

Cross Party Group on Dementia

Minutes of the meeting

13th June 2018 – 5.30pm-7.15pm

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

Present:

MSPs

Colin Smyth MSP (Chair) and Finlay Carson MSP.

Organisations

Alzheimer Scotland (Owen Miller, Jim Pearson, Robert Bain), National Dementia Carers Action Network (Anne Bissett and David Beyt), MECOPP (Jennifer Paton), Care Inspectorate (Heather Edwards), Mental Welfare Commission (Kate Fearnley), Scottish Care (Donald MacAskill), Life Changes Trust (Arlene Crockett, James McKillop and Maureen McKillop), ALLIANCE (Matthew Hilferty), Outside the Box (Anne Connor), BDA Scotland (Lucy Clark), Age Scotland (Martyn Walker), UWS (Debbie Tolson), DEEP (Paul Thomas), CrossReach (Laura MacLeod and Bonnie McDowell), Paths for All (Carl Greenwood), TIDE (Lorraine Bairstow, Ray Fallon, John Stephen, Moyra Templeton) and NHS NES (Patricia Howie).

Individuals

Natasha Hamilton, Michael Turnbull and Lilian Davidson.

1. Welcome and apologies

The following apologies were received: Richard Lyle MSP, Archie Noone, Fiona Kelly, Craig Ritchie, Peter Gordon, Rebecca Paterson, Sandra Shields, Andrew Senew, Margaret Ann Beggs, Alison Murray, Alison Keir, Rebecca Kellet, Charlotte Clarke, Elaine Hunter, Agnes Houston, Donna Houston, Ruth Mantl, Brenda Cornwallis and Michael Craig.

Colin Smyth MSP noted that Richard Lyle MSP had submitted apologies and that he would chair the meeting.

2. Approval of Minutes

The group approved the minutes, with Paul Thomas of DEEP having submitted a correction.

3. MECOPP – Rights, Respect and Responsibilities Project Presentation

Jennifer Paton, Legal Officer (Dementia) with MECOPP introduced the Three R's Project, which focuses on the experience of people with dementia accessing Self-Directed Support (SDS).

Jennifer explained that the 3 R's Project was a two-year project set-up due to SDS legislation not delivering its intended aims of improved choice and control for those accessing social services. Unlike previous MECOPP projects, it was explained the project was nationally focused and open to any person with dementia who was accessing social care services; referrals could come from organisations or by self-referral. The project has three key aims:

- Increase knowledge of existing rights and entitlements under SDS, human rights and equalities legislation.
- Increase third sector capacity to scrutinise and challenge local authority decision making.
- Increase links between the third sector and the legal profession.

Jennifer explained that whilst MECOPP could take on casework, it did not give legal advice or take on litigation but could be advised on the legal framework supporting the Act.

The project developed resources primarily aimed at people delivering support and advocacy, but Jennifer explained she was in the process of developing resources for carers and families, which would be added to MECOPP's website in due course.

As part of the work, MECOPP had held awareness raising and free training sessions in 2017, which they would repeat in 2018. The training was primarily aimed at professional delivering advocacy and support role, incorporating three days of training. The next session would take place in September 2018 in Inverness.

One year into the project, Jennifer noted that themes around a lack of transparency in decision making, poor communication, delays in assessments and allocation of resources SDS, as well as a lack of accessible information, were emergent themes which were barriers to people having a good experience of SDS. The complications of accessing SDS and the interaction with Adults with Incapacity legislation were also noted.

Jennifer explained that year two of the project would build on this work through continuation of awareness raising and training events, seeking to establish the reason for low rates of referral and further partnership working with the third sector.

Presentation Question and Answer

A question and answer session followed, which included:

- Discussion about some of the issues around SDS, including how some may be specific to people with dementia, whilst others may be broadly applicable to older people.
- Both professionals and carers commending the work of MECOPP, both for the resources created and for building an evidence base about the need for better implementation of the legislation to improve people's experiences.
- A number of carers sharing their poor experiences of trying to access SDS which had resulted in inconsistent, disjointed and poor-quality care.

- Discussions about the accessibility of information and resources, with one carer sharing they had found MECOPPs resources incredibly helpful. Another member asked about the accessibility of the resources for the deaf community, with Jennifer indicated she would follow up on.
- Brief examination of the interaction between the Carers (Scotland) Act 2016 and SDS legislation, particularly in relation to carers accessing support for themselves.
- Discussion about how to eliminate variation in implementation of SDS between areas, with different ways of ensuring compliance discussed, including punitive measures and improvement work based on the Audit Scotland report from 2017.

4. Care Inspectorate – My Life, My Care Home Report Presentation

Heather Edwards, AHP Consultant with the Care Inspectorate presented on the regulator's 'My Life, My Care Home' report which focused on the dementia-specific themed inspections of 150 care homes in Scotland. Heather gave a background to the report, including some of the resources and methods used in the inspection process, including the Dementia Standards from 2011 which were mapped against the Care Inspectorate's standard four quality themes.

Heather highlighted the 2009 'Remember I'm Still Me' report by the (then) Care Commission and the Mental Welfare Commission which had indicated poor practice in a number of areas related to the care and support of people with dementia. Although many positives were seen in the 2017 report, demonstrating that progress had been made, it was evident that much work remained to be done to improve care and support.

It was shown that there was a mixed picture of around person-centred support and care plans – whilst work was being done to collect personal information about what matters to the person, it was not always evident this was being used. Although the numbers of care homes in which a diagnosis of dementia was made in the past year were relatively low, less than half of people received the year of PDS to which they were entitled.

In relation to care, support and healthcare, there was a positive shift, especially around the use of non-pharmacological interventions as a first response to stress and distressed behaviour. In addition, many care homes were proactively looking to do more around oral health, linking in with local caring for smiles teams. However, it was noted that in many cases, incontinence was still 'managed' rather than prevented.

However, Heather noted that connections to communities and the importance of activities were still not being universally embraced beyond a timed/fixed element of care. Furthermore, risk aversion continued to prevent access to secure gardens or allowing residents to undertake activities alone.

Heather explained that 97% of inspected care homes had some level of training and development in relation to dementia which considered as excellent progress although the Promoting Excellence Framework was not always being used. In addition, training did not always translate to practice. Only where staff understood the ethos of the care home were outcomes consistently better across the board.

Finally, Heather spoke about the need to challenged expectations of what care homes should be, noting that at present moving a person into care home can be seen as a measure of last resort or as a reflection on the carers. Care homes should be seen as a positive choice which can improve the person's experience in relation to continence, isolation etc.

Presentation Question and Answer

A question and answer session followed, which included:

- Discussion about elements of care and support which are not regulated by bodies such as the Care Inspectorate or the Scottish Social Services Council, e.g. Personal Assistants, which can make accessing training for these staff difficult.
- Explanation of Care Inspectorate involving people with lived experience in the inspections; Heather noted this had resonated with many of the staff in care homes.
- A number of carers shared their experiences of poor services, both care homes and non-residential services. This included disjointed care, unsuitable services (either due to age or unavailability because of cost) and particularly in relation to care transitions and respite services, which often were the result of delays in the system.
- Discussion about the specialist and nuanced training needed for staff, as well as an inconsistency of specialist services, including for people with early onset dementia, learning disabilities and end of life. As part of this, Heather noted the need to look at different models of care.
- General agreement that there needed to be a re-examination of how care homes were seen as part of the care mix; it was felt that it was not simply about how good care homes were in practice but rather about how they are used and offered to families as part of a package of care.

5. Open Discussion

The discussion was opened up to members to discuss any issues of importance to them. Conversations covered a broad range of issues, including:

- Agreement that that whilst significant improvements had taken place since 2009, there was risk of progress being lost, particularly in light of high turnover rates of staff – there is a low value placed on staff, with the low wages, stressful conditions and emotionally draining nature of the work not recognised.
- One carer sharing their experience whereby they were unable to keep their spouse at home at the end of life. Policies such as SDS which should have provided greater choice and control had the opposite intended effect, diminishing their choice.
- Acknowledgement that SDS would be one of the areas that the joint Strategic Inspections between the Care Inspectorate and Healthcare Improvement Scotland would examine as part of the next round of inspections.

- Highlighting the number of carers in the Scotland, as well as the limited financial support provided, especially with the complex interactions of SDS, pensions and POA which creates financial strain for carers.
- Carers sharing their experience of the gap between policy and practice, as well as a lack of bereavement services available for former carers, with little financial, emotional or practical support available.

6. AOCB

Owen shared that the group has had a number of requests to present, including:

- Scottish Dementia Working Group.
- University of Edinburgh PhD student wishing to present on findings from an event exploring the future of dementia research in Scotland.
- A Scam Prevention Project in East Renfrewshire.
- The Scottish Government on a forthcoming report into Specialist Dementia Units.
- The Mental Welfare Commission wished to present on its recent report on dementia in community hospitals.

The group indicated it would like to hear from all of those who had requested to present, spread over a couple of meetings, with no preference as to the order.

Owen announced this would be his last as Secretariat to the group as he would be leaving Alzheimer Scotland to take up a position with Alzheimer Europe. He thanked members of the group for their support and attendance at meetings of the group over the years, noting that the contributions made the group a valuable and useful platform. It was noted that Alzheimer Scotland would continue to provide the Secretariat.

7. Close and Date of Next Meeting

The next meeting will take place on Tuesday 19th September 2018 in Committee Room 6. The secretariat will issue papers closer to the event.