

**Joint meeting of the Cross Party Group on Dementia**  
**Minutes of the meeting**  
**23<sup>rd</sup> January 2018 – 5.30pm-7.30pm**  
**Committee Room 4, Scottish Parliament Building, Edinburgh EH99 1SP**

**Present:**

MSPs

Richard Lyle MSP, Finlay Carson MSP and Bill Bowman MSP (for the election of office bearers only).

Organisations

Alzheimer Scotland (Jim Pearson, Elaine Hunter and Owen Miller), SDWG (Archie Noone and Caroline Church), NDCAN (Jane Hasler), The Alliance (Tommy Whitelaw, Irene Oldfather, Matthew Hilferty), TIDE (Ray Fallan, Beau Nieuwenhuis), DEEP (Paul Thomas), Age Scotland (Martyn Walker), Alzheimer Scotland Centre for Policy and Practice -UWS (Margaret Brown), Scottish Government (David Berry and Karen Geekie), Royal College of Speech and Language Therapists (Rebecca Kellet), Church of Scotland Presbytery of Stirling (Bonnie McDowell), Scottish Dementia Research Consortium (Craig Ritchie and Charlotte Clarke), Outside the Box (Outside the Box), Royal College of Occupational Therapy (Alison Keir) and MECOPP (Jennifer Paton).

Individuals

Natasha Hamilton (Carer), Patricia Seawright, Mary Seawright, Jordan Linden and Brian Wheat.

**1. Welcome and apologies**

Richard Lyle MSP welcomed everyone to the meeting and ran through the order of business, noting that there had been a change to accommodate the presenters and to ensure the meeting was quorate for the office bearer election.

The following apologies were received: Colin Smyth MSP, Bob Doris MSP, Donald MacAskill, Heather Edwards, Hilary Pipiette, Karen Watchman, Christine Steel, Helen Skinner, Agnes Houston, Donna Houston, Tilda McCrimmon, Margaret Beggs, Fiona Kelly, Sue Northrop, Michelle Miller, Ruth Mantle, Anne Buchannan, James McKillop, Maureen McKillop and Peter Gordon.

**2. Approval of Minutes**

The group approved the minutes, with any corrections directed to the secretariat.

### **3. Dementia Carers Voices presentation**

Irene Oldfather and Tommy Whitelaw presented on some of the work undertaken by the Alliance through the Dementia Carers Voices project over the past year.

Irene provided a timeline of the progress in recent years, including the establishment of the previous Cross-Party Group on Alzheimer's, the publication of the Charter of Rights by the group and the Scottish Government's publication of the National Dementia Strategies. As part of this, the underpinning of this work by the rights-based approach using the PANEL (Participation, Accountability, Non-discrimination and equality, Empowerment and Legality) was highlighted. The recent report from the Care Inspectorate was highlighted as a demonstration that whilst progress had been made, there was much still to do.

Tommy Whitelaw highlighted the work of Dementia Carers Voices as part of the 'You Can Make a Difference' campaign, giving an overview of the 17,000 pledges made by health and social care professionals and students across Scotland, with the aim of improving the experiences of people with dementia and their carers. Around a third of the pledges had been analysed to examine the content of the pledges, with care and compassion the most common theme, with other themes around time and listening to the person also common. In addition, Tommy shared some of the barriers to high quality care, which had emerged throughout the analysis of the pledges. These included the lack of time-pressures faced by many staff, the confidence and skills of staff to be deliver change and the competing pressures in ward environments.

### **4. AGM and Re-election of office bearers**

This item was taken as soon as the meeting became quorate. The group was advised that the AGM need to take place to elect office bearers and that an Annual Return needed to be submitted by the convenor within 30 days of the AGM taking place.

Richard Lyle MSP resigned the chair of the meeting for the election of the Convenor of the meeting. Owen Miller chaired, nominating Richard Lyle MSP as convenor, seconded by Finlay Carson MSP. Members agreed to Richard Lyle MSP as convenor, who then resumed as chair of the meeting.

Finlay Carson MSP and Colin Smyth MSP both had indicated to the secretariat their willingness to put themselves forward again for as co vice-convenors. Richard Lyle MSP nominated each both members, seconded by Bill Bowman MSP. Members agreed to both members continuing as joint co-convenors (Colin Smyth MSP in absentia).

Alzheimer Scotland had indicated willingness to continue as secretariat to the CPG. Richard Lyle MSP nominated Alzheimer Scotland to continue, seconded by Finlay Carson MSP. Members agreed to Alzheimer Scotland continuing as secretariat.

## **5. Dementia Empowerment and Engagement Project (DEEP) presentation**

Paul Thomas of DEEP noted he had intended to present with people with dementia who had been involved in the project but that had been unable to attend on the evening.

Paul provided a brief overview DEEP as a network of organisations across the UK, with his remit taking in the North of England, Scotland and Northern Ireland. He explained that DEEP as a network had 20 groups within Scotland and 100 in the UK, within different contexts and settings, with the network aiming to provide a platform to discuss and campaign on a range of different matters, reflecting the views of people with dementia.

The presentation focused on three Scottish Gatherings which had taken place in Hawick, Inverness and Edinburgh prior to the publication of the third National Dementia Strategy in June 2017, which sought to examine the priorities of people with dementia. Paul read out a number of quotes taken from the events, in which people described their lived experience and what their priorities were. This included 12 priority themes which had been developed with people with dementia, which were compared with the commitments in the National Dementia Strategy (2017-20), with a strong message emerging of the need to see the 'social' aspect of dementia. A broad range of themes were covered, including the importance of a human rights based approach to improving the lives of people with dementia, too great a focus within the strategy on clinical or strategic pieces of work and no mention of capacity and decision making (and related legal matters), with a total of 13 key themes identified. Paul noted that DEEP intended to hold more of these events in 2018.

## **6. Open Discussion Led by People With Dementia and Carers**

An open discussion took place amongst the group, with members having the opportunity to ask questions of the presenters but also to share their own experiences or views. The discussions covered a number of areas including:

- How society could do more to challenge the stigma attached to dementia, including how lonely and isolating the condition was for both carers and carers. Members discussed the need for both to be seen as active participants within their communities. It was highlighted that the Scottish Government's Social Isolation Strategy would be out for consultation and there was potential for a dementia-themed engagement.
- A number of carers and members spoke about the loneliness and isolation in their caring role and feeling that they often felt that there was not a platform available to share their negative experiences. It was also noted that people with the most difficult experiences were sometimes the most difficult to reach – more needed to be done to ensure their voices were heard as the negative stories were important in driving changes within the system.
- A carer shared their ongoing experience in the insufficient and disjointed nature of support, which had led to their spouse not receiving the care in the place they would have wanted at the end of life. The carer described a power imbalance in trying to access support, having fought the council for two years, also sharing their feeling of frustrations and anger at having been unable to ensure their spouse had their wishes respected.

- Representatives of the Scottish Government and MECOPP who had responsibility for Self-Directed Support offered to follow-up with the carer.
- There was broad agreement from members about the importance of rights being at the centre of care for people with dementia and their carers, and how by taking this approach, the crisis points and challenges described in the presentations and by carers could more often be avoided.
- Another carer shared their perspective, noting some of the challenges associated with early-onset dementia, including getting a diagnosis. In addition, they described how the challenges in communicating with a person with dementia were often a barrier to providing appropriate care and support. The carer noted that they were fortunate that within their family were familiar with the system, but felt it was often the case that dementia itself was dismissed or not given significant priority.
- The group discussed the lack of a robust complaints process within Local Authorities or the NHS complaints processes which can deliver accountability, and quick and effective resolutions for people who do not receive a high quality support. It was noted that there are different ways to do this emerging, such as Care Opinion. Members agreed that often by the time a matter reaches a complaints process, the relationship and trust between the organisation and the person, their family or carer, has broken down.

## **7. AOCB**

Jennifer Paton of MECOPP highlighted that she had been in touch with the secretariat about the possibility of presenting at the next meeting on their 3Rs Project (Rights, Respect, Responsibility) at the next meeting. Richard Lyle MSP indicated that they would look to include this as an item for the next agenda.

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

The next meeting will take place on 21<sup>st</sup> March 2018 and will be a joint meeting with the Scotland's Future's Forum. The secretariat will send out meeting invites in due course.