

Cross Party Group on Dementia

Minutes: December 2016 meeting

Committee Room 21, Ty Hywel

12.30pm – 1.25pm, Tuesday 13th December 2016

Chair: Lynne Neagle AM

Topic: Welsh Government's Dementia Strategic Action Plan

Present

Lynne Neagle AM (Chair); Hannah Blythyn AM; Mark Isherwood AM; Julie Price (on behalf of Nathan Gill AM); Craig Lawton (on behalf of Suzy Davies AM).

Ed Bridges, Morgan Griffith-David, Jaz Williams (Alzheimer's Society); Paul Harding (Marie Curie); Rosie Raison, Nicola Davis-Job (RCN Wales); Iwan Williams (Older People's Commissioner for Wales); Allison Hughes (BASW Cymru); Nesta Lloyd-Jones (Welsh NHS Confederation); Nigel Hullah, Rachel Niblock (DEEP).

Elizabeth Williams, Robert Williams, Kim Watkins, Gavin Watkins, Linda Willis, Adele Morgan, Scott Morgan, Denise Saunders, Tina Barker, Ceri Higgins (people affected by dementia / carers / volunteers).

Chair's welcome and apologies

- Lynne Neagle AM welcomed everyone to the meeting
- No apologies received

Welsh Government Dementia Strategy:

- The Strategy had been due to be launched on 14th December, but has now been put back until early January
- Morgan Griffith-David (Policy Officer for Alzheimer's Society Cymru) reported on the structure of the Welsh Government's Task & Finish Group advising on the Dementia Strategy, and the process by which it has been developed so far. There has been a particular focus on the life course of dementia (from increasing public awareness, to diagnosis and support, through living well with dementia and onto supporting late-stage dementia and end-of-life care); alongside this has been discussion of cross-cutting themes such as Welsh language, dementia in diverse communities and support for people in rural areas. It is also worth stressing that the dementia strategy overlaps with other policy documents (eg, carers strategy) and attention will need to be paid to ensuring the different documents complement each other.

In addition, Morgan also talked through the [joint letter](#) which has been submitted to the Health Secretary from a range of interested organisations (mostly third sector or professional bodies) identifying some of the features which it is suggested are reflected in the strategy. These are in addition to (but in many cases overlap with) the points raised in the public consultation events.

- Ed Bridges (External Affairs Manager for Alzheimer's Society Cymru) and Rachel Niblock (Co-Ordinator for the DEEP Network in Wales) reported on the views of people affected by dementia as expressed in the [consultation events](#) that have taken place throughout Wales in recent months, and which will continue in the New Year. A report based on the points raised

is currently being prepared and will be submitted to Welsh Government in the New Year, but will cover, *inter alia*, the need for the following:

- More/better training for health and social care workers
 - More flexibility in terms of respite care
 - More/better support post-diagnosis
 - A recognition of the savings which can be made by preventing interventions at crisis point
 - Recognition of the benefits of peer support and buddying systems
 - Better continuity of care (named support worker etc)
 - Funding for dementia which reflects the fact that it is the leading cause of death
- We also heard from Jaz Williams (Service User Involvement Officer with Alzheimer's Society Cymru) regarding the [Community Voice: Co-creating Healthy Change](#) project in Cardiff & Vale. Although not linked to the Dementia Strategy, the project has given people affected by dementia the chance to influence policy decisions about health and wellbeing services by reporting on their experiences of accessing Memory Clinics, diagnosis and support from hospitals and care settings. Many of the themes raised fit with the list above, and the work has also identified significant discrepancies between different people's experiences based on where they live or how much support they received at the point of diagnosis.

Contributions from the floor

During a lengthy discussion about the Dementia Strategy and what those affected by dementia would like to see reflected in it, the following points were raised:

- The Strategy needs to be properly-resourced so that it can improve on existing levels of support.
- The Strategy needs to capture the voices of people affected by dementia –the consultation events have been welcome and positive opportunities, but the final document needs to respond to the points raised in them. There must be more – and more meaningful – involvement of people affected by dementia at all steps of the Strategy's development and evaluation.
- Access to diagnosis through the medium of Welsh is an area where the Strategy should seek to give particular direction and drive improvements.
- There was concern about support groups becoming increasingly dependent on volunteers to run them rather than trained, professional staff. The contribution of volunteers is welcome, but it shouldn't be seen as a 'cheap fix'.

Actions for next meeting / date of next meeting

It had been suggested that the next meeting could be on 14th or 15th February 2017. However, the meeting felt that it would be useful to invite the Health Secretary to lead a discussion about the dementia strategy and, as such, we will have to be flexible to fit in with his diary. Information about the details for the next meeting will therefore be circulated once a date can be identified.

Action: Lynne Neagle AM to write to the Health Secretary, Vaughan Gething AM, to invite him to suggest a date when he can attend and speak about the dementia strategy.