

The future
of diabetes



What needs to happen in Scotland



We've heard from over 9,000 people across the UK about what it is like to live with diabetes and their hopes and fears for the future; people of all ages, ethnicities and backgrounds. 750 of them live in Scotland. 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.

Health inequalities developed over generations continue to affect people across Scotland. People from areas of multiple deprivation are more likely to be affected by diabetes and its complications, and experience poorer outcomes.

Diabetes affects all aspects of a person's life: at home with family, mealtimes, work, exercise and socialising. It can make it hard to live with spontaneity. Lack of understanding about diabetes in the health service, workplace, school and society generally can lead to people feeling isolated, misunderstood and stigmatised.

To build a better future we must listen to what people with diabetes are telling us. Their needs and experiences must be central to the care and support they receive. And by working together we can tackle the issues that matter.

We need to address these issues in Scotland in partnership with health services, local Integration Joint Boards and Scottish Government.

More support for emotional and psychological health

Diabetes can be a constant struggle. Good mental health is the key to managing it successfully. But at least four in 10 people with diabetes experience emotional or psychological problems such as depression, anxiety and diabetes-related emotional distress.

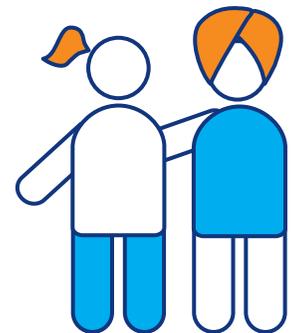
All too often, mental and physical health services are fragmented which means people with diabetes lack access to the right emotional and psychological support. It's essential that the psychological and emotional wellbeing of people living with diabetes is an integral part of their care.

We want to see a world where people's emotional needs are properly taken into account. Where those who need it, get specialist mental health support from people who understand diabetes.

We call for:

- The availability of fully trained staff to meet the emotional and psychological needs of people living with diabetes. NHS Education for Scotland's comprehensive workforce strategy should include:
 - Core training in mental health skills for all healthcare professionals working in diabetes, including GPs and specialists.
 - More psychology staff with expertise in diabetes. Specialist emotional and psychological support should be routinely available within every diabetes team.
- Healthcare professionals and organisations to explore and create opportunities for peer support for people with diabetes.

“This is quite deep to say but it's a chronic illness where every day you are reminded how mortal you are. It's very difficult for people to feel they can cope. Mental health is the thing that isn't addressed.”



Better access to healthcare professionals who understand diabetes

People with diabetes tell us that it would be easier to live with it if they saw healthcare professionals, outside of their diabetes team, who really understood it.

Having a health and care workforce that is skilled and knowledgeable in diabetes care and management improves and supports people's physical and mental health.

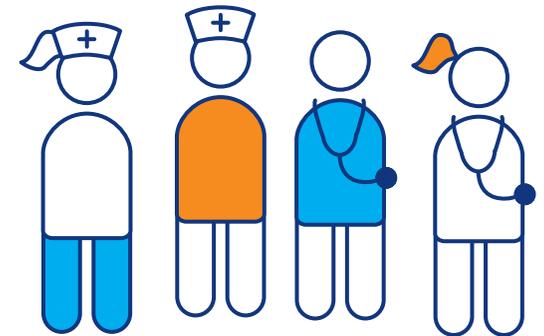
The root causes of the disparity in diabetes care across Scotland needs to be understood and tackled. It is unacceptable that there is significant variance in the delivery of the nine care processes between Health Board areas.

As well as geographical inequality, there is a disparity of care between those with Type 1 diabetes and those with Type 2 diabetes. People with Type 1 diabetes are less likely to receive all nine care processes. We need to know why this is happening and NHS Scotland must lead a co-ordinated effort across the 14 Health Boards to address it.

“My Diabetes My Way project: I used my data to go in and show my GP – look my levels aren't right. It's a platform to work together.”

We call for:

- Health Boards to redouble their efforts to make sure that health inequality has no place in a fair and prosperous Scotland. They must take action to reach people in all communities so that the right to health is a reality for everyone.
- The person-centred care recommendations of Chief Medical Officer Catherine Calderwood in her report *Realistic Medicine* to be delivered. Every person with diabetes must have meaningful conversations with their healthcare teams and be fully involved in deciding which treatment options are right for them.
- An improvement in screening for gestational diabetes as it is likely that it is under-diagnosed relative to other countries. We need better pre-pregnancy and pregnancy care for those with established diabetes.
- Further promotion and improvement of the *My Diabetes My Way* online resource so that more people can benefit from it.
- A review of the SIGN 116 guidelines on diabetes to ensure the recommendations cover the best practice given progression of treatment and support for people with diabetes.



Better access to technology and treatments

Technological advances in diabetes management are increasingly successful and popular. Over the past five years there has been significant improvement in the provision of insulin pumps across Scotland but availability is inconsistent between Health Boards.

We are keen to work alongside healthcare providers to ensure fair and equal access to insulin pumps, flash monitoring and continuous glucose monitoring. Availability is also limited by a lack of skilled staff to deliver services.

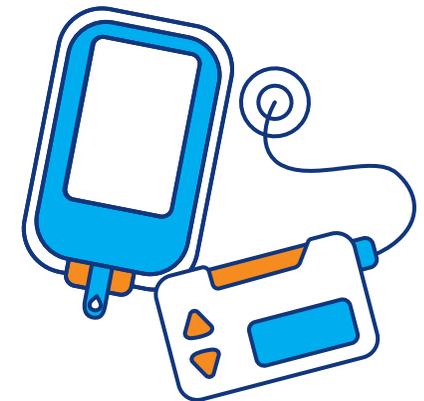
Everyone has the right to the treatment and support which will help them to live well with diabetes. We want to see a world where the daily and longer-term complications of diabetes are minimised through access to the best treatments and technology. Those who can benefit must not be subject to barriers.

We call for:

- Fair and equal access to insulin pumps and continuous glucose monitoring across the 14 Health Boards following the welcome £10m commitment from the Scottish Government.
- Everyone who can benefit from existing and emerging technology to receive it. They must be supported by healthcare teams who are trained to provide support to people who use technology to manage their diabetes.

“I eventually got funding for CGM but had to fight hard to get it.”

“People have more access to technology to help them manage their diabetes. But they also need to be shown how to use it effectively.”



Widely available information and education

Living with diabetes can be tough. You never get a day off. It's not just about the time you spend with healthcare professionals and in NHS appointments. It's about having to manage your diabetes constantly in every aspect of daily life; balancing medication with the food you buy and cook, and with the exercise you take.

That's why good information from the start with regular opportunities to learn more is so important.

We want to see a world where no one leaves an appointment having been told that they have diabetes – or are at high risk – without knowing where to get information and support.

The knowledge and support people get from diabetes education is essential, but currently not everyone receives it.

“More and more people are expected to self-manage their diabetes but they're not given the education to do it properly.”

We call for:

- Sustained investment in the development and delivery of diabetes education across Scotland.
- Everyone to be able to access education in a way that suits them. Education opportunities that better reflect people's age and background should be made more widely available and any education that is provided should have evidence to prove it's effective.
- Roll out of Diabetes Scotland's new Type 2 education pack for newly diagnosed people across the country.
- Healthcare professionals to promote clear and consistent evidence-based information on diet, medication and diabetes management; using tools like Diabetes UK's information prescriptions to communicate this. Information must be widely available, timely, delivered in a range of formats, tailored to people's cultural experience and encouraging peer support.
- Healthcare professionals to direct people to Diabetes UK's website and Diabetes Scotland Helpline. Telephone **0141 212 8710*** or email **helpline.scotland@diabetes.org.uk**



*Calls may be recorded for quality and training purposes.

More support and understanding at work and school

Work can be difficult if you have diabetes. But people often don't talk about their diabetes with colleagues or employers as they're not confident it'll be understood. They don't want to be seen as a problem.

Care in school for children and young people with diabetes is varied across Scotland. Lack of support for children in school can lead to poorer control and require medical attention and even hospital admissions.

There is clear policy and guidance on how to support children and young people with healthcare needs in schools. But it's not enshrined in legislation. Every child with Type 1 diabetes should have access to the same childhood experiences and opportunities.

We want to see a world where the impact of diabetes on school and working life is minimised because the needs of people living with it are understood. We want workplace and school policies to give people the confidence to ask for the adjustments they need without feeling they are a problem.



We call for:

- Each school and local authority to have a 'medical conditions in school' policy, to ensure that individual healthcare plans are produced in partnership with the parent, child and Local Paediatric Diabetes Team. The policy must set out how children with conditions like diabetes will be supported and be available on their website. The responsibilities have been laid out in the Making Connections guidelines supported by Scottish Government and Diabetes Scotland.
- The public sector in Scotland to lead by example in supporting people with diabetes in the workplace. They must make sure their employees with diabetes can attend appointments and education, that their needs are understood, and that peer support is encouraged. Supporting people with diabetes in the workplace helps to deliver the Fair Work Agenda, ensuring opportunities for all.

“It's difficult to bring up psychological problems at work. When I did need help, they did nothing.”

“Employer awareness is key.”

Hope for the future

Once diagnosed, people live with diabetes for the rest of their lives. So they want to know more about what is being done to work towards a world where it can be prevented or cured. It provides hope for people and for their families.

1 Research

Research has delivered major breakthroughs in diabetes diagnosis and treatment since the discovery of insulin in 1921.

Access to new and better treatments can radically improve people's quality of life and help avoid serious complications. This can only come from continued investment in research.

Sustained research into all forms of diabetes is needed to understand why and how it develops, how it can be prevented, and ultimately to find a cure that will stop the diabetes crisis altogether.

This research needs to be translated into practice so people with diabetes benefit from evidence-based approaches.

But currently we estimate that in the NHS, of every £1 spent caring for diabetes, just half a penny goes to research². Diabetes UK is the single biggest charity funder for diabetes in the UK and a large proportion of that funding is invested here in Scotland.

We call for:

- The research community to respond to the priorities identified by people with diabetes and healthcare professionals through priority setting partnerships and Diabetes UK's Clinical Study Groups.
- The Scottish Government to make sure that funding for diabetes research is increased and that the Scottish Diabetes Research Network is maintained and developed.

“Ideally find a cure. In reality though, find a non-painful way to test blood sugar levels.”



2 Prevention of Type 2 diabetes

We want to see a world where fewer people live with diabetes and where it is easier to live a life with a low risk of developing Type 2 diabetes.

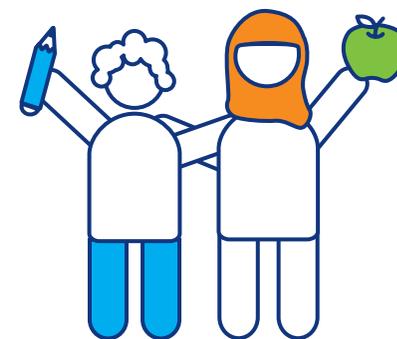
Obesity is driving the increase in Type 2 diabetes. We need to tackle this now to stop more people developing the condition in the future.

We need to transform our obesogenic environment and make healthy living integral to all decisions in Scotland. From town planning which encourages more walking and outdoor activity; to children's education which incorporates significant active learning about diet and exercise; to addressing poverty and access to fresh, healthy and affordable food.

We call for:

- The enactment of the Scottish Government's Programme for Government 2017–18 commitment to limit the marketing of products high in fat, sugar and salt which disproportionately contribute to ill health and obesity.
- Publication of a dedicated Type 2 Prevention Framework that lays out a road map for tackling the rise in numbers of people developing Type 2 diabetes. Including a consistent, easy-to-access approach to weight management across Scotland's Health Boards.
- Greater opportunities to engage with and educate communities, particularly children and young people, on healthy living.

“My most sincere hope is that this [Type 2 diabetes] pandemic will be reversed.”



Join us

People with diabetes need change, now. Diabetes Scotland has a vision of a world where diabetes can do no harm, but we can't do it alone. To achieve a better future for people living with diabetes we need action from across government, the health service and society.

Visit diabetes.org.uk/futureofdiabetes and work with us to create a better future for people living with diabetes.