

Cross Party Group on Dementia

Minutes: September 2017 AGM



Conference Room A, Tŷ Hywel

12 noon – 1.15pm, Tuesday 26 September 2017

Chair: Lynne Neagle AM

Topic: Carers of people affected by dementia

Present

Lynne Neagle AM (Chair); Dr Dai Lloyd AM; Joshua Bell (for Hannah Blythyn AM); Ryland Doyle (for Mike Hedges AM); Calum Davies (for Suzy Davies AM); Mark Major (for Caroline Jones AM)

Sue Phelps, Ed Bridges, Sophie Douglas (Alzheimer's Society Cymru – secretariat to the CPG); Kate Cubbage (Carers Trust Wales); Monica Reardon (Marie Curie); Dr Rosslyn Offord (British Psychological Society); Claire Hardcastle (Royal College of Speech and Language Therapists); Catrin Edwards (Hospice UK); Daisy Cole (Older People's Commissioner Wales)

Linda Willis, Adele Morgan, 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

Election of office holders

- **Lynne Neagle AM** was re-elected as chair
- **Sophie Douglas** (Alzheimer's Society Cymru) was re-elected as secretary

Follow up of previous meeting

- **Lynne Neagle AM** wrote to the Cabinet Secretary for Health, Well-being and Sport to invite him to attend a future CPG meeting to discuss end of life care for people affected by dementia – the Cabinet Secretary responded and indicated that he would like to attend a CPG meeting after the Dementia Strategy for Wales has been published (letter circulated with minutes)

Presentation on the challenges faced by carers of people with dementia

Kate Cubbage (Carers Trust Wales) covered two broad themes:

- Triangle of care for carers of people with dementia – recommendation: all carers champions within health and social care settings should receive training and support to understand the principles of the triangle of care
- Respite – recommendation: the importance of short breaks and respite care must be recognised and funded in a sustainable way; this could be through a Scottish style short breaks fund, or through the long term ring fencing of respite funding within Local Authority or Local Health Board budgets.

PowerPoint slides circulated with the minutes.

Discussion

- **Nigel Hullah, Ceri Higgins, Adele Morgan and Linda Willis** all raised issues from personal experience of living with/caring for someone with dementia:
 - Carers may not ask for support because 'they know they won't get it'
 - People living with dementia also benefit from having breaks away from their family – the 'respite' isn't just for the carers
 - Many people who are caring do not identify as carers and/or are unaware that they are entitled to a carers assessment
 - A lot of 'respite' available is not dementia-specific and therefore unsuitable for a person with dementia
 - A written submission provided by Jayne Goodrick was read aloud by Nigel Hullah, detailing the experiences of two carers of people with dementia, entitled 'who cares for the carer?'

- **Daisy Cole** (Older People's Commissioner) raised the need to rethink the terminology around 'respite' and mentioned that the Older People's Commissioner will be doing a piece of work on this, exploring a holistic approach to respite and not labelling people.

- **Dr Rosslyn Offord** (BPS) echoed the point raised about unhelpful terminology around respite, and also suggested people may not identify as carers – rethinking language is significant. Also referred to an intervention called '[START – strategies for relatives](#)' - a manualised intervention aimed at promoting the development of coping strategies for carers of people with dementia.

- **Catrin Edwards** (Hospice UK) highlighted the success of 'ad hoc' services working well, for example the CARIAD (Care and Respect in Advanced Dementia) project in Blaenau Gwent, where Alzheimer's Society and Hospice of the Valleys are working together to support the delivery of palliative and end of life care in the community, supporting the person living with dementia and their carers, providing access to clinical nurse specialists and dementia support workers and befrienders.

- **Monica Reardon** (Marie Curie Cymru) suggested that many carers are not aware of what support is available and therefore don't know what to ask for – furthermore as a professional one may not always be clear on what is available, so it's important that professionals are equipped with up to date information to provide to carers.

- **Claire Hardcastle** (RCSLT) spoke about the disparity of services across the NHS in Wales, for example the project she works on for people with younger onset dementia provides more support than that which is available to people with other types of dementia, because the funding is not ring fenced in every health board.

Carers Strategy consultation

The Welsh Government's revised Carers Strategy is due out for consultation in the next few weeks, therefore the group will submit a response to the consultation encompassing the key themes discussed.

- **Kate Cubbage** (Carers Trust Wales) pointed out that the challenges facing carers are down to problems with the *delivery* of the strategy and legislation (Social Services and Well-being Act 2014), rather than the legislation and policy itself, which is fit for purpose.
- **Sue Phelps** (Alzheimer's Society Cymru) and **Nigel Hullah** echoed views that there needs to be a specific delivery plan attached to the revised Carers Strategy to ensure it is effective.

AOB

None

Actions for next meeting

- **Lynne Neagle AM** to respond to the consultation on the revised Carers Strategy on behalf of the group.
- **Lynne Neagle AM** to follow up with the Cabinet Secretary for Social Services and Well-being to enquire about the process for consulting on the Carers Strategy, and whether carers will be consulted with directly.

Dates of future meetings

- Tuesday 28 November 2017
- Tuesday 27 February 2018
- Tuesday 22 May 2018

Topics to be covered tbc – depending on the date of the publication of the Dementia Strategy