

# Diabetes UK response to the Health and Disability Green Paper October 2021

## About Diabetes UK

Diabetes UK is committed to creating a world where diabetes can do no harm. Diabetes affects over 4.7 million people in the UK, around 1 in 15 people, with 12.3m at risk of developing type 2 diabetes. Diabetes is a major health crisis of our time. Diabetes UK is the UK's leading funder of medical research for diabetes, and conducts policy and campaigns work to improve the lives and health outcomes of people living with, or at risk of, diabetes.

## Introduction

Diabetes UK welcome the opportunity to respond to the Green Paper on Health and Disability. We look forward to further engagement with the Department of Work and Pensions on the issues raised in this response, to ensure that employment and social security support can work for people living with diabetes.

Diabetes is a serious health condition, requiring careful self-management – every single day - alongside the support of specialist health services.

Diabetes is where a person's blood glucose level is too high. It can happen when the body doesn't produce enough insulin or the insulin it produces isn't effective. Or, when the body can't produce any insulin at all.

People with diabetes must constantly self-manage the condition. Requiring continual monitoring of blood sugar levels and, and for some administering insulin and other medications. All part of the daily reality people with diabetes must deal with to prevent hypoglycaemia and diabetic ketoacidosis. Both of which are life-threatening conditions. The self-management of blood sugars and medication is also essential in order to reduce the risk of life changing diabetic complications including, sight loss, heart failure and amputations.

Currently:

- One in 14 people in the UK are now living with diabetes, a total of 4.9 million.<sup>1</sup>
- The number of people diagnosed with diabetes has doubled in the last 15 years. Now, someone is diagnosed with diabetes every two minutes.
- Every week diabetes leads to more than 185 amputations, 770 strokes, 590 heart attacks and more than 2300 cases of heart failure.<sup>2</sup>

The complications of diabetes, and the impact of unmanaged diabetes, are severe and mean a person will often experience barriers to full participation in society. There is a need for improved employment and social security support to reduce the barriers people with long term health conditions experience in their daily life and employment. Living with diabetes is relentless, but with the right support people with diabetes can live healthy and full lives.

People with diabetes often don't identify as disabled, despite being covered by disability legislation. The stigma around diabetes and disability can also mean that people don't tell

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<sup>1</sup> Diabetes UK (2021), '[Diabetes Diagnoses Double in the Last 15 Years](#)'

<sup>2</sup> NHS Digital (2019), National Diabetes Audit 2017–18 – Report 2A: Complications and Mortality

their employer about their diabetes. People with diabetes can also be unaware of the protection and reasonable adjustments they can ask of their employer under equality legislation. Diabetes UK has also seen cases where employers have been ill-informed about their duties to employees with diabetes under the Equality Act (2010).

We know the inequalities that exist in health and work outcomes for people with long-term health conditions, such as diabetes, and that employment and social security support from DWP should play a key role in supporting people with diabetes to live healthier lives.

There's also a need to look at the wider social determinants of health that are driving up increases in the prevalence of conditions, including type 2 diabetes.

## **Diabetes and employment**

There are around 2.25m people of working age in the UK living with diabetes. Managing diabetes can involve taking medication – including injecting insulin at the right time – and for some people testing blood glucose levels multiple times a day. To prevent the onset of serious complications there are vital checks that everyone with diabetes should be getting which can require time off work.

Despite being covered by disability legislation (Equality Act 2010), people find working with diabetes can be difficult. In the Future of Diabetes survey<sup>3</sup> carried out by Diabetes UK in 2017, we found:

- 37% of those in employment said that diabetes had caused them or their family member difficulty at work.
- 16% said they felt they had been discriminated against by their employer because of their diabetes.
- 7% had not told their employer that they had diabetes.
- While 40% said they felt supported enough at work, 25% said they would like the flexibility to take breaks to eat, test their blood glucose or take medication and 24% said they would like time off work for diabetes related appointments.

Detailed below is the experience of a Diabetes UK supporter, Megan, who had to quit her job as a management consultant so she could better manage her type 1 diabetes after insufficient employer support and a lack of understanding in the workplace<sup>4</sup>:

*“I’ve experienced a lot of problems in the workplace due to staff not understanding my diabetes. In my previous job as a management consultant, I was constantly undermined and told that my diabetes wasn’t that serious.*

*This included being told off for having medical appointments during the day, and being made to feel bad for talking about my diabetes, even though it’s really important for staff to know I have diabetes in case of an emergency.*

*The impact of all of this left me feeling frustrated, anxious and stressed, and in turn meant I struggled to manage my diabetes. I eventually decided that enough was enough, and I quit my job so I could spend some time taking care of myself.”*

The National Diabetes Audit data shows that people of working age are less likely to receive the essential annual checks that can keep them healthy and better manage their condition, compared to older people with diabetes.

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<sup>3</sup> Diabetes UK (2017) [Future of Diabetes](#)

<sup>4</sup> [Megan quit her job over lack of support for her diabetes | Diabetes UK](#)

We know that good work is a key indicator of health. However, those with diabetes, particularly if living with complications – such as blindness or amputations – are less likely to be in work and when they are, they often face difficulties. Where someone is unable to work due to their diabetes, or diabetes related complications, it's essential that adequate social security support is available.

Where people can and are ready to work there are several steps that should be taken to improve employment outcomes for people with diabetes. These include a greater enforcement of legal requirements on employers, increased awareness of rights at work and greater awareness of the support available to get into work. These measures would also help to keep more people living with diabetes, and other health conditions and disabilities, in work.

### **Diabetes UK recommend:**

- The DWP and BEIS should work to ensure employers are informed about their duties to employees living with a health condition or disability under the Equality Act (2010), including taking enforcement action where required. Diabetes UK produced a short guide for employers 'Supporting people with diabetes in the workplace – top ten things you need to know'<sup>5</sup> that could form part of a package of employer guidance on common health conditions.
- Development of a central resource of specialists in common health conditions that affect people in the workplace in order to support and inform policies and practices that keep people healthy, and in work – that is accessible to employers.
- Employers should demonstrate what action they have been willing to take to help prevent people with a health condition or disability falling out of work and how they are creating a fair employment environment.
- The DWP should improve awareness of the employment support available, doing this in an empathetic and understanding manner and utilising existing points of contact through clinics, stakeholders such as Diabetes UK and Job Centres.
- Work coaches must be informed about diabetes. Where a person is having problems managing their diabetes, Work Coaches should be informed to signpost to additional health support (such as NHS diabetic education) if appropriate.
- Ensuring that people in employment and seeking employment are aware of their employment rights and the legal requirements on employers, by raising awareness of measures such as reasonable adjustments and broader equality legislation protections. Diabetes UK has produced an online guide aimed at people with diabetes 'Your rights at Work'<sup>6</sup>.

### **Diabetes and social security**

Most people living with diabetes as adults are unable to get social security support for the condition, despite children with diabetes often being entitled to DLA. The discrepancy between support for under and over 16s, results in a hard stop to financial support when a child reaches the age of 16.

However, we know diabetes is a serious condition that requires careful self-management, every day, and the support of diabetes specialists. For people with diabetes complications – such as blindness and amputation, those who are newly diagnosed, experiencing issues in

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<sup>5</sup> Diabetes UK, [Supporting people with diabetes in the workplace – top ten things you need to know](#)

<sup>6</sup> Diabetes UK, [Work and diabetes | Life with diabetes | Diabetes UK](#)

managing their diabetes or in maintaining employment due their condition, access to adequate social security support is vital.

When someone with diabetes is interacting with the Department of Work and Pensions services it's essential that Work Coaches, Assessors and Decision Makers are knowledgeable about diabetes. Knowledge and understanding about diabetes, as well as an empathetic and understanding approach, are vital for people with diabetes to have the best experience of interacting with the social security system and the greatest opportunity for positive outcomes.

## **Children and transitions to PIP**

All children with diabetes are entitled to make a claim for DLA and are usually successful, however we are aware of reports of cases where people must appeal to tribunal in order to be awarded DLA for a child with diabetes. There's a need to improve assessor and decision maker guidance and training, as well as tribunal feedback to assessors and decision makers.

Families of children with type 1 often report the difficulty of transitions at age 16, where a child is unable to get any more support.

In the recently devolved Disability Assistance for Children and Young People, being rolled out in Scotland this year, the payment will be available up to the age of 18. For children in the rest of the UK receiving DWP administered payments the cut off age will remain 16. Diabetes UK believe this could result in more young people in Scotland with diabetes between 16-18 being able to access essential social security support, compared to counterparts aged 16-18 years in the rest of the UK who will have to claim PIP, most likely unsuccessfully.

Diabetes UK welcome what appears to be increased access to social security support for 16-18 year olds in Scotland and recommend the DWP consider extending the age at which DLA is available to children to 18 to ensure all children and young people with diabetes are able to access support.

## **Diabetes and deprivation**

Statistics show that those living with long-term health conditions and disabilities are more likely to be living in poverty, with many of these people relying solely on social security for their income.<sup>7</sup> Diabetes UK believe there should be consideration given to whether the current structure of social security support for health conditions is working for all people that could benefit from support, particularly given the higher rates of poverty among people with a long-term health condition or disability.

Recent research funded by Diabetes UK outlined that people living in more socially deprived areas had higher rates of diabetic ketoacidosis, hospitalisation and death than those from less socially deprived areas.<sup>8</sup> Rates of DKA admissions and deaths were lower in those who used an insulin pump too, but less people in deprived areas use an insulin pump compared to more affluent areas.

The DWP should work with the DHSC to ensure that people with diabetes can easily access life-enhancing diabetes technology, such as flash glucose sensors. To bring an end to the

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<sup>7</sup> Health Foundation (2018) [Poverty and health](#)

<sup>8</sup> Diabetes UK (2021) [DUKPC research highlights: Day 5 | Diabetes UK](#)

postcode lottery that causes unequal access to diabetes technology depending on where a person lives, their level of deprivation and their ethnicity.

#### **Diabetes UK recommend:**

- The DWP working with other government departments should ensure a healthy standard of living for all – by putting health equity and wellbeing at the heart of economic planning and strategy at all levels
- The DWP consider extending the age at which DLA is available to children to 18, to ensure all children and young people with diabetes are able to access support.
- The DWP should raise awareness of the social security support available to people living with health conditions and disabilities, to ensure support is reaching everyone who requires it.
- Assessors and decision makers must be informed about diabetes, its complications and the impact it can have on daily life, through sufficient education and training.
- Signposting to health interventions by Work Coaches, including NHS diabetes education programmes, and recognising the role of Work Coaches in improving access to diabetes technology that can support a person to live a fuller, healthier life.
- The DWP should work with the DHSC to ensure that people with diabetes can easily access life-enhancing diabetes tech.

#### **Tackling health inequalities and the social determinants of health**

Tackling health inequalities and addressing the social determinants of health is a key priority for Diabetes UK. If nothing changes, we predict that by 2030, 5.5 million people in the UK will have diabetes. As well as the harm diabetes will cause to peoples' lives, this also has a cost for the DWP, DHSC and the wider economy.

Creating a world where diabetes can do no harm, including harm to employment and health outcomes, requires a long-term plan to tackle health inequalities that stem from social determinants of health i.e. the conditions where we are born, grow up, live and work.

We know that type 2 diabetes can be prevented, and that with the adequate support and access to care and treatment people with all types of diabetes can live healthier lives.

But currently:

- The poorest people in the UK are 2.5 times more likely to have diabetes at any age than the average person.<sup>9</sup>
- Once they have the condition, those in the most deprived homes are twice as likely to develop complications of diabetes as those in the least deprived.<sup>10</sup>
- The average healthy life expectancy across socio-economic groups ranges from 52 years in the most deprived areas to 70.4 years in the most affluent.<sup>11</sup>

Addressing the social determinants of health and levelling up health by reducing the burden of preventable conditions must be a key focus of future government policy. Without strategic,

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<sup>9</sup> Diabetes UK (2009) [UK's poorest twice as likely to have diabetes and its complications | Diabetes UK](#)

<sup>10</sup> Diabetes UK (2009) [UK's poorest twice as likely to have diabetes and its complications | Diabetes UK](#)

<sup>11</sup> ONS (2020) [Health state life expectancies by national deprivation deciles, England - Office for National Statistics \(ons.gov.uk\)](#)

long-term action and planning the number of people living with health conditions and disabilities that could have been prevented will continue to grow. Addressing the social determinants of health is a matter of fairness to provide everyone with the right and ability to live a healthy life.

**Diabetes UK recommend the Government develop and implement a cross-government strategy to tackle health inequalities by addressing the social determinants of health.**

**For further information, or to discuss the content of this response in more detail, please contact Debbie Horne, Senior Policy Officer (Social Justice and Poverty), at [Debbie.Horne@diabetes.org.uk](mailto:Debbie.Horne@diabetes.org.uk).**