

Cross Party Group on Dementia

Minutes of the meeting

Tuesday 31 January 2017 – 6pm-7.15pm

Committee Room 4, Scottish Parliament Building, Edinburgh EH99 1SP

Present:

MSPs

Richard Lyle, Colin Smyth, Miles Briggs and Stewart McMillan.

Organisations

Alzheimer Scotland (Owen Miller, Amy Dalrymple, Rachael McMurchy and Jim Pearson), Scottish Dementia Working Group (Archie Noon), Dementia Friendly East Lothian (Sue Northrop), National Dementia Carers Action Network (Anne Bisset), TIDE – Together in Dementia Everyday (Anna Gaughan), Queen Margaret University (Fiona Kelly), The ALLIANCE (Thomas Whitelaw), Life Changes Trust (Anna Buchanan), University of Stirling (Karen Watchman), Care Inspectorate (Heather Edwards), Dementia Engagement and Empowerment Project (Paul Thomas), Scottish Dementia Research Consortium (Alison Murray – University of Aberdeen, Frank Gunn-Moore – St Andrews, Charlotte Clarke – University of Edinburgh), Age Scotland (Richard Baker and Grace Hinchcliffe), Scottish Neuroprotective and Neurodegenerative Clinical Research Network), University of the West of Scotland (Margaret Brown), NHS Education for Scotland (Patricia Howie), Scottish Social Services Council (Jess Alexander), Royal College of Speech and Language Therapists (Robert MacBean), NHS Health Scotland (Michael Tornow), Dementia Friendly Arora (Paula Brown), Cobhair Bharraigh (Margaret Ann Beggs).

Individuals

Donna Houston (Carer), Agnes Houston (Person with dementia), Katharyn Barnet (Carer), Ruth Mantle (Alzheimer Scotland Dementia Nurse Consultant – NHS Highland), Helen Skinner (Alzheimer Scotland Dementia Nurse Consultant – NHS Fife), Andy Shewan (Alzheimer Scotland Dementia Nurse Consultant – NHS Tayside), Peter Lerpinière (Alzheimer Scotland Dementia Nurse Consultant – NHS Borders), Nicola Wood (Commitment 10 Lead – NHS Forth Valley), Sandra Shields (Alzheimer Scotland Dementia Nurse Consultant – NHS Greater Glasgow and Clyde), Tilda McCrimmon (Alzheimer Scotland Dementia Nurse Consultant – NHS 24 and Golden Jubilee National Hospital), Natasha Hamilton (Carer).

In attendance:

David Berry (Scottish Government), Geoff Huggins (Scottish Government), Mike Liddle (Scottish Government).

1. Welcomes and Introductions

Richard Lyle MSP welcomed people to the meeting to establish the Cross Party Group on Dementia and noted the large turnout. Richard explained the purpose of the group, which aims to ensure engagement and knowledge sharing between MSPs and people living with dementia, carers, professionals and academics.

Attendees were asked to introduce themselves and their role/organisation so everyone was familiar with each other and for the purpose of the minutes.

2. Election of Office Bearers

Richard Lyle MSP passed the chair of the meeting to Myles Briggs MSP for the purpose of electing a convener for the Cross Party Group. Members of the group elected Richard Lyle MSP as convener (proposed by Colin Smyth MSP, seconded by Miles Briggs MSP).

Richard Lyle MSP resumed the chair. Members elected the following further office bearers:

- Colin Smyth MSP and Finlay Carson MSP as co-vice-convenors (both nominated by Richard Lyle MSP, seconded by Miles Briggs MSP).
- Alzheimer Scotland to provide secretariat (nominated by Richard Lyle MSP, seconded by Miles Briggs MSP).

Richard Lyle MSP thanked Miles Briggs MSP and Colin Smyth MSP for their support in facilitating the process of electing office bearers.

Due to a technical issue, the presentations were unable to be displayed. The group were informed they would be sent the slides following the meeting.

3. Scotland's Third National Dementia Strategy – Geoff Huggins

Geoff Huggins, Director of Health and Social Care Integration, Scottish Government, explained the process undertaken to develop the next strategy, indicating that it would be published within the next couple of months. He explained that Scotland was the only country in the world to have a third strategy and that the focus would be on practical outcomes, rather than 'aspirational' commitments.

The context for dementia policy in Scotland was set out, including the [recent publication by the Scottish Government/Information Services Division](#), noting that the estimates from the first dementia strategy had anticipated about 4000 people per year being diagnosed with dementia; the report shows about three/four times this number have been diagnosed. In addition, he acknowledged [another Scottish Government/Information Services Division publication](#) which showed that the Post-Diagnostic Support (PDS) guarantee of every person receiving a diagnosis receiving 1 year of PDS has not been met; however, 50% more people than had been expected received support. In light of this increase, the way in which PDS needs is delivered needs to be revised, as current provision does not take into account the progression of a person's illness or the readiness of the person to receive the service.

Geoff further noted the forthcoming publication (expected February) of the findings of the testing process for Alzheimer Scotland's 8 Pillars Model of Community Based Support, which had been undertaken as part of the previous dementia strategy.

The increasing numbers of people dying with and from dementia was highlighted as a key area of focus for the next dementia strategy, with current provision requiring further development to better support people at the end of life. Geoff highlighted the ongoing work as part of the Strategic Framework for Action on Palliative and End of Life Care, as well as a commitment to test Alzheimer Scotland's Advanced Dementia Practice Model.

Geoff also noted that dementia policy within Scotland includes international projects related to dementia including the European Union Joint Action on Dementia and the International Consortium for Health Outcomes Measurement (ICHOM) project.

4. Alzheimer Scotland's Vision For Change – Jim Pearson

Jim Pearson, Director of Policy and Research, Alzheimer Scotland, set out the wider policy context of in Scotland, noting some of the key development in recent years.

Jim explained that in 2009, the Cross Party Group on Alzheimer's (the precursor to the Cross Party Group on Dementia), had developed the [Charter of Rights for People with Dementia](#), which had articulated the legal basis of the rights of people with dementia and had underpinned much of the policy development in Scotland, including the National Dementia Strategies.

Jim reflected on the PDS Guarantee and associated HEAT Target put in place by the Scottish Government, explaining the importance of the service in ensuring that people were not socially isolated, understood their diagnosis and felt able to manage their condition, and understood the supports available. He further emphasised that a suitable alternative model needed to be developed before the current PDS guarantee could be replaced.

Jim noted the importance of coordinated health and social care services which met the needs of people with dementia, and the needs of their carers, reflecting on Alzheimer Scotland's [8 Pillar Model of Community Support](#) which proposes to do this with Dementia Practice Coordinators who have the requisite skills and authority to coordinate and access health and social care services for the person with dementia and their carer. He further noted that this co-ordinated approach was the basis of the [Advanced Dementia Practice Model](#), acknowledging the Scottish Government's commitment to test this as part of the next strategy.

Jim also covered some of the work that had been undertaken in acute settings by Dementia Nurse Consultants, implementing the [10 Care Actions](#) to improve the experience of people with dementia and carers in hospital settings.

As part of the removal of stigma and ensuring people can continue to live in their communities, Jim highlighted the work being undertaken by organisations across Scotland to create Dementia Friendly Communities (DFCs).

Jim concluded by noting the importance of dementia research in Scotland, highlighting Scotland as an excellent place for researchers across disciplines to undertake research in Scotland. He noted the excellent work taking place across different institutions to research treatments and cures, whilst emphasising that this was some time off, meaning the importance of practice-based research to ensure better care and support for people currently living with the condition.

5. Group Discussion and Questions for Presenters

The discussion was opened up to the floor for questions and additional contributions.

There was discussion amongst the group about the PDS figures published by the Scottish Government, including both the service being delivered to 40% of people with a new diagnosis, as well as the reasons why people chose not to take-up or complete the service. There were contributions from the group about the importance of the quality of the offer of PDS so people understood what the service was and why it is important. It was noted that there was no significant

variance across areas in terms of take up, but that some qualitative research suggested people were reluctant to engage in services if they felt they would be taken away from them.

The group further contributed on the importance person-centred approaches being delivered in community settings. Some members of the group highlighted that there was a 'middle group' whose needs weren't met after PDS as they were not eligible for support after PDS but before the condition had become more advanced. It was noted that the current models of service could not sure an equity of provision amongst people, whilst delivering support tailored to individuals.

The work of the dementia strategy was discussed in the context of other ongoing work including Self Directed Support and the Carers Act; the group agreed IJBs and commissioners need to ensure that the necessary support is in place for people with dementia and carers.

Many members of the group raised issues around support for carers as it was felt that their needs and the expectations upon them were undervalued. In particular, the financial pressures placed upon carers were highlighted, particularly where they had to give up work and the lack of support despite the money they saved the economy. Additionally, it was felt amongst the group that carers were often not acknowledged as people in their own right, with a life outside their caregiving role.

Richard Lyle highlighted this was a good forum for these points to be raised and for solutions to be proposed, which would influence professionals, decision makers and members of the group.

6. AOCB

Amy Dalrymple noted that there were some outlines on plans for future meetings, including holding another meeting when the Dementia Strategy was published. She further highlighted that there was the opportunity to have a joint meeting with the Cross Party Group on Palliative Care which Bob Dorris MSP (also a member of this group) convenes and also asked about the possibility of using one of the groups to hold a Dementia Friends session. Suggestions for future meetings should be emailed to the secretariat.

7. Close and Date of Next Meeting

Richard Lyle thanked everyone for taking the time to come to the meeting, including the MSPs. He also thanked the presenters and those who had contributed, noting the quality of the discussions.

The date of the next meeting will be sent out to members as soon as a suitable date has been identified.