

Joint meeting of the Cross Party Group on Dementia and Cross Party Group on Palliative Care

Minutes of the meeting Wednesday 31 May 2017 – 5.45pm-7.15pm Committee Room 5, Scottish Parliament Building, Edinburgh EH99 1SP

Present:

MSPs

Richard Lyle MSP, Bob Doris MSP, Colin Smyth MSP, and Finlay Carson MSP.

Organisations

Alzheimer Scotland (Owen Miller, Amy Dalrymple, David Beyt), Scottish Partnership for Palliative Care (Mark Hazelwood and Rebecca Patterson), Scottish Dementia Working Group (Archie Noon), National Dementia Carers Action Network (Anne Bisset), TIDE – Together in Dementia Everyday (Anna Gaughan), Life Changes Trust (Elizabeth Morrison, James McKillop, Maureen McKillop), CHAS (Pat Carragher), DCP British Psychological Society (Leigh Whitnall), Queen Margaret University (Fiona Kelly), Dementia Engagement and Empowerment Project (Paul Thomas), Scottish Dementia Research Consortium (Charlotte Clarke – University of Edinburgh), Age Scotland (Richard Baker), University of the West of Scotland (Margaret Brown), NHS Education for Scotland (Patricia Howie and Elizabeth Sanchez-Vivar), Royal College of Speech and Language Therapists (Robert MacBean and Rebecca Kellet), MND Scotland (Susan Webster), Parkinson's UK (Tanith Muller), Marie Curie (Juliet Spiller and Susan Lowes), Prince and Princess of Wales Hospice (Liz Smith), Kilbryde Hospice (Lynsay Bain), University of Edinburgh (Julie Wilson), Barchester Healthcare (Janice Stewart), Hospice UK (Eilidh MacDonald), Scottish Care (Donald MacAskill), Mental Welfare Commission (Alison Thomson), St. Columba's Hospice (Janice Stone), Action Duchene (John Miller), Healthcare Improvement Scotland, (Paul Baughan), Scottish Government (Gillian Barclay and Tim Warren) .

Individuals

Donna Houston (Carer), Agnes Houston (Person with dementia), Elaine Hunter (National AHP Consultant – Alzheimer Scotland), Sandra Campbell (National Clinical Lead for Palliative and End of Life Care), Peter Lerpiniere (Alzheimer Scotland Dementia Nurse Consultant – NHS Borders), Sandra Shields (Alzheimer Scotland Dementia Nurse Consultant – NHS Greater Glasgow and Clyde), Andrew Senew (Home Instead Senior Care), Gordon McLaren (NHS Fife), (Gerry Finnan) NHS Borders, Maggie Ellis (St. Andrew's University), Vicky Carson (MSP Assistant).

1. Welcome, introductions and apologies

Bob Doris MSP and Richard Lyle MSP welcome people to the joint meeting of the two groups and introduced attendees.

Apologies were received from: Alex Cole-Hamilton MSP, Miles Briggs MSP, John Starr, Christine Steel, Ruth Mantle, Alison Murray, Karen Watchman, Nicola Wood, Medina McDonald, Carolynne Hunter, Belinda Hacking, Hilary Peppiette and Kenny Steele.

2. Approval of Minutes

The minutes of the 14 December 2016 meeting of the Palliative Care Cross Party Group and the 31 January 2017 meeting of Dementia Cross Party Group had been circulated to members and were approved as accurate.

Bob Doris noted that as the meeting of the Palliative Care CPG on 22 March 2017 was an informal meeting of the group (a decision taken as a result of the attack at Westminster that day) therefore the note of the meeting did not require formal approval. The group was happy with the meeting record.

3. Matters arising from previous meeting of Palliative Care Cross Party Group

3.1 Scottish Parliament Health and Sport Committee interest in palliative care

Colin Smyth MSP, who is a member of the Health & Sport Committee, fed back to the group that though palliative care is of ongoing interest to the committee and remains on their agenda, there are no new developments to report at this time.

3.2 Strategic commissioning relating to the social care sector

Bob Doris reminded the group that at its March meeting, the Palliative Care CPG had discussed Aileen Campbell's response to Bob Doris' letter and sought greater clarification on the extent to which the particular needs of the social care sector will be addressed. The Strategic Framework for Action on Palliative and end of life care contained a commitment by Scottish Government to "Provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships".

Discussions at the meeting had highlighted that the initial draft Advice Note produced by the Strategic Commissioning subgroup of the National Implementation and Advisory Group was written in general terms and did not address the particular issues raised in the Cross Party Group's letter to Aileen Campbell. Specifically, it did not highlight the need to explore within homecare contracts the impact of a strict time and task (and thus time-monitored) approach to the delivery of effective palliative care. It was felt that the Guidance Note should robustly address these issues.

At that time, Tim Warren from the Scottish Government had assured the group that the draft Advice Note has not yet been signed off, that there was still scope to influence its content and undertaken to keep the group informed of relevant developments.

Tim shared that the Strategic Commissioning group had recently met and the issue of time and task approaches was raised; however, the outcome of these discussions was unclear as

it may not be within the remit of the group to direct how Integration Authorities commission and procure services.

Donald MacAskill urged the Health and Sports Committee to pursue this issue as an urgent area of concern.

4. Presentations on the forthcoming National Dementia Strategy for Scotland

The Scottish Government are expected to publish a new Dementia Strategy this summer. This meeting provides an opportunity to explore and discuss expectations of the strategy.

4.1 Amy Dalrymple, Head of Policy, Alzheimer Scotland.

Amy noted that the forthcoming dementia strategy represented and the strategic framework for action on palliative and end of life care presented an excellent opportunity for a joint meeting of the two cross party groups to come together and discuss areas of mutual interest.

Amy set out the policy context in Scotland, with reference to Alzheimer Scotland's vision for change which sets out six priority areas (diagnosis, post-diagnostic support, coordinated care, advanced illness, acute care and dementia friendly communities), before explaining Alzheimer Scotland's development of models of care and support with for people with dementia and their carers.

Underpinning Alzheimer Scotland's approach to advanced illness (and its Advanced Dementia Practice Model) is the 8 pillars model of care and support, which emphasises keeping people in a community, with good care coordination across health and social care, drawing on a range of different clinical and therapeutic interventions. The continuity of care is vital, however, as the physical symptoms come to the fore, there is a need for additional input from specialists, including psychologist, palliative care specialists etc. These professionals not only deliver their own interventions but can upskill and support other staff and carers.

Amy concluded by showing the different models of care and support through the progression of the person's illness, noting that early diagnosis and post diagnostic support were crucial for end of life and palliative care planning. She noted the nature of palliative care means practitioners in this area often understand the benefit of these early conversations and interventions.

4.2 Gillian Barclay, Head of Dementia Innovations Unit, Scottish Government.

Gillian Barclay presented on the Scottish Government's work so far in relation to dementia policy and practice in Scotland, before going on to touch upon the themes which would emerge in the next Dementia Strategy (expected for publication in June 2017).

Gillian noted that around 90,000 in Scotland are estimated to have dementia, although research and statistics appear to indicate that the rates of prevalence and incidence may be slowing. However, with 80% of care home residents estimate to have some form of

dementia and a societal cost of approximately £2 Billion, work in this area remains important. Gillian noted that in 2016, that dementia as the underlying cause of death in Scotland is 10% and this figure is expected to rise.

The Scottish Government's support for Alzheimer Scotland's models was highlighted, including the 5 Pillars model as a basis for the Post-Diagnostic Support Guarantee, as well as the development of the Standards of Care for People with Dementia, the Promoting Excellence Framework and the increase in dementia diagnosis rates.

Gillian confirmed that the forthcoming strategy would seek to build on the existing work of the previous two dementia strategies but that no new additional resources would be attached to the strategy. Some of the key areas of focus would be around unnecessary hospitalisation and improving training to ensure people were sufficiently skilled to support people with dementia. In addition, it was discussed that the PDS figures, as per the Scottish Government reports, were poor and will continue to be a focus of the new strategy. The PDS guarantee requires revision so it is more flexible and able to be support people whose dementia is further progressed.

4.3 Peter Lerpiniere, Lead Nurse for Mental Health & Learning Disabilities, NHS Borders.

Peter Lerpiniere set out a practice example of how professionals can best support people at the end of life. He commended Alzheimer Scotland and the Scottish Government on the work carried out to date, noting the how far we had come whilst also noting that there was some way still to go.

Peter gave a case study example of examining all areas of practice during which palliative care was identified as a key area for improvement. This was felt by some clinical professionals to be an area where they could not try new ways of working or put forward ideas, especially for fear of upsetting families of patients. Through the delivery of training (including PATCH training) and support, staff felt empowered to try new ways of working or to have more difficult conversations with family members, especially where there was perceived conflict between patients wanted and what the family wanted. Staff felt more confident in recognising behaviours, body language and responses from patients, linked into their knowledge of the person (through activities such as life history work), they felt they had 'permission' to convey this to families and work with them to agree the best way to support the person.

Peter noted that nursing a person at the end of life also involved 'nursing' the family through the experience or losing a family member. The perception of a family member being difficult or challenging is an aspect of end of life care and support integral to the professional role.

Peter recognised that whilst this may not be revolutionary for palliative care staff who have worked this way for a long time and have experience in this area, for other staff this is a new way of working and an area they may not feel comfortable addressing. There needs to be a recognition of the different ways in which 'compassion' can be delivered and requires support for front-line staff to embolden them to try new ways of working.

4.4 Group discussion.

People with dementia and their carers shared their experiences of receiving care and support from the system at different stages. The overarching theme which emerged was that the system was difficult to navigate, was not fully understood (by people living with dementia or professionals) and that people were often left without support because they did not meet eligibility criteria. This made advance planning and preventative work difficult. One carer shared her experience of end of life which whilst broadly positive, involved a specific and ongoing issue; a number of members offered to support and follow-up with the carer.

Adequate training of professionals to identify dementia and support people was discussed, particularly in relation to the work of GPs. The Promoting Excellence Framework for dementia was highlighted as was the recently launched palliative and end of life education framework.

The use of AHPs in primary care to allow GPs to extend consultation times beyond 10 minutes was raised. Other staffing issues were identified as problematic including time and task orientation within health and social care, and staffing levels within care home settings were also discussed. Members also discussed the need to support people who may not have previously accessed formal services or supports which may be helped by the move of PDS to primary care settings.

Ensuring the wishes of people with dementia are met where they may have lost capacity and/or are at the end of life was discussed, including the need for to balance supported and proxy decision-making. Anticipatory Care Planning and the use of personal outcome plans (as part of PDS) were discussed as a way of ensuring that people have the opportunity to have their wishes recorded and followed once their condition had progressed. It was discussed that included within GP's KIS (key information summary) there are limitations to how this information can be shared and updated.

The importance of Good Life, Good Death, Good Grief's work to create open cultures around death, dying and bereavement was raised. It is helpful for GPs to know whether a Power of Attorney exists, and also to have information about who a person would want them to get in touch with in case of an emergency. It was suggested that, under new IJB structures, there is the potential to lose focus on bereavement, and that this is something the Cross Party Group on Palliative Care should keep an eye on.

Members also highlighted that the Standards of Care for People with Dementia were written about seven years ago and were still not being fully delivered. It was suggested that people should be aware and able to demand these as they articulate what people with dementia and their carers should receive. It was also suggested that these should be refreshed to account for the changes which have occurred since their publication.

The group discussed the need to sharing knowledge and learning from test sites as quickly as possible, instead of waiting until the work is completed. It was explained that interim papers would be published during testing periods and that Healthcare Improvement

Scotland were setting up learning networks so that good practice and learning could be shared.

5. AOCB

There was no other AOCB from members.

6. Close and Date of Next Meeting

The next meeting of the Cross Party Group on Palliative Care will take place on Wednesday 6 September 2017 in Committee Room 4.

The next date of the Cross Party Group on Dementia had yet to be identified and would be decided in line with the next Dementia Strategy.