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TITLE

**Launch of new diabetes report by All  
Party Parliamentary Group**

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On Behalf of DWED

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*Figure 1 Rt Hon Jeremy Hunt MP: Treatment providers "should be embarrassed if their diabetes support is not up to scratch"*

## Introduction

DWED was invited to the launch of a new report **‘Levelling up: Tackling Variations in Care’** which has been produced by the All Party Parliamentary Group for Diabetes (APPG Diabetes). The event which took place on 23<sup>rd</sup> November was chaired by Rt Hon Keith Vaz MP with speakers Rt Hon Jeremy Hunt MP, patient voice Lauren Proctor and health care professional Ruth Miller.

Publication of **‘Levelling up’** results from a yearlong span of investigations into the causes for variations in care for people with type 1 and type 2 diabetes and provides suggestions for how to change the current state of a post code lottery NHS service. Three key areas of particular interest within the paper were structured education, expertise of health care professionals and innovative advances in medical technology. DWED is keen to outline particular areas of this report that may be of interest to individuals with diabetes and an eating

disorder including Diabulimia (deliberate insulin omission).

**The All Party Parliamentary Group for Diabetes** is an informal cross-party group made up of MPs, healthcare professionals, commissioners, academics and people living with diabetes that have a shared interest in improving the current quality of diabetes care. Rather than being an official publication of the House of Commons or Lords, views expressed within the report are that of the APPG only. Research and funding was provided by the charities **Diabetes UK** and **JDRF**.

Recommendations put forward by the report are not mandatory but suggested as a blueprint to be

presented to Clinical Commissioning Groups (CCGs) with a push for change. Just recently, £40 million in funding has been announced by the Government to be put towards making improvements in diabetes treatment.

But how much of this report applies to someone with ED-DMT1 and/or diabulimia? DWED provides a breakdown of the most relevant details from the report below and urges our members to present this information to their clinicians should they feel it may be of use.

## ‘High Quality Conversations with the Right Healthcare Professionals.’

Suitably in keeping with the above, the first part of the report centres on **‘high quality conversations with the right healthcare professionals.’** It reads:

*“A big part of how care is perceived by people with diabetes is how they are communicated with by healthcare professionals. People often felt that they were being criticised in appointments for not meeting treatment targets and dictated to about how to manage a condition they lived with....*

*The use of NICE guidelines around diabetes care and relevant NHS policies that help determine a course of care are not always adapted for a particular individual’s needs, which often resulted in care that was unsatisfactory with treatment targets that were believed unachievable by the patient. Equally when specialist advice was given by non-specialists such as foot care or dietary advice, patients felt that this information was too basic and often conflicting with advice given by specialists, or what was working for them.*

*Great value is found by those who are given the opportunity to input into the decision-making process with their healthcare team. Consideration of their lifestyle alongside their diabetes management as well as interpretation of NICE guidance to fit their needs allows for tailored treatment plans.*

*This means better treatment outcomes as individuals have more confidence in themselves and their healthcare team to manage their diabetes.”*

The report draws on the importance of seeking healthcare professionals who understand diabetes. *“People with diabetes and HCPs both said that expertise in diabetes was a real issue outside of diabetes specialists, for example in primary and secondary care...”* revealed the report, *“HCPs need to have the knowledge and skills to give accurate advice...”* The APPG heard that getting access to specialists was also a problem with vital services described as *“simply overwhelmed”*. DWED would extend this point to say that for sufferers of diabetes and eating disorders access to professionals



Figure 2 Ruth Miller talks about negligent inpatient care as a “big problem.”

who understand both sides of their condition and how they intertwine and overlap is crucial. So many individuals are falling through the cracks between fragmented services as they are often bounced back and forth between one team dealing with their diabetes and another acknowledging their eating disorder.



Figure 3 DWED representative Claire Kearns with Long Time Political Ally MP George Howarth

One positive aspect of this exploration involves advances made in how health professionals communicate with one another and their patients. DWED finds the examples given from various NHS trusts on the comprehensive approaches they are using to facilitate care as well as the channels being used to be encouraging. These strategies include online modules for health care providers, telephone hotlines for patients and communication between clinicians and patients by means of Skype, e-mail and text messages. Particularly encouraging is the APPG's assertion that attention should be paid

to sharing health data between different parts of the NHS. DWED knows that more fluid communication needs to take place in order to arrange a more integrated care system for treating someone with an eating disorder and diabetes. If clinicians from both specialist sides have access to the same information then this can only be a good thing. Additionally, Jeremy Hunt promised at the launch that we would become the first country to provide blood test result data to all patients nationwide within the near future.

## 'Support for People Living with Diabetes'

**'Support for people living with diabetes'** is the title of the second part of the APPG report. Evidence provided with regards to *"information and one-to-one advice"* states that *"Those with a Type 1 Diabetes diagnosed as an inpatient received varying amounts of information around carbohydrate counting, insulin injections and general diabetes management, usually in the form of literature.*

*Those diagnosed in childhood have limited recollection of the information given to them about how to manage their diabetes, as their parents generally dealt with their management. Even though many do remember having follow-up appointments with a Diabetes Specialist Team for more in-depth education and management advice. However, these appointments were felt to be varied in quality."*

This evidence certainly seems true from the experiences of DWED members. Of course diagnosis can be a precarious and frightening time, especially for young patients. It has been shown that young

girls in particular can be at risk of developing harmful beliefs about their bodies during such time, which combined with a somewhat obsessive focus on food, can be a hotbed for eating disorder development in later years. Therefore it is so important that individual care is given and that any signs of eating disorder behaviours including insulin manipulation that may arise can be flagged up at the earliest stage to try and avoid progression and complications.

Informal learning in the way of the diabetes online community and local groups can provide *“invaluable learning and support”* suggests the report. *“Speaking with those who have faced similar experiences was often cited by patients as the most useful resource in understanding how to manage their condition... Many of those who submitted evidence were proactive individuals who took it upon themselves to learn as much as possible about their condition from online forums, health charity websites and joining local group.”* In light of this DWED urges sufferers of ED-DMT1 to seek out peer support and to utilize our upcoming forum which is due to open at diabetes.co.uk as soon as possible.

## ‘Structured Education’

The portion of the report which tackles **‘structured education’** is regarded as somewhat problematic by DWED. Through the lived in experiences of our members we know that structured education courses such as ‘DAFNE’ are not particularly helpful for individuals with diabetes and eating disorders. This is because the ability to think about food in a rational way is overridden by eating disordered tendencies and the contents and ratios of carbohydrate and insulin for example cannot be looked at without promoting uncomfortable feelings around shape, weight and self care.



*to revolutionise our thinking as far as diabetes is concerned.” Lauren Proctor: “Good diabetes care is not a prize, it should be a standard available for all.”*

Furthermore, those with ED-DMT1 and Diabulimia are usually completely clued up on the mechanics of their bodies, even more so than a non-eating disordered type 1 diabetic. It is this extensive knowledge that enables sufferers to manipulate their blood sugar levels and what appears to be lack of control is in fact by means of deliberate control. In such patients it is mental well-being that is lacking and in need of address, rather than any gaps in knowledge regarding nutrition or the general physical mechanisms of type 1 diabetes.

Despite this view, DWED can see the benefits of having support and encouragement with carbohydrate counting and portion control during early stages of recovery from ED-DMT1 and the reintroduction of a structured insulin regime. This is mostly due to the fact that we are mindful that sometimes despite having all the correct knowledge someone with an eating disorder may require



reassurance and even 'permission' to undertake the tasks of eating and injecting correctly. However, even under such circumstances we understand from our members that this kind of assistance should not be framed as 'education' which may come across as patronising and should also be offered on a tailored individual level rather than in a group setting.

## 'Emotional and Psychological Support'

The segment that addresses '**Emotional and psychological support**' clearly shows why DWED continues to do the work we do in trying to raise awareness and advocate on behalf of those with ED-DMT1 and Diabulimia. It reads: *"The need for psychological and emotional support was a common theme in much of the evidence given to this inquiry. On diagnosis of Type 1 diabetes in particular, there is anxiety and stress associated with the management of a long-term health condition; the administration of insulin and avoiding hypos and hypers. The stigma still associated with Type 2 diabetes, that it is a self-inflicted condition due to poor diet and obesity, has harmed people's motivation to care for themselves. "*

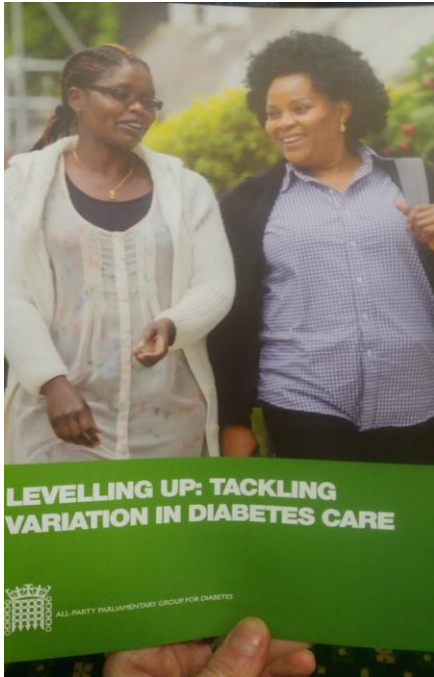
DWED would argue that there is also stigma attached to type 1 diabetes, owing in part to the lack of distinguishing between type 1 and 2 by the media and so absorbed by society.

Sadly the most startling and unsettling finding from the report is that of which DWED is most concerned with as it concludes: *"Despite the importance of this to people with diabetes we received little evidence about how the NHS can provide better psychological support."*

Alarming, there is no further exploration of this or any suggestions made for targeted improvement. In fact this segment sticks out as the only summary that is not followed up with *"What the NHS is doing."* A patient voice, Becca Smith is included to underline this which reads: *"I struggled for over five years with disordered eating, and diabetes has been a massive part of that. I was on anti-depressants for over two and a half years. If I had had counselling and the help of a dietician to begin with, I think that this could have been avoided."*

This is not good enough. The association between emotional and physical health has been explored more so during recent years with various awareness and anti stigma campaigns. Yet this consideration with regards to diabetes care is still kept to one paragraph in this document. During the launch 'mental health' was uttered just once and it was Lauren Proctor who gave voice to the type 1 diabetes community most of all. Much of the discussion revolved around the cost of diabetes and the need for prevention which of course is not ever applicable to those with type 1. The sugar





tax was applauded as well as the fact that the hosts had not laid on cakes and biscuits for the launch. As can often be the case, considerations for type 1 as well as mental health seemed to be tacked on to the agenda with less thought than was deserved. This was disheartening.

## ‘Technology’

The third and final portion of the report concerns ‘**Technology**’ that can be used to help improve diabetes care and make living with diabetes less stressful. It mentions blood testing meters, insulin pumps and continuous blood glucose monitoring, and finally touches on flash glucose monitoring systems, regarded as the most modern form of accessible technology for people with diabetes, notably the Freestyle Libre. DWED has seen that access to pumps can be life changing for individuals with with type 1 diabetes, whether they may suffer from an eating disorder or not . However, the use of such should always be regarded with caution in the case of someone with an ED-DMT1, especially when insulin omission is a primary behaviour as the suspension of insulin by use of a pump can be extremely lethal when there is no long acting insulin on board.

‘**Levelling up: Tackling Variations in Diabetes Care**’ can be downloaded here: <https://diabetes-appg.co.uk/2016/11/23/tackling-variation-in-diabetes-care/>

## Recommendations:

The APPG report closes with the following recommendations: please see next page

## Recommendations

The APPG for Diabetes has heard evidence that indicated that people with diabetes experience a wide variation in their care and treatment.

The APPG has heard exciting examples of how local areas have worked together across different organisations to improve care standards and outcomes for people living with both Type 1 and Type 2 diabetes. From the evidence submitted to this inquiry, the APPG makes the following recommendations:

### Local health economies

#### 1) Care and Support Planning

- a) Local areas need to implement the training and processes for HCPs so that person centred care and support planning that involves the patient becomes routine.
- b) Networking and sharing of expertise between specialists and generalists is needed, so more people are supported by primary care clinicians with greater expertise in managing diabetes and who are able to recognise when timely referral to specialists is needed.
- c) Integrated IT systems that allow for a patients' information to follow them across primary and hospital care are essential to improve communication between HCPs working in different organisations and patients.

#### 2) Support for self-management

- a) CCGs need to plan a radical expansion in structured diabetes education meeting NICE criteria and ensure that people with diabetes within a year of diagnosis have attended a structured education course, as suggested in the CCG IAF.
- b) Develop a wider menu of other options for people to have better access to ongoing flexible learning opportunities.
- c) A national standard of diabetes education for children and young people under the age of 18, which, where appropriate, includes training on how to use diabetes technologies such as insulin pumps and CGM.

#### 3) Access to key technologies

- a) Funding pathways for technologies need to become much clearer to both people with diabetes and HCPs.
- b) Healthcare professionals need to have access to training so they can support people to use devices successfully.
- c) More staff need to be available in specialist care to support people using new technologies.

#### 4) A strong local diabetes system

- a) Local health economies need to have effective local networks that share data, reduce financial barriers between organisations and undertake a regular quality improvement cycle.
- b) Leadership development needs to be supported to drive effective change.

### Health Education England

- 1) Health Education England needs to recognise the growing increase in diabetes prevalence in training curricula. This means ensuring that non-diabetes specialists are able to look after people with diabetes well and ensuring there are enough healthcare professionals trained in the various services that care for people with diabetes: dietitians, podiatrists, pharmacists, optometrists and nurses.

### NHS England

- 1) The National Diabetes Programme care and treatment priorities focus on improving treatment targets, increasing uptake of structured education, reducing amputations and improving inpatient care. These initiatives all play a central part in reducing variations in care and need to be maintained.
- 2) NHS England needs to work collaboratively with local health economies to support the effective use of transformation funds to address the recommendations in this report, supporting and monitoring delivery to enable people with Type 1 and Type 2 with diabetes receive consistently high quality care.

### Department of Health

- 3) To ensure that the Mandate to NHS England recognises the importance of reducing the variation in diabetes care, by including a specific measurables on reducing variation in the number of people reaching the three treatment targets.