

# Cross Party Group on Dementia

Minutes: March 2020



Tuesday 3 March 2020, 12:00pm-1.30pm

Seminar Rooms 1 & 2, Y Pierhead

Chair: Lynne Neagle AM

Present:

Lynne Neagle AM (Chair), Dr Dai Lloyd AM, Sue Phelps, Huw Owen, Meryl Randell-Jones, George Parish-Wallace (Alzheimer's Society Cymru), Dr Eleri Cubbage, Heledd Roberts (Welsh Assembly), Rebecca Cicero (Social Care Wales), Michaela Morris, Rebecca Hanmer (Improvement Cymru), Daisy Cole (Action on Hearing Loss), Gwyneth Sweatman, Monica Rearden (Marie Curie), Karyn Davies (University of South Wales), Catrin Edwards (Hospice UK), Dr Natalie Elliott, Dr Anna Colquhoun (Cardiff & Vale University Health Board), Helen Cunliffe (Swansea Bay UHB), Amy Kordiak (Life Story Network/TIDE), Callum Hughes (Welsh NHS Confed), Nigel Hullah (3 Nations Dementia Learning Group), Ceri Higgins, Linda Willis, Chris Roberts, Jane Goodrick

**Lynne Neagle AM (Chair)** welcomed everyone to the meeting and asked if anybody present had any amends to the Minutes from the previous meeting held on 3 December 2019 and if there were any matters arising.

There being no such amendments or matters arising, the Chair welcomed Rebecca Cicero (**RB**) to present on the work of the Learning & Development Group (LDG) within the Dementia Oversight Implementation and Impact Group (DOIIG).

## Presentation by Rebecca Cicero (Social Care Wales)

**RB** started the presentation by referencing the handout that was circulated to those in attendance at the meeting updating attendees on the scope of the LDG within DOIIG.

**RB** then explained the purpose of this particular Sub-Group within DOIIG, stating that a national Learning & Development working group was established with a purpose to develop practical resources to help structure learning and development more consistently for health and social care in Wales. It was explained that this work follows on from the implementation of the Good Work Framework.

**RB** said that it is important that the Sub-Group develops an approach which is inclusive of the voice of people living with dementia, their family and carers and health and social care professionals. As such, the Sub-Group aims to formulate a strength-based and person-centred approach to dementia care in Wales.

In terms of the Sub-Groups mandate, it seeks to examine current ways of learning and development across health and social care and how this can be turned into a toolkit resource that will help to shape a more consistent, collaborative and joined-up approach across Wales. This will be underpinned by the Good Work Framework in order to change the culture, environment and ethos of work within dementia care.

To date, the LDG has shaped the new level 4 qualification and level 5 Unit on Dementia Care which form part of the new suite of social care qualifications delivered across Wales. In addition, the LDG will be publishing a toolkit next month to help regions compare their learning activity against the Good Work Framework.

At the centre of the work carried out by the LDG is to involve those living with and affected by dementia. As such, it was recognised that there are not a lot of resources available in the health and social care space to help those living with and affected by dementia. Therefore, good practice is often not explained, and a practice-based approach needs to be established going forwards.

Two engagement workshops were recently held in North and South Wales to help improve communication with people living with and affected by dementia. The purposes of the workshops, which were run by Alzheimer's Society, Improvement Cymru and Social Care Wales, were to build a shared purpose across Wales and to build an ongoing infrastructure for engagement. Also included was a mapping of the ways in which engagement is managed with those living with and affected by dementia and the identification of ongoing infrastructure and communication.

It was noted that this work will shape the communications and engagement plan for the National Dementia Learning & Development Group and will link to the National Dementia Action Plan for Wales.

**The Chair** then asked if any attendees had any questions based on the presentation.

**Ceri Higgins (CH)** said that there is concern across the board that there is only tokenistic involvement and inclusion of people living with dementia in the development of health and social care policy across Wales. She asked how we will ensure that people living with dementia are included in such work going forwards.

**CH** noted that people living with dementia and their carers are experts in dementia care and are highly qualified. However, qualifications are stereotyped and there is generally under-representation of people living with and affected by dementia in working groups.

It was agreed that there is a network of experts in the community who can help to formulate health and social care policy going forwards for people living with and affected by dementia.

**RC** said that everyone should be equal and that currently, health and social care is developed in pockets. It was noted that a values-based approach is needed and there is little infrastructure around the involvement of people living with dementia in learning and development practice.

**RC** added that it is important to remember that it is about a person-centred approach which takes account of the person and their lived experience. As such, dignity and respect are important elements of dementia care.

**CH** said that all groups need to include and actively involve those living with and affected by dementia, adding that the inclusion of one service-user is not enough.

**RC** said that the network must include those living with and affected by dementia and that the LDG workshops recognised that this will inform how we open-up better dialogue and communication with people living with dementia.

**The Chair** then welcomed Huw Owen (**HO**) to present on the Welsh Language Sub-Group of DOIIG.

### **Presentation by Huw Owen (Alzheimer's Society Cymru)**

**Huw Owen (HO)** said that 18-months ago the Welsh Language Sub-Group published a report entitled *Gofal Siaradwyr Cymraeg/Welsh Language Dementia Care* into care for dementia in the Welsh language along with the Welsh Language Commission.

Following the publication of the report, there has been engagement between the Welsh Language Commissioners Office and Alzheimer's Society with the Cabinet Minister for Health and Social Services, Vaughan Gething AM and the Welsh Government, as well as Cathays Park to recommend and engage with policymakers as a follow-up from the report.

The Welsh Language Group (WLG) has met three times to date and creates a network to share good practice. As such, **HO** said that too often, good work and practice is isolated and individualistic in nature.

Therefore, the WLG exists to bring work together in a spirit of collaboration and coordination across the different regions of Wales and Health Boards. This helps to create learning and development and opportunities to share areas of good practice. The three meetings to date have taken place in Bangor, Carmarthen and Cardiff.

The meetings are attended by Welsh language-speakers and people living with dementia who are Welsh-speakers. This helps those living with and affected by dementia to share their experiences.

The overall aim of the WLG is to check-in with the work that Welsh Government and the Civil Service are doing in this area in order to improve people's lived experiences in Welsh language care. As such, the WLG act as an effective check-and-balance on the work of Welsh Government and actively engage with wider audiences on this issue.

**Action: HO** to share correspondence between WLG and Welsh Government regarding its response to the report.

**The Chair** then welcomed Michaela Morris (**MM**) and Rebecca Hanmer (**RH**) to present on the Hospital Charter Work within DOIIG.

## Presentation by Michaela Morris and Rebecca Hanmer (Improvement Cymru)

**Michaela Morris (MM) & Rebecca Hanmer (RH)** began the presentation by introducing the Hospital Charter and explaining the structure of the Dementia Friendly Hospital Charter (DFHC) Governance Structure.

**MM** then explained that to date, the DFHC team has actively engaged face-to-face with 1,650 people in order to review standards of care in hospitals across Wales. As such, anybody is welcome to join the various Sub-Groups across the regions of Wales and the team recognise the important role that people living with and affected by dementia play in the development of the DFHC.

**RH** explained that the DFHC project started in October as part of the Dementia Action Alliance. The work undertaken by the DFHC is very much pointed and directed at each Health Board region and is supported and assisted to improve dementia care in hospitals across Wales. In addition, it was explained that there is a big campaign to organise a Taskforce around this.

**Nigel Hullah (NH)** stated that the DFHC aims to deliver improvements for hospitals and hospital staff across regions, adding that hospital care in Wales needs improving.

**RH** said that DFHC is being coproduced with all partners. This includes people living with dementia, their carer partners, people providing service and people connected to services, governing bodies HIW and DU. Principles of the charter are currently being drafted and a self-assessment will be developed from these, alongside a tool to ascertain people's experiences of hospital care. Each region will have a task force to undertake the self-assessment and review the person's experience of hospital care. The Charter aims to make improvements for dementia care within hospitals over time.

**MM** added that underpinning this is a new group is to improve dementia care in Wales as there is currently too much fragmented work across regions and a lack of consistency in the quality of care for those living with dementia. There are also a number of DFHC Steering Groups with a focus on helping to draft the DFHC for Wales.

**RH** said that the DFHC is currently being drafted.

**MM** added that practitioner experience will be developed and woven into the DFHC for Wales.

**RH** said that the DFHC will be officially launched with Ministerial support in August or September 2020 and that sign-up in regions across Wales will follow.

**MM** said that the DFHC has to align with the Dementia in Hospital Standards Alzheimer's Societies In-Hospital Care.

**MM** and **RH** then shared the various overarching themes that encompass the DFHC team, which are all underpinned and inspired by kindness.

It was also stated that the Health Boards will have to be involved in the development of the Finish Task-Force Group and that work is ongoing with every Health Board to make sure that dementia care is improving in hospital across Wales.

**The Chair** then welcomed Daisy Cole (**DC**) to present on Hearing Loss within DOIIG.

### **Presentation by Daisy Cole (Action on Hearing Loss)**

**Daisy Cole (DC)** stated that hearing loss is the number one risk factor for those living with dementia that is currently not included in campaigns and public health communications.

As such, there is a large body of evidence to suggest that healthy hearing and good cognitive ability are strongly linked to good health and working memory. Therefore, deafness and hearing loss poses major risks to health and to the lived experience of those living with dementia.

**DC** said that hearing aids are of vital importance to tackle the issues of hearing loss for those who are hard of hearing. Whilst not the same as normal hearing, the use of hearing aids nonetheless reduces the risk of dementia.

It is also well documented that hearing loss increases the likelihood of depression, language failure and decreases cognitive ability, whilst leading to an increased risk of cognitive impairment. Therefore, hearing loss needs to be included in public health policy going forwards.

**Linda Willis (LW)** said that, in her experience, the use of hearing aids has increased her ability to hear more than one conversation at once.

**DC** said that there are many people living with dementia who do not have a hearing loss diagnosis. Hearing loss represents a substantive risk to those living with dementia and therefore must be included in the DFHC.

With the right support, those living with dementia in the deaf and hard of hearing communities can increase the quality of their lived experience and involvement in community life, leading to improved health and wellbeing. However, the prevalence of hearing loss within the community of those living with dementia is still high.

**DC** said that dementia assessments are currently failing deaf people. There is a cultural misunderstanding and interpreters are needed to bridge the gap of cultures.

As part of the ongoing work in this area, it is the aim to decrease the number of those living with dementia in Wales and improve care for those with hearing loss and dementia. This will lead to a material improvement in the lived experiences and increase cultural, linguistic and the quality of care for people living with dementia within deaf communities.

The group will meet in June and report to Welsh Government in September.

**The Chair** then thanked all presenters and asked those present if there were any questions or comments.

## Discussion

**Sue Phelps (SP)** said that the work with the DFHC is very exciting and that there will be very good outcomes from this particular piece of work.

There is also potential to link the DFHC strongly to the outcomes of the CPG Hospital Inquiry Report due to be published in the spring. As such, one of the reports key recommendations to Welsh Government will be that hospitals in Wales must sign-up to the DFHC with robust monitoring systems in place to improve dementia care in Wales.

In terms of the WLG, Alzheimer's Society Cymru is looking forward to Catrin Hedd Jones of Bangor University speaking on this subject at its annual conference on 12 March in Llandudno, North Wales. The recommendations and outcomes of the conference will inform future work in this area.

**Catrine Edwards (CE)** then referenced the Compassionate Country Charter in relation to the DFHC.

**MM** said that it is important to bring people living with dementia to improve care pathways in Wales. As such, it was agreed that kindness is an excellent driving theme for those involved in the DFHC.

**DC** asked if the CPG on Dementia could possibly follow-up regarding the Health & Social Care Quality Bill to take a recommendation through the CPG to make Sensory Communication Issues forward in Statute to Welsh Government.

**The Chair** said that Stage 3 of the Bill is fast-approaching. However, it would be possible for the CPG to write to the relevant Minister regarding this to raise the issue in the debate for guidance powers in the Bill.

## Agreed Actions:

**HO** to share correspondence with the CPG between the WLG and Welsh Government regarding the publication of the *Gofal Siaradwyr Cymraeg/Welsh Language Dementia Care Report*. (Available on the link [here](#).)

**The Chair (LN)** to write to the Minister for Health & Social Services to raise the issue of Sensory Communication with regards to the Health & Social Care Quality Bill in order to influence the debate in the legislative process.

## **AOB**

### **Dates of future meetings**

Tuesday 19 May 2020

Tuesday 6 October 2020 (AGM)

Tuesday 8 December 2020

Tuesday 2 March 2021

12 noon – 1.30pm in Y Pierhead