What needs to happen in Wales

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.

400 of them live in Wales. 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.

A better future

Welsh Government’s Together for Health: A Diabetes Delivery Plan (2016–2020)\(^1\) sets out how diabetes care should be delivered in Wales. By working together, we can improve outcomes for people living with diabetes.

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More support for emotional and psychological health

Managing a condition like diabetes can be a constant struggle. Good mental health is 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 in Wales 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 diabetes care.

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

We call for:

• Increased support for adults and children living with diabetes from a multidisciplinary diabetes team, as defined by NICE. To include specialist consultants, diabetes specialist nurses, dietitians with specialist training, and psychologists.

• 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.

• Healthcare professionals to make use of all available resources, like video prescriptions, information prescriptions and local support groups, and encourage health boards to partner with Diabetes UK Cymru to establish peer support groups in primary care.

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

People with diabetes need a health and care workforce that is skilled and knowledgeable in diabetes care and management.

We call for:

• Welsh Government and NHS Wales’ continued commitment to funding to support the delivery of the Together for Health: A Diabetes Delivery Plan.

• Welsh Government to carry out a review of current diabetes-related staff, including diabetes specialist nurses and dietetic staff. Appropriate training should be made available to non-diabetes specialist staff, including GPs, practice nurses and psychologists.

• Health boards to make sure everyone with diabetes in hospital has access to trained specialist staff and is supported to self-manage their condition when appropriate. Every hospital should have a multidisciplinary diabetes inpatient team. Health boards to fully implement the ‘Think Glucose’ staff training initiative so that all hospital staff understand what they need to do to care for their patients with diabetes.

• All Wales Diabetes Implementation Group to focus on reducing the number of children and young people diagnosed in the life-threatening stage of diabetic ketoacidosis, including supporting Diabetes UK Cymru’s Know Type 1 campaign.

• Welsh Government and NHS Wales to work together to make sure people living with diabetes remain at the centre of their care, so people are involved with decisions that affect them across the whole system, and that any complaints are quickly resolved.

• Public Health Wales and health boards to educate all staff about the role they play in supporting behaviour change and reducing the risk of developing long-term conditions by offering motivational interviewing training.

• Effective monitoring and evaluation of progress via the All Wales Diabetes Implementation Group (AWDIG), using established diabetes audits.

• Welsh Government’s continued commitment to an integrated IT system that links primary and secondary care and is fully accessible to patients.

“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 Wales. Availability is also limited by a lack of skilled staff to deliver services.

We call for:

• NICE guidance and processes to support faster access to treatments and technologies, so they can be adopted by the NHS and made available more quickly.

• Less variation in access to new and existing technologies, like flash glucose monitoring, continuous glucose monitoring (CGM) and insulin pumps.

• Health boards, working with the AWDIG, to increase the availability and effectiveness of insulin pump therapy through the education of staff and patients. National standards to be introduced, accompanied by educational resources, to improve safety and maximise the benefit of insulin pumps.

“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.”
Living with diabetes can be tough. It’s not just about medical appointments, you also have to constantly manage your diabetes yourself. It affects every aspect of daily life, from the food you buy and eat to the exercise you take, and you never get a day off.

We know that the knowledge and support people get from diabetes education is essential, but not everyone gets it. And not everyone gets consistent information about what to eat or support around the day-to-day choices they have to make.

We call for:

• Everyone diagnosed with Type 2 diabetes to be provided with clear information and signposted to Diabetes UK resources at diagnosis.

• Equal access to evidence-based, structured education courses that support people living with diabetes to self-manage. Health boards must assess the resources already available to them, and commit to fully funding and supporting courses.

• Healthcare professionals to promote clear, consistent evidence-based information on all aspects of diabetes, including diet, medication and self-management.

• Health boards to work together to implement the new Type 2 Diabetes Education Pathway in Wales.

“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

We want to see a world where the needs of people living with diabetes are well understood and supported in the workplace and during school life.

While good care at school is achievable, evidence shows that there are barriers for children and young people in accessing education if they have a medical condition like diabetes. Diabetes UK Cymru is leading a group of health and children’s organisations in Wales to make sure that children and young people with medical conditions are able to achieve their full potential in education, and are not prevented from taking part in any aspect of school life.

We call for:

- All schools to have a medical conditions policy in place and available on their websites.
- Each child and young person with a medical condition to be provided with an agreed individual plan detailing their needs at school.
- Greater understanding by employers of the needs of employees with diabetes, to make working life easier. Employers to support employees to attend diabetes appointments and education during work hours.

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"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."

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2 Type 1 diabetes in schools in Wales: “An Excellent Chance” (2016)
https://www.diabetes.org.uk/resources-s3/2017-09/Type%201%20diabetes%20in%20schools%20in%20Wales%20-%20An%20Excellent%20Chance%20public.pdf
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.

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 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:

- Welsh Government to commit to continued funding of the Diabetes Research Unit in Wales and its beneficial related activities.
- The Diabetes Research Unit to continue to promote high quality research within the medical community.

“Ideally find a cure. In reality though, find a non-painful way to test blood sugar levels.”
Prevention of Type 2 diabetes

The single greatest risk factor for Type 2 diabetes is being overweight or obese. If you’re overweight or obese you are five times more likely to develop Type 2 diabetes. Other risk factors for Type 2 diabetes include gender, ethnicity and family history.

In Wales around 58% of adults are overweight or obese. These figures rise with increasing deprivation, from 54% in the least deprived areas to 63% in the most deprived areas.

In addition, over 27% of children in Wales are overweight or obese\(^3\). 26% of children aged four to five in reception year in Wales are overweight or obese. This is higher than in England (23%) and higher than any individual English region, where the highest is 24%.

These rates also rise with increasing deprivation, from over 22% in the least deprived areas to over 28% in the most deprived areas.

We call for:

- Welsh Government and Public Health Wales to make sure Wales’ national obesity strategy fulfils the requirements of the Public Health Wales Act 2017.

- The national obesity strategy must follow the current Obesity Pathway (2010), by covering both prevention and treatment, and a committing to fully funding service provision at all levels.

- Health boards and Public Health Wales to work together to identify those at highest risk of Type 2 diabetes through existing risk assessment programmes, as well as to support and roll out proactive preventative campaigns.

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.

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\(^3\) Public Health Wales’ Child Measurement Programme: http://www.wales.nhs.uk/sitesplus/888/page/67795