

Cross Party Group on Dementia

Minutes: December 2018



Seminar Rooms 1 & 2, Y Pierhead
12 noon – 1.15pm, Tuesday 4 December
Chair: Lynne Neagle AM
Topic: Welsh speakers' dementia care report

Present

Lynne Neagle AM (Chair); Ioan Bellin (for Helen Mary Jones AM)

Meri Huws (Welsh Language Commissioner); Lowri Williams (Welsh Language Commissioner's office)

Sophie Douglas (Alzheimer's Society Cymru – secretariat to the CPG); Sue Phelps, Huw Owen, (Alzheimer's Society Cymru); Janet Bevan (Cwm Taf UHB); Catrin Edwards (Hospice UK); Daisy Cole (office of Older People's Commissioner for Wales); Dr Rosslyn Offord (British Psychological Society); Chineze Ivenso (Royal College of Psychiatrists); Oliver John (Royal College of Psychiatrists); Ceri Higgins, Nigel Hullah (people affected by dementia / volunteers / 3 Nations Dementia Working Group); Natalie Elliott (Royal College of Speech and Language Therapists); Iwan Williams (Social Care Wales); Beti George; Irina Erchova (Stroke Association / Cardiff University); Daniel Jones (Royal College of Psychiatry)

Chair's welcome and apologies

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

Update on Inquiry into hospital care

- **Sophie Douglas** updated on the progress so far:
 - 168 responses to online survey – 50% of responses from carers and family members of people living with dementia, 25% of responses from former carers
 - Good media coverage – will look to 'push' in press again in the new year
 - Need for professional organisations to respond – **Natalie Elliott** explained that RCLST intend to respond but the deadline appears to be June – **Sophie Douglas** agreed to clarify for the group [further information will be circulated]
 - **Rosslyn Offord** asked whether a response could be put together at a group meeting for the British Psychological Society – **Sue Phelps** and **Sophie Douglas** agreed Alzheimer's Society Cymru could facilitate
 - **Daisy Cole** asked whether there is a timescale for which we are gathering data (for example the last 3-5 years) and asked about safeguarding concerns raised through survey responses – **Sophie Douglas** agreed this needs to be clarified

Written update from Dr Liz Davies – Chair of Dementia Oversight of Implementation and Impact Group

- The group agreed the letter does not provide as much detail on allocation of funding as hoped (copy of letter circulated with minutes)
- **Action: Lynne Neagle** to write to Welsh Government on behalf of the group to ask for a minister to attend a future CPG meeting to provide clarity around funding and oversight of implementation
- A letter from the Dementia Roundtable to Dr Davies raising concerns about the DOIIG was shared at the meeting (copy circulated with the minutes)

Presentation by Meri Huws and Lowri Williams

Meri Huws and Lowri Williams presented the research report produced jointly between Alzheimer's Society and the Welsh Language Commissioner.

Notes circulated with the minutes.

Key discussion points

- **Meri Huws** emphasised the importance of focusing on implementing the recommendations within the report.
- **Rosslyn Offord** and **Sue Phelps** highlighted challenges around recruitment and the requirement of speaking Welsh
- **Meri Huws** agreed that Welsh must be seen as a work skill and given status – and that HEIW acknowledge the importance of Welsh
- **Ceri Higgins** highlighted that there are hundreds of unpaid carers supporting family members, and that many families have generational differences in ability to speak Welsh – how can we support them?
- **Meri Huws** pointed out that we don't necessarily need 'sophisticated' Welsh to help, a little goes a long way
- **Natalie Elliott** commented on the impact of dementia on language and the fact that first-language Welsh speakers may revert to only speaking Welsh, hence the importance of this report
- **Sue Phelps** suggested lobbying Welsh Government around the 'making rights real' programme of work

- **Action:** Lynne Neagle to write to the chair of the Health, Social Care and Sport Committee following up on the report, and to Welsh Government.

Dates of future meetings

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