

Health and Social Care Committee

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

DB 12 Robin V Wright

Response from Robert V Wright - Patient Representative, Diabetes National Specialist Advisory Group.

Delivery Group.

(Disbanded by Powys LHB April 2011)

Patient Representative, Powys LHB Diabetes Planning and

Formerly Chair, North Powys Patient Reference Group

NB. Insulin dependent Diabetic (4 injections per day).

As a lay person I describe below some issues which occur to me as a patient representative and whilst they are personal views they are influenced by those other patients/friends/colleagues who have participated in various voluntary or ad hoc meetings.

STRUCTURED EDUCATION. With the support and participation of local patients it has been possible to establish a programme of education designed for Type 1 and Type 2 diabetics as envisaged in the NSF. Some inadequacy in staffing levels were overcome through representations by Patient Reference Groups in Powys and the intervention of the local AM. Whilst the Expert and Daffyd programmes are now well established the demands upon the limited resources of Diabetic Specialist Nurses and Dieticians are resulting in a failure to satisfy demand. (the position is exasperated by the suggestions from patients for follow up courses).

NB. One of the key agenda items for Powys Patient Reference Groups was the monitoring and promotion of patient education throughout the county. Regular information was supplied to the groups and feedback welcomed by the staff. Given the success of structured education programmes and their importance as a cornerstone of the National Service Framework the promotion ie publicity and development could be more effective through greater national co-ordination.

SHARED CARE PLAN. In Standard 3 of the NSF, and emphasised in the Consensus Guidelines is "an agreed and shared care plan in an appropriate format and language". This element of "empowering people with diabetes" has been extremely difficult to define and many patients whilst making regular visits to a GP, Practice Nurse, Specialist Nurse, Podiatrist, Consultant or Retinopathy Screening service do not have any concept of how their treatment falls within a Care Plan. Similarly the "locally agreed information package" which is defined at p34 of the Consensus Guidelines has not been implemented in the manner in which it is clearly intended. The North Powys Patient Reference Group, prior to its demise, regularly sought clarification on what constituted a Care Plan. Perhaps any review of the NSF could attempt to define the constituents of a Care Plan and ally those components to information which is passed on to the patient.

HAND HELD RECORD. I am aware, through membership of the NSAG, that work is currently underway to establish an all Wales document which would satisfy the intention laid down in the NSF. Some 3 years ago in Powys the Local Patient Reference Groups devised, printed and promoted a simple A3 card "MY DIABETES RECORD". Personally it has proved extremely useful in recording the outcome of various tests and visits. Important to ensure that any agreed document includes not only personal information but also the matters dealt with at p34 of the Consensus Guidelines particularly details of a local education programme.

PARTNERSHIP IN DECISION MAKING. This noble aspiration of the NSF has been reiterated in the more recent WAG document "Guidance on Involving Adult NHS Service Users and Carers" and is encapsulated in the "Actions" to "Objective 3.2" to Standard 3. viz. ..."Develop and support mechanisms to ensure active involvement of people with diabetes and carers in the planning and delivery of services eg. LDSAG's." (Now of course retitled DPDG's).

This key role of the DPDG's is clearly defined in the letter of the Minister of 23 June 2010, Ref: SF-EH-0326-EH/ML/028/10 to the Chairs of Local Health Boards which states..."Each DPDG should take responsibility for leading, managing and reporting to the LHB Board and to the Chief Executive of NHS on progress with the delivery of the NSF."

As the sole patient representative on the Powys LHB, DPDG I can report that not only have the LHB closed down the Patient Reference Groups which are a major conduit of patient feedback but more seriously have failed to provide the necessary commitment to the DPDG to ensure the Ministerial expectation is fulfilled. Leadership is non-existent and there is no evidence of the "management and reporting" to the LHB Board of matters which are the responsibility of the DPDG. I can highlight the current situation. In anticipation of a meeting of the DPDG called for Wednesday 19th September, I contacted the Secretariat on Monday 17th asking for an agenda and papers for the meeting. By email return I was informed in stark terms that "there are no papers or agenda". The mismanagement was further compounded when on arrival at the Bronllys venue I, along with 6 other Group members (from across the county and beyond) was informed that a mistake had been made and the meeting had been booked for the following day. (I had made a 100 mile round trip and given up a day of my time to attend the meeting). It is indicative of the Powys LHB commitment to the DPDG and its members that although the nominal lead officer for diabetes in Powys was in the building he would not, although requested, apologise to those present for the aborted arrangements. Please excuse the detail. This incident is fresh in my memory given it occurred only 2 days prior to writing this note.

In summary therefore, and as one of those persons outside the NHS structures but prepared to have an "active involvement", I find it difficult to comprehend how the intent, decision and guidance of the Assembly, as articulated by the Minister, can be ignored by the Board and management of a LHB. Any review of the NSF must surely address this conundrum.

In welcoming the opportunity to contribute to this enquiry I must stress that the views expressed are my own as a longstanding and appreciative patient of the NHS. I have never been in the employ of the NHS and my experience of close NHS contact has been over the recent past as a patient representative

on the North Powys Reference Group, the Powys DPDG (previously the LDSAG) and the NSAG (previously the AWDF).

Although a member of the Powys DPDG I am not aware of any discussion within the Group or submission by the Group of matters being addressed by this inquiry. Similarly I have no knowledge of any response by Powys LHB.

I would be prepared to give oral evidence to the Committee if so requested.

Robert V Wright.

Patient of the NHS.