

Hello

In this edition of the Diabetes Voices newsletter:

- Find out how to get involved with a patient participation group at your local surgery.
- Help put diabetes on the agenda for the general election.
- Get updates on Diabetes UK's current campaigns.
- Read 60 seconds with... Sue Briggs from Taunton.

Keep up to date

For up-to-date information about current opportunities to get involved, check the Take Action notice board online at www.diabetes.org.uk/diabetesvoices

Get in touch

The Diabetes Voices team is here to help you.

Email diabetesvoices@diabetes.org.uk or call **020 7424 1008** to speak to one of the team.

We are always keen to find out what's happening where you live, so please keep in touch.

The Diabetes Voices Team

NHS England welcomes GP contract changes to improve care for patients



Patient groups help GPs to provide services that truly reflect what patients need

NHS England is welcoming changes to the national GP contract from April 2015. As part of these changes there will be a contractual requirement for all practices to have a patient participation group (PPG) from 1 April 2015. The changes follow an agreement between NHS Employers, on behalf of NHS England, the British Medical Association (BMA) and the General Practitioners Committee (GPC).

Dame Barbara Hakin, National Director for Commissioning Operations at NHS England, said:

"Having been a GP, I know how central primary care is to the health and well-being of patients and their carers. This continues to grow as more patients with complex health needs receive care in the community. Our vision is to see general practice play an even stronger role at the heart of local communities, offering more joined up and proactive care for patients. This is vital in addressing the rising demands on NHS services."

More information about PPGs

If you are interested in having your say and helping to shape the services your own GP surgery or health centre provide, you may be interested in joining a PPG. These groups are a great way for patients and GP surgeries/health centres to work together to improve the delivery of health services locally.

What is a PPG?

PPGs are made up of people who take an active interest in their own healthcare. Every group is different and will determine its own activities according to local needs and the needs of the practice. The groups meet to gather opinions from people about how the NHS works for them – both what works well and what could be better.

Most PPGs operate within GP surgeries and health centres, although some groups look beyond the surgery to decisions made within the NHS that will directly influence their community.

The group will work with their GP surgery or health centre to offer their own personal perspective on the services that they provide.

What will I get out of joining a PPG?

By joining your local PPG you will get the opportunity to meet other like-minded people who want to have a say in their healthcare.

As a group, you will be consulted about arrangements for your healthcare before decisions are made and you will have the chance to help shape the delivery of services. You will have a forum for expressing your own views and making sure the view of the patient is always represented.

Getting involved in your local PPG is also a great way to meet new people and develop new skills.

How do I find out if my GP surgery has a PPG?

Start by asking at your GP surgery or health centre to see if they already have an established PPG. The best people to speak to would be the reception staff or the practice manager, who is likely to be involved in running the group.

If your GP surgery or health centre doesn't already have a PPG, why not start one yourself?

The idea to start a PPG can come from a practice manager, other members of practice staff or from someone like you, a patient at the surgery.

If you want to start a PPG, here are some tips that might be useful:

- You should approach the practice manager at your surgery first. You might find that they have been considering setting up a group.
- Contact the National Association for Patient Participation (NAPP) for some advice.
- Talk to other practices that already have a PPG to find out how it works for them.

- Find out the level of interest among other patients. Perhaps you could start by putting up a poster in your GP surgery or health centre.

You may find the following website useful for more information on how to start a group:

www.napp.org.uk

If you are already involved with a PPG, or you are in the process of starting one at your local GP surgery, please let us know.

We are always interested to hear about how you have been involved or what you have achieved, either personally or as part of a group.

Email us at diabetesvoices@diabetes.org.uk or call **020 7424 1008**.

NEWS

Update on Diabetes Voices activity

In October 2014, a number of Diabetes Voices took part in a focus group to share what is important to them when they stay in hospital. Their experiences will be used to help improve the inpatient questionnaire used to collect data for the National Diabetes Audit. This will give us a better understanding of where diabetes care for patients is good, and where there is a need for hospitals to raise their overall standards.

Thank you to all Diabetes Voices who have shared their experiences of sharps disposal in our recent survey. Diabetes UK is aware that some people with diabetes find it difficult to safely dispose of the sharps they use to treat themselves at home, and will use this information in considering whether influencing and campaigning activities would be useful this year.

In November 2014 Lynda Stewart, a Diabetes Voice from London, spoke to ITV News London to share her experience of diabetes care in Tower Hamlets. This was to coincide with a Public Health England report published to highlight the postcode lottery of care across the country.

Diabetes Voices highlight the difficulties in accessing test strips



In 2014, a large number of Diabetes Voices in England took part in a survey to share their experience of accessing test strips to manage their diabetes.

Of the 1,300 people who took part in the online survey, 46 per cent had prescriptions refused or restricted within the last 12 months.

Of the respondents who said they had experienced restrictions, 39 per cent were people with Type 1 diabetes. This is particularly alarming because everyone with Type 1 needs to use test strips every day. It also suggested that 51 per cent of respondents with Type 2 diabetes are having access to the strips restricted.

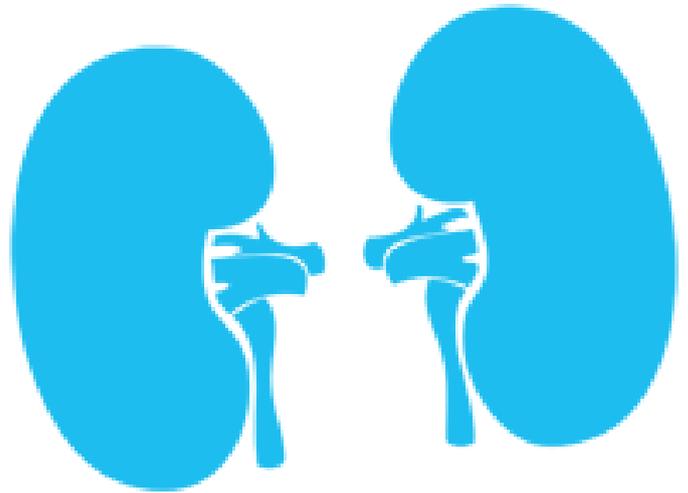
This is a problem because people who treat their diabetes with insulin or other blood glucose lowering medication need to know their blood glucose level in order to work out how much medication to take.

Failure to monitor blood glucose levels effectively can cause blood glucose levels to go either too high or too low, both of which are potentially fatal. In the long-term, poorly managed blood glucose levels can lead to serious complications, such as blindness, amputations and a stroke.

This is despite the fact that the Department of Health has previously written to all GPs to remind them that people with Type 1 diabetes should not have their access to the strips restricted. This survey shows that it is still an issue.

Diabetes UK is calling on NHS England to make sure that everyone with diabetes gets the test strips they need from their GP. We'll keep you updated as the campaign progresses through the year.

15 Healthcare Essentials campaign update



The 15 Healthcare Essentials are the essential health checks and services that everyone with diabetes – whether Type 1 or Type 2 – should receive from their healthcare team. If you aren't getting all the care you need, take the checklist to your diabetes healthcare team and discuss it with them.

Last autumn, Diabetes UK highlighted kidney checks. More than a quarter of people with diabetes don't receive an annual urine test to monitor their kidney function. In people with Type 1 diabetes, this number is as high as 42 per cent.

The urine test is important because having diabetes means you are at increased risk of kidney problems – with up to 40 per cent of people developing kidney disease at some point in their lives. In the very early stages there are usually no symptoms, so the test is really important to pick up any problems early, before they develop and you begin to feel unwell.

What can you do?

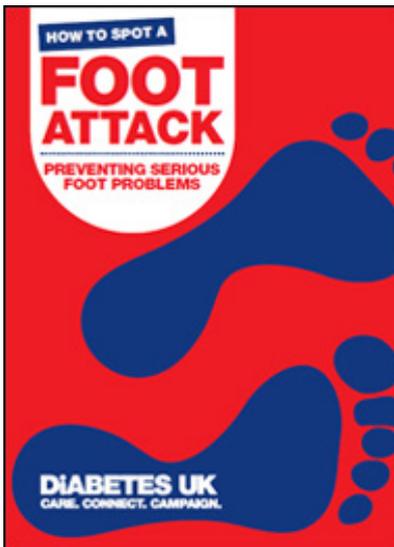
- Remember to ask for your annual urine kidney test. It can help prevent complications like diabetes-related kidney failure. If you don't receive one as part of your annual review, ask for it.
- If you're asked to take a urine sample to your

appointment – make sure you do. It's a really important way to monitor your kidney health, and help you avoid complications in the future.

- Has your care got better or worse in the last year? We want to hear about it. Tell us by filling in our online care survey: www.surveymonkey.com/s/diabetes-care-feedback-14-15
The more we know, the better we can campaign for better care for everyone.
- Order a copy of the checklist for you or someone you know.

Please let us know how you have taken action to support the campaign. Email diabetesvoices@diabetes.org.uk or call us on **020 7424 1008**.

Putting Feet First campaign update



Diabetes UK is campaigning to Put Feet First. Over the past few months lots of you have helped us reach thousands of people at risk of amputation with our new How to Spot a Foot Attack leaflet.

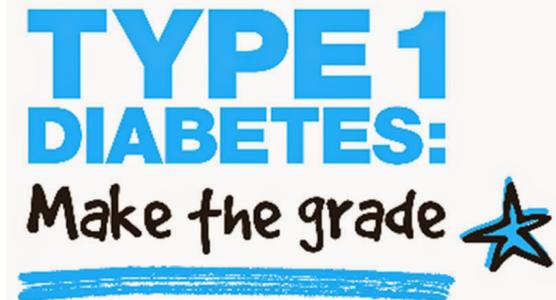
If you've not yet taken part and would like to help bring an end to thousands of potentially preventable

amputations affecting people with diabetes, you can:

- Take copies of our new How to Spot a Foot Attack leaflet to your local GP practice, hospital clinic and nursing home.
- If you know other people living with diabetes, give them a copy of our leaflet 10 Steps Towards Healthy Feet. It tells people what to look for and how to check their feet.

To request free copies of any leaflet, email diabetesvoices@diabetes.org.uk or call **020 7424 1008**.

Children and Young Person's campaign update



In July 2014, a new law was introduced requiring schools in England to arrange appropriate support for children with medical conditions. Thank you again to all Diabetes Voices who campaigned with us to make this happen.

The new law will hopefully make sure that all children with Type 1 diabetes get the support they need to stay healthy and get the most out of their time in school.

Since the launch, Diabetes Voices have been busy writing to MPs and local authorities to spread the word on the new legislation. As a result, many schools have made arrangements to give more support to students with Type 1 diabetes, using the resources Diabetes UK has provided to support them.

The campaign is continuing throughout 2015 to raise awareness in more schools. We will keep you up to date with how you can take action to help schools in your area 'make the grade'.

Care in School helpline launched



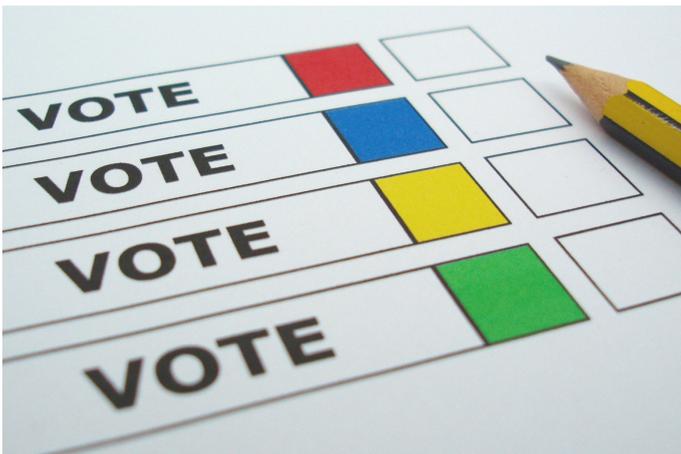
The Care in School Helpline launched in October 2014 and has already helped two parents get their children back into school.

This new service is for parents of children with diabetes who are not receiving adequate care at school, or who have had to leave school. It is part of our Type 1 diabetes: Make the grade campaign and is funded by

Diabetes UK's National Charity Partnership with Tesco. Twenty one volunteers have been trained to provide advocacy support to parents struggling to get their voice heard about issues affecting their child's care. All of the volunteers are either parents of a child with Type 1 diabetes or are living with it themselves. Many of them are also teachers, HCPs or governors. The service is available in England, Scotland and Wales, with the possibility of expansion into Northern Ireland later this year.

General election 2015 – putting diabetes on the agenda

ENGLAND ONLY



Diabetes is now one of the biggest health threats facing the UK. If you live in England, the general election is a chance for you to tell candidates that you want a representative who is committed to doing something about it.

Whether you have five minutes to spare or a few hours to give, there will be some way you can help ensure diabetes gets the attention it deserves.

The key messages:

DIABETES IS BIG: There are now **3.8 million people** living with diabetes in the UK, which is equivalent to **six per cent** of the population.

DIABETES IS GROWING: More than a **quarter of a million people** are diagnosed with diabetes every year. **By 2025**, it is estimated that **5 million**

people will be living with diabetes in the UK.

DIABETES IS SERIOUS: Good diabetes management reduces the risk of complications, but around **four in 10** diabetes patients are not receiving all essential health checks and services. When diabetes is not well managed, it is associated with **serious complications**, including heart disease, stroke, blindness, kidney disease and amputations, leading to disability and premature mortality.

DIABETES IS EXPENSIVE: Diabetes spending already accounts for **10 per cent** of the entire NHS budget and if the rise continues it will bankrupt the NHS.

BUT DIABETES IS FIXABLE: We know what to do and the time for action is NOW!

Why local campaigning matters

Prospective Parliamentary Candidates (PPCs) will be paying particularly close attention to the views of people living in their constituency. While Diabetes UK will be talking directly to all the political parties, local campaigning will be the most effective way to keep diabetes high on the political agenda.

If you speak to parliamentary candidates between now and the election, ask them what they plan to do about:

Prevention: With the number of people with diabetes rocketing, what are they going to do about turning back the rising tide of Type 2 diabetes? What are they going to do to make sure people identified as high risk of developing Type 2 are given the support that they need? What do they think about taxes for unhealthy foods and tougher regulation of the food industry, both of which would help reduce the obesity rate that is fuelling the increase in Type 2 diabetes?

Treatment: As well as a massive postcode lottery of care, across the country there simply isn't enough support for people with diabetes to stay healthy. The end result is that too many people have health complications that are personally devastating and expensive to treat.

How do candidates plan to make sure people with diabetes finally get the quality of healthcare that they deserve?

How to take action

You can help by writing to or emailing your local PPCs to ask them what they're going to do to make sure people living with diabetes get the care that they need.

Download the template letter on our website www.diabetes.org.uk/diabetesvoices or call **020 7424 1008** to request a template email.

If you use Twitter or Facebook you can also tweet or message your candidates to ask them what they're going to do for people living with diabetes where you live.

You can find names and contact details for your PPCs by visiting the three main political parties' websites:

- The Conservative Party www.conservatives.com
- The Labour Party www.labour.org.uk
- The Liberal Democrats www.libdems.org.uk

You can find out who your local MP is by going to www.theyworkforyou.com

Keep us updated

Let us know what you've been up to by emailing diabetesvoices@diabetes.org.uk or calling **020 7424 1008**.

What's next?

It's not just about what you can do in the build up to election day. After the election is over, make sure you're the first to ask your new MP what they'll do to improve the lives of people living with diabetes in your area. Watch this space for more information on how you can get involved.

Diabetes Voices represented at the National Diabetes Commissioning Assembly

On 12 November 2014, the National Diabetes Commissioning Assembly took place at BMA House, London. The assembly was chaired by Adrian Sanders MP and the keynote speech was delivered by Professor Jonathan Valabhji, National Clinical Director for Obesity and Diabetes, NHS England.

The event was attended by clinicians, Clinical Commissioning Group representatives, academics and healthcare professionals.



Diabetes Voices were represented by Mark Duman from Salford, who attended to share his experiences of living with diabetes and discuss what services he needs to manage his condition effectively. Mark gave a lively insight into his own experience of the NHS and suggested measures that could help to make diabetes services more patient centred.

Speaking about the event, Mark said:

"I was honoured to be asked and although I am experienced in public speaking I still found the experience a little nerve-racking."

Prof Valabhji gave an overview of the work currently being undertaken by NHS England to combat the rapidly increasing prevalence of Type 2 diabetes.

Prof Valabhji's presentation was followed by a panel session focusing on some of the innovative programmes being undertaken by CCGs to improve outcomes for people with Type 2 diabetes in their local areas.

Local campaign groups



Do you have an issue that you would like to campaign about locally? Is there something in your local area that you would like to change?

We can help you set up a local campaign group and support you in getting your campaign off the ground. To register your interest, or to find out more, please email diabetesvoices@diabetes.org.uk

SCOTLAND UPDATE

New diabetes plan for Scotland

A new strategy to improve early detection and treatment for diabetes has been launched by the Scottish Government.

Diabetes Voices have played an important part in helping to shape the new improvement plan. Diabetes Scotland will be working to make sure the plan has a robust approach to patient engagement, holding to the maxim, 'Nothing about us, without us'.

The Diabetes Improvement Plan aims to 'deliver world-leading health and social care which is person-centred, clinically effective and safe'. Diabetes Scotland is urging the Scottish Government to take speedy action to ensure this becomes a reality, rather than simply words on a page.

Including prevention as a priority in the plan for the first time is a positive step. There are almost 1 million people in Scotland considered at high risk of Type 2 diabetes. It's crucial that people know how to reduce their risk and it is reassuring that the Scottish Government is now giving prevention its due prominence.



For more information about Diabetes Voices in Scotland, please contact Rupert Pigot:
rupert.pigot@diabetes.org.uk

N. IRELAND UPDATE

Type 1 diabetes: Make the grade campaign comes to Northern Ireland

The Type 1 diabetes: Make the grade campaign will soon be starting in Northern Ireland to improve support offered in school to children with diabetes. The launch is planned for February 2015. We will keep you up to date with how Diabetes Voices can take action to help schools in their area 'make the grade'.

Guidance published on diabetes care in schools

New guidance for parents of newly diagnosed children was published on World Diabetes Day entitled *What Diabetes Care to Expect in Schools*. Diabetes UK has been working in collaboration with education and library boards and the Regional Paediatric Nurse Specialist Group to produce the guidance.

Florence Findlay White, Diabetes UK National Care Advisor, welcomed the publication. Florence convened many of the meetings, which achieved agreement on the final content.

Florence said: "This initiative came from the Minister and we look forward to a formal launch early in 2015. The publication builds on the existing Education Department policy, *Supporting Pupils with Medication Needs*, from 2008.

Copies of the guide will be available in every school and in some paediatric clinics, and are currently available from Diabetes UK's Belfast office.

4 Ts campaign adopted by all health trusts and education boards

The Director of the Transforming Your Care plan, Pamela McCreedy, has highlighted the progress of Integrated Care Partnerships (ICPs) in improving care for people with diabetes. She told a conference attended by the new Health Minister, Jim Wells MLA, that "ICPs have recently worked together with Diabetes UK to highlight the symptoms of Type 1 diabetes and 4 Ts campaign posters and leaflets have been distributed to all primary schools and GP surgeries across all trusts in Northern Ireland." She also paid tribute to the carers and Diabetes Voices who have given up their time to get involved.

For more information about Diabetes Voices in Northern Ireland, please contact Brendan at
brendan.heaney@diabetes.org.uk

New Year's resolutions 2015

How will you make a difference this year? Please go to www.diabetes.org.uk/Get_involved/Campaigning/Diabetes-Voices/Take-Action/If-you-have-a-bit-more-time/Improve-care-2015 to let us know how you plan to improve diabetes care in your area in 2015.

60 SECOND INTERVIEW



“Once you have started, one thing can easily lead to another”

‘Focus on Diabetes’ evening. This included information for patients with diabetes about the importance of their regular checks, as well as the different treatments that are used to treat each of the conditions.

I was invited by the medical staff at the practice to talk about the use of insulin pump therapy for treating Type 1 diabetes. Also, in response to Diabetes Voices emails, I’m making regular contact with the lead nurse for diabetes at the practice to follow up on highlighted issues. For example, the recent concerns regarding annual checks for kidney function.

In addition to these roles, I have joined Diabetes UK Roadshows as an assessor and I am a member of the peer support team. This year I am already booked in to talk to a WI group and the local Diabetes Support Group, and I look forward to following up visits to some schools.

What advice would you give to other people who want to get involved?

Register for Diabetes Voices. The regular emails include advice on ways in which you can campaign on behalf of people with diabetes. These can be small things, but each of these together can help to raise awareness of issues relating to diagnosis and treatment of diabetes. Once you have started, one thing can easily lead to another.

Look out for the next issue of the DIABETES VOICES newsletter in April 2015

SUE BRIGGS

Diabetes Voice

Why did you decide to join Diabetes Voices?

Through Diabetes Voices, I receive regular emails along with hyperlinks to relevant documents. It is an easy way to keep up to date with current issues, and includes suggestions about ways to raise awareness of them.

How have you been involved in campaigning?

At the end of 2013, I attended the launch of the Diabetes UK report *State of The Nation 2013*, in the House of Commons. Along with other Diabetes Voices and staff from Diabetes UK, we talked to members of both the House of Commons and the House of Lords about issues raised in the report. In preparation for this, I found the briefing notes sent out very useful.

As a member of the Patient Participation Group at my GP Practice, supported by the medical staff, we ran a