

Cross-Party Group on Dementia
Minutes of the meeting
30th July 2020 – 6-8pm
Microsoft Teams

Present:

MSPs

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

Secretariat

Alzheimer Scotland (Carleen Smith)

Organisations

Alzheimer Scotland (Jim Pearson, Marri Welsh, Marc Buchanan), Alzheimer Scotland Centre for Policy and Practice (Debbie Tolson, Margaret Brown), Scottish Government (David Berry, Suzanne Kinross, Linsey Oughton, Fiona Hodgkiss), Life Changes Trust (Arlene Crockett, Andrena Coburn), The ALLIANCE (Raveena Sajjan), DEEP (Karen Taylor, Ron Coleman), Alzheimer Scotland National Allied Health Professions Consultant (Elaine Hunter), Alzheimer Scotland Dementia Nurse Consultant (Helen Skinner, Tilda McCrimmon), Scottish Dementia Working Group (Archie Noone), Royal College of Speech and Language Therapists (Rebecca Kellett), Care Inspectorate (Angella Fulton, Gareth Hammond), Dementia UK (Bob Cochrane), Royal College of Occupational Therapists (Claire McFadyen), Shared Lives Plus (Ben Hall), Life Story Network/ TIDE (Amanda McCarren), Scottish Association of Social Work (Karin Heber), Royal College of Occupational Therapists (Alison Keir)

Individuals

Ray Fallan, Natasha Hamilton, James McKillop, Jane Douglas, Alison Leitch, Lyn Mathieson

1. Welcome and apologies

Meeting opened by Richard Lyle MSP.

The following apologies were received: Finlay Carson MSP (Co-Vice Convenor), Susanne Forrest, Christine Proudfoot, Hilary Davidson, Carole Hargreaves, Andy Shewan, Agnes Houston

2. Approval of Minutes

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

3. Launch of COVID-19 Learning Report- Life Changes Trust

Arlene Crockett introduced the COVID-19 Learning Report to group. This report has not been launched yet, and this presentation is a preview for the CPG. It goes along with flash reports that the Life Changes Trust have produced, dedicated to the community response to COVID-19 available on the Life Changes Trust website.

Arlene provided an overview of the Life Changes Trust, then introduced Andrena Coburn, the author of report, who discussed its findings. The report explored the specific experiences of people with dementia and carers, and how they have responded.

The report features key learning that has emerged from discussions of what people with dementia are their carers need now the country is transitioning out of lockdown. Examples of how temporary closure of services impact people with dementia include loss of connection, peer support, routine, and fear of or actual loss of mobility and cognitive decline. These include:

- Lockdown has also created additional caring responsibilities for unpaid carers, increasing anxiety and making carers feel overwhelmed. This has had a significant impact on their mental health and wellbeing. COVID has also created a fear of leaving their loved one if they need hospital treatment.
- Delays in receiving a diagnosis and PDS.
- The report also highlights the anxieties faced by people with dementia regarding the withdrawal or reduction of social care services, and SDS budgets.
- The report also highlights the anxiety over care homes. There are also human rights concerns of people with dementia in care homes.
- Shielding and voluntary self-isolation, and the fact the high-risk category, who are not in the shielding category, are not receiving the same support. There is a fear among this group of going into public again.

The report then provides many examples of how Life Changes Trust and their services have adapted in light of COVID. Finally, Life Changes Trust report gives recommendations of what they think needs to be done to further support people with dementia and their carers.

Online discussion sessions will be held at the end of August about the report. Those within funded projects have been invited. Life Changes Trust extended invitation to those in the group if they wish to be included.

Question and answer

- Attendees from other organisations echoed the findings of the report from their own research. People with dementia and carers shared their own experiences.

- One member asked how many people with dementia were consulted in the report. Life Changes Trust responded that those included in the report were from funded projects and stakeholders who work with people with dementia and did not speak to people with dementia directly.
- Another member referenced human rights in this report, and their view that COVID restrictions have violated the human rights of people with dementia in care homes.

4. Open Discussion – Introduced by Richard Lyle 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:

- If there is a second wave of COVID, it cannot be the same as the first. People with dementia and carers are disproportionately affected by the restrictions, their cognitive decline has accelerated since day services been stopped.
- There is a need for people with dementia and carers to continue to access rehabilitation throughout COVID restrictions.
- Members who are carers raised concerns regarding telephone conversations between social work and people with dementia to reassess their care needs, without asking about Power of Attorneys or consulting family members. Other members raised the same issue of GPs contacting people with dementia around DNACPR. It was felt there is a sense of urgency to put plans in place to free up resources, without considering a different approach for people with dementia.
- People with dementia are feeling isolated in the community. For example, wearing masks may cause communication issues for people with dementia and has caused undue distress. A representative from the Scottish Dementia Working Group raised that in these instances, exemption forms can be accessed where necessary. It was acknowledged the importance to strike a balance between managing distress but also keeping safe and the need to balance risks.

The majority of the discussion in this part on the meeting focussed on family members being unable to visit their loved ones in care homes, except in end of life. The following points were raised regarding this:

- Care homes have often not been able to facilitate essential visitors, when guidelines have stated this is possible. Carers stressed that they should be equal partners in care, they can provide help care for and comfort their family members, helping avoid stress and distress, and by doing do to be of great assistance to care home staff.
- Some members are unhappy about what they described as a U-turn on indoor visits to care homes in that the Government have apparently changed their mind on the timescale for allowing indoor visits.
- There is a lack of clear communication from Scottish Government about visiting and a lack of consistency across Scotland.

- National guidance reflecting the balancing of risks of isolation and COVID with recognition that there may be an associated increase in COVID. Others raised the point that care home staff are as likely to take COVID into a care home than a family member.
- There is a substantial risk to the person with dementia because they are not getting visits, i.e. physical, emotional health. It was felt by some members that these risks do not seem to be seen as relevant as the risk of COVID.
- Many members felt it was important to asking carers what they want regarding care home visits, but the point was also raised that not everyone is going to agree. Risk assessments are very important.
- There needs to be a greater relationship between care homes and acute care, older people have more complex needs than ever, and it is not the responsibility of the private sector to solve. These are health care issues, not a social care issue.
- Professor Debbie Tolson from the University of the West of Scotland discussed her research on care home COVID rapid response. The Chief Scientist Office has funded a rapid study to investigate psychological impact and experiences of care home lock down on family carers, Debbie invited members to get in touch if they would like to contribute to this research.

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.