### InDependent Diabetes Trust Newsletter



SPRING 2025 Newsletter, Issue 124

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## New Year welcome

This is our first Newsletter of 2025 and so our first opportunity to give our best wishes for the New Year to all our readers. We know that life can have its difficulties but let us hope that 2025 can be as happy and healthy as possible, for us all.

This is also an opportunity to remind you that IDDT is here to help in whatever way we can. Sometimes, a worry or query may seem trivial, but it is worth asking about it to put your mind at rest, so give us a call or send an email and we will do our best to help.



## **Update from Ukraine**

Just before Christmas, Dmytro and his partner came to England to collect all the unwanted, in-date items that have been donated to IDDT to help people with diabetes in Ukraine. The number of items that were donated last year was tremendous and Dmytro expressed the thanks of people in Ukraine.

In addition, we have to express our gratitude to our knitters for their continued support – we have sent 52 boxes of knitted hats, gloves, scarves and teddy bears. We also sent sweets and all these goods went to children in orphanages to give them some cheer at Christmas.

The main items donated to IDDT were:

- 730 Blood glucose meters
- 20,640 Test strips
- 28,805 Pen needles
- 83,720 Lancets
- 83,720 Syringes
- 28 Boxes of pump items
- 897 Insulin cartridges
- 2,174 Pre-filled pens
- 293 Insulin vials
- 7,029 Tablets for Type 2 diabetes



## Sad news to report

### Written by Jenny Hirst, Co-chair

As I am Co-chair of IDDT, this is particularly difficult for me to write. Martin Hirst, who until recently has been IDDT's Chief Executive (CEO), is my son and in January 2024, Martin had a fall which caused a severe brain injury. He was initially treated in critical care but has been in a neuro rehab hospital since May 2024. After more than a year, it is clear that Martin is not likely to recover sufficiently to be able to continue in his role as CEO.

Martin joined IDDT in 2008 and has carried out many roles within the Charity and 10 years ago he became Chief Executive. He has been responsible for much of the growth of IDDT and its increasing membership, some of our booklets and has written the guarterly Newsletters for

people with Type 2 diabetes, 'Type 2 & You'. Martin never liked being in the limelight or the centre of attention, but he was incredibly organised, and his management of the Charity enabled it to be very efficiently run with just a small team. It is thanks to his organisational skills that we have been able to pick up the pieces so easily and continue with the smooth running of IDDT.

IDDT Trustee, John Birbeck, said: "Under Martin's leadership of IDDT, he has ensured that the Charity is run as an efficient organisation with all the key roles and responsibilities clearly identified and resourced. He has recruited a small multidisciplined dedicated team who embody the aims of

the Charity and are willing to go the 'extra mile'. This is clearly demonstrated by how effectively the organisation has been run in his absence, thereby leaving a lasting legacy of his time as CEO of IDDT – he will be sorely missed."

With two hats on, as Martin's mother and as Co-chair of IDDT, I have to say a huge thank you to the staff team for their support both personally and for the extra work they have taken on. I also have to thank Olly Jelley and the staff at Orange Juice Communications for taking on some of the workload, to Stuart Lacey our webmaster and Rupert Campbell-Black our IT adviser for their support and help throughout what has been a difficult year.



## You are not alone

A survey conducted by the International Diabetes Federation (IDF) that was released towards the end of 2024 showed 77% of people living with diabetes have experienced anxiety, depression or another mental health condition. The survey also showed that three in four people living with diabetes have asked for support for their emotional and mental wellbeing from their healthcare teams. The most common causes were:

- Fear of developing complications (83%)
- Daily diabetes management (76%)
- Stigma and discrimination (58%)
- Fear of needles (55%)

The survey also showed that as many as 79% diabetes but all of people living with diabetes have had, or are it or not, soor experiencing, 'diabetes burnout' mainly due to the demands of daily management. 

When by Importantly, three in four of those with burnout admitted to stopping or interrupting their treatment due to feeling overwhelmed.

One doctor, who has been as a whole person, not as treating people with diabetes a patient, we're seeing for over 30 years, commented: "Mental health is not something a human being, so we that most doctors are concerned will treat them about because in the consultations differently." they are focused on treatment, test results and prescribing. When someone comes to the consultations, if we see that person as a whole person, not as a patient, we're seeing a human being, so we will treat them differently. If we do that with every patient, the world can change."

The IDF is calling on healthcare providers, policy makers and communities to recognise the profound effect diabetes has on well-being. Putting well-being



at the heart of diabetes care can improve health outcomes and overall quality of life for millions of people with diabetes around the world.

#### Just a personal perspective...

My daughter was diagnosed with Type 1 diabetes 50 years ago when she was five years old before home blood glucose testing and all today's technology, so times were very different. Yes, we concentrated on trying to achieve 'good' glucose results using urine testing but to do this, the emphasis was on education – learning about diet, exercise and their effects.

At the same time, it was recognised that living with diabetes took its toll not only on the person with diabetes but also on other family members. Believe ad, or are it or not, soon after my daughter's diagnosis, we were offered support and understanding by the first diabetes specialist nurses who visited people at home! We

had someone to talk to about our worries and fears who understood that our quality of life was important.

However, as technology developed, targets and results seem to have become the most important aspect of living with diabetes. I can understand this because we all live with the fear of the

long-term complications, but this does seem to be at the expense of quality of life. Perhaps there is a difference in priorities – people who have to live with a long-term condition know the importance of quality of life but professionals looking after them have different priorities; good blood glucose results seem to be the most important. Of course, I have to mention the huge increase in the amount of profit being made from technology, insulin and drug developments by the pharmaceutical industry. There's not much profit to be made from quality of life improvements!

Perhaps the final words must go to Sara, an advanced practice nurse in the US who wrote the following: "People aren't being taught lifestyle changes. They want to continue to eat and not exercise. We should be pushing nutritional education and healthy living the way drugs are pushed."

## Fasting and diabetes

Two major religions, Islam and Christianity, have periods of fasting around this time of year (many other religions also have fast periods), so we are looking at religious fasting and its impact on the management of diabetes. Many readers will have fasted before, so this article may be just a reminder but for those of you who have not, we look at fasting practices and general issues around diabetes and fasting and hope that we provide some helpful tips for staying safe and well during your fast.

#### Islam - Ramadan

Ramadan is based on the ninth month of the lunar calendar and moves forward each year by about 11 days which means the length of fasting is greater in certain years than others.

This year the fast of Ramadan will commence at sunset of 28th February / 1st March and will last until 30th / 31st March 2025. During Ramadan it is expected that Muslims who participate will abstain from food, water, beverages, smoking, oral drugs and sexual intercourse from sunrise to sunset.

#### **Christianity - Lent / Easter**

Easter Sunday is celebrated on the first Sunday following the full Moon that occurs on or just after the spring equinox. Although not followed by all Christian denominations, Lent lasts for 40 days, concluding on Maundy Thursday, immediately prior to Easter Sunday. This year, Lent is from 5<sup>th</sup> March to 17<sup>th</sup> April, with Good Friday on 18<sup>th</sup> April and Easter Sunday on 20<sup>th</sup> April. During Lent, certain days are regarded as fast days, which again has implications for people with diabetes.

#### Diabetes and fasting

People with diabetes of either faith may be exempted from fasting but the majority of people with diabetes do fast so run increased risks of health adverse effects, such as hypoglycaemia, hyperglycaemia, diabetic ketoacidosis and dehydration. Most of these are as a result of a reduction of food and fluid intake and the timing of meals.

If you have diabetes, fasting can cause complications in managing the condition, some, arguably more serious than others. The best first step is to speak to your doctor or diabetes nurse to discuss the potential risks and problems associated with fasting.

This will help you to formulate a plan to manage the period of your fast.

Things you may want to think about and discuss could include:

- Complications of diabetes, such as poor vision or heart or kidney disease, can be aggravated by fasting and you may want to consider whether to fast or not
- If you take insulin and / or certain tablets, you
  may need to think about changing the amount
  and timing of your insulin dose to control blood
  sugar levels. You may also need to change the
  type of insulin you are using, for example, premixed insulins are not recommended during
  fasting

Research has shown that both education about the effects of fasting and relevant advice can dramatically reduce the likelihood of problems occurring with either low or high blood sugar levels. High blood glucose levels can develop during a fast if you do not take prescribed medication or if you are less physically active than normal, which, in turn, could lead to diabetic ketoacidosis (DKA) – a serious condition requiring hospital treatment.

If you are still happy to proceed with your fast then there are some simple, common-sense tips and tricks to help manage your diabetes:

- Before starting the fast, you should eat foods containing slowly absorbed carbohydrates, such as rice, dhal, potatoes and pasta, along with fruit and vegetables
- You should check your blood glucose levels more often than you normally would
- When you break the fast, have only small quantities food and avoid eating only sweet or fatty foods
- Try to eat just before the break of dawn, when you commence the next day's fast
- At the end of fasting, you should drink plenty of sugarfree and decaffeinated fluids to avoid being dehydrated

Above all - stay safe!



### Funding for health and social services

### £30 million for NHS Trusts to deliver high quality research

In October 2024, the Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health (Baroness Merron) made the following statement: "I am pleased to announce Department of Health and Social Care (DHSC) funding of nearly £30 million through the National Institute for Health and Care Research (NIHR) for capital equipment, technology and modular buildings to support NHS trusts in England to deliver high-quality research to improve the health of the population."

She explained that this large-scale investment will:

- Support 36 NHS trusts to develop and deliver research which aims to reduce early death from major conditions and improve access to highquality health and care
- Increase NHS capacity to deliver commercial clinical trials which bring innovative medicines to patients earlier and maximise our potential to lead the world in clinical trials
- Include investment in modular buildings to expand the footprint for research in hospitals, many of which are in rural and coastal areas. It is important that everyone, regardless of where they live, can access the latest innovations in the health and care system through research

### Examples of funding going to NHS Trusts up and down the country:

- A mobile research unit in Hull will increase participation in trials in East Yorkshire; and modular buildings will expand capacity for clinical research in Bradford, Essex, Exeter and Derby
- Walsall Healthcare NHS Trust is receiving funding for a mobile X-ray unit to increase their capability to carry out trials that are normally only available in large research units
- Alder Hey Children's NHS Foundation Trust is to receive funding for equipment which applies red and near infra-red light to injuries or lesions to improve wound and soft tissue healing. This enables children to participate in studies at their regular clinic, reducing travel and reaching underserved communities
- Southern Health NHS Foundation Trust and East

Lancashire Hospitals NHS Trust will expand their capacity for commercial trials in conditions such as dementia with a standalone pharmacy space and a pharmacy dispensary, respectively, to enable studies in new medicines

 The Royal Marsden has received funding for equipment to increase capability and capacity in advanced therapy areas in oncology

According to Baroness Merron's statement, this funding will support cutting edge research to improve the health of the population and support commercial research delivery in NHS settings. This will benefit patients but also the economic growth of the country by the UK being seen as an attractive place for companies to invest in research.

While the equipment or technology is primarily for research, when not in use in this way, equipment such as MRI Scanners will be used for clinical care. This will bolster the capacity of the health system to carry out procedures such as diagnostic testing to inform care and reduce the time taken to treatment, maximising the benefit from this investment.

### What did the budget say about health and social care?

As we all are aware, the October 2024 budget was the first one for the Labour Party for many years and the first one ever for a female Chancellor! Putting all this aside, as a charity concerned with health and wellbeing, we need to be aware of the promises that have been made because they affect our futures. It is good to see that the NHS plan is for 10 years, taking us over the next general election which hopefully may mean that the NHS will not be used as a political football! Here are the promises:

- £600 million worth of grant funding to be delivered to local authorities to pay for social care
- 10-year NHS plan to be published in Spring 2025
- Day-to-day health spending is to rise by £22.6 billion and capital spending by £3.1 billion this year and next year
- £1 billion provided to address the backlog of repairs and upgrades in the NHS.
- £1.5 billion for new hospital beds, extra capacity for diagnostic tests, and surgical hubs

## BITS AND PIECES

#### Latest life expectancy data

Life expectancy in large areas of Britain is still below pre-pandemic levels:

- Compared with 2017-19, male life expectancy in 2021-23 was just over half a year lower for men and a quarter of a year lower for women
- Over the same period, male life expectancy was lower in over 80% of local areas and female life expectancy was lower in 70% of local areas
- At 79 years for males and 83 years for females in 2021-23, life expectancy in England is lower than in most western European countries where, by 2023, it had recovered to pre-pandemic levels or was slightly higher

Life expectancy in both males and females is highest in parts of southern England and lowest in some northern areas:

- The gap between areas with the highest and lowest life expectancy is now 10.3 years for males and 0.8 years for females. This is wider than it was in 2021-23
- Males and females in Blackpool continue to have the lowest life expectancy in England, six and four years lower than the national average respectively



The Government has an ambitious goal of improving healthy life expectancy and halving the regional gap, but this looks increasingly challenging. The Government will need to take bold action to reduce the prevalence of preventable conditions like cardiovascular disease and diabetes. Tackling the wide geographical inequalities in ill health and premature mortality, and the socio-economic factors that drive them, must be a core part of these strategies if the goal of reducing the 2.8 million people unable to work because of long-term sickness is to be achieved. (5th December 2024)

### MHRA press release for people using CGMs or insulin pumps

In a press release issued on 8<sup>th</sup> October 2024, the Medicines and Healthcare products Regulatory Agency (MHRA) asked patients to report any safety problems with their continuous glucose monitor or insulin pump through the MHRA Yellow Card scheme without delay. Here is what it says:

"Over 5.6 million people in the UK live with diabetes, many of whom rely on these devices to manage their condition and their use can significantly improve the quality of life for patients. However, adverse incidents relating to these devices can occur, and while most of these incidents do not result in harm to the patient, they can potentially lead to the incorrect amount of insulin which can lead to abnormal blood sugar levels, with potentially serious health consequences."

The MHRA utilises the Yellow Card reporting scheme for signal detection and trending activities to identify safety concerns that may require action. As of January 2023, the MHRA received fewer than 300 Yellow Card reports from healthcare professionals and members of the public relating to these devices, which is significantly fewer than would be expected given their widespread use. The MHRA is therefore reminding users how to report adverse incidents and potential safety issues for patients.

To aid this vital reporting, the MHRA has introduced new step-by-step guidance, giving people living with diabetes detailed information on how to report any safety concerns with their device and what information they need to include. This guidance



provides examples of the types of issues which should be flagged and images to help guide users in their reporting.

Dr Alison Cave, MHRA Chief Safety Officer, said:

"Patient safety is our top priority, which is why we urge anyone using devices to manage their diabetes to report to us without delay any safety concerns they may have. We know adverse incidents can occur with the use of these devices. The vast majority of these incidents don't result in harm but potentially could have serious consequences.

"Every report is valuable to us as it will provide valuable insight and potentially inform future regulatory measures designed to protect patients. We are ready to take whatever action is needed.

"If you are concerned that there is an issue with any of your diabetes devices, please use the guidance at <a href="https://www.gov.uk/government/publications/report-safety-concerns-with-insulin-pumps-and-continuous-glucose-monitoring-equipment to complete a Yellow Card report online using the Yellow Card website at <a href="https://www.gov.uk/guidance/the-yellow-card-scheme-guidance-for-healthcare-professionals">https://www.gov.uk/guidance/the-yellow-card-scheme-guidance-for-healthcare-professionals</a> or via the free Yellow Card app."

Professor Partha Kar, past NHS England Type 1 Diabetes & Technology lead, said:

"These devices can be life-changing for people living

with diabetes, giving them the confidence to go about their days knowing they are safe and able to enjoy themselves, so their operational effectiveness is of paramount importance.

"The MHRA also urges people to speak to a healthcare professional without delay if they have concerns that their health may have been impacted by a potential safety issue relating to their device."

Here are examples of the types of issues:

- Concerns with accuracy of delivery from the insulin pump (e.g. suspected underdose or overdose, unexpected bolus doses, non-delivery of insulin).
- Concerns with accuracy of results from a continuous glucose monitor (CGM). As part of your report, please say what the readings were on the CGM and the approved blood glucose meter including the time elapsed between the two readings
- Skin reaction to the sensor adhesive. If a patch test was carried out, please let us know
- Technology concerns, such as:
  - Connectivity issues between the various parts of the diabetes management system
  - Concerns with the touchscreen, display or buttons
- Physical failures, including leaks and cracks

## Research

#### Are expensive new drugs worth it?



A new study has found that the approval of new drugs in England has come at a heavy cost to many others due to a loss of funding. The analysis has found that while new medicines can be a lifeline for millions of people, in the last 20 years in England public spending on them came with significant trade-offs that indicate the money paid for new drugs may be better spent on other health services. Once the National Institute for Care and Excellence (NICE) recommends a new drug, the NHS must pay for it, if it's prescribed by a doctor.

However, with a limited budget, NHS spending on new drugs means other health services won't be funded, and this is not always considered when policymakers and health professionals weigh up the cost-effectiveness of new medicines. So, there are people who are losing out as a result of prioritising new drugs.

### Other analyses

Other analyses have shown that, on average, it costs about £15,000 to pay for one year of health. This measure is known as quality-adjusted life years (QALYs). The researchers used this figure to estimate the number of healthy years that could be bought with the £75.1 billion the NHS spent on new drugs between 2000 and 2020.

The analysis showed that:

 The new drugs earned nearly 3.75 million QALYS for about 19.8 million patients but if that funding had been used for other health services or treatments, it could have supported 5 million QALYs. That's a net loss of about 1.25 million healthy life years

There is no doubt that NICE recommendations for spending money on new drugs could fund other health services, but NICE only recommends new treatments that offer value-for-money for the taxpayer.

The study authors said that the UK government should consider adjusting how it decides on the cost-effectiveness of new medicines and could even push to bring down drug costs so they are more in line with other medical services. However, they did point out that this would probably face fierce opposition from the pharmaceutical industry. In the meantime, it has been suggested that NICE should be more transparent about the potential consequences of prioritising new drugs over other treatments with suggestions that NICE committee members may reach different decisions if they're presented with that trade-off.

(The Lancet, December 2024)

### Vitamin D deficiency can lead to autoimmune diseases



Researchers have discovered a link between vitamin D deficiency and autoimmune diseases, highlighting the importance of adequate intake, especially during childhood development.

During winter the sun's angle is too low to produce vitamin D in the skin affecting our levels of this essential nutrient which can lead to a vitamin D deficiency. Vitamin D is an essential nutrient that:

- Helps the body absorb calcium to promote strong bones
- Helps to strengthen the immune system
- Plays an important role in cardiovascular health
- Helps to build and maintain muscle mass
- Helps to regulate blood pressure by helping the kidneys to manage salt
- Plays roles in brain and cognitive function

More recent research has discovered another important role of vitamin D – it helps to regulate the immune system. As children develop, the thymus helps to train immune cells to distinguish between body tissues and invading cells. The thymus is the

organ primarily responsible for the production and maturation of immune cells. This new research suggests that a vitamin D deficiency during this crucial stage of life causes the thymus to age more quickly and become less effective at filtering out immune cells that could mistakenly attack healthy tissues increasing the risk of autoimmune disease like Type 1 diabetes.

These findings could lead to new strategies for preventing autoimmune diseases.

Although this study was conducted with mice, the researchers say the findings are still relevant as the thymus functions similarly in mice and humans.

Moving forward the researchers hope to further explore how vitamin D impacts the thymus and also to conduct future studies involving the human thymus, which have never been done before.

(Science Advances, October, 2024)

#### **Tips**

It is harder to get vitamin D from the sun in the winter, but getting outside for 20 minutes a few times a week helps to mitigate the seasonal drop in vitamin D levels. There are food sources that help to avoid developing a vitamin D deficiency during the long winter months and these are fatty fish like salmon, tuna and sardines, as well as cod liver oil, beef liver, egg yolks and some types of mushrooms.

### 1 in 4 people unaware of the signs of kidney disease



In October 2024, Kidney Care UK reported that chronic kidney disease (CKD) currently affects one in 10 people in the UK (over 7 million people) but 1 million of those are not even aware they have CKD.

Diabetes and high blood pressure are the two leading causes of CKD but the following figures are of great concern:

- Over 70% of people with high blood pressure do not have an annual urine test for CKD
- 45% of people with Type 1 diabetes and 32% of people with Type 2 diabetes do not have their annual urine test for CKD

Unless urgent preventative action is taken to improve

diagnosis and treatment rates, CKD is predicted to be the fifth leading cause of death globally by 2040.

IDDT is particularly worried about these figures because both blood pressure and kidney problems are just two of the annual checks that should be carried out in ALL people with diabetes, according to NICE recommendations. So clearly significant numbers of people with diabetes are not receiving the care and treatment they should. Although age-based screening is offered for people aged 40 to 75 via the NHS Health Check, only half attend. It is also important to be aware that people with pre-existing conditions such as diabetes, are not included in the NHS Health Check programme.

#### The most common signs of CKD

These are cramps, itchy skin, dietary changes (food tasting different to how it is normally), nausea and / or vomiting, exhaustion, changes to your wee and swelling of your ankles / legs or face.

Research also showed:

- Over one third of people (35%) do not recognise that changes to their wee are linked to kidney disease
- More than three quarters (76%) do not realise that itchy skin is a sign of kidney disease
- More than three quarters (76%) do not realise that muscle cramps are a sign that their kidneys may not be working properly
- Almost two thirds (64%) of people do not know that a puffy face, or swollen ankles / legs is a sign
- Only half of people recognise that exhaustion is a sign

In response to this, Kidney Care UK is urging people in at risk groups to be screened. Delay in the diagnosis of moderate to advanced CKD by just one year results in a 63% higher likelihood of kidney failure requiring costly and burdensome treatment to stay alive, such as dialysis or a transplant. Whether people are identified early or late, there will always be a cost to the NHS, but by identifying people sooner, more can be done to prolong their kidney health, improve their quality of life and reduce the impact on health and other services.

Note: IDDT has booklets with more information about kidneys and diabetes and about the nine key checks that you should have. If you would like copies, give us a call on 01604 622837 or email enquiries@iddtinternational.org.

## Type 3c diabetes

IDDT has members who have Type 3c diabetes but we have not really given space in our Newsletters to discuss what it is, what causes it or how it is treated. For this, we apologise!

Type 3c diabetes develops when another disease causes damage to the pancreas and it is linked to other conditions, all of which affect the pancreas and include:

- Acute pancreatitis
- Chronic pancreatitis
- Pancreatic cancer
- Cystic fibrosis
- Haemochromatosis
- Pancreas removal because of any other damage

Type 3c diabetes may also be called pancreatogenic diabetes, pancreatic diabetes, and post-pancreatitis diabetes. You can only get Type 3c diabetes because of an illness or condition that affects your pancreas.

Although it's different to other types of diabetes, it may be misdiagnosed as Type 2 diabetes because Type 3c isn't as well known. If you are being tested for diabetes, then you should make sure you mention your pancreatic issues so that they know that you're at risk for Type 3c.

Note: The following organisations can offer support for some of the conditions related to Type 3c:

Pancreatic Cancer UK, tel: 0203 3537090 email: <a href="mailto:supportercare@pancreaticcancer.org.uk">supportercare@pancreaticcancer.org.uk</a>

Haemochromatosis UK, tel: 0303 401101

email: helpline@huk.org.uk

**Cystic Fibrosis Trust**, tel: 0300 3731000 email: <a href="mailto:helpline@cysticfribrosis.org.uk">helpline@cysticfribrosis.org.uk</a>

#### What is Type 3c diabetes?

When the pancreas is damaged by conditions like pancreatitis, this can harm the islet cells. This is different from other types of diabetes, like Type 1 or Type 2 where the main problem is in the islet cells – either because the islets are destroyed (Type 1) or don't work as well as they need to (Type 2).

In Type 3c diabetes, the damaged pancreas causes dysfunction or destruction of the insulin-producing islets, so the pancreas can't make enough insulin

anymore, which makes it hard for your body to regulate blood sugar levels. This damage can also affect other hormones made by the pancreas that help to regulate blood sugar. As a result, people with Type 3c diabetes can experience both high blood sugars (hyperglycaemia) and low blood sugars (hypoglycaemia).

In addition to the pancreas's role to produce insulin, it also creates and releases digestive enzymes that break down nutrients from the foods we eat so people with Type 3c also have these issues, known as its exocrine function. Some people also have maldigestion or malnutrition because of the injury to the digestive functions of the pancreas which can make blood glucose levels more unpredictable and challenging to manage.

### Is Type 3c diabetes rare?

Approximately 9% of all diabetes cases are Type 3c, but there is a lack of awareness among the general public and some health care professionals. The exact number of people with Type 3c is unknown but a 2008 study of 1,922 people with diabetes found that 8% had Type 3c diabetes. As Type 2 diabetes is the most common form of diabetes and Type 3c diabetes may present like Type 2 diabetes, Type 3c diabetes is often misdiagnosed as Type 2. Unlike Type 2 diabetes, Type 3c is caused by damage to the pancreas, which then also injures the insulin producing islet cells which means Type 2 diabetes and Type 3c diabetes can have different treatment needs.

#### **Symptoms of Type 3c diabetes**

As we have said, with Type 3c your pancreas may not be able to give you what you need to digest your food, called pancreatic exocrine insufficiency (PEI).

The signs to look out for can include:

- Unintentional weight loss
- Stomach pain
- Feeling more tired than usual
- Slow wound healing
- Frequent infections and headaches
- Frequently passing urine
- Diarrhoea



- Fatty or oily stools
- Hypoglycaemia (low blood sugar)
- Weakened immune system
- Organ damage

If you notice any of these symptoms, or have any concerns, then you should speak to your doctor.

#### Tests used to diagnose Type 3c diabetes include:

- Blood glucose tests your doctor may order a blood test to find out if your blood glucose levels are within normal range and may also recommend an HbA1c test to determine your average blood glucose levels from the past two to three months
- Pancreatic imaging tests if you have not been diagnosed with a risk factor for Type 3c diabetes, your doctor may order a pancreatic imaging test to confirm if your pancreas has been damaged. There are several different pancreatic imaging tests

#### Managing Type 3c diabetes

Managing Type 3c diabetes in the right way can be a challenge because there isn't a one-size-fits-all treatment as it depends on how much damage there is to the pancreas. There are currently no generally accepted guidelines for treating Type 3c diabetes.

Treatment is likely to start with metformin to help manage blood sugar levels as metformin helps the body to use the naturally produced insulin to work better. This should then reduce your blood sugar levels, but if this isn't enough to manage blood sugars and there is weight loss, then it is likely that insulin will be prescribed.

Many people with Type 3c diabetes require insulin at an earlier stage compared to people with Type 2 but if metformin is working for you, then you should have a six monthly check with your healthcare team to see if you need to move on to insulin.

It is likely that your healthcare team will also discuss

with you any diet and lifestyle changes you might need to make.

Type 3c diabetes patients may also have exocrine pancreatic insufficiency (EPI) and if so, they may need pancreatic enzyme supplementation (PERT) to improve digestion and help avoid malnutrition.

#### Lifestyle changes

Lifestyle changes have also been shown to improve symptoms of Type 3c diabetes, such as:

- Monitor Blood Sugar regularly monitoring blood sugars may help decrease diabetes symptoms. Depending on the monitor's reading, you may need to alter your blood sugar levels by taking medication for diabetes, synthetic insulin, or consuming foods that are high or low in sugar
- Adjust Diet Type 3c diabetes can make it difficult to ensure your body is getting all the nutrients it needs. In general, the recommended diet includes protein, fruits and vegetables and is low in sugar and fat. It is better to avoid eating large portions and, instead, space your meals throughout the day
- Physical Exercise this has been shown to improve overall physical and mental health and can include various activities such as jogging, stretching, swimming, yoga, and dancing. In addition, guidelines for treating Type 3c diabetes recommend about 150 minutes of moderate exercise per week

### Just a note – not to be confused with Type 3 diabetes!

The term Type 3 diabetes has been used unofficially to describe diabetes that affects people with Alzheimer's and is NOT the same as Type 3c diabetes. Currently research is being carried out to look at the link between Alzheimer's and Type 2 diabetes which should give a better insight into why people with Type 2 diabetes are more likely to develop Alzheimer's.

## The weather and diabetes

#### Cold weather and diabetes

Over the winter months, people with all diabetes types tend to have higher HbA1c levels than during the warmer months. So, blood sugar levels can creep up as temperatures drop. Colder temperatures can trigger the release of stress hormones such as cortisol and adrenaline which in turn, can raise blood glucose levels by stimulating the liver to release more glucose. In addition, the body's natural response to cold is to conserve energy, which can also affect insulin sensitivity.

### Tips to manage blood glucose levels in cold weather

**Keep testing your blood** – with cold weather you can get cold hands which can make blood testing more difficult, but don't let the cold put you off testing. If your hands are cold, you could try warming them up on a warm mug or placing them near a radiator (with a towel or thick clothing over it) before testing.

**Stay hydrated** – it is easy to forget to drink enough water during colder months but staying hydrated is essential for blood glucose control. Dehydration can lead to higher blood sugar levels making management of blood glucose more difficult. So, drink plenty of fluids and watch for signs of dehydration, such as dry lips or feeling unusually tired.

**Keep your activity levels up –** even only a little daily physical activity can help glucose levels in the following ways:

- Increasing insulin sensitivity this allows your body to use insulin more effectively to regulate sugar levels. If you use insulin, remember that your insulin needs may decrease with physical activity and this can affect glucose levels for up to 48 hours after you exercise
- Keeping warm exercise also helps keep you warm. While you may cool down immediately after stopping, the longer-term effect of exercise is to boost your metabolism which helps maintain body temperature
- Good for the mind exercise is excellent for your mental health. The saying "healthy body, healthy mind" holds true, especially in winter

If you don't want to exercise outside because of the cold, try being active indoors – dancing, jumping, aerobics, yoga or even climbing stairs can keep you active.

**Consider vitamin D and its impact –** with limited sunlight in the winter, many people experience lower levels of vitamin D, which can affect both mood and insulin sensitivity. Vitamin D plays a role in the body's ability to manage glucose so consider speaking to your healthcare provider about taking a vitamin D supplement.

**Keep an eye on your diet –** people often eat more during the winter, opting for 'comfort foods' and chilly weather may make it tempting to order takeaways instead of cooking. The body may crave more calories to stay warm but don't overeat and stick to nutritious foods. Home cooked meals, whole grains, modest portions of fruit, nuts and vegetables are good choices.

**Keep depression out in the cold –** cold, dark weather, less sunlight and financial stress can lead to feelings of depression. If this is the case, then talking to family and friends can improve your mood. Additionally, connecting with people who understand diabetes can be incredibly helpful.

**Take winter safety precautions** – if you have diabetic neuropathy or reduced sensation in your extremities, take extra care to protect yourself from the cold and injuries. Wear appropriate clothing, such as thermal socks to keep your feet warm and safe from the cold.

#### Hot weather and diabetes

High temperatures can change how your body uses insulin. You may need to test your blood sugar more often, adjust your insulin dose and what you eat and drink.

Some diabetes complications, such as damage to blood vessels and nerves, can affect your sweat glands so your body can't cool as effectively. This can lead to heat exhaustion and heat stroke, which is a medical emergency. People with diabetes get dehydrated (lose too much water from their bodies) more quickly.

In addition, high temperatures can make insulin less effective and affect how your equipment works (e.g.



pump, test strips, CGM, glucagon).

### Tips to manage blood glucose levels as temperatures rise:

- Drink plenty of water, even if you don't feel thirsty
- Check your blood sugar levels more frequently
- Protect your diabetes medicine and equipment
- Avoid midday outdoor activity
- Wear sunscreen, a hat if necessary, sunglasses
- Spend time indoors

When you are on a summer holiday or day trip in hot weather, it is important to keep supplies cool in a portable cooler or fridge. One of the well-known ways of doing this is with a Frio Wallet which keeps in-use insulin cool and within safe temperatures of 18-26°C (64.4-78.8°F) for a minimum of 45 hours, even in a constant environmental temperature of 37.8°C (100°F). They last up to five times longer than ice packs and are much more convenient than inconvenient packs or vacuum flasks.

You can learn more about Frio wallets by visiting <a href="https://www.friouk.com">www.friouk.com</a> or phoning 01437 741700.

### British Summer Time – should it be abolished?

In the UK, the clocks go forward one hour at 1am on the last Sunday in March, and back one hour at 2am on the last Sunday in October. The period when the clocks are one hour ahead is called British Summer Time (BST) or sometimes Daylight Saving Time.

Members of the British Sleep Society (BSS) are medical, scientific and health workers and they have said that evidence clearly shows that natural daylight in the morning is good for sleep patterns, while changing the clocks has a negative impact. They maintain that the Government must abolish the UK's twice-yearly clock changes because they are harming the nation's sleep.

Circadian rhythms are the physical, mental and behavioural changes we all experience over 24 hours, and they are the most impacted by clocks moving forward in the spring.



Last year, the British Sleep Society issued a statement saying it "strongly recommends" that Greenwich Mean Time (GMT) runs throughout the year – this is when clocks go back and is also known as Standard Time.

The researchers said that GMT aligns closely with the natural light-dark cycles of the day and night and natural daylight in the morning is crucial for maintaining an optimal alignment of our body clocks with day and night, which is essential for optimal sleep and overall health. Restoring permanent Standard Time (GMT) would mean our clocks would be closely aligned to solar time, and while it would mean earlier sunsets in the summer, there would be additional benefits to health from improved sleep and circadian alignment due to increased exposure to morning sunlight from autumn to spring.

Daylight Saving Time (BST) changes our schedules, moving them forward by one hour while daylight remains the same, something we are not always aware of. It forces us all to get up and go to work or school one hour earlier so in seasons with fewer daylight hours like autumn, it means most of us have to get up and commute in the dark. Mornings are the time when our body clocks have the greatest need for light to stay in synch.

At our latitudes, there is no spare daylight to save during the winter months and given the choice between natural light in the morning and natural light in the afternoon, the scientific evidence favours light in the morning.

While this may be the situation, it is understood the Government has no plans to change the daylight savings system.

## **NHS News**

### NHS trial to boost health and support people in work

The effectiveness of health measures in getting people back into work or keeping them in work is to be trialled by the NHS during 2025 backed by £45 million. In this trial, the NHS will create 'Health and Growth Accelerators' in South Yorkshire, North East and North Cumbria, and West Yorkshire, areas of the country most affected by economic inactivity driven by ill health.

#### What will the trial look into?

- Boosting people's health and tackling the conditions that most impact on people's ability to work, ranging from cardiovascular issues and diabetes to back pain and mental health problems
- NHS England and the Office for National Statistics assessing the economic benefits of several health interventions including talking therapies, bariatric surgery, endometriosis treatment and the NHS Type 2 Diabetes Prevention Programme
- Analysing the impact on waiting times, employment rates, earnings and the effects on labour market effects

The broader priority is to shift from treating sickness that leads to people dropping out of work, including diabetes, heart attacks and stroke to prevention. This could include more support for people to manage their blood pressure or diabetes, more action to find people at risk and supporting people to make lifestyle changes.

#### Then what?

A pilot scheme involving the accelerators South Yorkshire, North East and North Cumbria and West Yorkshire run by the ICB and Department of Work and Pensions has already helped nearly 2,000 people back to work. Similar progress was made in other areas.

There is a strong link between good health and a good job and vice versa. Having a job, a steady income and feeling useful make a big difference to people's health – and so far, almost one-third of patients seeing an advisor have successfully got

back to working life. If the trials are successful in boosting health and impacting local employment, they could be rolled out by the NHS on a wider scale.

(NHS England press release, 6th December 2024)

### NHS installs 'Boris-bike style' wheelchairs in hospitals which must be hired by the hour



Patients who are unable to walk around the A&E at King's College Hospital are being pointed to wheelchairs. They are in a hiring dock locked by a credit card machine which will cost patients £2 an hour – however the first four hours are free.

The NHS has installed the 'Boris-bike style' wheelchairs which are being run by a private healthcare service. A similar service was recently installed at Hillingdon Hospital in Uxbridge and is being rolled out at other hospitals. It is part of an expansion plan by healthcare service Wheelshare, but patients have criticised it as part of a system to make going to the hospital more expensive.

People who regularly visit hospitals, either as patients or visitors are already paying a lot in car park charges, especially if they have long waits – as people wait up to 12 hours in struggling A&E departments – now the cost of a wheelchair will add to it.

Last year, MailOnline revealed NHS trusts saw their car parking profits jump by up to 60-fold in 2022. Across the whole of England, hospital patients and visitors were forced to pay out £146 million for car parking last year, or £400,000 every day. The overall sum was up 50% on the £96.7 million taken one year earlier and triple the £47.9 million logged two years previously.

Campaign groups also warned 'sky high' prices

could put people off seeking care or deprive them of the support they get from visitors.

(Published: 9th October 2024)

### Poor arm position may significantly affect BP readings

Hypertension affects approximately one billion people globally. A study has shown that common arm positions for blood pressure (BP) measurements that stray from guidelines led to substantial overestimation of hypertension, which can lead to unnecessary patient follow-up and overtreatment.

Guidelines for BP measurement recommend arm support on a desk with the midcuff at heart level. This study has widespread implications given the number of settings where BP checks are carried out and the increased numbers of people who are advised to take their own BP readings at home.

- Supporting the arm on the lap overestimated systolic BP (SBP) by 3.9 mm Hg and diastolic BP (DBP) by 4.0 mm Hg
- When the arm hung unsupported at the side, readings overestimated systolic BP by 6.5 mm Hg and diastolic DBP by 4.4 mm Hg, with consistent results across subgroups

The researchers also noted that different arm positions not recommended by guidelines could potentially result in underestimation of hypertension.

### Incorrect BP readings are common for many reasons

Incorrect measures are common given the number of settings and number of providers and patients taking blood pressure some with training, certification in the method and educational materials. However, much of the time blood pressure is taken in busy primary care situations or by the patient themselves who has had no training. In addition, many times just one reading is taken which is not necessarily accurate.

It was concluded that more education is needed for patients as well as providers as patients may be monitoring their own BP at home. Patients should also know they can ask for a measurement to be repeated, know the correct arm position recommended by guidelines, and the implications of incorrect readings.

(JAMA Internal Medicine, October 2024)

Although this study was carried out in the US, it received publicity in the UK on various news broadcasts showing how important this is.

## NICE – diabetic foot guidelines, compliance could be better

Research published at the end of 2024 showed in England overall national compliance with National Institute for Health and Care Excellence (NICE) guidelines for diabetic foot referral and screening was good. However, the local decision makers, the Integrated Care Boards (ICBs) were more compliant with acute diabetic foot care guidance than with diabetic foot screening guidelines. The main causes of non-compliance were referral timelines and screening regularity.

#### Methods used

Freedom of Information requests were submitted to all 42 ICBs in England, asking for any available referral pathways between primary and secondary care, specifically for people with diabetes who are at moderate to high risk of developing lower limb diabetic complications. All ICBs responded:

- 43% (18 ICBs) said they did not possess any guidelines
- 57% (24 ICBs) provided information, which was divided into acute diabetic foot and diabetic foot screening referral pathways separately

#### **Results:**

- For acute diabetic foot pathways, 83% fully complied with the NICE guidelines
- 13% were partially compliant and did not refer within 24 hours of presentation)
- One ICB was completely non-compliant

In terms of diabetic foot screening, 62% (15 ICBs) were fully compliant and 34% (eight ICBs) were partially compliant, in that they did not recommend reviews at the correct regularity. Again, one ICB was completely non-compliant.

The researchers concluded possible reasons for incorrect screening appointments may be a lack resources or lack of awareness of the guidelines. However, they also point out that 20% of diabetic foot ulcers are found at a routine consultation rather than during screening and that regular screening appointments are essential to improve patient outcomes. (14th December, 2024, Diabetic Medicine)

Don't forget IDDT has a free booklet 'Looking After Your Feet'. If you would like a copy, call 01604 622837 or email: <a href="mailto:enquiries@iddtinternational.org">enquiries@iddtinternational.org</a>

### Physician Associates follow up

In previous Newsletters, we have discussed the role of physician associates. They are trained to perform various clinical duties – taking medical histories, conducting physical examinations and developing and managing treatment plans. They work under the supervision of senior doctors such as a hospital consultant or a GP.

Despite having 'physician' in their title, physician associates are not doctors. Physician associates:

- Have around two years of training compared to the 10 years of an average fully qualified GP
- Must be supervised by a senior doctor
- Are not currently allowed to prescribe medication or request ionising radiation, such as a chest X-ray or a CT scan

Before your appointment, your GP practice should tell you which healthcare professional you will see. You may also see a physician associate in a hospital.

### When you first meet a physician associate, they should:

- Offer you the opportunity to ask about their role
- Explain that they are not a doctor and give enough time to explain their job, including their training and qualifications
- Tell you that they work under the supervision of a named senior doctor

### The NHS is planning to employ more physician associates

The plan is to increase the number of physician associates from 3,000 to 12,000 over the next 12 years, so it is important that their role is based on evidence of safety, cost effectiveness and efficiency.

### On 13<sup>th</sup> November the Health Secretary suggested a re-think

In November 2024, Health Secretary Wes Streeting told the BBC that there are "legitimate concerns" over the role of physician associates amid worries they are being used to replace fully qualified doctors. He said he wanted to look into the issues around the roles before a planned expansion in the number of medical associates. He also acknowledged that patients did not necessarily realise they were not being treated by a doctor.

In December 2024, the Health Secretary went on to make a further statement and here are the key points he made:

- The Government has commissioned Professor Gillian Leng CBE to conduct an independent review of the Physician Associate (PA) and Anaesthesia Associate (AA) professions
- It will examine their safety, cost-effectiveness, efficiency and integration into healthcare teams, aiming to ensure they deliver high-quality care while supporting doctors. It will look into blurred lines of responsibility and whether PAs and AAs are replacing doctors inappropriately
- The review will gather evidence from patients, employers, professionals and researchers from the UK and globally
- It will evaluate the roles' contributions to team productivity, patient experience and care quality across various settings. The findings, due in Spring 2025, will guide future reforms and contribute to the 10-Year Health Plan

The General Medical Council (GMC) began regulating physician associates on 13<sup>th</sup> December 2024 to uphold professional standards. The review will clarify how these roles are deployed and address gaps in understanding, providing confidence to both patients and healthcare professionals.



### The importance of looking after your feet

Written by the podiatrists at Randall's Footcare in Aylsham. This quarter's topic is about diabetic neuropathy.

#### Understanding diabetic neuropathy

Diabetic neuropathy is a form of nerve damage that occurs in people with diabetes, often leading to a range of debilitating symptoms. Understanding the different types of diabetic neuropathy can help in managing it as well as reducing their effects. There are four main types of neuropathies, each affecting different parts of the body.

### 1. Peripheral Neuropathy (Distal Symmetric Peripheral Neuropathy)

Peripheral neuropathy is the most common type of neuropathy among people with diabetes. It primarily affects the feet and legs, and later the arms and hands. Symptoms include:

- Numbness or reduced ability to feel pain: this can lead to unnoticed injuries and infections
- **Tingling and burning sensations:** often described as pins and needles, these sensations can be uncomfortable and persistent
- Sharp pains and cramps: these can occur suddenly and may be severe
- Muscle weakness: this can affect mobility and balance
- Extreme sensitivity to touch: even light touches can cause pain
- **Serious foot problems:** initial issues may be development of corns, hard skin areas, and blisters. However, these can go on to include ulcers, infections, and bone and joint damage, often requiring immediate medical attention

#### 2. Autonomic Neuropathy

Autonomic neuropathy impacts the nerves that control involuntary functions, such as heart rate, digestion, and bladder function. Symptoms can include:

- Lack of awareness of low blood sugar levels: this can be dangerous as it prevents timely treatment
- Drop in blood pressure upon standing or sitting: this can cause dizziness and fainting
- Bladder and bowel issues: these can include incontinence or difficulty with bowel movements

- **Slow stomach emptying:** this condition, known as gastroparesis, can cause nausea and vomiting
- **Difficulty swallowing:** this can lead to nutritional deficiencies and weight loss

#### 3. Proximal Neuropathy

Proximal neuropathy affects the nerves in the thighs, hips, and buttocks, usually impacting one side of the body. Symptoms include:

- Severe pain in the buttocks, hips, or thighs: this can be debilitating and affect daily activities
- Weak or shrinking muscles: muscle atrophy can occur, leading to further weakness
- **Difficulty rising from a sitting position:** this can significantly impact mobility and independence

#### 4. Mononeuropathy

Mononeuropathy refers to damage to a specific nerve, often in the face, arm, or leg. Symptoms include:

- Difficulty focusing or double vision: this can occur if nerves controlling eye muscles are affected
- Pain in the shin or foot: this pain is often sharp and sudden
- Weakness causing difficulty lifting the front part of the foot: known as foot drop, this condition can lead to tripping and falls
- Numbness and tingling in the hands or fingers: this can affect fine motor skills and daily tasks

### **Managing Diabetic Neuropathy**

Understanding these types of neuropathies can help in managing and limiting their effects. Early detection and intervention are crucial in preventing further damage.

If you experience any of these symptoms, it's essential to consult with your podiatrist or other healthcare provider. They can help develop a comprehensive treatment plan tailored to your specific needs, including medications, lifestyle changes, and regular monitoring to manage symptoms and improve quality of life.

If you suffer from diabetic neuropathy or just generally struggle to keep your feet in good health, arrange an appointment with your local HCPC registered podiatrist.

## **Pharma News**



### Novo Nordisk to slash prices of insulins but not until 2026

In the US, at the beginning of 2024 Novo Nordisk cut the price of its NovoLog insulin by 75% (called NovoRapid in the UK). Now the company is going to do the same with two of its other insulins, Fiasp and Tresiba, and this will take effect at the start of 2026.

- Rapid-acting Fiasp (insulin aspart) for patients to take at mealtime the price will be cut by 75%.
   Fiasp is the same formulation as NovoRapid with vitamin B3 and an amino acid added to increase the speed of absorption and stabilise the treatment
- Long-acting Tresiba (insulin degludec) is injected daily and the price will be cut by 72%

In money terms, this means the monthly list price In money terms, this means the monthly list price for Fiasp FlexTouch will fall from \$599 to \$140 and for Tresiba's U-100 FlexTouch, from \$508 to \$141.

Note: As we have previously reported, in the US Levemir was phased out during 2024, a very unpopular decision with many people.

#### What next?

Meanwhile, Novo is trying to gain FDA approval for a once-weekly insulin, Awiqli (insulin icodec). In July 2024, the FDA rejected this treatment because of a manufacturing issue, despite, Awiqli being approved for Type 1 and Type 2 diabetes in Europe, Canada, Japan, Australia, Switzerland and in China for Type 2 diabetes.

#### Once weekly insulin not happening in the UK!

In previous Newsletters we have reported the development of lodec by Novo Nordisk. It is a oncea-week injection that has been shown to achieve steady blood glucose levels after three to four once-weekly injections.

However, it still has not been approved in the US, nor in the UK so currently does not have marketing authorisation for Type 1 or Type 2 diabetes. In the UK in July 2024, NICE invited interested parties to be involved in an appraisal of iodec but in October 2024, Novo Nordisk informed NICE that following

an update of their plans, the planned timelines for this appraisal are no longer appropriate. They will inform NICE when the appraisal can be resumed.

#### CagriSema – new novel drug from Novo Nordisk

In December 2024, the press covered the results of a head-to-head trial comparing weight loss drugs Zepbound from Lilly and Wegovy from Novo Nordisk:

- People taking Zepbound lost 47% more weight than those taking Wegovy
- Zepbound helped people to lose an average of 20.2% of their weight after 72 weeks compared to 13.7% for those treated with Wegovy after 68 weeks
- This shows that Lilly's Zepbound which mimics two gut hormones is more effective that Novo's Wegovy with its single way of action

After these results became public, Lilly's share rose 2.5%, adding \$19 billion to its market value of over \$790 billion while Novo's shares fell as much as 1.8%.

Novo Nordisk's development of novel drug – this is called CagriSema and it has the same dual action as Lilly's Zepbound. Novo Nordisk hope this will give them higher sales and they predict that it could result in 25% weight loss.

#### MHRA warns of weight loss drug side effects

With all the publicity around weight loss drugs, good and bad, we feel we cannot ignore discussing them in the Newsletters.

In October 2024, the Medicines and Healthcare products Regulatory Agency (MHRA) issued a drug safety update to remind health professionals to warn patients about common and serious side effects associated with glucagon-like peptide-1 receptor agonists (GLP-1RAs). The MHRA said that GLP-1RAs are "effective and acceptably safe treatments" when used within their licensed indications, but carry risks like all medicines. They are used to treat Type 2 diabetes and obesity:

 Five GLP-1RAs are licensed dulaglutide, exenatide, liraglutide, lixisenatide and semaglutide

- In addition, tirzepatide (Mounjaro), a dual GLP-1 and glucose-dependent insulinotropic polypeptide receptor agonist
- Semaglutide (Wegovy) is also licensed to reduce the risk of major cardiovascular events in patients with established disease

The MHRA drug safety update listed the risks these drugs pose:

- Gastrointestinal side effects such as vomiting and diarrhoea for more than one in 10 patients
- In turn the above side effects can cause possible complications including severe dehydration, kidney damage, and hospitalisation
- There are less common but serious side effects that patients should be warned about – hypoglycaemia, pancreatitis and gall bladder disorders

#### Warning of misuse from Health Secretary

Health Secretary, Wes Streeting said weight loss drugs have enormous potential in tackling obesity but he warned: "These are not cosmetic drugs that should be taken to help get a body-beautiful picture for Instagram. They should only be used responsibly and under medical supervision. They're not a quick fix to lose a few pounds, and buying them online without appropriate assessment can put people's health at risk."

### Reporting adverse reactions to drugs via the Yellow Card scheme

Both healthcare professionals and members of the public can make reports of adverse drug reactions to the MHRA Yellow Card scheme.

This can be done online at <a href="https://yellowcard.mhra.gov.uk">https://yellowcard.mhra.gov.uk</a>

If you cannot complete the online report or form, you can call the MHRA on 0800 731 6789. Adverse incidents involving medical devices cannot be reported by telephone but online or by email to aic@mhra.gov.uk

Note: There are many reports of possible adverse and behavioural effects of these drugs which we will cover in the next Newsletter.

# Children and young people with Type 1 diabetes

### Children with Type 1 doing better but still not meeting targets

The international paediatric Type 1 diabetes registry shows improvements in average HbA1cs from 2013 to 2022 and also improvements in the number of children meeting their HbA1c targets with lower rates of diabetic ketoacidosis and severe hypoglycaemia. However, many are still not meeting the 2022 glycaemic targets recommended by the International Society for Paediatric and Adolescent Diabetes.

The analysis used registries in Europe, the UK and the US which showed:

- Average HbA1c of all registries dropped during the study time – from 8.2% (66.5mmol/mol) to 7.6% (59.4mmol/mol)
- The overall proportion achieving the target of less than 7% (53mmol/mol) increased from 19.0% in 2013 to 38.8% in 2022

- The number using insulin pumps increased from 42.9% to 60.2% and using CGM devices from 18.7% in 2016 to 81.7% in 2022 in all registries
- The rate of diabetic ketoacidosis dropped but not significantly, from 3.1 to 2.2 events per 100 person-years from 2013 to 2022 and severe hypoglycaemia from 3.0 to 1.7 events per 100 person-years across most registries

The researchers concluded that there have been improved glycaemia outcomes in children internationally which was likely to be due to: setting stringent HbA1c targets and increased use of diabetes technology, especially continuous glucose monitoring.

The rates of acute diabetes complications seem to be decreasing due to many possible reasons: modern insulins, insulin delivery, glucose monitoring systems.

(Lancet Diabetes & Endocrinology, November 2024)

### Adolescence and young adulthood are risky periods

For young people living with diabetes in Quebec, adolescence and young adulthood are periods marked by a significantly higher risk of interruptions in clinical care, hospitalisations and A&E visits, which applies to young people with Type 1 diabetes everywhere. This was revealed in a study conducted at McGill University and highlights the need to improve care for youth living with diabetes during this important period of their lives.

As we know, Type 1 diabetes is an autoimmune disease where the pancreas is unable to produce insulin, a hormone which regulates blood sugar. For young people affected by this complex disease, daily insulin injections and regular clinical follow-up are essential, as deterioration in blood sugar control can lead to serious diabetes complications.

The study is the first to examine the relationship between age and diabetes-related hospital care from childhood through to early adulthood. The research included young people with diabetes between the ages of two and 22 years who were followed for at least 18 months. The researchers estimated the risks across eight age groups (less than 10 years, 10–11 years, 12–13 years, 14–15 years, 16–17 years, 18–19 years, 20–21 years and 22–23 years).

#### Risks increase at an early age

The researchers point out that to date, research has focused on the challenges associated with the transition from paediatric to adult care, which occurs at 18 years but the research showed the following:

- Interruptions in care of 12 months or more began at 16 years and worsened after the age of 18
- The risk of diabetes-related hospitalisations and A&E visits doubled from early adolescence (ages 12–14 years), compared with children under 10, and worsened into young adulthood
- Young people from disadvantaged families have an increased risk of diabetes-related hospitalisations, A&E visits and disruptions in care

Normally, regular diabetes clinic visits take place at least every three months for children and adolescents living with Type 1 diabetes, as recommended by international diabetes guidelines, and every three to six months for young adults. These visits are an opportunity to improve blood sugar levels and also

a time to offer young people training and support in the self-management of the disease, and to screen for possible complications.

The researchers hypothesise that transportation difficulties or work obligations may prevent families from attending follow-up appointments.

#### A risky period for a variety of reasons

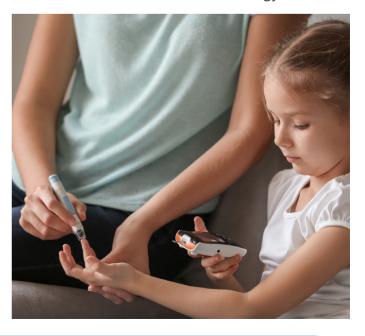
During adolescence and young adulthood, young people establish their personal identity, develop their autonomy and make educational and professional choices.

For those with Type 1 diabetes, these phases are complicated by the day-to-day demands of diabetes management and the transition to adulthood. These periods are known to be high-risk periods due to increased insulin requirements that cause blood glucose levels to rise and young people's difficulty in juggling all their competing priorities – social and educational, while trying to manage their diabetes.

One commentator said: "Many efforts are made by hospitals to ease the transition from paediatric to adult care, but more needs to be done. New models of care using more creative and flexible strategies for this high-risk population are needed and are needed at a younger age than previously thought."

The researchers said that their results suggest that as currently organised, the care offered to adolescents and young adults living with diabetes is not effective in helping them to overcome the obstacles they face during this critical period in their development. Their involvement in their care should be encouraged well before their transition to adult care.

(The Lancet Diabetes and Endocrinology)





### **IDDT News**



#### **IDDT** welcomes new Trustees

At the end of 2024, IDDT issued the following press release to announce the addition of two new Trustees to its Board of Trustees – Mabel Blades and Karen Merrey. Their expertise and insights will bolster the charity's efforts and ensure its vital work continues to thrive.

IDDT formed in 1994 to fight for choice of treatment for all. It now provides a free, confidential helpline, has published dozens of helpful publications, stages events and lobbies the Government on behalf of its members.

#### **Karen Merrey**



Living with Type 1 diabetes for nearly 43 years, Karen understands the challenges faced by those managing the condition. As an original member of the IDDT and an early recipient of pork insulin following her diagnosis, Karen is still being treated with pork insulin today and she is passionate about supporting the charity's growth and impact within the diabetes community.

When Karen's daughter was diagnosed with Type 1 diabetes at six-years-old, she took the initiative to lead parent support groups in Pontefract and Wakefield. Her efforts aimed to raise awareness about the condition and provide encouragement and guidance to families navigating similar challenges.

Karen said: "Joining IDDT as a Trustee is a deeply personal and meaningful step for me. As someone who has lived with Type 1 diabetes for many years, I understand the daily challenges and the importance of having the right support. I'm passionate about advocating for better awareness, better care, and greater resources for everyone affected by diabetes."

She added: "Through my new role, I hope to contribute to the incredible work IDDT is doing to ensure that no one feels alone in their journey and that everyone has access to the information, care, and community they need to live well."

#### **Mabel Blades**



Registered dietitian Mabel is also delighted to join the IDDT board of trustees and is hoping to put her diabetes expertise to good use. With a PhD in diabetes, Mabel is passionate about contributing to a charity that aligns with her commitment to patient-centred care.

She said: "I am truly honoured to join the IDDT trustee board, and I am passionate about ensuring that people living with diabetes have access to the best possible information and support. The IDDT is doing incredible work in this area, and I look forward to helping spread the word, amplify its impact, and continue to empower individuals on their diabetes journey."

Jenny Hirst, Co-chair of IDDT, said: "We are absolutely thrilled to welcome Karen and Mabel to the IDDT board. Karen has been a valued member of our community since the very beginning, and her personal experience with Type 1 diabetes will bring invaluable insight to our work."

She added: "Mabel, with her expertise as a registered dietician and her passion for diabetes care, will further strengthen our commitment to improving lives. Together, they will play a key role in guiding the future of our charity and helping us continue to support those living with diabetes."



### **IDDT News**



### Reaching people with diabetes

Reaching people with diabetes, Type 1 or Type 2, is an important part of IDDT's work because this way we are able to offer support and information that people need to manage their diabetes and live comfortably with it.

One of the ways we do this is by supplying healthcare professionals with our free booklets to give to their patients. This begs the question of how do we reach health professionals? We have stands at conferences attended by healthcare professionals manned by Dan and his colleagues from Orange Juice Communications.

In addition to supplying booklets to healthcare professionals at conferences, we reach many more of them by advertising in professional journals. During 2024, we sent out over 20,000 free booklets to healthcare professionals, many of whom re-order them for their patients. The most popular booklets with healthcare professionals, and therefore their patients, are 'Diabetes Everyday Eating' followed

closely by 'Looking After Your Feet' and 'Diabetes, 9 Key Checks'.

We are very grateful to all the healthcare professionals for providing our booklets to help people with diabetes, especially to those who are newly diagnosed. We are also very grateful to all of the people who make donations to help IDDT in its work. Provision of information booklets is a very important (and expensive) part of our work, so a huge thank you for all your support during 2024.



## Making your will for free

Goodwill

Partnership

Last year we wrote about the importance of making a will, in order to protect the future of our loved ones. We also explained about how important it is to

consider leaving a gift to charity and how reliant IDDT is on the generosity of people who have remembered us when drafting their will.

With this in mind, IDDT has joined with The Goodwill Partnership to offer its members

the opportunity to draft a new will at no cost to themselves. The Goodwill Partnership is a well-established organisation that currently works with over 150 charities to assist their supporters to make their will at no cost or a reduced cost. All wills are drafted by fully qualified solicitors.

In recognition of the value IDDT places on the support it receives from its members, we are not making this offer open to the general public, unlike

other charity schemes you may have seen advertised on television.

Accompanying this newsletter is a flyer that provides more information about the scheme. If you are considering making or updating your will, we do hope

you will take us up on this offer and possibly give us favourable consideration when you do so.

If you would like to discuss making your Will for Free further, then please call 01492 510 340 or visit www.thegoodwillparnership.co.uk/iddt/.

### **LOTTERY JACKPOT!**

As a thank you to our members and Lottery players and as a celebration that 2024 was 30 years since IDDT formed, the December Lottery was a JACKPOT Lottery.

### THE WINNERS ARE:

1st prize of £1,000 goes to Nina from Wolverhampton
 2nd prize of £750 goes to Andrew from Brighton
 3rd prize of £500 goes to Andrew from Brighton
 4th prize of £250 goes to Anne from Grantham

The JACKPOT Draw took place on January 3<sup>rd</sup> 2025. All Lottery players were automatically entered into the JACKPOT. We have to say well done to Andrew who won second and third prizes proving that it is the luck of the draw.



### **IDDT Lottery Results**

### **WINNERS OF THE SEPTEMBER 2024 DRAW:**

1st prize of £460.32 goes to Patrick from Durham 2nd prize of £345.24 goes to Jean from Old Felixstowe 3rd prize of £230.16 goes to Andrew from Stanwix 4th prize of £115.08 goes to Lorraine from Goodwick

### WINNERS OF THE OCTOBER 2024 DRAW:

1st prize of £460.32 goes to Lyn from Deal 2nd prize of £345.24 goes to Patrick from Norwich 3rd prize of £230.16 goes to Andrew from Carlisle 4th prize of £115.08 goes to Terry from Romford

### **WINNERS OF THE NOVEMBER 2024 DRAW:**

1st prize of £465.12 goes to Susan from Hinton 2nd prize of £348.84 goes to Peter from Bromsgrove 3rd prize of £232.56 goes to Mrs Clark from Orpington 4th prize of £116.28 goes to Anon from Swanley

Note: The winners of the draws for January, February and March 2025 will be announced in our June 2025 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 per month,
then give us a call on 01604 622837 or email karl@iddtinternational.org

### INDEPENDENT DIABETES TRUST



### **SNIPPETS**

#### **JDRF** rebrands

The Juvenile Diabetes Research Foundation rebranded in 2024 to become Breakthrough T1D. The Juvenile Diabetes Foundation (JDF) formed in 1970 in the US, then in 2012 it became the Juvenile Diabetes Research Foundation (JDRF). It has always been dedicated to research into better treatments and eventual cures for Type 1 diabetes.

The need for rebranding is understandable because for many years, Type 1 diabetes was called insulin dependent diabetes or juvenile diabetes because it was diagnosed in children and younger people. We know now that although Type 1 diabetes is largely diagnosed in these age groups, it can occur at any age and so 'juvenile diabetes' is not an appropriate name.

### Stem cells reverse a woman's diabetes — a world first

A 25-year-old woman with Type 1 diabetes started producing her own insulin less than three months after receiving a transplant of reprogrammed stem cells. She is the first person with the disease to be treated using cells that were extracted from her own body.

(Nature, September 2024)

#### Slapping therapist jailed after woman's death

An alternative healer has been put in prison for 10 years for the gross negligence manslaughter of a 71-year-old woman with Type 1 diabetes who stopped taking insulin at his slapping therapy workshop.

Danielle Carr-Gomm died in October 2016 while taking part in the Paida Lajin therapy event at which people are slapped or slap themselves repeatedly as they believe this expels the toxins from their body.

Hongchi Xiao from California was convicted in July 2024 of manslaughter by gross negligence at Winchester Crown Court after he failed to get medical help for Ms Carr-Gomm when she said she had stopped taking insulin. She had a lifelong fear of needles and had frequently sought other ways to deal with the disease and it was this that drove her to look for alternative therapies. She believed it worked and delivered glowing testimonials and the court heard that Xiao said "well done" to her after she told the other participants that she had stopped taking her insulin.

(6th December 2024)

### Patients with IBD more likely to develop, or have prior Type 1 diabetes

Research has shown that people with inflammatory bowel disease (IBD) had a moderately increased risk for Type 1 diabetes and higher odds of having prior Type 1 diabetes than the general population. Such relationships are referred to as bidirectional and were partially independent of shared familial factors.

Although the absolute risk for Type 1 diabetes is low in those with IBD, this research suggests that if there are nonspecific symptoms, such as weight loss and fatigue, which are typical of Type 1 but not of IBD, then it is reasonable to test for diabetes. Patients with IBD and Type 1 diabetes also tend to have worse disease outcomes for both diseases.

(The Lancet, October 2024)

### Airplane flights may affect how insulin pumps work

A study has found that insulin pumps may deliver inconsistent doses for patients flying in an airplane which potentially could lead to fluctuations in blood sugar levels. To prevent any unintended metabolic consequences, it is recommended that people who use insulin pumps consider temporarily disconnecting their pumps before take-off and removing air bubbles before reconnecting it at cruising altitude.

(The European Association for the Study of Diabetes, 2024)

