

The future of diabetes

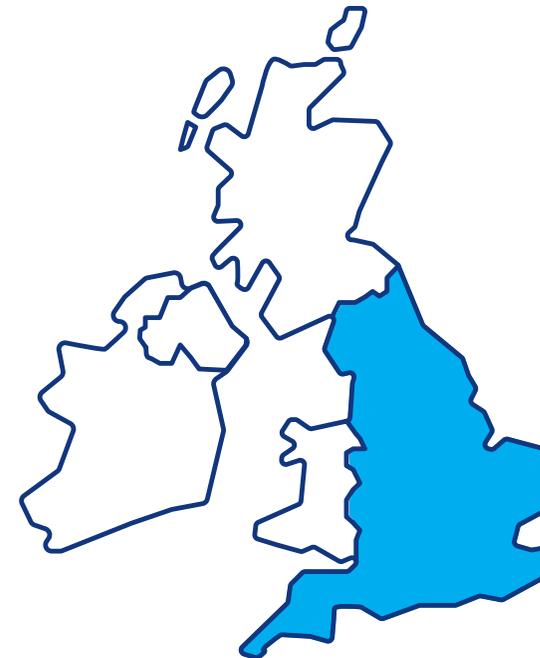


What needs to happen in England

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. Over 6,000 of them live in England; people of all ages, ethnicities and backgrounds. 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. There is progress, but for this to continue, we need a continued commitment to the NHS Diabetes Programme from NHS England and Public Health England.



More support for emotional and psychological health

Living with 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 like depression, anxiety and diabetes-related emotional distress.

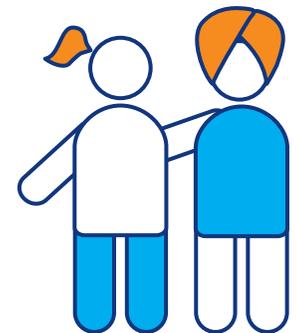
All too often, mental and physical health services are fragmented which means people with diabetes lack access to the right emotional and psychological support. It's essential that the psychological and emotional wellbeing of people living with diabetes is an integral part of diabetes care.

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.

“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.”

We call for:

- Commissioners to support providers in having processes and training in place so that people with diabetes are involved in decisions about their care. It must take account of both the physical and mental health aspects of living with the condition.
- The NHS and Royal Colleges to work with Diabetes UK to identify solutions for gaps in mental health support.
- Health Education England to make sure – as part of a comprehensive workforce strategy – that the right staff with the right skills are available to meet the emotional and psychological needs of people living with diabetes. This requires:
 - Core training in mental health skills for all healthcare professionals working with diabetes, including GPs, practice nurses and specialists.
 - Expanding the psychological workforce expertise 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, create and signpost to opportunities for peer support for people with diabetes.



Better access to healthcare professionals who understand diabetes

People with diabetes are telling us that it would be easier to live with it if they always saw healthcare professionals who really understood it, wherever they are accessing care across the whole NHS.

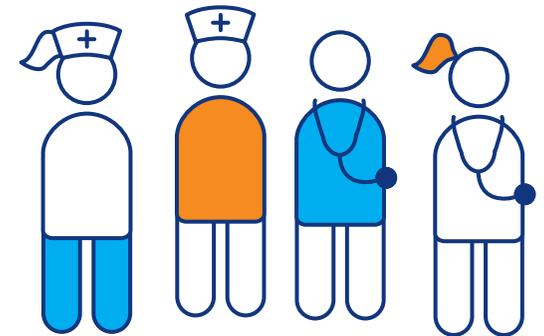
They need a health and care workforce that is skilled and knowledgeable in diabetes care and management. People with diabetes also need those professionals to be in a system that works together to focus on their needs rather than a hotchpotch of different services.

We call for:

- NHS England's investment in transforming diabetes services to be sustained so that it reaches all those areas that most need to improve. This would build on the strong start from the central investment that began in the summer of 2017 as local areas scale up tried and tested ways of improving care that also save money.
- Local services to join up to provide more supportive and efficient care. This needs networks and clinical leadership to plan diabetes services across an area, information sharing and financial incentives that get different parts of the NHS to work together rather than apart.
- Primary care to deliver collaborative care planning for adults and children with diabetes, which takes account of both the physical and mental health aspects of living with the condition.
- Health Education England to lead on a comprehensive workforce strategy. So that all health and care professionals have the training and knowledge of diabetes to deliver good care, and are supported by trained specialists, like diabetes specialist nurses.

- Hospital trusts to make sure that anyone in hospital who has diabetes can access specialist support – and be supported to self-manage when appropriate. Every hospital must have a multidisciplinary diabetes inpatient team so frontline staff are trained and confident in delivering good diabetes care.
- The experiences of people with diabetes to be recorded, reported and acted on by care providers.

“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

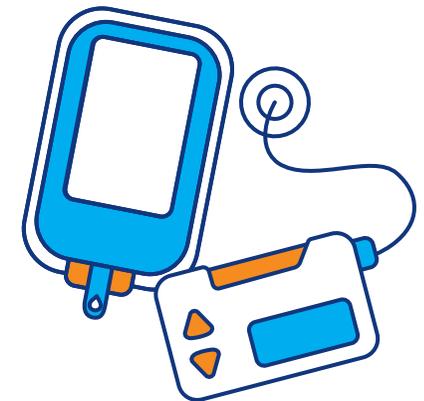
Technological advances in diabetes management are increasingly successful and popular. Evidence shows that the availability of the latest equipment and treatments is inconsistent across England. Availability is also limited by a lack of skilled staff to deliver services.

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 because people have access to the best treatments and technology.

We call for:

- The NHS to reduce variation in the provision of new and established diabetes treatments and technologies, like insulin pumps, continuous glucose monitoring (CGM), flash glucose monitoring, and test strips. Local policies, formularies and procurement to provide access to the best treatments and devices for those who can benefit. Healthcare professionals to be trained to support their use.
- NICE guidance and processes to provide faster access to treatments and technologies so that they can be quickly adopted by the NHS. And then made available to those people with diabetes who will benefit.
- Developers of new treatments and technologies to make sure that these are focused on the needs of people with diabetes.

“For nearly 10 years I had tried for a pump. I changed hospitals and within months I was on a pump! The last three years have been the best in my 42 diabetic years, very few hypos and my HbA1c is perfect.”



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.

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

We know that the information and support people get from diabetes education is essential, but currently not everyone gets it. Not everyone is getting consistent information about what to eat or support around day-to-day choices. They're not getting it from healthcare professionals or more widely from food labelling.

We call for:

- Healthcare professionals to promote clear and consistent evidence-based information on diet, medication and diabetes management, using tools like Diabetes UK information prescriptions. There must be sustained investment and support in the development of innovative diabetes education that meets its life-changing potential.
- Healthcare professionals to signpost people to the Diabetes UK Helpline, our website and other sources of support, especially at diagnosis.
- NHS England to provide 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. And they need to be able to access it in the ways that best suit them.
- The Government to make sure consistent nutritional labelling is available to consumers at the point of purchase, in an easy to understand format. The Government should be exploring ways to make the traffic light labelling system mandatory as we leave the European Union.

“When my daughter was diagnosed, there was little info provided on the ward. 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 told us about ongoing problems they have with schools. They struggle to make sure their children get the same chances as their classmates in all parts of school life. Making sure their children are safe in school is an issue for too many.

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. Workplace and school policies must allow people to ask for the support and adjustments they need without feeling they're a problem.

We call for:

- All schools to have a medical conditions policy published on their website that sets out how children with conditions like diabetes will be supported.
- Ofsted to make sure schools have these policies and use healthcare plans effectively to support children with diabetes.
- The NHS to lead by example by supporting their employees with diabetes in the workplace. Everyone should have a good understanding of diabetes so people can attend appointments and education. Peer support should be encouraged.
- The Department of Work and Pensions to conduct research into the impact of diabetes in the workplace and how people with diabetes can be better supported.

“I've had three appointments in the last week, a lot of places wouldn't stand for it.”

“It just seems like really simple, obvious things aren't being done, like teachers talking to each other and sharing information.”



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 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 no more than £60 million was spent on diabetes research in 2014, whereas £500 million a year is spent on cancer research. In the NHS, of every £1 spent caring for diabetes, just half a penny goes to research¹.

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 Government to make sure that funding for diabetes research is increased and has greater parity with funding for research on other serious health conditions.

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



¹ R. I. G. Holt (2017) A crisis in diabetes research funding. *Diabetic Medicine*

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.

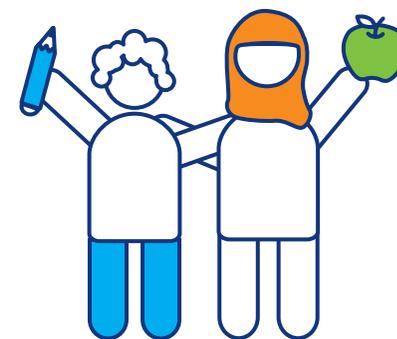
We know that obesity is driving the increase in Type 2 diabetes and we need to tackle this now to stop more people developing the condition in the future.

We need to end the marketing of unhealthy food to children and make sure the food all of us eat is healthier. More people who are at increased risk of Type 2 diabetes must be identified so that they can get the education, care and support they need to reduce their risk. And we need to make sure effective interventions for people at increased risk are widely available.

We call for:

- NHS England and Public Health England to maintain their commitment to the NHS Diabetes Prevention Programme and NHS Health Checks, improving roll-out and increasing and widening uptake.
- The Government to challenge the food and drink industry to make their products healthier. This includes applying pressure on the industry to reduce sugar and salt in their products as well as ambitious targets for reducing calories and saturated fat levels in our foods. If the industry fails to deliver this then mandatory targets must be introduced through legislation.
- The Government to build on the Childhood Obesity Plan and commit to further action, particularly across marketing, reducing portion sizes and price promotions to make sure the healthiest choice becomes the easiest choice for us all.

“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.