



The future
of diabetes



About diabetes

Diabetes affects more than 4.5 million people in the UK. That's more than any other serious health condition in the UK. More than dementia and cancer combined.

Every week, diabetes leads to:



Over **460**
early deaths



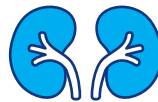
Over **160**
lower limb
amputations



Over
1,850 people
experiencing
heart attacks
or heart failure



Over
540 people
experiencing
strokes



Over
270 people
needing renal
replacement
therapy

The number of people living with diabetes is rising fast. Every day, around 700 people are diagnosed with diabetes. That's one person every two minutes. It's potentially the most devastating health crisis of our time.

Diabetes can affect all aspects of someone's life, but a lack of awareness and understanding can lead to stigma and people not getting the support they need.

We have to take action now.

Because Diabetes UK is the leading UK charity for people affected by diabetes it's our responsibility to make change happen. But this involves us all – people living with diabetes, parents and carers, healthcare professionals, researchers, campaigners and governments.

By coming together to share knowledge and fight diabetes we can build a better future – a world where diabetes can do no harm.

Foreword



At long last people are recognising the impact of diabetes. All four UK nations now have national level plans to make progress in areas of diabetes care which we have highlighted for years – such as more education courses in self-management and improved care in hospital.

The scale of the diabetes challenge today means we need new ways to support people with diabetes to live well and that starts with listening to their experiences of living with diabetes. So throughout 2017, we've been listening to people share what it's like to live with diabetes today and what their hopes and fears are for the future.

We have sought the views of Diabetes UK groups right across the United Kingdom, from Ballynahinch to Ipswich, from Sheffield to Canterbury and run 'Big Conversation' events in Belfast, Bristol, Cardiff, Glasgow, Leeds and London. Thousands of you have responded to an online survey and hundreds got involved in online discussion on Facebook and Twitter.

“We've come a long way in the past 20 years... compared to where we were, it's bloody fantastic. So let's preserve what's brilliant... celebrate that we have made a lot of progress and expand upon that so more people can benefit.”

Woman with Type 1, diagnosed in the 1970s

And people's experiences of living with diabetes are as diverse as we are, one from another. We've spoken to people with different types of diabetes, from different ethnic backgrounds and income groups. We've heard from people who talk often about their diabetes, as well as those who don't think about their diabetes much day-to-day. We've heard, too, from parents, partners and carers of people living with diabetes.

Diabetes is often stigmatised. It can take courage to talk about it. We are deeply grateful to every one of the more than 9,000 people who talked to us. We've put what you've told us at the heart of our message about what must change to create a better future for everyone living with diabetes.

A handwritten signature in black ink, appearing to read 'C. Askew'. The signature is stylized and fluid, with a long horizontal stroke extending to the right.

Chris Askew
Chief Executive

Introduction

“Is that the good or bad type?”

Vision for a better future

Our nationwide conversation with over 9,000 people affected by diabetes tells us loud and clear that living with diabetes is hard. There’s never a day off. It affects work and social lives. It affects daily lives too, what people eat and their ability to exercise. For one in three of the people we surveyed, diabetes had got in the way of something they or their family wanted to do that week.

Things aren’t helped by a lack of understanding about diabetes at work, at school and even among friends. This makes people feel isolated, misunderstood and stigmatised.

Even some healthcare professionals do not properly understand diabetes. Some people get great care, but many want better conversations with more informed healthcare professionals.

People can feel alone and unsupported. But contact with people who understand diabetes helps. Education and information works for those who get it. And the right technology and treatment is vital to help people keep on top of their diabetes, every day.

Finally, people want hope for the future.

People with diabetes have told us that as well as more understanding and awareness of diabetes, there are a number of ways we can make it easier to live with diabetes in the future. **And it’s these six things:**

- **More support for emotional and psychological health.**
- **Better access to healthcare professionals who understand diabetes.**
- **Better access to technology and treatments.**
- **Widely available information and education.**
- **More support and understanding at work and school.**
- **Hope for the future.**

Read on to find out more about what needs to change to create a better future for people living with diabetes.

All of the quotes in this report come directly from the people who talked to us at the events, online and through the survey responses.

This is the voice of people affected by diabetes in the UK.

How did we engage people with diabetes?



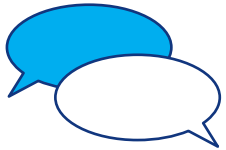
We held seven Big Conversation events across the UK.
225 people



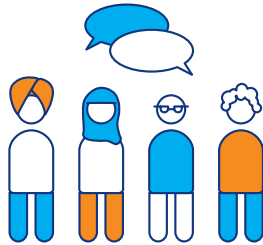
We promoted an online conversation on social media and our forum.
100 people



We carried out an online survey.
8,500 responses



Focus groups and interviews were held with people from groups we'd not reached.
40 people

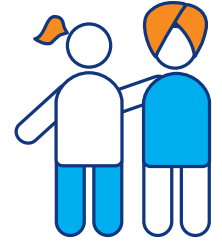


More than 40 local conversations were hosted by our Local Groups.
500 people

The themes in this report are based on the discussions captured at the big and local conversations, combined with the most prominent themes from the free text questions in the survey. For more detail on the methodology, please visit diabetes.org.uk/futureofdiabetes



More support for emotional and psychological health



“I told my consultant that I felt horrendous, he replied ‘I’m not here to talk about your emotions’.”

Living with diabetes can be exhausting. People need support to manage it well and protect their mental health.

Diabetes doesn’t just affect someone physically. The effect of varying blood sugar levels on mood – and the relentless need to manage the condition – affects mental health. Fear of hypos is also a constant concern for people with Type 1 diabetes and was one of the most talked about issues at the Big Conversation events and in focus groups.

“You feel awful and they can take ages to get under control. They are always in your mind as you have to be aware all the time.”

People don’t want to give in to depression and anxiety. They want more joy in their life. And they’re worried about the effect that diabetes has on family and personal relationships.

Managing an invisible condition can be isolating, and other people do not always understand what it’s like to live with diabetes.

“The worst thing is the sheer isolation, I’m left to work it all out on my own with no help or support.”

We’re also being told there’s a lack of support at diagnosis, especially when diagnosed with Type 2 diabetes. One person described their diagnosis as “like someone has dropped a weight on top of you”.

One third of people told us they are interested in support or counselling from a trained professional. But we know that people can experience problems getting a referral when they need it. A survey in 2015 found that 76 per cent of people with diabetes who needed emotional or psychological support from a specialist were not offered it¹.

People also want peer support – 25 per cent of survey respondents said that they would like a local support group and 15 per cent were interested in getting online support through a forum or social media.

“I attend lovely local hospital peer support pump meetings.”

¹ Diabetes UK (2015). *15 Healthcare Essentials online survey 2015*. Baseline: 3,000 responses



64% of people sometimes or often feel down because of their diabetes

In our survey, parents of children with Type 1 diabetes were most likely to feel down and to want more support.



Vision for a better future

No one should feel unsupported and alone with their diabetes. We need a health service where the physical and mental health aspects of living with diabetes are treated equally, and together, in every consultation. Where those who need it, get specialist mental health support from people who understand diabetes. And where people are connected to other people living with diabetes.

“The only people who get it are other people with diabetes.”

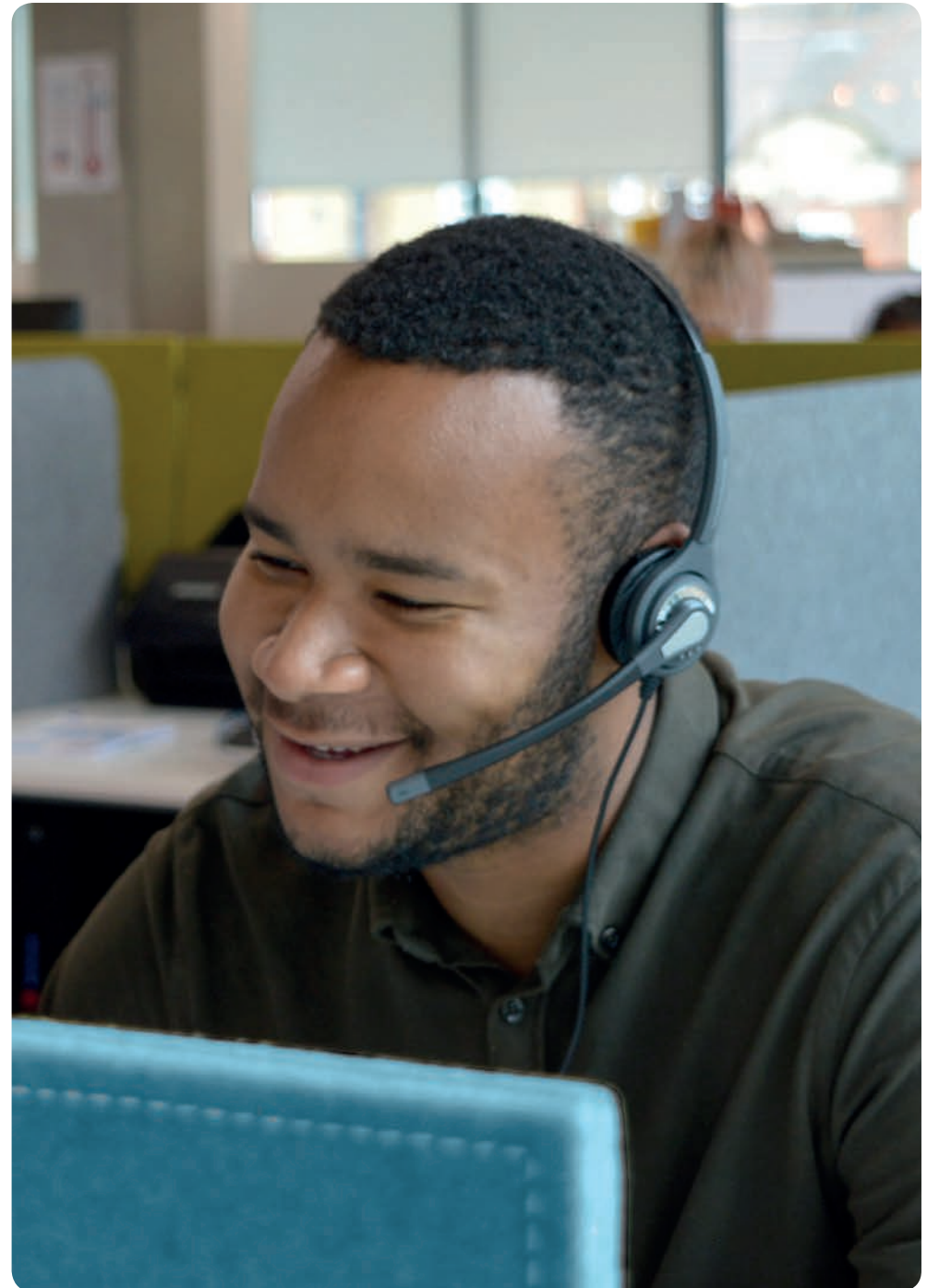
“The GP has never mentioned any support groups or external agencies that could offer support. All I hear is that change starts with me. I know that! But I am fat, frustrated, out of puff and most of all fed up to the back teeth of being bloody diabetic.”

“You go shaky and feel weak and ill. They [hypos] can come on fast and it’s bad if you have to ask to be taken off the shop floor, to make sure you eat, so that you don’t get a bad one.”

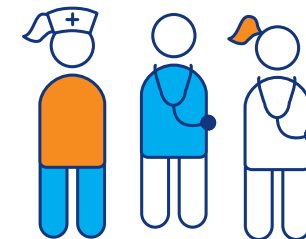
“It’s hard for friends and family to really understand and they misinterpret your mood.”

How we can make this happen

- It can make a real difference when healthcare professionals take someone's emotional needs into account. All healthcare professionals should receive training so they can routinely support emotional and mental health, and can refer to specialist support when appropriate. And we need to improve the specialist psychological support available to people with diabetes.
- A diagnosis of diabetes should be delivered without blame or stigma. No one should leave an appointment where they are told they have diabetes without being given sources of information and support, and the time to agree a care plan. People must also be referred to existing online and telephone support.
- We also need to find new ways for people with diabetes to get together – from support groups and online forums, to diabetes courses that “help put things into perspective”. People want more support groups that recognise and reflect their different experiences, ages and cultures. Some have set up their own groups in order to fill this gap, and this needs to be made easier.



Better access to healthcare professionals who understand diabetes



“I would like to be asked “how are you”? Not how is your diabetes? How are your sugars? How’s your sight, feet, kidney function... I am not a computer screen of test results and even a nod to that would improve matters so much for me.”

Diabetes is a long-term condition. People live with it every day, and their needs may change over time. Getting the right care is life-changing, but poor care and support can result in devastating complications and life-threatening illness.

Children and young people in particular need access to specialist care. But we heard that all too often people with diabetes are being let down by the health system.

Day-to-day care

“Going into the clinic I feel like I walk in as a time slot and walk out as an appointment.”

Multiple appointments, short appointments and limited involvement in decision-making about their care can lead to frustration and leave people living with diabetes feeling unsupported. The support of healthcare professionals who really understand diabetes makes a big difference.

One third of people responding to the survey said that having access to a one stop clinic where you get all your appointments at the same place on the same day was the thing they would most like to change about their healthcare.

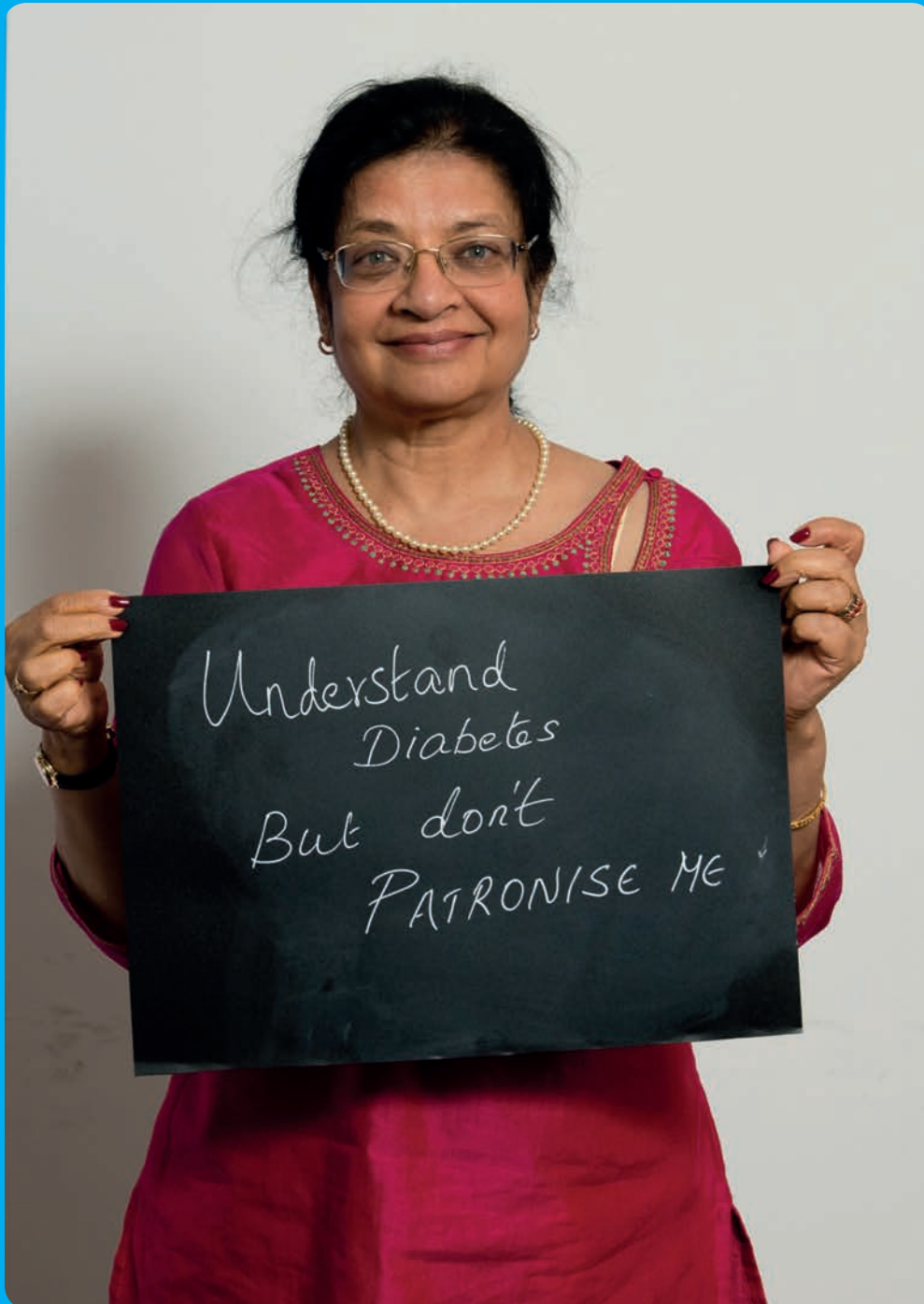
Care in hospital

“They’re rigid about meal times but chaotic about medications and ward rounds are inconsistent. It has such a big impact.”

Too many people feel unsafe and anxious about hospital stays. People with diabetes report not being provided support to manage their diabetes and medication when in hospital. Others want to know that whilst they’re ill, or unable to look after themselves, they’re being cared for by people competent in diabetes management. These concerns reflect the picture that emerges from the inpatient audit in England and Wales¹.

¹ National Diabetes Inpatient Audit. content.digital.nhs.uk/diabetesinpatientaudit





Vision for a better future

People with diabetes want to be treated as a person, not a condition. They need care that is joined up and centred around them, so it's easier to access the support they need, when they need it. And they need a health and care workforce that understands the realities of living with diabetes.

“Consultations can feel like tick box exercises.”

“A good GP appointment is someone taking the time to explain what test results mean, suggesting lifestyle tips to manage diabetes better and explaining how to manage medication.”

“I recently spent 12 days in hospital, and didn't see anyone from the diabetes team. I was put on a sliding scale, and I had to switch off the machine to stop it giving me too much insulin. I ended up passing out.”

“It helps when you have a hospital team with their heads screwed on, when mine hear of GPs rationing test strips they go out to the surgery to educate GPs.”

How we can make this happen

- We need a workforce with the capacity and confidence to care for people with diabetes. Every healthcare professional that people with diabetes come into contact with should have good understanding of diabetes – and be able to support the needs of those living with it. Consultations should be long enough for clinical teams to provide the quality of care they would like to.
- We need to plan care around people's lives. This means coordinated annual checks that don't require unnecessary multiple appointments, and collaborative care planning with results sent to people in advance of their consultation.
- We need to explore the flexibility to provide appointments outside working hours, as well as using channels like email and Skype.
- While there are many examples of good care, sadly it's not everywhere. To tackle this variation we need to identify and promote models of effective diabetes care and share what works so every person with diabetes can benefit.

“My DSN is amazing, she goes out of her way to make sure I'm ok calling me every two weeks or to encourage me to go to appointments when I don't want to.”

“I've got a really good dietitian who's been able to help me understand more about what I'm eating and how it helps me more with carb counting and spreading out my carbs with meals. Also helped me with managing my diet in line with exercise.”



Better access to technology and treatments



“I am only given one pack of test strips per month, I have to pay for the others I need myself.”

Making it easier to access the best technology and medicines is a major priority for people with diabetes.

People with Type 1 diabetes and many people with Type 2 need insulin and other medications to manage their condition. As well as this type of treatment, new technologies are also making it easier for some people to monitor their diabetes and often help them to avoid disruptive and draining hypos, caused by low blood sugar levels.

Many people are benefiting from the treatments and equipment that are right for them, but it can feel like a lottery.

Some people with diabetes have had their number of test strips reduced or their meter changed without consultation. They feel decisions are made with little consideration of the impact on their diabetes management.


Others report problems when asking for different brands of insulin. There can be delays with prescriptions because pharmacies don't have the right stock, as well as challenges with repeat prescriptions that can make planned travel or work away from home difficult. People with Type 2 say they are struggling to self-manage and meet driving regulations from the DVLA because they're not given access to testing equipment.

Managing diabetes is time-consuming. No one needs the extra burden of having to “battle to get what you need”.

“We have been questioned why my daughter is testing so frequently and it required a letter of complaint to make sure we get the required number of strips on prescription. This is outrageous.”

“My insulin got cut off my repeat prescription [and I] had to wait 72 hours when I was down to my last insulin pen.”

“[There is] no CGM funding for anyone at all in our area.”



28% of the people who took part in the survey have problems getting the medication or equipment they need to manage their diabetes

Particularly test strips, pumps and continuous glucose monitoring.



Vision for a better future

The right technology, medication and equipment can be life-changing. They can put people in control of their diabetes and revolutionise the way they deal with their diabetes every day.

Everyone is different, which is why people with diabetes need access to the right technology and treatments for them. Healthcare professionals need to have the skills and understanding to help them use it well, and new treatments should be made available as soon as possible once approved, so that everyone who could benefit, does.



How we can make this happen

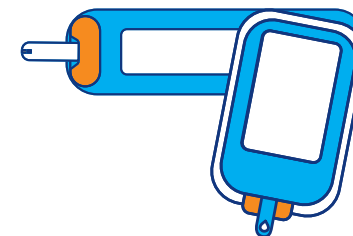
- Access to the right treatments and technologies can still depend on where you live and the knowledge of local healthcare professionals. Variation in providing new and established diabetes treatments and technologies, like insulin pumps, continuous glucose monitoring (CGM), flash glucose monitoring and test strips must be reduced.
- Local policies and procurement should support access to the best treatment and devices for those who can benefit, and healthcare professionals should be trained to support their use.
- National guidance, such as from NICE and SIGN, needs to support faster access to treatments and technologies so that these can be more quickly adopted and made available to people who could benefit.
- Better knowledge and understanding of diabetes technology is needed. This needs to be through training and diabetes specialists supporting other professionals.
- Research and development is leading to huge advances, and we need to keep people with diabetes updated with information about future and current technology and medicines.

“We had to write to our MP to get a pump funded for our seven year old daughter.”

Diabetes technology explained



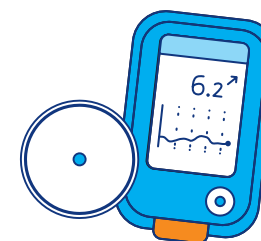
Insulin pumps deliver a steady flow of short-acting insulin around the clock. They can help adults and children with diabetes to improve HbA1c, reduce hypos and manage their blood sugar levels in the long-term¹.



Blood glucose meter. All people with Type 1 diabetes and insulin-treated Type 2 diabetes need to test their blood sugar levels. Other people with Type 2 can also find this helpful. This is usually done with a finger prick blood test using a blood glucose meter that indicates the blood sugar level at the time of the test. This needs a test strip for each test.



Continuous glucose monitoring (CGM) gives constant readings of blood sugar levels and can have alarms if blood sugar levels drop too low. They're for people who cannot tell they're having a hypo, can improve HbA1C and reduce severe hypos².



Flash glucose monitoring uses a small sensor worn just under the skin. It stores blood sugar levels which you can access by scanning the sensor whenever you want to. It gives people more information, more conveniently and can help people better manage their diabetes.

¹ Diabetes UK position statement on pumps (July 2017)

² Diabetes UK position statement – Self-monitoring of blood glucose levels for adults with Type 1 diabetes (March 2017)

Widely available information and education



“It was eight years before I knew I should be carb-counting. I went on a DAFNE course, and it changed my life. I don’t know how I never knew this!”

Diabetes can affect every part of someone’s life. It impacts on family life, mealtimes, work, exercise and social life. Getting the right support and information helps people manage the day-to-day reality of diabetes.

But too often people with diabetes are left to find the information they need themselves, from basic medical information about the condition through to advice around diet, exercising with diabetes, and managing relationships.

Information and education

“You need more information on diagnosis, all I was given was a prescription and a piece of paper that basically said nothing.”

People told us that a lack of information at diagnosis can be particularly damaging. But that when they were offered education and support, it was transformative. As one person commented, a diabetes education course “made the biggest difference to me – more than anything else, ever”.

Only 39 per cent of respondents to our survey had attended a diabetes education course, but 70 per cent were interested in going on such a course.

“Sometimes there are good services out there, but it feels like you have to search for them.”

And it’s important that courses are adapted for all communities. One woman described her course as “useful but totally Eurocentric”.

People also want and need information and support on an ongoing basis – not just at the start of their journey with diabetes.

Food and diet

“It’s not always sugar that is the problem but carbs – there is a need to raise awareness of this so people have a better understanding.”

Living with diabetes can mean adapting to a new relationship with food – whether carb-counting for people who use insulin, or managing Type 2 diabetes through diet and exercise.

But in today’s world it’s difficult to know what foods to eat when there are many advocates of different dietary approaches, and it can also be hard to know what’s in the food we eat either at home or when out and about.



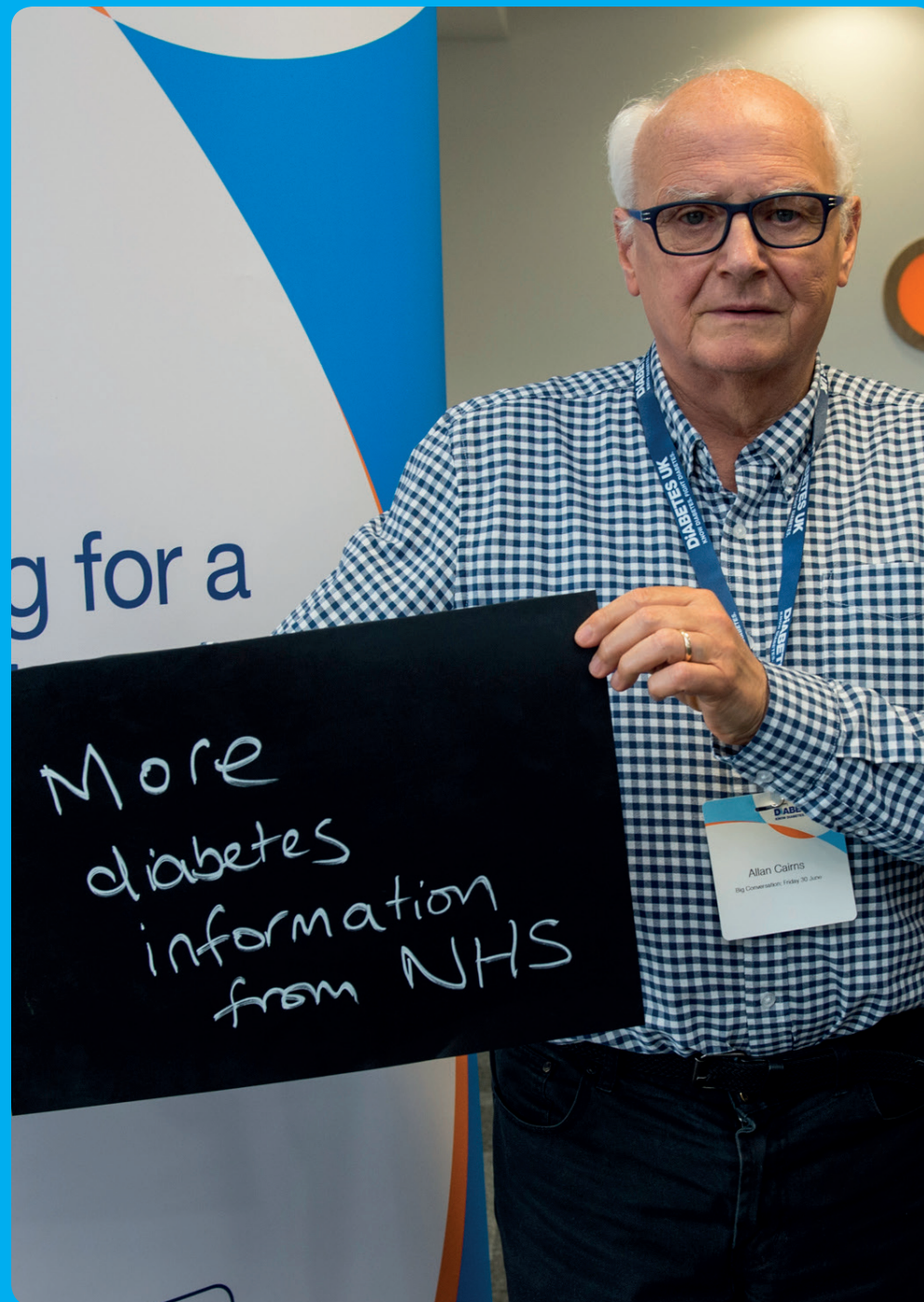
Vision for a better future

People with diabetes need access to the right information and advice, at diagnosis and throughout their lives. No one should leave an appointment being told they have diabetes, or are at high risk of developing it, without knowing where to go for information and support. People with diabetes also need access to education programmes that help them experiment, learn and take action to manage the condition well.

How we can make this happen

- Healthcare professionals should promote clear and consistent evidence-based information on diet, medication and diabetes management, using tools like Diabetes UK's information prescriptions.
- Information should be widely available, delivered in a range of formats and tailored to people's cultural experience. Healthcare professionals should signpost people to the Diabetes UK Helpline, website and other sources of support, especially at diagnosis.
- More diabetes education should be provided, and a greater variety of ways to access it must be made available.
- Easy to understand nutritional information should be available on all foods at the point of purchase in shops, and in places where people eat outside the home.

“The traffic light system should be used more, and foods with hidden sugars should be labelled more clearly.”



More support and understanding at work and school



“I’ve gone in after a hypo, you can’t take time off.”

Diabetes at work

“A big part of why I left teaching was that we didn’t have the chance to eat and such with all the lunchtime duties, and I struggled to control my sugars under that stress.”

People find working with diabetes can be difficult, but they often don’t talk about it with colleagues or employers. They are not confident they’ll be understood and don’t want to be seen as a problem. We’ve heard from people who have dropped out of the workplace because they find it too difficult and exhausting to manage diabetes and their job.

- **37%** of survey respondents in employment said that diabetes had caused them or their family member difficulty at work.
- **16%** of people in employment said they felt they’d been discriminated against by their employer because of their diabetes.
- **7%** of those in employment hadn’t told their employer that they have diabetes.

People with diabetes do not often seek support to help them at work. We’ve found it’s a common experience for them to fit their diabetes around their work. They have low expectations of how employers might respond to their diabetes. This might mean they don’t always manage their diabetes well whilst at work, or that they miss appointments as they don’t want to ask for time off.

Some people do feel supported at work, and it helps when a manager has a good understanding of diabetes. But 24 per cent of the people we surveyed would like more time off work for diabetes related appointments and 25 per cent need more flexibility to take breaks to eat, test blood sugar or take medication.

“They’re not supposed to discriminate but how would you prove it.”

Diabetes at school

“The school are not very good at problem solving. They just call me. It’s easier as he’s got older and better at managing his diabetes himself but it’s hard when I’m teaching for my livelihood – I can’t always just get up and leave.”

Parents of children with diabetes told us of significant challenges they can face making sure their children get the same chances to learn and play as full a part in school life as their classmates.

Good care at school is vital. Where schools do not have an effective care plan in place, young people may not be allowed to test blood sugar or inject in front of other pupils, or are not listened to by teachers when feeling unwell. This can affect the whole family, as parents may have to drop everything to attend school and be anxious that their children are not getting the support they need.



Vision for a better future

People with diabetes need more understanding, flexibility and support from schools, colleges and employers. They need to feel confident in asking for their needs to be met in the workplace, and while some schools are providing excellent support, many need to do more to ensure young people are provided the care they need to fully achieve their potential.

How we can make this happen

- Every school must have a medical conditions policy that sets out how children with conditions like diabetes will be supported. This should involve a named person responsible for a young person's care, and a clear individual care plan in place.
- A line manager's attitude was most often cited as the make or break factor for whether people can make a job work for them. Employers need to have more understanding of diabetes and the impact it can have, as well as their responsibility to provide support to their staff. This includes making time for employees to attend appointments or education courses.
- As the largest employer in the UK, the health service should lead by example by making sure the needs of people with diabetes are understood in their workplaces.

“It was a complete nightmare, it took over our lives, I had to give up everything because they [the school] wouldn't do what they were meant to.”



Hope for the future

“My long-term hope is a cure for diabetes in my lifetime.”

Once diagnosed, you live with diabetes for the rest of your life. People want to know what is being done to work towards a world where diabetes can be prevented, and cured. It provides hope for them and for their families.

1 Diabetes research

Research changes lives – leading to major breakthroughs in diabetes diagnosis and treatment since the discovery of insulin in 1921.

People with diabetes can see the changes new treatments and technology have on their lives, and they want to see more invested in diabetes research. They want to know more about what research is taking place, how they can get involved and what the impact could be.

1 diabetes.org.uk/research/our-approach-to-research/have-your-say/type-1-diabetes-priority-setting-partnership

2 Diabetes UK, forthcoming

3 R. I. G. Holt (2017) A crisis in diabetes research funding. *Diabetic Medicine*



Vision for a better future

Diabetes UK has been leading projects to identify the top 10 priorities for research in Type 1¹ and Type 2 diabetes².

For Type 1 diabetes, research priorities include reducing hypos, exploring the effectiveness of different insulins and technologies, and research into the artificial pancreas that monitors blood sugar levels and then automatically injects the right amount of insulin.

For Type 2, people want to know whether their diabetes can be cured, for example through surgery or very low calorie diets. They are keen to find out more about why Type 2 diabetes gets progressively worse, how it causes nerve damage and the role of different food groups in managing diabetes.

How we can make this happen

- More money must be invested in diabetes research. We estimate that no more than £60 million was spent on diabetes research in 2014, whereas £500 million a year is spent on cancer research. In the health service, of every £1 spent caring for diabetes, just half a penny goes to research³.
- We need the research community to respond to the research priorities identified by people with diabetes and healthcare professionals.
- And the Government must make sure that funding for diabetes research is increased and has greater parity with funding for research on other serious health conditions.



Hope for the future



“By the time people are diagnosed they are a long way down their life, we need to get them at the beginning. It’s about forming a habit that is going to last a lifetime.”

2 Preventing Type 2 diabetes

People with diabetes want to see action to help prevent others developing Type 2 diabetes in the future if avoidable. While not all cases of Type 2 diabetes can be prevented, for some people being overweight or obese can put you more at risk.

Too often, people are only given the support they need to make changes to their diet or levels of activity once they are diagnosed with Type 2 diabetes. And with two thirds of adults in the UK now overweight or obese, we must take urgent action to make our society healthier.



Vision for a better future

We need to help people reduce their risk of developing Type 2 diabetes by supporting them to make changes to their diet, levels of activity and their weight if they are overweight. But we also need to tackle the reasons for the increasing rates of obesity that are putting more people at risk of Type 2, and make the healthy choice the easy choice for everyone.

How we can make this happen

- The health system needs to identify people who are already at high risk of Type 2 diabetes and offer them programmes that help them reduce their risk.
- The food and drink industry must continue to take steps to make their products healthier for everyone through, for example, reducing saturated fat, sugar, salt and calories in their products.



What's next



We've heard from over 9,000 people affected by diabetes. They told us that diabetes affects all aspects of their lives: at home with their families, mealtimes, work, exercise and socialising. They told us that things can be tough. And they told us that there are steps we can and must take, right now, to build a better future for people living with diabetes.

Diabetes UK has a vision of a world where diabetes can do no harm. We'll continue to raise awareness and tackle the stigma of diabetes, invest in diabetes research and directly support people with diabetes, healthcare professionals, and researchers.

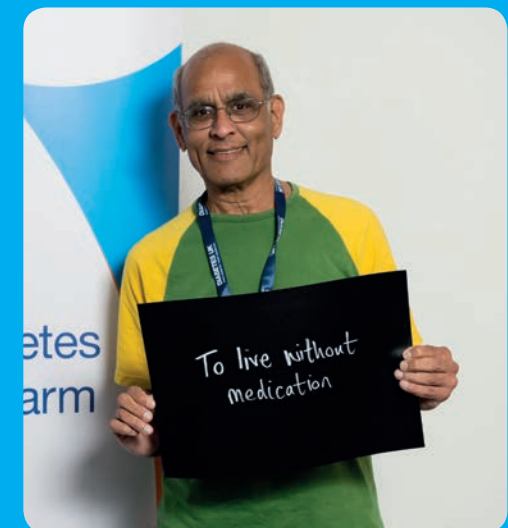
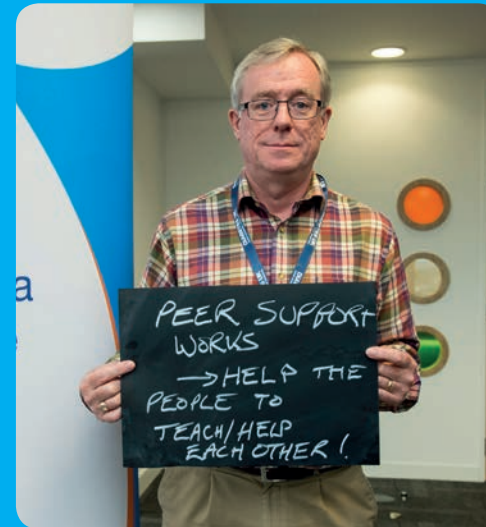
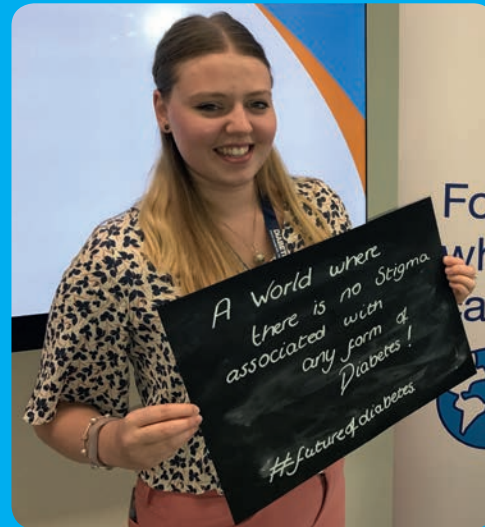
But we can't do this alone. To achieve a better future for people living with diabetes we need action from governments, health services, policy makers, healthcare professionals, local decision makers and from across society.

Together, we can achieve so much more.



Visit diabetes.org.uk/futureofdiabetes to add your voice to the thousands who have already had their say, and find out how you can work with us to build a better future for people living with diabetes.

My future of diabetes



Thank you to everyone who took part

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diabetes.org.uk