

**Joint meeting of the Cross Party Group on Dementia**  
**Minutes of the meeting**  
**24 October 2017 – 5.45pm-7.15pm**  
**Committee Room 4, Scottish Parliament Building, Edinburgh EH99 1SP**

**Present:**

MSPs

Richard Lyle MSP, Maureen Watt MSP, Scottish Government Minister for Mental Health and Sport, Colin Smyth MSP, and Finlay Carson MSP.

Organisations

Alzheimer Scotland (Jim Pearson, Owen Miller, Amy Dalrymple, David Beyt), Scottish Dementia Working Group (Archie Noon, Anne Ramsay), National Dementia Carers Action Network (Anne Bisset, Frank Ramsay), TIDE – Together in Dementia Everyday (Ray Fallan, Amanda McCarren, Beau Nieuwenhuis), Life Changes Trust (Anna Buchanan, James McKillop, Maureen McKillop), Queen Margaret University (Fiona Kelly), Dementia Engagement and Empowerment Project (Paul Thomas, Agnes Houston), Age Scotland (Richard Baker), University of the West of Scotland (Margaret Brown), Marie Curie (Susan Lowes), Scottish Care (Karen Hedge), Healthcare Improvement Scotland, (Michelle Miller), Scottish Government (David Berry), NHS Health Scotland (Michael Tornrow, Emma Kennedy), University of Aberdeen (Alison Murray). Royal College of Psychiatrists (Katharyn Barnton), British Deaf Association (Lucy Clark), Cobhair Barragh SCIO (Margaret Ann Beggs), NHS Tayside (Andy Shewan – Alzheimer Scotland Dementia Nurse Consultant), British Association of Music Therapy (Emma MacLean), Royal College of Speech and Language Therapists (Rebecca Kellet), ABPI (Alison Culpan), The Alliance (William Griffiths, Tommy Whitelaw), Paths for All (Carl Greenwood), Church of Scotland Presbytery of Stirling (Bonnie McDowell).

Individuals

Donna Houston (Carer), Natasha Hamilton (Carer)

**1. Welcome, introductions and apologies**

Richard Lyle MSP welcomed everyone and attendees introduced themselves.

Apologies were received from: Peter Lerpiniere, Ruth Mantle, Sheila Clark, Karen Watchman, Peter Connelly and Christine Steele.

**2. Approval of Minutes**

The minutes of the 31 May 2017 joint meeting of the group with the Cross Party Group on Palliative Care had been circulated to members. Their approval was proposed by Maureen McKillop and seconded by Colin Smyth MSP.

### 3. Scotland's Third National Dementia Strategy

Richard Lyle MSP introduced Maureen Watt MSP, Scottish Government Minister for Mental Health and Sport.

Maureen's remarks included the following points:

- She is the first ever dedicated minister for mental health in the British Isles.
- The portfolio includes dementia.
- Dementia has been a Scottish Government priority for 10 years. Significant improvements have been made over this time, though challenges remain.
- There was a 25% increase in dementia diagnosis between 2008 and 2012 thanks to the diagnosis target put in place by the Scottish Government.
- The first dementia strategy was published in 2010, followed by the Dementia Care Standards and the Promoting Excellence Framework for workforce education.
- The 2013 strategy included the post diagnostic support HEAT target and measures to improve acute care for people with dementia.
- The new strategy includes a lot of continuity from this previous work. Its focus is on giving people more control over their care.
- The Promoting Excellence Framework remains key; it needs to be implemented across the full range of care settings at all stages of the illness including palliative care.
- There are currently over 700 dementia champions with a further 100 now undertaking training. There are also 1000 dementia ambassadors working in social care.
- The Scottish Government values and makes sure to engage closely with people living with dementia, their families and carers. They take a rights based approach, using the Charter of Rights for people with dementia and carers developed by this group's predecessor in an earlier Parliament.
- The new strategy includes implementing 'Connecting People, Connecting Support' the newly launched document about the role of Allied Health Professionals supporting people with dementia and carers, and where that role fits with other professional inputs.
- The first commitments in the new strategy are about ensuring tailored and appropriate post diagnostic support. Scotland has made progress with this but there is more work to do to make sure post diagnostic support is flexible and person centred – the offer needs to include integrated home care and palliative care when that is needed.
- The Scottish Government published a report on the incidence of dementia diagnosis in December 2016. This tells us that the number of people with the dementia diagnosis is rising and is likely to continue to do so.

- There is a focus on early diagnosis and early intervention to help people with dementia live independently.
- More people are being diagnosed later in life, who already have significant other care needs, which is which the new strategy includes the proposal that these people move directly to a coordinated home-based approach to care for their post diagnostic support, using Alzheimer Scotland's 8 Pillars Model. How this happens will be developed over the next three years.
- The strategy includes a commitment to test moving post diagnostic support delivery from mental health teams to primary care. This is to promote accessibility and encourage people to come forward for support earlier. This commitment sits within the Scottish Government's vision for primary care multi-disciplinary teams. The test sites are Shetland, Nithsdale and north east Edinburgh.
- There is a commitment to better and more coordinated home care. This can only be delivered by Integrated Joint Boards so engagement with those bodies is crucial and the Scottish Government is supporting the Scottish Dementia Working Group and the National Dementia Carers Action Network to pursue such engagement. There are important lessons from the test of the 8 Pillars model as part of the previous strategy. Beyond the dementia strategy, there will be further Scottish Government work on improving care at home.
- There is a commitment to improving palliative care, which fits with the Scottish Government Strategic Framework for Action on Palliative Care. This will include new guidance for Integrated Joint Boards on commissioning. It also includes work on anticipatory care planning, and testing the Alzheimer Scotland Advanced Dementia Practice Model. People with palliative care needs often have multi-morbidities. Quality conversations are key to good palliative care and this process can begin during post diagnostic support.
- Good progress has been seen in improving acute care thanks to the Alzheimer Scotland Dementia Nurse Consultants and the Dementia Champions. There is also good progress being made in improving Scotland's Specialist Dementia units, with a great response from staff there. This will continue under the new strategy.
- There is a commitment to use the Promoting Excellence Framework to improve services in care homes and care at home. There will also be continued monitoring of the use of psychoactive medication in these environments.
- Further commitments include:
  - Continuing resourcing of Focus on Dementia, the dementia improvement programme within Healthcare improvement Scotland
  - Continued support for the Scottish Dementia Research Consortium
  - Looking to improve dementia care and support through use of technology
  - Looking to improve housing for people with dementia
  - Looking to improve transport for people with dementia
  - A national approach to befriending to increase the number of people benefitting from this community support.

- Health and Social Care integration provides the context for implementing the strategy. Scottish Government has invested half a billion GBP in to support integration this year. Scottish Government spend on adult health and social care has risen in real terms. There is a focus on enabling people to be cared for at home. Care workers must now all receive at least the Living Wage. They are testing the Buurtzorg Model which enables great autonomy for care workers and the people they support in how care is managed.
- The Scottish Government have also undertaken a feasibility study into the extension of Free Personal Care to people under the age of 65, and they will now take that forward, benefitting up to 9000 people, 3000 of whom have dementia – the minister recognises Amanda Kopel’s campaigning driving this forward. This measure will be implemented through subordinate legislation from April 2019.

#### **4. Question and answer, with group discussion.**

Members were invited to ask questions of the Minister or to make wider points about the strategy and experiences. The discussions were broad and included the following points:

- a. There isn’t sufficient investment in post diagnostic support – this is evident from the waiting lists that exist, which are very long in some areas. The Minister acknowledged that post diagnostic support availability is variable, mentioning that in her own area of Grampian it needs to improve. The hope is that the shift to primary care will help. David Berry of the Scottish Government added that the national commitment to 12 months of post diagnostic support for everyone receiving a dementia diagnosis is maintained, and the Scottish Government is providing funding to support people with dementia and carers to influence local Health and Social Care Partnership decision making on this. From 2015/2016 the post diagnostic support data has been collected by health and social care partnership rather than by health board, making it more transparent.
- b. How do people receiving post diagnostic support feed back about their experience of it? The Minister cited her regular meetings with the Scottish Dementia Working Group and the National Dementia Carers Action Network where she gets extremely important feedback, with the national groups informed by local networks. She also meets individuals, attends as many events as possible to meet people living with dementia, meets with other organisations, and liaises with MSP colleagues about issues their constituents with dementia have.
- c. There is an issue for people diagnosed before the advent of post diagnostic support, and how they get linked into the system to access support, especially as accessing self-directed support can be so difficult with such tight eligibility criteria. Richard Lyle MSP offered to follow up specifically with the questioner. The Minister responded that self directed support is transformational change but that she is aware that local authorities are not all using the Scottish Government funds to implement this as intended - £35m to fund the change to SDS and £16.1m to enable access to SDS. David

Berry added that the Scottish Government know that there is variation between different local areas, there is work to ensure that providers have a full understanding of SDS. They would be keen to hear about the experiences that people living with dementia, including carers, have with SDS.

- d. A carer described how she has been trying to get care for her husband, who has dementia, for 18 months; he is now nearing the end of his life and she is still having to provide all his care. Richard Lyle MSP also offered to follow this up individually after the meeting. The Minister responded that the Scottish Government expect Councils to implement national policy and provide care, and that the Scottish Government have resourced them to do so. She asked the carer to email her.
- e. There is a lack of quality staff to support people at home, especially responding to personal care needs. The Minister responded that the Scottish Government are encouraging training for more dementia champions in the social care (as well as health) sector. There has been a huge improvement but she recognised that there is a long way to go in many areas.
- f. Dementia Friendly Communities are about taking a neighbourhood approach to support rather than about services – what support is available to help with such work in light of the commitment to it in the strategy? The Minister responded that this work has to be bottom up, Government can't do it. She commended Alzheimer Scotland's Dementia Friends initiative. She cited the 'Boogie in the Bar' sessions and the slow aisle in Forres Tesco branch in her local area. This work all relies on community based organisations and a community spirit directed towards supporting local people who are living with dementia.
- g. How is training being standardised to ensure every practitioner has the required expertise? The minister asked Jim Pearson of Alzheimer Scotland to respond. Jim described the history of the Promoting Excellence Framework for workforce education about dementia in health and social care. This has four levels – 'informed' for people who work with people with dementia but do not care for them directly, 'skilled' for many practitioners, 'enhanced' for dementia specific practitioners and 'expert' for specialists. People living with dementia have been involved in developing and implementing this framework, including close involvement from the Scottish Dementia Working Group in delivering training. The Minister added that many different ways of learning are needed across the health and social care workforce.
- h. The Minister concluded this section of the meeting by saying that though we are likely never to get it absolutely right for absolutely everyone, we know from the international attention on this work here, that Scotland is doing well compared to many other places.

Richard Lyle MSP thanked the Minister and David Berry. He also encouraged people to discuss issues with their local MSPs to raise their awareness and take up constituents' issues with the Scottish Government.

## **5. AOCB**

- a. Richard Lyle MSP suggested that in light of the previous discussion, it would be useful for the next CPG meeting to have a general discussion about whether the system is working and whether the money is going to the right places. Finlay Carson MSP reinforced the encouragement for people to take their issues to local MSPs – for example if community support is in place for people being discharged from hospital. Colin Smyth MSP and Richard Baker of Age Scotland both stressed the importance of, in that suggested discussion, hearing first from people living with dementia and carers.
- b. Paul Thomas said he had sent Alzheimer Scotland an email asking for time to outline DEEP's priorities to the group. Owen Miller suggested this could be part of the agenda for the suggested next meeting. David Berry suggested that he could help arrange for someone from the Scottish Government SDS policy team to come along to that meeting too if that would be helpful.
- c. Owen Miller informed the group about an approach from the Scottish Futures Trust to hold a joint meeting in March 2018. The group were amenable to this and Owen will take forward to arrange this.
- d. Owen Miller also informed the group about an approach from the Westminster Parliament All Party Parliamentary Group (APPG) to hold a joint meeting. The group were also amenable to this suggestion and this will be arranged for probably late 2018.
- e. Tommy Whitelaw said that he had also written to Alzheimer Scotland to request to present to the Group about the data from engagement with professionals that Dementia Carer Voices has undertaken. Owen again suggested this could be included in the next meeting of the group.
- f. Owen Miller and Richard Lyle MSP agreed to work together on a programme of meetings for 2018 that incorporates as many of these requests and suggestions as possible. They will be in touch with the group once this has been done.

## **6. Close and Date of Next Meeting**

The secretariat will meet with the convenor to examine dates and topics for 2018.