

Cross-Party Group on Dementia

Minutes of the meeting

14th November 2018 – 5:45pm-7:45pm

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

Present:

MSPs

Richard Lyle MSP (Chair) and Finlay Carson MSP.

Organisations

Age Scotland (Jim Eadie), Alzheimer Scotland (David Beyt, Grant Mackin, Jim Pearson), Angus Care & Repair (Judith Leslie), British Deaf Association Scotland (Lucy Clark), Chartered Institute of Housing (Callum Chomzcuk), Crossreach – Heart for Art (Laura MacLeod), DEEP (Agnes Houston, Paul Thomas), Dementia UK (Bob Cochrane) Life Changes Trust (Arlene Crockett), MECOPP (Jennifer Paton), Presbytery of Stirling (Bonnie McDowell), Scam Prevention – East Renfrewshire Council (Paul Holland), Scottish Dementia Working Group (Rachael McMurchy, Archie Noone), Scottish Government (David Berry, Linsey Oughton), Royal College of Speech & Language Therapists (Rebecca Kellett), TIDE (Lorraine Bairstow, Natasha Hamilton, Beau Nieuwenhuijs), University of the West of Scotland (Margaret Brown)

Individuals

Amanda Britain

1. Welcome and apologies

The following apologies were received: Jackie Baillie MSP, Anna Buchanan, Margaret Ann Beggs, Lilian Davidson, Jane Douglas, Heather Edwards, Alison Keir, James McKillop, Alison Murray, Katherine Ross, Andrew Senew, Helen Skinner, Karen Watchman

2. Approval of Minutes

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

3. University of the West of Scotland – “Being Home” Housing and Dementia in Scotland

Margaret Brown, Senior Lecturer and Depute Director at the University of the West of Scotland, presented on her report, “Being Home,” which provides an overview of housing for people with dementia in Scotland, including the existing range of housing services,

support and options, and some potential solutions. The report was commissioned by the Life Changes Trust and Angus Care and Repair.

Published last year, the report is a combination of desktop literature review and focus groups with housing specialists and practitioners as well as people with dementia and carers. Key findings of the report include:

- Planning guidance and policies focus on care rather than housing and environment despite emphasis on supporting people to remain independent at home for as long as possible.
- Distinct and independent policies and guidance exist in Scotland, but they are not sufficiently tied together into a cohesive strategy for support.
- There is a lack of accessible information to enable people with dementia to make informed choices about their home environment.
- 73% of older people live in owner occupied housing, and much of this is in an advanced state of disrepair. This means, whilst social housing is useful, it misses the majority of older people. Dementia specific housing is similarly good but very rare.
- Health and social care integration present an opportunity to improve housing and adaptations for people with dementia as Strategic Commissioning Plans must include a Housing Contribution Statement.
- Given the current lack of suitable housing supply, it is important to consider how to adapt existing housing stock to meet the needs of people with dementia, across all tenures.
- People must be connected to housing supports and adaptations at the earliest opportunity, even prior to diagnosis.

Margaret's key message was that, as a community, we are not ready. People must take personal responsibility and decide what we each need to do to prepare our home environment for later life. Currently, most people don't know what they will need from home environment. They need to take early action and make changes before it is too late to manage and cope with those changes. Currently, there is not enough information to make informed decisions and not enough support to help people make them.

As there is not enough new or purpose built housing for older people, it is important to adapt and retrofit houses. This is made more problematic by the fact that nearly half of older people housing is in an advanced state of disrepair. People need support to plan ahead, make choices and carry them out.

There is a dearth of suitable accommodation to meet diverse needs of people with dementia. Very little info out there. Policy isn't cohesive or coordinated. Innovations aren't being spread widely enough and adaptations and tech needs to start earlier that continually adapts to people's changing needs.

Key recommendations from the report: "5 E's"

- Early information and accessible support are essential.
- Easy guidance.
- Extend good practice.

- Expand options and quality housing as retrofitting existing homes doesn't always work.
- Educate people.

The full report can be found here:

<https://www.lifechangestrust.org.uk/sites/default/files/publications/Being%20Home%20-%20Full%20Report.pdf>

There is also a summary report, which can be found here:

https://www.uws.ac.uk/media/4048/uws609025_housing-dementia-scotland-signed-off-brochure_12pt-type_v4.pdf

Action: The secretariat to inquire about putting the report on the CPG's webpage.

Finally, as part of this work, a prototype online resource was designed with the intention of showing an example of a 'One Stop Shop'. This would be envisaged as an information portal providing a wide range of information that is currently only available piecemeal along with provisions for a discussion forum to enhance opportunities for peer support.

The prototype online resource can be found here: <https://bregroup.com/dip/>

Presentation Question and Answer

A question and answer session followed, which included:

- People with dementia from diverse backgrounds. The authors of this paper tried to gather their views as part of this paper but were surprised by the lack of response.
- Attendees commented on the fact that all new builds must be wheelchair accessible, yet there isn't a similar requirement that all new housing should be dementia friendly.
- The extent to which responsibility for appropriate housing extends beyond the housing sector, that there is a level of responsibility for many stakeholders. It is not one person's role.
- Early onset dementia was brought up and the extent to which age acts as a barrier to accessing care. This was highlighted by the fact that the Margaret was unable to get data for under 65's for this report.
- Scams prevention and preventing people with dementia from being targeted on their doorstep. Attendees discussed the need to look at adaptations to the doorstep, but need to do something about the doorstep. Angus Care and Repair developed a doorstopper button. Paul Holland of Scam Prevention – East Renfrewshire Council is scheduled to speak at the April meeting of the CPG.
- In the new year LCT will host a seminar on this report and the evaluation. Details will be publicised at a later date, however the convenor offered to host the launch at Parliament. **Action:** Life Changes Trust to speak to the secretariat about booking a venue.

Action: The CPG attendees unanimously agreed to send the “Being Home” report to Scottish government and the 32 local authorities to ask for their comments.

Scottish Government dementia team would be interested in reading the report and tabling it at an upcoming meeting of the Dementia Strategy’s National Implementation and Monitoring Group. Scottish Government support local authorities to estimate future housing needs for people with dementia. In particular, they project incidence for dementia in each Integration Joint Board area, which could help with determining future council housing need.

4. Dementia Enablement Pilot Project – Care and Repair

Judith Leslie of Angus Care and Repair (ACR) presented on the organisation’s dementia enablement project. The programme works in Angus, Aberdeen, Lochaber and Lochalsh and Skye to improve, adapt and personalise the home environment for people living with Dementia. The programme fits equipment such as door locks, coloured rails/grab rails, daylight bulbs for increased lighting levels, dementia friendly clocks, level thresholds, privacy locks for the bathroom (which can be opened in an emergency), coloured toilet seats that provide a visible contrast, wall planners with stickers for activities, and highlight paint to make steps more visible.

Judith explained that Care and Repair started in 1980’s, and in 1998, Angus became the first independent Care and Repair in Scotland. They began providing major adaptations, then received funding for smaller adaptations followed by security services, home safety and solutions for people returning home from hospital discharge. Most of these services were originally to support people with physical disabilities though. The organisation became involved in supporting people with dementia later through both work and the family experiences of employees.

Judith reiterated Margaret Brown’s earlier point that people with dementia need more practical home improvement options at very early stages. Life Changes Trust agreed with this strategy so they worked with ACR to start service for individuals in early stage of dementia – before, during or after diagnosis. In this programme, diagnosis trained officers go into a home and look at environmental conditions. They take a person-centred focus, also looking at social factors. They work with carers if there is one and support with any equipment that might help with the living situation.

Judith also agreed with the previous presentation that people receiving the service often say they don’t need any support but will open up in conversation and be happy with services by the time it is over. Judith said they will often refer to the visit as a home safety check rather than a dementia check as people are more open to ‘home safety.’

65-73% of people ACR supports (depending on the area) live in their own house, and 73% older households never have a safety check. A personalised assessment of injury hazards in the home followed by a systematic removal of these hazards, adding grab rails in and

around the shower and toilet, adding hand rails on both sides of stairways and improving home lighting reduced the rate of falls by 19%.

The largest group of referrals is for people aged 80-84, though in Lochalsh and Skye they are older. The service receives the majority of its referrals through Link Workers, self or friend referrals and the wider Care and Repair services. In terms of the types of dementia that people who receive the service have, Alzheimers was higher than vascular everywhere but Aberdeen. In Skye, the found a majority had an unknown or unspecified dementia diagnosis as people are less willing to speak about dementia there. For this reason, ACR call their visits a safety check rather than a dementia check.

Judith said funding for third sector services in general, and ACR in particular, is a real problem. They have experienced funding cuts to the majority of the Care and Repair services mentioned at the beginning of the presentation. The service spends an average of 5.5 hours with each client at a total cost per case of £505. She compared this with the cost of a hip fracture (£16,302), a week in residential accommodation (£1,500) and one week in dementia care support (£800). She pointed that this service fills the same need as fire and rescue providing four officers and a truck for a safety check or social work conducting an assessment for a grab rail. In a time when local areas are reducing preventative services because of money pressures, there is greater cost effectiveness of third sector preventative services.

As part of this project, they built an online tool to enable people receiving the service to get information and leave comments to support each other.

The work has been heavily evaluated and ACR hope to roll it out across Scotland.

Presentation Question and Answer

A question and answer session followed, which included:

- The relationship between Health and Social Care Partnerships and third sector organisations, and the extent to which HSCPs support the third sector to provide preventative services. Attendees also discussed the role of Third Sector Interfaces (TSI) in facilitating and coordinating these relationships. TSI's have a seat on Integration Joint Boards in order to represent the third sector, however they do not have a vote. Not everyone present felt they represent all organisations equally nor have a great deal of power/influence.
- LCT just completed a tendering process for a Dementia Policy and Practice Forum, the winner of which will be announced in the coming week. The focus of this Forum will be to bring together grassroots organisations to look at good practice and how to influence local decision makers and give local people a voice.
- Scottish Government said they are looking at how integration is working at an IJB level. They also mentioned that, in addition to supporting TSI's to represent grassroots organisations, they also support Alzheimer Scotland to support local people to have a voice.

- Alzheimer Scotland mentioned that they also fund a great deal of their local engagement work themselves as they have made a choice to support local community voice and a proactive approach to connecting with councillors and elected representatives.
- The autonomy of local areas and councils were discussed and the role of Audit Scotland and auditors in the council play in overseeing local expenditure.

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:

- The group discussed the need for councils to advertise grants and services so people know what supports they are entitled to. Raising awareness of services such as ACR is essential so that people can be referred to them in a timely fashion for early intervention. People with dementia and their carers often don't have the time or energy for that kind of forethought. Judith mentioned that ACR is IJB-funded, and the group discussed the advantages and disadvantages of ringfencing Scottish Government funding for such services.
- There was agreement that, at a future meeting, the group should discuss what overall offer and support councils should have for people with dementia. The group should consider what ask it has for councils.
- The group discussed the home environment in the context of the 5 and 8 Pillars Models of Dementia Support as well as the commitment in the National Dementia Strategy for early consideration of adaptations. Scottish Government mentioned that PDS can now be delivered within the 8 Pillars Model and that, with the increasingly aging population and higher numbers of people with dementia, more people need to be receiving this type of service.
- The group also discussed obstacles deaf people with dementia face in accessing support and technology as well as the need to train deaf people or someone who understands deaf culture to conduct assessments so they can understand the needs of deaf people. Lucy Clark of the British Deaf Association encouraged attendees to think about how little access people have to services if they are deaf. This lack of access means they are forced to rely too heavily on family members to act as their advocate. She also mentioned that care homes that support deaf people with dementia have been closed. **Action:** The secretariat to discuss inviting Lucy Clark to present at a future meeting.

6. AOCB

Richard mentioned that there have been multiple requests to present at future meetings of the CPG. These include:

- The 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.

TIDE requested a speaking slot at a future meeting of the CPG.

Scottish Government mentioned it is developing a social isolation strategy. Transport was the first issue to come out of it, and it would be good to have this as a topic at a future meeting. The Alumni Group mentioned that it looks at transport and accessibility. It would like to work with Scottish Government on transport.

Attendees also discussed promoting the CPG and having a greater diversity of attendees. Richard pointed out that this is one of the better attended CPG's, and he encouraged attendees to let the secretariat know of anyone who is interested in attending and should be added to the invite list. Finlay Carson encouraged attendees to write to their MSP and encourage them to attend.

7. Close and Date of Next Meeting

Future meetings of the CPG are tentatively scheduled (pending room availability) for:

- Wednesday, 23 January – at which the Mental Welfare Commission, Scottish Government's SDU report and Kenneth Davidson are scheduled to present.
- Wednesday, 24 April – at which SDWG, East Renfrewshire Council's Scam Prevention and British Deaf Association are scheduled to present.