

Health and Social Care Committee

Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction

DB 14 Tegryn Jones

RE: The National Assembly for Wales' Health and Social Care Committee inquiry into the implementation of the national service framework for diabetes in Wales and its future direction.

Thank you for the opportunity of submitting evidence to the Committee's Inquiry into the implementation of National Service Framework for Diabetes and its future direction. I submit the evidence not as a health care professional, or as a person who has any experience of working in the Health Service but as an individual who was diagnosed with Type 1 Diabetes in December 2011.

In view of this, my understanding of the policies and protocols adopted by the Health Service is limited, however, I am able to provide the perspective of patient undergoing diagnoses and treatment in Pembrokeshire.

Information

From a position of knowing very little about diabetes and its treatment I now feel that I have adequate information to control key indicators such as blood glucose level. This information has been received from:

- Healthcare professionals both as an in-patient and an out-patient;
- Through publications and electronic information produced by voluntary organisations such as Diabetes UK and JDRF;
- Through attending the DAFYDD (Dose Adjustment For Your Daily Diet) course – this excellent two day course provided a great deal of information and an opportunity to share experiences with others with diabetes. As a newly diagnosed diabetic the opportunity to meet and discuss issues with healthcare professionals and individuals with decades of experience of dealing with the condition was invaluable. This relatively new initiative provides an opportunity for newly diagnosed diabetics to develop the good habits essential to control diabetes. I was particularly grateful that my wife was also able to attend the course.

Knowledge of the condition

I have benefited from the expert knowledge and care provided by the Diabetes team based in Withybush Hospital in Haverfordwest. The Diabetic Nurse and Dietician have always been on hand to provide advice and feedback. This feedback is provided face-to-face, over the phone or by e-mail.

I also feel a debt of gratitude to my GP who was involved in my diagnoses. Originally I was diagnosed with Type 2 diabetes, prescribed tablets and advised to adopt a healthy lifestyle, which is understandable as I was 43 years of age. However, later that day the GP contacted me with a request to undergo further tests, as she was of the view that despite my age I did

not conform with many of the characteristics associated with a Type 2 Diabetic. As I was admitted to hospital with Diabetic ketoacidosis the following day, this intervention by the GP was potentially life-saving. This highlights the need for all medical professionals to keep their knowledge of the condition up-to-date.

Accessibility of the service

The presence of the Diabetic Team at Witybush Hospital, 5 miles from my home has ensured that the services I need have been accessible. The process from initial visit to diagnoses and treatment has been seamless.

The only areas of concern have been:

- Blood Test – it took me nine days to have a blood test. While there could be a number of reasons for this delay, some of them due to my work commitments, this delay in getting a blood test potentially delayed my diagnosis by up to a week;
- Availability of blood sugar testing equipment – on diagnoses I was advised to test my blood sugar seven times a day. In addition, I am expected to test everytime I drive a car. The testing process requires a testing monitor, non-reusable testing strip and a lancet. While the GP surgery was very effective in providing the prescription, only one box of 50 testing strips was provided. This meant that there was a need to renew my prescription every week. After a few weeks I was able to get the prescription changed to give me 200 testing strips which now means that I only need to collect a prescription once a month. I am also fortunate that there is a good relationship between my GP Surgery and a local pharmacy, which means I am able to drop-off the repeat prescription at the Surgery, they will pass it onto the pharmacy and I will collect it a few days later from the pharmacy.

A less sympathetic GP, who would be unwilling to increase the number of testing strips per prescription and also pass on the prescription to a pharmacy, could lead to a diabetic patient needing to make three separate visits a week to obtain what they need to test their blood sugar levels. This would be challenging for most people, but particularly for a person without access to a car or someone who works long hours.

The benefit of greater flexibility can make a significant difference to the quality of life of a diabetic patient.

- Retinopathy – the Wales Retinopathy programme provided an excellent service and an annual check up will provide much needed peace of mind.
- Healthcare Essentials - I feel as if I have the necessary support to manage my condition. However, I note that Diabetes UK have identified a check list of 15 Healthcare essentials. I have not had access to all of these. Some may not be relevant to my particular circumstances, however, consideration should be given to including these on an future framework.

Other Issues

Having been a healthy person for over 40 years I find my view of many health related issues has changed over the past year:

- Free care – The past year has seen me undertake a number of hospital visits as well as other appointments. While I am fortunate to be able to work full time, for a sympathetic employer, and on a good salary, I am aware that many diabetic patients are not as fortunate. Welsh Government policies such as free parking at hospitals,

free eye test and prescriptions can minimise the financial impact and worry for patients. In addition, many diabetic patients do not have access to a car, and therefore it is important to ensure that hospitals and surgeries are on public transport routes.

- Food labelling – diabetes is managed by ensuring that sufficient insulin is taken to match the carbohydrates taken. The information provided on food is critically important to enable good management of diabetes. While most food brought in shops has this information, it is important that this information is clear and of sufficient size to enable all to read it.
- Campaigning and public information – as mentioned earlier prior to diagnosis I had little knowledge or understanding of the condition. While I understand that little can be done to prevent being diagnosed as a Type 1 diabetic this is not the case with Type 2. In view of the projected exponential growth in diagnosis of Type 2 diabetes it is essential that resources are invested to seek to prevent as many people as possible being diagnosed with diabetes. Funding provided today could potentially save several times that amount in the future.
- Research – while it is commonly accepted that diabetes is a life-long condition. I still hold out hope that medical advances will lead to a cure. I hope that public bodies will ensure that sufficient resources are invested in medical research to provide an opportunity of finding a cure.

If you require any additional information, please do not hesitate to contact me.

Yours Sincerely

A handwritten signature in black ink, appearing to read 'T. D. Jones', with a stylized flourish at the end.

Tegryn Jones