further problems. I hope I don't get refused again, but will insist on speaking to pharmacy and surgery manager if so. (Bonus feature is that an acquaintance has recently become surgery manager!) I hope this helps anyone else having similar problems.

By email

IDDT Comment: years ago, people with full sharps boxes were advised to telephone the local authority waste disposal department to arrange an appointment for collection.

It may be worth a try, but many people report that this is not happening any more. The writer of the above letter says that her local council do collect clinical waste and broken glass but not sharps boxes!



SNIPPETS

Maybe you didn't know this about dahlias!



The dahlia is native to Mexico and is the national flower. It was known by the Aztecs as Acocitli or Acocoxochitl. It was considered to be an important plant to the Aztecs as they considered it a source of medicine for epilepsy, among other things. Antibiotics are found in the tubers which also provide a source of inulin which is NOT to be confused with insulin. Inulin is a natural sweetener that was used for diabetes. Gardeners are advised not to self-medicate with dahlias – just admire them. Sent by a reader in Auckland, New Zealand from the Torbay Garden Club magazine!

High sugars after exercise

High sugars after exercise is not what we are led to believe will happen – usually exercise lowers blood sugars and we have to take precautions to avoid hypos either during exercise or in the time afterwards. However, sometimes blood sugars go high during exercise, so why?

The reason for this is high intensity exercise can result in a rise in blood glucose levels which indicates that you are mobilising stored glycogen in the liver. This means that the exercise is too intense for your body to firstly rely on fat to provide energy and so needs to use the stored glycogen as fuel. Glycogen is released from the liver when there is an emergency, such as a severe hypo, and changes into glucose to raise blood glucose levels.

Sugary drinks tied to Type 2 diabetes risk in boys

Preliminary findings of a recent study have shown that consumption of sugary drinks and fruit juice by boys was associated with developing Type 2 diabetes later in life. Each 8 ounce daily sweetened drink was associated with a 34% increase in insulin resistance when boys reached their teens but researchers said the same results were not found in girls. (American Heart Association, March 2024)

It's a huge amount of money!

Healthcare bodies in England spent a record £4,800,000,000 with technology suppliers in the year 2022/2023. This figure is set to grow as a result of the 2024 Spring Budget which promised to boost NHS productivity through digital transformation.

- 104% growth in the healthtech market's size between years 2018/19 and 2022/23.
- 10 technology firms occupy 43% of the market.
- £329m worth of healthtech contracts are due to happen in 2024

Neurological conditions – world's number one reason for ill health and disability

A new study has shown that neurological conditions are now the leading cause of ill health and disability globally, affecting 3.4 billion people worldwide in 2021. The major causes of this increase in neurological ill health were stroke, neonatal encephalopathy (brain injury), migraine, Alzheimer's and other dementias and diabetic neuropathy (nerve damage). The fastest-growing condition was diabetic neuropathy, which mirrored the global rise in diabetes.

Globally, the number of people living with, or dying from, neurological conditions has risen substantially over the past 30 years, rising by 18% over the past 31 years. Researchers say this could be due to the growth and ageing of the global population as well as increased exposure to environmental and lifestyle risk factors. (The Lancet Neurology, 15th March 2024)

Scotland - new-onset Type 1 diabetes cases among children decline in 2022 after sharp increase

In 2022, rates of new-onset Type 1 diabetes among children in Scotland fell to pre-pandemic levels after sharply increasing in 2021, according to a population-wide analysis of data from Scotland. The highest incidence of new cases from 2015 to 2022 occurred in children ages 6 to 14 years. (Diabetes Care, March 2024)