

Cross Party Group on Dementia

Minutes: October 2018



Seminar Rooms 1 & 2, Y Pierhead

12 noon – 1.15pm, Tuesday 9 October

Chair: Lynne Neagle AM

Topic: Hospital care for people living with dementia

Present

Lynne Neagle AM (Chair); Rhun ap Iorwerth AM; Heledd Roberts (for Rhun ap Iorwerth AM); Craig Lawton (for Suzy Davies AM); Dai Lloyd AM

Sophie Douglas (Alzheimer's Society Cymru – secretariat to the CPG); Sue Phelps, Huw Owen, Natalie Owen, Rhys Edwards (Alzheimer's Society Cymru); Janet Bevan (Cwm Taf UHB); Catrin Edwards (Hospice UK); Daisy Cole (office of Older People's Commissioner for Wales); Karyn Davies (University of South Wales); Ceri Smith (Alzheimer's Research UK); Michael Banner (Marie Curie); Dr Rosslyn Offord (British Psychological Society); Michaela Morris (Public Health Wales); Dr Jane Harden, Dr Katie Featherstone, Ed Bridges (Cardiff University), Sam Bolam (Dementia Matters Powys); Chineze Ivenso (Royal College of Psychiatrists); Suzanne Duval (Diverse Cymru); Oliver John (Royal College of Psychiatrists)

Peggy Martin, Ceri Higgins, Nigel Hullah, Linda Willis (people affected by dementia / volunteers / 3 Nations Dementia Working Group)

Chair's welcome and apologies

- **Lynne Neagle AM** welcomed everyone to the meeting

AGM

- **Lynne Neagle AM** re-elected as Chair
- **Sophie Douglas** re-elected as secretariat (on behalf of Alzheimer's Society Cymru)

Feedback from previous meeting

- Correspondence between **Lynne Neagle AM** and the **Cabinet Secretary for Education** – recognising the value of inter-generational work between school children and people living with dementia
- Answers to written questions tabled by **Lynne Neagle AM** to the **Cabinet Secretary for Health and Social Services** – WAQ76901, WAQ76900, WAQ76899 regarding funding attached to the Dementia Action Plan.

Feedback from DOIIG meeting

- Once published, minutes can be found [here](#)
- **Action:** Lynne Neagle to invite Jo Maddaford and/or Sally Thompson (Welsh Government) to a future CPG meeting for an update on funding attached to the Dementia Action Plan

Presentation by Dr Katie Featherstone

Dr Featherstone presented her research into the everyday care of people living with dementia admitted to acute hospital wards. The study focused on the 'refusal and resistance of care'.

Findings included:

- So called 'resistance' was typically in response to how care is organised (routinised, compartmentalised, provided by many different people) and/or a response to the delivery of care
- Staff are caught in an 'organisational trap' – focused on timetables, risk reduction and efficiency

Recommendations included:

- Evidence-based interventions – a need for robust research into care for people living with dementia during an acute admission
- Awareness raising
- Training for all

For further information:

storiesofdementia.com/

@storiesofdementia

@Drkfeatherstone

Discussion

- **Nigel Hullah** raised concerns that Deprivation of Liberty standards have become a systematic aid for containing people, which is extremely worrying given Human Rights and Equality legislation
- **Daisy Cole** emphasised the importance of training and awareness, and queried how we can ensure LHBs are on board
- **Suzanne Duval** asked whether any research explored the experience of patients whose first language is not English, **Dr Katie Featherstone** explained that a new research project will be looking into that topic
- **Sam Bolam** highlighted a small project having a big impact in Powys, **Dr Katie Featherstone** reiterated that interventions must be evidence-based, hence the need for further research
- **Dr Jane Harden** posed the question how do we use existing staff culture to effect changes we want, for example by prescribing 5-10 minutes of time for nurses to sit with patients
- **Dr Rosslyn Offord** suggested that training often doesn't 'stick', and we do need to address a significant change in culture, shifting away from being risk-averse and prioritising fall-prevention
- **Michaela Morris** asked if it's possible to see a timetable of tasks on the ward, to look into how it corresponds to the Safe Staffing levels, **Dr Katie Featherstone** responded that they are included in the full report available online (see above)
- **Ceri Higgins** shared an experience she had in hospital with her dad, and commented that it's about basic human senses and attitude, and that it takes the same amount of time to provide bad care as it does to provide good care – and having red plates does not make a hospital ward dementia-friendly in reality

- **Linda Willis** shared a personal experience of being in hospital, and explained that a lot of care required should be common sense, simply asking ‘do you need help with this?’ rather than leaving something at the end of the person’s hospital bed
- **Dr Katie Featherstone** commented on a culture she observed of staff suggesting ‘people with dementia shouldn’t be on this ward’ / ‘people with dementia should be in specialist care’ / ‘there are too many people with dementia on this ward’ – demonstrating a lack of understanding
- **Michaela Morris** asked how wards reacted to the research findings, **Dr Katie Featherstone** commented on a ‘learned helplessness’ among staff, who feel that they are unable to do anything about the problems

Inquiry into hospital care

- **Sophie Douglas** outlined the plan for the inquiry into hospital care for people living with dementia – call for evidence circulated with minutes.
- A link to the survey in English or Welsh can be found [here](#)

AOB

- **Suzanne Duval** highlighted work by Diverse Cymru raising awareness of BAME communities’ experiences of dementia – poster circulated with minutes

Dates of future meetings

- Tuesday 4 December 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