

Cross-Party Group on Dementia
Minutes of the meeting
14th October 2020 – 6-8pm
Microsoft Teams

Present:

MSPs

Richard Lyle MSP (Chair) Colin Smyth (Co-Convener)

Secretariat

Alzheimer Scotland (Carleen Smith)

Organisations

Alzheimer Scotland (Jim Pearson, Katharyn Barnett), Royal College of Occupational Therapists (Claire McFadyen, Alison Keir), Alzheimer Scotland National Allied Health Professionals (Elaine Hunter, Alison McKean, Ashleigh Gray, Fiona McLean), Royal College of Speech and Language Therapists (Rebecca Kellett), NHS Healthcare Improvement Scotland (Lynn Flannigan), Dementia UK (Bob Cochrane), Scottish Association of Social Work (Karin Heber), Alzheimer Scotland Centre for Policy and Practice (Debbie Tolson, Margaret Brown), Scottish Government (David Berry, Suzanne Kinross, Linsey Oughton, Jan Beattie, Hugh Masters), Life Changes Trust (Andrena Coburn), Alzheimer Scotland Dementia Nurse Consultant (Helen Skinner, Tilda McCrimmon), Fife Council (Ailsa Dow, Morag Gilchrist, Karen Whyte), NHS Fife (Alan White), Queen Margaret University (Brendan McCormack, Fiona Kelly), Mental Welfare Commission (David Hall), Stirling University (Karen Watchman), British Deaf Association (Avril Hepner), About Dementia (Michael McMahan)

Individuals

Ray Fallan, Natasha Hamilton, James McKillop, Alison Leitch, Maureen McKillop, Anne Bisset, Gill Wood, Janice Murdoch, Laura Irvine, Sarah McCullough, Lyn Mathieson, Tommy Whitelaw, Jane Douglas, Helen McLellan, Susan Ross, Evelyn Fitzpatrick, Kathryn Irvine, Jaqueline Campbell

1. Welcome and apologies

Meeting opened by Colin Smyth MSP.

The following apologies were received: Finlay Carson MSP (Co-Vice Convener), Archie Noone, Daniel Lafferty, Christine Proudfoot, Ann Connor, Marc Buchanan, Margaret Ann Beggs

2. Approval of Minutes

The group approved the minutes without any corrections directed to the secretariat.

3. Royal College of Occupational Therapists

Alison Keir introduced the presentation. Gave an overview of who Allied Health Professionals (AHPs) are and what they do. Occupational Therapists (OT) work with all ages across NHS and social care, third sector and another range of settings to return to everyday activities.

The current campaign is on the right to rehabilitation, no matter what condition, and to promote equal rights to rehabilitation for every person living with dementia. This includes rehab for supporting people with dementia during Covid.

Alison then discussed what rehab looks like for people with dementia, helping them stay at home for longer. Treating carers as equal partners. Working together between professionals and people with dementia get the best outcomes. This forms part of a tiered approach of rehab for people with dementia.

Alison introduced colleagues who provided an overview of their work.

- Clare McFadyen, Clinical Specialist, gave information on rehabilitation in an acute setting. They check for cognition and signs of delirium, suggest adaptations to home environment to support their return, encouraging self-management approaches, recommend packages of care.
- Alison McKean, Occupational Therapy Home Based Rehabilitation
- Ashleigh Gray presented on journeying through dementia. Aims to support people in the earlier stages of dementia. It is a personalised approach, with 22 themes available.
- Alison Keir then discussed a case study of stair lift assessments in the Fife HSCP

Alison emphasised the need to share the importance of rehabilitation for people with dementia. Alison then shared key asks with the group including letter writing and promoting rehabilitation with decision makers. Group agreed to take this forward, look at questions or motions for parliament, and write a letter to the Cabinet Secretary.

Questions & Answer

- The point was raised that it is potentially discriminatory to deny people with dementia rehab equipment. People with dementia are being denied rehab equipment after discharge from hospital into care homes, and rehab is being stopped. RCOT are aware that these issues exist and acknowledge timely rehab

produces the best outcomes. They advocate right to timely rehabilitation for everyone, as part of the Right to Rehab coalition.

- Despite the evidence of the importance of timely rehab- the issue of waiting times has increased due to COVID. The argument was made regarding cost efficiency and savings of timely rehab.
- Has the fact COVID discharged people from hospital changed how need to ensure people have rehab is fulfilled? Wherever a person with dementia is discharged to, they still have a right to rehab.
- Has the lockdown, and the changing needs of people with dementia that this has caused, changed how their needs are assessed? Have their needs changed? People clearly and understandably did not want people such as OTs in their homes at the start of lockdown. This emphasises making sure there is high-quality evidence based self-management. Information is important as is being creative according to people's situations.
- What is the experience of rehabilitation on people with dementia who now have had COVID. Now that we understand the longer-term implications of COVID, it reiterates the importance of rehab for this group.
- It is important that people have access to rehab and OT services, that has a role as part of post-diagnostic support. Sharing evidence of the benefits of this early on in diagnosis. Members would like to see more preventative, anticipatory interventions from all of the AHP professions, as currently referrals often only are made after a crisis
- A member quoted that around 82% people living with dementia have reported a deterioration in their symptoms due to lockdown - both physical and cognitive. The lack of physical and social opportunities is a massive issue. People living with dementia are losing abilities which were present prior to lockdown.
- It was asked if care homes should be included in the right to rehab campaign. Members would like to see AHPs in care homes. Has there been an opportunity to train care home staff, or informal carers to deliver these services? Another member stated that they are aware some care homes do have this but is something that we need to try and find funding for. Sometimes you do need specialist support from an OT, but as part of the universal strategy. There is a lot of opportunity for formal and informal carers to gain confidence to provide interventions. It is better to help people do things for themselves, that do it for them.

4. Open Discussion – Introduced by Colin Smyth MSP

The meeting then moved to a discussion where people with dementia and their carers could share their experiences of COVID and how lockdown restrictions have affected them. The following points were raised:

- A carer described feeling alone, because carers are not included to form support bubbles with other families. Members did agree that often the needs of carers are forgotten about.

- Carers are finding it difficult as they are getting no respite from their caring role, particularly now that they are not able to spend as much time outside. Carers do not know where to turn.
- Regarding care home visits for family and carers, members acknowledged that at a government level, quick decisions had to be made to prevent infection spread. It is understood why care homes are frightened about allowing visits. However, there is agreement that it cannot continue like this. We need to learn how to support carers to visit their families in care homes. We need to find a way to manage visits safely. A member raised that it is peoples' right to have visitors.
- There is frustration that despite recent updates to guidance, care homes are free to set their own guidance still do not feel confident to have indoor visitors
- The government understand get that guidance is one thing and implementation is another and are working to ensure this happens. Need to balance risk of COVID with wellbeing of people in care homes in families. Government are listening and the Cabinet Secretary is engaging with carers groups. Everything is being talked about regarding testing, and quick testing are being looked at. Reminder that essential visiting is still allowed, and this category is being expanded.
- There was reassurance that government are aware of the issues being faced, but it is difficult to find solutions. Not everyone involved in making decisions about people in care homes are doing so from a clinical perspective and are working on the balance between maximising human rights and keeping people safe from COVID.
- There is frustration that carers feel powerless and like they do not have a voice. There needs to be an opportunity for family members and carers to have their voices heard. Government looks to consult with care home providers on a regular basis and it is at the heart of what they do. However, it can be difficult to find groups that represent residents of care homes. There is a difference between family's perspectives and resident's perspectives and these need to be balanced.

AOB & Date of next meeting

The date of the next Cross Party Group meeting is to be decided and will be circulated to group members as soon as possible.