

# Cross Party Group on Dementia

Minutes: June 2017 meeting



Seminar Rooms 1&2, Pierhead Building

12.30pm – 1.25pm, Tuesday 13 June 2017

Chair: Lynne Neagle AM

Topic: End of life care for people affected by dementia

## Present

Lynne Neagle AM (Chair); Hannah Blythyn AM; Dr Dai Lloyd AM; Mark Isherwood AM; Rhun ap Iorwerth AM; Owen Jones (for Jayne Bryant AM); Joshua Bell (for Hannah Blythyn AM); Kelly Preston (for Alun Davies AM)

Sue Phelps, Ed Bridges, Sophie Douglas (Alzheimer's Society Cymru – secretariat to the CPG); Monica Reardon (Marie Curie); Dr Rosslyn Offord (British Psychological Society); Claire Hardcastle (Royal College of Speech and Language Therapists); Nicola Davis-Job (RCN Wales); Nesta Lloyd-Jones (Welsh NHS Confederation); Iwan Hughes (Royal Pharmaceutical Society); Adrian Neal (DCP Wales, British Psychological Society); Rachel Niblock (DEEP).

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

## Presentation on end of life care for people affected by dementia

**Monica Reardon** (Marie Curie)

- Barriers to end of life care for people with dementia – people with dementia don't 'fit' into traditional service models, lots are designed for people dying of cancer which has a different trajectory
- Planning for death – having the 'difficult conversations', presumption of capacity under the Mental Capacity Act, importance of professionals understanding what this means in practice
- Assisted dying – presumed attitudes and concerns can be a barrier to receiving care

## Discussion

- **Nigel Hullah, Ceri Higgins, Adele Morgan and Linda Willis** all raised issues from personal experience of living with/caring for someone with dementia:
  - Importance of the 'difficult conversation' – and professionals ensuring they discuss end of life whilst the person with dementia is able to;
  - Lack of respite for carers across Wales;
  - Lack of understanding amongst health professionals that dementia is a terminal illness
  - Importance of support for carers after a person with dementia has died – speaking of the 'void' left with no support;
  - Importance of supportive relationship with GP to begin end of life planning.

- **Dr Rosslyn Offord** (BPS) raised the challenges of working out when and how to begin end of life planning, and that a 'one size fits all' approach doesn't work. Questioned whether support might be available from organisations such as Marie Curie for professionals not directly working in end of life care. (**Monica Reardon** explained this is something Marie Curie are exploring for the future).
- **Sue Phelps** (Alzheimer's Society Cymru) raised the importance of collaborative working, and praised a new service in Blaenau Gwent jointly run between Alzheimer's Society Cymru and Hospice of the Valleys – Dementia Support Workers and Palliative Care Nurses working together. Also discussed the partnership with Cruse Bereavement Care, providing support for carers of people with dementia at all stages of grief (which can begin before the person with dementia has died).
- **Owen Jones** (for Jayne Bryant AM) raised the inequality between, for example, cancer patients and people with dementia – people with cancer often begin end of life planning much sooner than people with dementia.

### Suggestions of future topics for CPG meetings

- **Intergenerational services** – inviting young people involved in a project working with people with dementia to share their experiences
- **Carers of people with dementia** – challenges faced
- **Human rights**

### AOB

Sophie Douglas (Alzheimer's Society Cymru) appointed as secretariat to the CPG

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

**Action** – Sophie Douglas (Alzheimer's Society Cymru) to email round to invite further suggestions of future topics for discussion

Dates of future meetings:

- Tuesday 26<sup>th</sup> September, 12:30pm (AGM) – Tŷ Hywel