

The future of diabetes



What needs to happen in Northern Ireland



We have heard from over 9,000 people across the UK about what it's like to live with diabetes and their hopes and fears for the future; people of all ages, ethnicities and backgrounds. 300 of them live in Northern Ireland. 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 affects all aspects of their lives: at home with family, mealtimes, work, exercise and socialising. It can make it hard to live with spontaneity and hope. 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.

In Northern Ireland we have the plans in place to tackle these issues; but they must be carried out. We need to work together

to make sure the Department of Health's 2026 strategy, *Delivering Together* and the 2016 *Diabetes Strategic Framework* are fully implemented to improve diabetes care and outcomes for over 100,000 people living with the condition in Northern Ireland and those who care for them.

We need to improve outcomes for people with diabetes consistent with the draft *Programme for Government* published in 2016 and supported by all of the local political parties. This programme must tackle and reduce diabetes complications – and the human and financial cost diabetes can bring.

We need to involve people with the condition in the design and development of diabetes plans across Northern Ireland.

More support for emotional and psychological health

Managing diabetes can be a constant struggle. Good mental health is the key to managing it successfully. But at least 4 in 10 people with diabetes experience emotional or psychological problems such as depression, anxiety and diabetes-related emotional distress.

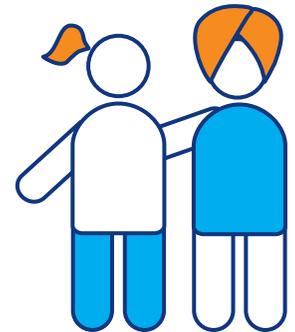
All too often, mental and physical health services are fragmented which means people with diabetes lack access to the right emotional and psychological support. It's essential that the psychological and emotional wellbeing of people living with diabetes becomes a key part of diabetes care.

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

We call for:

- A workforce who are able to meet the emotional and psychological needs of people with diabetes. Core training about diabetes and mental health should be given to all healthcare professionals from GPs to nursing assistants and specialists.
- A larger psychological workforce expert in diabetes. So that this specialist support is routinely and consistently available as part of the diabetes multidisciplinary team in both primary and specialist care.
- Healthcare professionals and organisations to explore and create opportunities for peer support for people with diabetes.

“I’ve got it under control so I’m fine day-to-day but it’s when those annual checks come up that I find myself lying in bed at 4am worrying about going blind or leaving my kids without a mother.”



Better access to healthcare professionals who understand diabetes

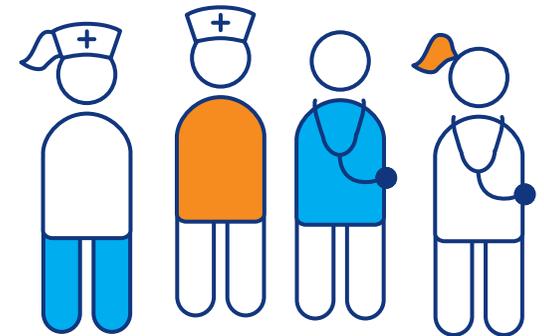
People are telling us that it would be easier to live with diabetes in the future if they saw healthcare professionals who really understood it.

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

We call for:

- Publication of data on diabetes and comorbidities to increase awareness of the prevalence of Type 1 and Type 2 diabetes. To also increase awareness of the growing number of children diagnosed each year with Type 1, and the significantly increased number of women developing gestational diabetes.
- Investment in the Diabetes Network to lead and advise on strategic improvement of care for all people living with all types of diabetes – and those at risk of developing it.
- Local and regional collaborative networks – so that treatment of diabetes is co-ordinated around the needs of people living with it. Networks should include all elements of the health and social care sector, from General Practice to specialist services, and the range of healthcare practitioners engaged with them.
- The establishment of a standard that guarantees access to the best care and treatment wherever you live in Northern Ireland, irrespective of the type of diabetes you have.
- Full engagement from the whole health system with the National Diabetes Audit in Northern Ireland. It must establish a baseline for what good care is and involve both Diabetes UK and the Department of Health in supporting improved care.

“I access a variety of diabetic services but they don't seem to share the same view of what my needs are – even their priorities and advice get confusing.”



Better access to technology and treatments

Technological advances in diabetes management are increasingly successful and popular. And improved access to the best technology and medicines is a priority for people with diabetes.

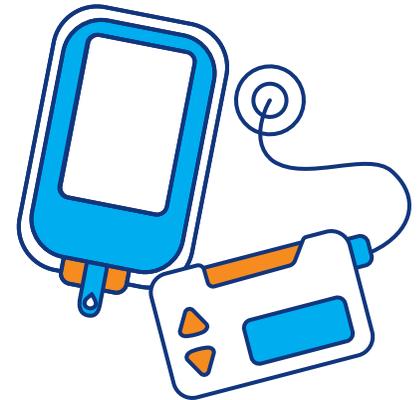
Availability can be patchy and is limited by a lack of skilled staff to deliver services. Too often access is based on a postcode lottery, or on someone's ability to pay.

Everyone has the right to the treatment and support which will help them to live well with their diabetes. We want to see a world where the daily and longer-term complications of diabetes are minimised because people have access to the best treatments and technology available.

We call for:

- Fair and equal access across Northern Ireland to new and existing technologies and treatments that can improve care, including medicines, insulin pumps, flash glucose monitoring and continuous glucose monitoring.

“My life has been turned around by my FreeStyle Libre [flash glucose monitoring] – I wish I could have free access to it rather than self-expense.”



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 in appointments. It's about having to manage your diabetes constantly in every aspect of daily life.

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

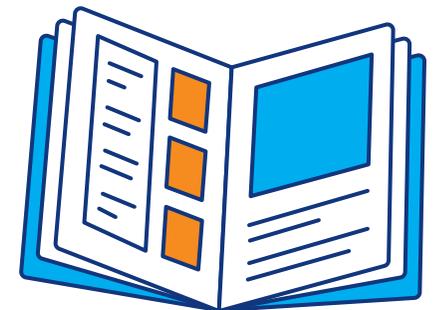
We want to see a world where no one leaves an appointment having been told that they have diabetes – or are at high risk – without knowing where to go for information and support.

We know that the information and support people get from diabetes education is essential, but currently not everyone gets it.

We call for:

- Provision of more diabetes education which we know works and helps people manage their condition. Education needs to be more varied and diverse so that people can get information tailored to their age and cultural experience. They need to be able to access it in the ways that best suit them. There must be sustained investment and support in the development of innovative diabetes education that meets quality standards.
- Healthcare professionals to promote clear and consistent evidence-based information on diet, medication and diabetes management, using tools like Diabetes UK information prescriptions. Information must be widely available, timely, delivered in a range of formats, tailored to cultural experience and must encourage peer support. Healthcare professionals should signpost people to the Diabetes UK Helpline, our website and other sources of support, especially at diagnosis.

“When my daughter was diagnosed, there was little info provided...they talked about carb levels in food but I didn't understand what it all meant. Different bits of kit were handed out but I didn't know what it all meant.”



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.

Parents of children with diabetes are telling us about ongoing problems they have with schools. Their children are not always getting the same chances as their classmates to learn and take a full and active part in school life. Some parents are having problems making sure their children are safe in school.

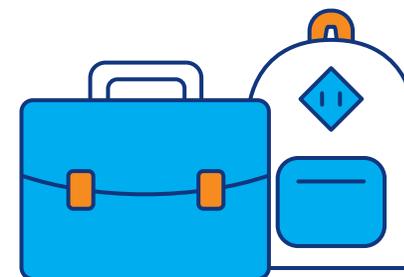
We want to see a world where the impact of diabetes on school and working life is minimised. Where the needs of people living with diabetes are understood and workplace and school policies support them. People must be able to ask for the support and adjustments they need to make a full contribution without feeling that they're a problem.

“My work colleagues need to understand my condition more – they clearly don't – my boss asks me to fix appointments on my days off – I am terrified of having a hypo at work.”

“With services currently being so disjointed, and with even school nursing staff not sufficiently diabetes aware, it is hard to plan children's care and daily routine.”

We call for:

- Health and education services to work in partnership so that all children with diabetes participate fully in academic and other school initiatives.
- Health and care services should lead by example by properly supporting their employees with diabetes. They should make sure everyone has a good understanding of diabetes, that people are able to attend appointments and education courses, and that peer support is encouraged.



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 them 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.

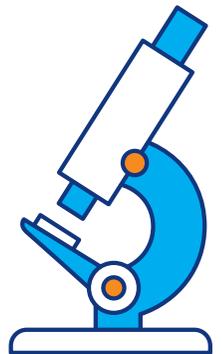
Sustained research into all forms of diabetes is needed to understand why and how it develops, how it can be prevented and ultimately to find a cure that will stop the diabetes crisis altogether.

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

We call for:

- Recognition that industry, universities, health services and charities need to work together to produce the research we need for all types of diabetes.
- 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.

“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.

We know that obesity is driving the increase in Type 2 diabetes and we need to tackle this now to stop more people developing the condition in the future.

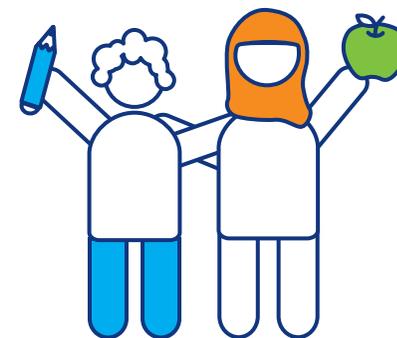
There is a need to take a whole society approach from childhood, including tackling the marketing of unhealthy food to children and making sure that the food we buy is healthier.

We also need to make sure that more people who are at increased risk of Type 2 diabetes are identified so that they can get the education, care and support they need to reduce their risk. And we need to make sure that effective interventions for people at increased risk are widely available.

We call for:

- Prevention programmes and early intervention for people at high risk of Type 2 diabetes. To achieve this primary care must have better access to data and upskill their workforce so that practices can identify patients at risk and refer them to prevention programmes. In addition, these programmes must be put in place.
- An increase in the percentage of children and adults eating a healthy, nutritionally balanced diet, and the percentage of the population meeting the Chief Medical Officer's guidelines on physical activity by the stated target for 2022, in line with the *Fitter Future For All Strategy 2012–2022*.

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



Join us

People with diabetes need change, now. Diabetes UK 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.