

Cross Party Group on Dementia

Minutes: March 2017



Seminar Rooms 1 & 2, Y Pierhead

12 noon – 1.15pm, Tuesday 6 March 2018

Chair: Lynne Neagle AM

Topic: Dementia Action Plan, Carers of people with dementia

Present

Lynne Neagle AM (Chair); Dr Dai Lloyd AM; Craig Lawton (for Suzy Davies AM); Mandy Jones AM; Julie Price (with Mandy Jones AM); Huw Irranca-Davies AM; Louise Hicks (Welsh Government); Emma Homey (Welsh Government)

Sophie Douglas (Alzheimer's Society Cymru – secretariat to the CPG); Morgan Griffith-David, Angie Morgan (Alzheimer's Society Cymru); Daisy Cole (Older People's Commissioner Wales); Bethan Edwards (DEEP); Nesta Lloyd-Jones (Welsh NHS Confederation); Dr Natalie Elliott (Senior Specialist Speech and Language Therapist, Cardiff & Vale UHB); Oliver John (Royal College of Psychiatrists)

Ceri Higgins, Nigel Hullah (people affected by dementia / carers / volunteers).

Chair's welcome and apologies

- **Lynne Neagle AM** welcomed everyone to the meeting
- Apologies: Simon Thomas AM

Dementia Action Plan

- **Dementia Action Plan (DAP)** was published by Welsh Government on 14 February 2018
- **Lynne Neagle AM** suggested that as the DAP is intended to be a 'living document', the CPG should consider how the group can continue to influence its development and implementation, and invited comments on initial impressions:
 - **Nigel Hullah** – emphasis that this is the beginning of a long journey, and there are questions to be asked over delivery and implementation; also highlighted importance of feedback for community groups that contributed to the consultation process*
 - **Dr Natalie Elliott** – pleased to see recognition of team around the person, echoed questions over implementation; also raised importance of equity of services across Wales, and raised the question of how we ensure there is no disparity between regions
 - **Ceri Higgins** – raised concerns about the 'criteria-led' approach as opposed to allowing individuals to assert their needs
 - **Nesta Lloyd-Jones** – suggested individuals can write to the Cabinet Secretary for Health and Social services if any elements of the Parliamentary Review are of particular importance; also highlighted that Welsh government are developing the health strategy
 - **Daisy Cole** – welcome the plan overall, inclusion of elements such as John's Campaign, gave credit to the Cabinet Secretary. Also highlighted some concerns:

- Lack of mention of safeguarding and risks
- No clear measurement of advocacy
- No transparency so far of how the money will be spent
- Nothing about peer support within the plan
- Too much of a health focus

The intent is there but needs more join up, and it's a job for the delivery group to consider what is measured and how, with a human rights approach

The Minister for Children and Social Care gave an update on carers issues

- **Dementia Action Plan** – emphasis on the importance of support for the carer
- **Social Services and Well-being (Wales) Act** – 2 years on, progress being monitored by Carers Wales' 'Track the Act' and 'React to the Act' projects, it's clear more work is needed to raise awareness and understanding of carers assessments
- **3 Priorities** – as set out in [statement](#) on Carers' Rights Day 2017:
 - Supporting life alongside caring - All carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring.
 - Identifying and recognising carers - Fundamental to the success of delivering improved outcomes for carers is the need to improve carer's recognition of their role and to ensure they can access the necessary support.
 - Providing information, advice and assistance - It is important that carers receive the appropriate information and advice where and when they need it.
- **Ministerial Advisory Group** – will include carers

Questions to the Minister for Children and Social Care

- **Ceri Higgins**
 - requested that the Minister recognise and comment on the contribution of unpaid carers during the period of snow, as well as paid social care workers – the Minister agreed it is important to recognise the role of unpaid carers and pledged to tweet his support and thanks;
 - also highlighted that unpaid carers do not receive the same training as paid social care workers, and that as a carer she has had 4 days off in 8 years, as respite is expensive – the Minister agreed that 'respite should not impoverish people' and is a priority;
- **Nigel Hullah** – highlighted an upcoming campaign calling for Carers Allowance to reflect the National Minimum Wage – the Minister encouraged the campaign and pledged that from the perspective of the Welsh Government 'we will try and put the money in' however Carers Allowance is dictated by Westminster;
- **Julie Price** – highlighted the disjoint between health and social care in the case of her own mother-in-law who has Alzheimer's disease – the Minister agreed there is disparity between services, some demonstrating good practice and others less so, and mentioned the key message of the Parliamentary Review is emphasis on the need for links between health and social care;
- **Mandy Jones AM** – asked how we can ensure people living in rural and remote communities can be made aware of their entitlement to carers assessments and support –

the Minister agreed this is important and raising awareness across all cultural barriers is needed, beginning with ensuring the work force are fully informed and empowered;

- **Dr Natalie Elliott** – echoed that there can be barriers in her line of work to supporting people from diverse backgrounds – the Minister agreed the experiences of carers are markedly different from place to place, and the challenge is to get best practice across Wales;
- **Daisy Cole** – pointed out the cost implication and possible lack of resources leads to reluctance to offer carers assessments, and that a key message from the Welsh Government to Directors of Social Services should be around the entitlement to, and importance of, an assessment;
- **Craig Lawton** – highlighted that Suzy Davies AM has been pushing the Minister for an update on the Ministerial Advisory Group.

Actions for next meeting

- **Lynne Neagle AM** to write to the Minister for Children and Social Care asking recommending that carers of people with dementia be specifically represented on the Ministerial Advisory Group for carers;
- **Lynne Neagle AM** to write to the Cabinet Secretary for Health and Social Services asking for clarity on how the £10m funding attached to the Dementia Action Plan will be spent, and an outline of how the delivery group will monitor implementation.
- It was agreed that at the next meeting of the CPG the group will discuss options for continuing to influence the development and implementation of the Action Plan.

Dates of future meetings

- Tuesday 19 June 2018 – Seminar Rooms 1 & 2, Y Pierhead
- Tuesday 25 September 2018 – Seminar Rooms 1 & 2, Y Pierhead
- Tuesday 5 March 2019 – Seminar Rooms 1 & 2, Y Pierhead
- Tuesday 11 June 2019 – Seminar Rooms 1 & 2, Y Pierhead