



Welcome

Welcome to the thirty-fourth issue of Type 2 and You. In this issue we have a look at how to get the best support from your health professionals, dates for our biennial conference, as well as the usual updates on the latest pieces of research and the latest round of lottery winners.



Getting the most from your Health Care Professional

Health Care Professionals (HCPs) come in many forms and people with Type 2 diabetes will come into contact with several of them at some time or another. Examples include GPs, Practice Nurses, Dietitians, Diabetes Specialist Nurses (DSNs), Podiatrists and a range of Hospital Consultants.

Sadly, it is often the case that people come away from appointments feeling confused about their treatment or feeling that they have not got what they wanted. The aim of this article is to give you some knowledge to enable you to get the most out of any appointment that you may

have with a member of your diabetes health care team. It gives you some tips as to how to manage the actual appointment or consultation effectively, your rights as a patient, the standards of care you should expect and what to do if things go wrong.

Some tips for your appointment

- Be prepared. Make a list of what you want to get out of the consultation and questions you want to ask.
- Be informed. Do your research before you go so that you are aware about things like the various treatment options that may be available.
- Be honest with your HCP. If you are honest with them about your diabetes or related condition then you will be able to be treated more effectively.
- Make sure your HCP knows why you have come and that they fully understand the nature of the problem.
- Have mutual respect. Respect is a two way thing, you should respect your HCP for their medical knowledge but they should also respect you for your experiences as the patient.
- Make joint decisions. Having mutual respect will allow you both to make decisions that you are both happy with.

Know your rights

A key element in getting the most out of an appointment is to know your rights. You should know what standards of care you are entitled to, what to do if you feel you are not getting them and the support on offer to you if this is the case.

The National Institute for Health and Clinical Excellence (NICE) is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. It has recently issued a set of quality standards for adults with diabetes. These quality standards lay down what you level of care you should receive in relation to the management of your diabetes with medication or insulin. They are:

1. A structured education programme (such as DESMOND), annual review and ongoing education.
2. Personalised advice on nutrition and physical activity from a suitably trained healthcare provider.
3. Participation in annual care planning to agree goals and an action plan.
4. Agreement with your health professional of your target HbA1c and an ongoing review to minimise hypoglycaemia if appropriate.
5. Agreement with your health professional to start, review and stop

medications to lower blood glucose, blood pressure and cholesterol.

6. Trained health professionals to start and manage treatment with insulin as part of a structured education programme which includes learning dose adjustment.
7. Women of childbearing age should be regularly informed about the importance of preconception blood glucose levels and any risks, including medication, to the unborn child. If a pregnancy is planned, preconception care should be offered and if not, they should be offered contraceptive advice.
8. An annual assessment for complications and their management.
9. An assessment for psychological problems which if present, should be appropriately managed.
10. For people with or at risk of foot ulceration should receive regular reviews by a foot protection team. Those with a foot problem requiring urgent attention should be referred to a foot care team within 24 hours.
11. If admitted to hospital your care should be managed by appropriately trained staff, you should have access to a specialist diabetes

team and given the choice of self-monitoring and managing your own insulin.

12. If you are admitted to hospital with ketoacidosis you should receive educational and psychological support before being discharged and followed up by a specialist diabetes team.
13. If you have experienced hypoglycaemia which required medical attention, then you should be referred to a specialist diabetes team.

The full details can be found at:

<http://www.nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp>

Remember this is the care that you should receive. This is part of the government's promises to make sure that the standards of care are high quality.

If you are not receiving this standard of care, then you need to say so. You have a right to complain and this is laid down as a legal right in the NHS Constitution. The Constitution brings together in one place the details of what staff, patients and the public can expect from the NHS. It sets out your rights and responsibilities as an NHS patient including your right to complain if things go wrong. There can be subtle ways of doing this, such as asking when you are going to receive the education

programme that you should have (and don't be afraid to mention NICE Quality Standards) or the slightly less subtle ways, such as making a formal complaint.

Here's what to do if you need to make a formal complaint against an NHS organisation:

- You should first contact them directly either in writing, by e-mail or speaking to them and ask for a copy of their complaints procedure which will tell you what to do. By speaking to them they may be able to resolve your complaint without making a formal complaint
- If you are not sure how to make a complaint about an NHS organisation or

employee, the Patient Advice and Liaison Service [PALS] can help you. Its role is to make sure your concerns reach the right people and to support you in resolving any problems you may have. There are PALS offices in most general hospitals. To find your local PALS office, then visit the website: [https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-\(PALS\)/LocationSearch/363](https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363)

- You can also raise your concerns by getting in touch with regulatory bodies, such as the Care Quality Commission: Telephone 03000 616161 or on the web at www.cqc.org.uk

- If you have tried the NHS complaints procedure but are dissatisfied with the response, you can contact the Parliamentary and Health Service Ombudsman. The Ombudsman carries out independent investigations into complaints the NHS and can be contacted on the Complaints Helpline: 0345 015 4033, open Monday to Friday 8.30 am to 5.30pm or e-mail <https://www.ombudsman.org.uk/about-us/contact-us> or you can write to:
The Parliamentary and Health Service Ombudsman,
Millbank Tower,
Millbank,
London SW1P 4QP



Freestyle Libre available on the NHS, but is it?

In the last Newsletter, we reported that the Freestyle Libre by Abbott was made available on the NHS from November 1st 2017. This device checks glucose levels by scanning a sensor worn on the back of the arm without having to prick the fingers, so it is a non-invasive way of checking glucose. It actually checks the glucose levels in the interstitial fluid (the fluid in the cells). Glucose readings on the interstitial fluid have been proven to reliably reflect glucose levels.

It has been approved for use on the NHS across the UK for people with Type 1 and Type 2 diabetes who are treating their diabetes intensively with insulin. However, prescribing it is subject to local Clinical Commissioning Group (CCG) approval, which runs the risk of a postcode lottery of availability.

We asked Newsletter readers what was happening in their areas when they asked to be prescribed the FreeStyle Libre on the NHS and the results did not surprise us!

- Of all the people who responded, only one

succeeded in being prescribed the device.

- All those already using the FreeStyle Libre by paying privately for it were refused it on the NHS. This was despite their reports of improved control, no severe hypos since using it, improved quality of life and comments such as, 'it has transformed my life'.
- Some people were offered a free reader but only one sensor and then expected to buy them after using this one.
- More than one person has been told that they are 'too well controlled' for the device to be prescribed on the NHS which begs the question of whether this is due to the number of tests they are carrying out per day!

What were the reasons for refusal?

- The most common was 'It is not being prescribed in this area'.
- Cost.
- Not accurate enough.
- No evidence of benefit.

No evidence of benefit

It appears that some CCGs are prescribing the FreeStyle Libre for selected patients and monitoring the results and one of the four Regional Medicines Optimisation Committees has put out a Position Statement with recommendations of what information should be collected. So perhaps they will gather the evidence of the benefits which will enable the device to be available on the NHS.

It is hard to resist saying that if the evidence is good enough for the Prime Minister to use the FreeStyle Libre, surely it is good enough for other people with diabetes!

Quality of life

Are CCGs best placed to judge about improvements in quality of life? What do they really know about living with diabetes and all this entails? We could make a long list but it is worth remembering that home blood glucose testing first became available in 1981, so some people have been pricking their fingers for over 30 years. Don't they now deserve a painless, non-invasive way of testing?



What is IDDT doing about this?

Understandably, we have had some very angry calls and emails with demands to take action. IDDT believes that everyone with Type 1 and Type 2 diabetes using insulin, who wants to use this device, should be allowed to do so on the NHS, if it is suitable for them.

There have been several Parliamentary Questions asking why the FreeStyle Libre is not available to everyone but the answers

offered no explanations. In order to fight a case, we need to know on what basis these blanket refusals are being made. So we are sending Freedom of Information questions to all CCGs to ask:

- How many requests have you received from people with diabetes to have the FreeStyle Libre glucose monitoring system prescribed since September 2017 (when the announcement was made)?
- How many people have been successful

in getting the FreeStyle Libre system prescribed since it was included on the NHS Drug Tariff in November 2017?

- What are the criteria on which decisions about whether people are prescribed the FreeStyle Libre are made and who is responsible for making these criterion-based decisions?

Hopefully, the information provided will enable us to fight the decision to refuse to pay. We will keep you informed.

A Couple of Thank You's

Christmas Cards

We would like to say a big thank you to all of you who bought our Christmas cards last year. We sold over 700 packs and every pack sold raises funds that help us continue our work. We will be selling cards again later this year and hope you will buy your cards from us again.

Helping Developing Countries

As you may be aware IDDT acts as the UK arm of an organisation called Insulin for Life, collecting unwanted insulin and diabetes supplies and sending them out to developing countries, in our case Tanzania. In 2017 we sent out over 4,100 pens, vials cartridges etc. of insulin worth over £45,000, along with over 104,000 items of various diabetes supplies – so a big thank you to all of you who donated items.

We would also like to say thank you to all of you who continue to sponsor a child looked after by the Dream Trust in India – last year you raised over £7,000! We also need to thank the Dream Trust for their support for World Diabetes Day. The day was celebrated by educating children with diabetes

and their parents through lectures and interactive session. It was jointly organised by AMS, & DAI, Dr. Sanket Pendsey, Dr. P. P. Joshi, Dr. Pramod Gandhi, Dr. Attal.



Facts you need to know!

VAT free if buying privately

As the FreeStyle Libre is a medical device, it can be obtained without having to pay VAT when you are purchasing the device or sensors yourself. The way to do this may not be obvious on the website, so the best way is to telephone Abbott to place the order and tell them that you want to apply for VAT exemption, their number is: 0800 1701177. Once registered this way, all future orders will be VAT free.

FreeStyle Libre and Swimming

One of our members asked if she could wear the sensor while swimming and we thought this may be a question other people may ask. The sensors are water-resistant and can be worn while bathing, showering, or swimming as long as you:

- Do not take it deeper than 3 feet (1 meter)
- Do not keep it under water for longer than 30 minutes at a time.

Diabetes, HbA1c and Dementia

Although there is a well-established link between diabetes and dementia a recently published study has shed light on the relationship between cognitive decline and HbA1c levels. HbA1c levels can be used to diagnose diabetes and are also used as a measure of blood glucose control over a longer period of

time. The large study, carried out over time, showed that otherwise healthy adults with poorer blood glucose control showed a faster decline in memory and thinking than those with good control (ideally HbA1c levels should be between 6 and 6.5%). Unfortunately, it was not able to identify the mechanisms

underlying this decline. Diabetes is only one risk factor in the development of dementia among a complex mix of age, genetics and lifestyle factors but what the study shows is the importance of maintaining good blood glucose control with a view to maintaining good brain health as we age.

Type 3c Diabetes being misdiagnosed

The vast majority of people will not have heard of Type 3c diabetes. Type 3c diabetes, also known as pancreatogenic diabetes and develops in people who have previously suffered from pancreatic disease (acute or chronic pancreatitis), causing the pancreas to stop producing insulin. The study, involving two million people,

found that 97.3% who had suffered from pancreatic disease had been wrongly told they had Type 2 diabetes when, in fact, they actually had Type 3c.

Type 3c diabetes requires treatment with insulin straight away and a misdiagnosis means that there can be a significant

delay in someone receiving the correct treatment. Ironically, and perhaps dangerously, one of the groups of drugs (DPP4 Inhibitors – Alogliptin, Linagliptin, Saxagliptin, Sitagliptin and Vildagliptin) can actually cause pancreatitis. As ever, the advice is to consult your doctor if you are concerned.

2018 Conference a date for your diary!

In 2018 we will be holding our biennial Conference at the Kettering Park Hotel and Spa. As usual it will consist of discussion groups, talks and an open forum to discuss 'Hot Topics' for people with diabetes and for IDDT.

The date is **Saturday, October 6th 2018**, so please put the date in your diary if you would like to come along. There will be further details with our June 2018 Newsletters.

And 2020...

This sounds a long way off but the Trustees have to consider the venue for our 2020 Conference. We would like your views of where this should be held, so please let us know your preference by ticking the appropriate box below.

When making your choice, please bear in mind that for venues in London a minimum of 90 people have to attend and the hotels and accommodation are more expensive. Also for London and the North, the costs will be higher because IDDT will have to pay for the organisers, such as speakers, staff and Trustees to stay overnight and this will have to be reflected in the delegate price for the day.

Therefore, would you prefer the Conference to be held in:

(a) London

(b) The North eg York/Leeds

(c) The regular venue in Kettering

Please tick a box and return by post before the end of the month to:

InDependent Diabetes Trust (IDDT), PO Box 294, Northampton NN1 4XS





The winners of IDDT's lottery draws!

We are delighted to announce the winners of the draw of our monthly lottery for November 2017.

They are as follows:

- 1st prize of £455.28** goes to Dorothy from Doncaster
- 2nd prize of £341.46** goes to Susan from Milton Keynes
- 3rd prize of £227.60** goes to Anon. from Newcastle upon Tyne
- 4th prize of £113.80** goes to Ruth from Alton

Winners of the December 2017 draw are:

- 1st prize of £462.40** goes to Jane from Farnborough
- 2nd prize of £347.04** goes to Avice from Cheltenham
- 3rd prize of £231.36** goes to John from Dryslwyn
- 4th prize of £115.68** goes to Anon. from London

Winners of the January 2018 draw are:

- 1st prize of £469.92** to John from Farnborough
- 2nd prize of £352.20** goes to Barbara from Kirkheaton
- 3rd prize of £234.96** goes to Anon. from Chorley
- 4th prize of £117.48** goes to Anon from Middlesbrough

Note: the winners of the draws for February, March and April will be announced in our June 2018 Newsletter and will be available on our website.

In 2017, the Lottery raised over £7800.00 to help to fund IDDT!

A huge 'Thank You' to everyone who has supported 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 jo@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.iddtinternational.org