

# Cross Party Group on Dementia

Minutes: February 2017 meeting



Pierhead Building

12.30pm – 1.25pm, Wednesday 8<sup>th</sup> February 2017

Chair: Lynne Neagle AM

Topic: Welsh Government's Dementia Strategic Action Plan

## Present

Lynne Neagle AM (Chair); Vaughan Gething AM; Angela Burns AM; Huw Irranca-Davies AM; Craig Lawton (on behalf of Suzy Davies AM).

Dr Sarah Watkins and Matthew Morris (Welsh Government); Sian Thomas and Stephen Boyce (Health, Social Care and Sport Committee); Sue Phelps, Morgan Griffith-David, Helen Payton (Alzheimer's Society Cymru – secretariat to the CPG); Dr Caroline Walters and Natalie Elliott (Royal College of Speech and Language Therapists); Rosie Raison (RCN Wales); Ross Gregory (Royal Pharmaceutical Society Wales); Siobhan Conway (Royal College of Psychiatrists); Clair Houston (Care & Repair Cymru); Allison Hulmes (BASW Cymru), Rachael Litherland (DEEP).

Elizabeth Williams, Robert Williams, Linda Willis, Adele Morgan, Ceri Higgins, Chris Roberts, Jayne Goodrick, Nigel Hullah (people affected by dementia / carers / volunteers).

## Chair's welcome and apologies

- Lynne Neagle AM welcomed everyone to the meeting
- Apologies: Mark Isherwood AM, Neil Hamilton AM
- Alzheimer's Society Cymru were elected as secretariat for the Cross Party Group
- The proposed Terms of Reference were adopted without amendment

## Presentation on the Welsh Government Dementia Strategy

Vaughan Gething AM, Cabinet Secretary for Health, Wellbeing and Sport, gave a presentation on the draft Dementia Strategic Action Plan for Wales. He said that it was important to be both ambitious and realistic with the plan, that there was the need to manage challenges of today and tomorrow. He recognised the need to look at the person in the whole context. There has been a listening process throughout the drafting of the Dementia Strategy, and people affected by dementia have been engaged and listened to in the drafting – he hoped that those in attendance would recognise their voices in the draft that has been published for consultation.

Questions were then taken from the floor and Vaughan answered them in groups.

- Nigel Hullah and Chris Roberts asked about the **Older Persons' Delivery Assurance Group** and whether people affected by dementia would be invited as members to monitor the implementation of the Strategy. Vaughan said it "*would be useful to have those voices from people affected by dementia around the table*".
- Adele Morgan and Jayne Goodrick whether an **easy-read or more accessible version** of the document would be produced, something simplified and written in simpler terms. Vaughan said it was important that the consultation conveyed the knowledge and detail necessary for both the health professional and the citizen – it is difficult to combine, but

accepted perhaps a summary which was easier to read would be beneficial. There has been a clear ask for some technical detail in the document as well. However, he said it was important people weren't afraid to say "I don't understand this". He said they would seek to produce a summary of what people can expect from health and social care, in order to communicate effectively with the citizen.

- Linda Willis asked about the potential for **self-referral** to Alzheimer's Society or memory clinics, bypassing the need for a GP as some people were frightened to go to a GP or had not had a good experience. Vaughan said that it was important to make sure people find help in the right place. If we are to improve diagnosis rates, it will need to be with the involvement of someone from a medical field. He acknowledged concerns, but that fed in to training and understanding. We expect GPs to be expert generalists, but culture change is important. We would expect health and social care professionals to be understanding of an individual's experience of dementia. It is not unusual for the citizen to be the expert on their condition but they do need to be able to get their fears and hopes heard by a qualified person. Training and knowledge are key to this so that access is available to all across the board.
- Dr Caroline Walters of the RCSLT noted that there was little reference to difficulty communicating, swallowing and eating in the strategy and asked how the Strategy would address this. Communication is also key for people with dementia, who often need support. Ceri Higgins said that we don't expect GPs to be experts, but at least to have basic knowledge. Angela Burns AM asked about the potential to review doctors **training**. We now have a difficult understanding of what makes us ill, and have different priorities – we're not living longer, but we want to live well. Are there plans to review training and who would be involved? Rosie Raison of the RCN noted that training was important not just for GPs but for all health and social care workers. The prevalence of dementia in society means that everyone in the sector will need people affected by dementia. There needs to be a review of training and access to that training. In that nurses need to be given time to up skill, train and gain knowledge in this area. It is essential that people receive the right care at the right level. Vaughan accepted the need to improve people's understanding and training. There was a question of what we expect people to learn from education (such as university) and what we expected them to learn during their professional life. The *Good Work Framework* was launched recently, and there is a need to identify good practice and challenge professionals to move the bar upwards and forwards and to get fewer and fewer people having problems – there will, however, always be room for human error, and that is unavoidable.
- Linda said it was important for **carers** to have support and training in their own right. Vaughan noted that the law has been changed with the Social Services and Wellbeing Act to give all carers an assessment, and there is a need to embed this during this Assembly term.
- Chris noted there was not a lot about **peer support or advocacy**, and the Strategy needed more about the rights people can access. Vaughan said that the importance of talking to people who understand, people living with dementia having the chance to talk to people living with dementia and carers having the chance to talk to carers, had often been raised during the consultation period. When he visited [Ty Hapus](#), a day centre in Barry run by Ty Hapus and Alzheimer's Society, he saw how important it was for people to have somewhere they enjoy to go.
- Jayne said that **palliative care** starts earlier than end of life, in order to understand what a person with dementia's wishes are as because of dementia it is often impossible to have that conversation later. Until someone has a diagnosis, they won't know what conversations they need to have. Lack of a diagnosis and understanding also puts pressure on families. If you get it right, can save money with earlier support and save people to help live their lives. 3%

increase in **diagnosis rate** is so small, what about the rest? There was general agreement from the room that 3% was not sufficient. Adele noted that diagnosis should rise with GPs support – a 50% diagnosis rate wouldn't be accepted for cancer, so it shouldn't be accepted for dementia.

On palliative care, Vaughan noted that this is a challenge across the board, as it is difficult to have these conversations but it is important that they happen earlier on. He said that the Government was intending to have a refresh of the End of Life Care Delivery Plan.<sup>1</sup> It is important to help us avoid second guessing people's wishes, and we have to promote this as a normal conversation. There is a section in the draft Dementia Strategic Action Plan about this, and it will feed in to future delivery. On the issue of a target for a 3% increase in diagnosis rates, Vaughan noted that the Chair of the CPG (Lynne Neagle AM) had made it clear in the Chamber that the target had to be ambitious. He noted that we have not been able to meet a 3% increase in the past year-on-year, so this target would be more than ever before. There will be diagnosis rate increases and it will need support in order to empower people to make choices.

- Chris said that **awareness raising** should be in schools, as fear and misconception starts early – the Dementia Friends course is only 45 and is excellent. It was noted that Alzheimer's Society have produced resources for schools.<sup>2</sup>
- Vaughan closed by saying that he hoped he'd said what he thought the Welsh Government could do now, and he would be happy to come back and listen again when the final Strategy is published. He is interested in the realities of delivering services and engaging with the CPG and people affected by dementia more widely on this issue.
- Nigel said that the Strategy should be a philosophical document, not necessarily prescriptive, and that it was important that there was a rights-based, person-centred approach and talk of a national pathway. He asked whether there should be a Director of Dementia, potentially not statutory but there to drive things forward. Lynne noted that some form of Czar, one person ensuring that the Strategy didn't sit on a shelf could be of benefit.  
Allison Hulmes of BASW asked how the Welsh Government would ensure that there was engagement with the Gypsy, Roma and Traveller (GRT) community, given huge health inequalities. Lynne agreed to follow this up with Vaughan.
- Linda Willis asked whether the law could be changed to give people the right to die. Lynne noted that this was the responsibility of Westminster, not the Welsh Government.
- Sue Phelps of Alzheimer's Society Cymru welcomed that there had been so many fantastic contributions. She noted that it was important to support carers as well as remember that a third of people with dementia live alone, and perhaps this was where advocacy had to come in. It is important to help keep people in their communities for as long as possible. We acknowledge that this is important and we need to prevent carer breakdown, but feeling into this are concerns over eligibility criteria, and ensuring they don't raise so high that they prevent people from accessing services before breakdown or crisis point. We know there is not a lot of money to throw around but we need to look at current spend and how best to apply the limited resources we have available. There is a lot of good in the draft document and it is clear that the voices of people affected by dementia have been listened to.
- Lynne noted that it was important that the CPG was looking at this Strategy, as is the Health, Social Care and Sport Committee, and it would hopefully reassure people that it was being scrutinised in detail.

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<sup>1</sup> Welsh Government (2013) [Together for Health – Delivering End of Life Care](#), Cardiff: Welsh Government.

<sup>2</sup> Alzheimer's Society (2016) [Creating a dementia-friendly generation](#), date accessed 10/02/2017.

### **Actions for next meeting / date of next meeting**

*Action:* Alzheimer's Society Cymru to draft and circulate a letter for comment. Lynne Neagle AM would write to the Health Secretary on behalf of the CPG.

*Action:* Lynne Neagle AM to ask Vaughan Gething AM about engaging with the GRT community.

Dates of future meetings:

- Tuesday 13<sup>th</sup> June, 12:30pm – venue TBC
- Tuesday 26<sup>th</sup> September, 12:30pm (AGM) – venue TBC