

Cross-Party Group on Dementia
Minutes of the meeting
23rd January 2019 – 5:45pm-7:45pm
Committee Room 3, Scottish Parliament Building, Edinburgh EH99 1SP

Present:

MSPs

Richard Lyle MSP (Chair)

Organisations

University of Edinburgh (Dr Tom Russ), Alzheimer Scotland (Amy Dalrymple, Jim Pearson, Carleen Smith) Alzheimer Scotland Dementia Nurse Consultant (Sandra Shields, Tilda McCrimmon), Association of the British Pharmaceutical Industry (Graeme Rose), Life Changes Trust (Arlene Crockett, Adrena Coburn), MECOPP (Jennifer Paton), Queen Margaret University (Fiona Kelly), Royal College of Speech & Language Therapists (Rebecca Kellett), Scottish Government (David Berry, Linsey Oughton), Shared Lives Plus (Ben Hall), SDWG (Carol Hargreaves, Archie Noone, Marc Buchannan) Scottish Care (Caroline Deane) Alzheimer Scotland Centre for Policy & Practice – UWS (Margaret Brown) NHS Health Scotland (Avril McKenzie), NDCAN (Thea Laurie, Anne Bisset) NHS Lanarkshire (Leigh Whitnall) Tide (Alison Reynolds, Natasha Hamilton) Trading Standards East Renfrewshire (Paul Holland) The ALLIANCE (Matthew Hilferty)

Individuals

James McKillop, Maureen McKillop, Natasha Hamilton, Gail Fisher

1. Welcome and apologies

Meeting opened by Richard Lyle MSP.

The following apologies were received: Caritas Neuro Solutions (Leigh Fell), Alzheimer Scotland (Nicola Wood, Elaine Hunter, Helen Skinner), University of Edinburgh (Charlotte Clarke), Alzheimer Scotland Centre for Dementia Policy & Practice – UWS (Debbie Tolson) Queen Margaret University (Brendan McCormack), Royal College of Occupational Therapists (Alison Keir), Scottish Care (Donald Macaskill, Studio LR (Lucy Richards), The ALLIANCE (Irene Oldfather), Outside the Box (Anne Connor)

2. Approval of Minutes

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

3. Delivering Fair Dementia Care: The report's findings

Dr Tom Russ presented some of the findings of the Delivering Fair Dementia Care Report, which is led by former First Minister Henry McLeish and Alzheimer Scotland. Dr Russ, Clinical Psychiatrist and Honorary Clinical Senior Lecturer at the University of Edinburgh was one of the commission members of the report. Tom explained the definition of advanced dementia that is used in the report, how the commission estimated the prevalence of advanced dementia, and how they calculated how much people with advanced dementia pay for their own care.

Dementia is a progressive illness, and Dr Russ outlined the pathway of the experience of dementia. The Fair Dementia Care Report focuses on advanced dementia, which has not had enough attention paid to it, in terms of the condition itself and in the policy context within which advanced dementia exists.

Developing a definition of advanced dementia is not straightforward. Dr Russ referenced Palliare, a project led by the University of the West of Scotland, which informed the definition of advanced dementia in the Fair Dementia Care Report. This consensus definition was based on two focus groups- one of experts and one of carers of people with dementia. It defines advanced dementia as a health care issue and therefore the needs of people with advanced dementia are healthcare needs and should be free at the point of use.

The prevalence of advanced dementia in Scotland was estimated for this report as we do not know actual numbers. These estimations are based on studies of people in care homes with advanced dementia and people in the community reported as having dementia. The cost of providing care for people with advanced dementia was also calculated- estimated to be around £51 million per year.

4. Delivering Fair Dementia Care: Financial Impacts of Social Care Charging

Presentation by Jim Pearson, Director of Policy, Alzheimer Scotland

Summary:

This presentation put the report's research in a policy context, explaining the aims of commission and why the Fair Dementia Care report (found here https://www.alzscot.org/assets/0003/2670/McLeish_Report_WEB.pdf) was developed.

- Jim's presentation referenced the Advanced Dementia Practice Model (https://www.alzscot.org/campaigning/advanced_dementia_model), which asked Scottish government to acknowledge that the needs of people with advanced dementia are healthcare needs.
- Jim explained that healthcare is free at the point of use while social care is not. People with advanced dementia's needs are healthcare needs- but are still subject to social care charges. This is an inequality compared to other terminal illnesses.

- Local Authorities are free to set their own charging policies for non-residential care, and these charging policies are different for each Local Authority. Therefore, there is a lack of consistency and transparency due to so many variables in determining how people are charged.
- The Fair Dementia Care report calls for charging policies to be more consistent and transparent.

While home care charges are set by local authorities, care home costs have national guidelines. However, they are still difficult to understand. Transition of someone with dementia from their own home to a care home happens at a time of anxiety for carers, additionally information given to people may not always be correct. This increases stress for people with dementia and their carers.

Presentation Question and Answer

Following Dr Tom Russ' and Jim Pearson's presentations, a joint question and answer session followed, which included:

- We should be looking more into continuous care for people with advanced dementia- that people who may not be in acute settings still need continuous care.
- The Fair Dementia Care Report omitted retrospective assessments of a person's capital. Local Authorities can determine if an individual has deliberately deprived themselves of private assets to avail themselves of public services, and there is no time limit on this.
- Everyone with a terminal illness should be treated equally. They should get the care they need and have all their needs met regardless of what illness they have or what their needs are.
- The best decisions in how to diagnose and assess people with dementia are made by multidisciplinary teams involving clinicians, carers, and the people with dementia themselves, where appropriate. An important question to ask is if these people's needs can be met anywhere other than hospital. Someone looking after someone is best placed to make this decision.
- It is not known how likely these charges are to be abolished but given that Scotland is world-leading when it comes to dementia policies, pressure is on Scotland to continue to be progressive.
- Implementing recommendations from the report may or may not take legislative change. It is important that the government acknowledge the merit of the recommendations and that this inequity exists.
- If we want to support people to live better for longer, it is important to make better use of the resources we already have. We currently spend too much money fighting crises- this does not provide best outcomes for people with dementia.
- There is a need to acknowledge those that are under 65 as dementia can affect younger people as well. While figures for people over 65 were used to make assumptions for research, the recommendations of the Fair Dementia Care report

apply to people with dementia of all ages, as does the Scottish Government's guarantee of Post Diagnostic Support.

- If we are truly in an age of health and social care integration, all social care benefits should also be free, as they provide healthcare benefits.
- Social prescribing for carers to maintain emotional wellbeing would be less expensive than waiting until individual has crisis.
- The report only looks at the costs of looking after the person with advanced dementia- the healthcare issues and knock on costs for families could also be considered. Carers wellbeing is also not included in calculations.
- Healthcare costs for people with dementia can be very expensive. There is a fear that once all of someone's assets have been used to fund their care they will be moved to a different care home.
- The definition of advanced dementia used in the report includes those that are physically well but have communication or other cognitive issues.
- The prescribing of anti-psychotics and sleeping tablets are very expensive and not always appropriate for people with dementia. This money could be given appropriate specialists, rather than for drugs.

Richard asked what the key recommendations of the report are. Alzheimer Scotland would like an acknowledgement from the Scottish Government that inequality in care charging exists for people with advanced dementia and a commitment to working to rectify this. This report does not propose stopping social care charges but simply to increase transparency and consistency in how local authorities implement charging and can therefore be held accountable.

Action: Richard has agreed to chair a debate in parliament which will take place in May.

5. Open Discussion and AOCB- Introduced by Richard Lyle MSP

The group had an open discussion, particularly taking time to hear from people with dementia and carers.

- One person with dementia feels like policy progress in dementia is slow and that nothing will happen in their lifetime. Other illnesses are getting a lot of investment compared to dementia.
- A carer talked of their lack of support. There was no offer of post diagnostic support or palliative care, and there was no carer's assessment.
- People are not looked at as individuals, they are categorised in terms of age. However, often service providers need to know the age profile of people being diagnosed to provide more age appropriate services.
- Inequity of care costs exists with other neurological conditions as well as dementia.
- There needs to be a national debate around dementia, and go back to basics and define dementia properly.

- Paul Holland (Trading Standards East Renfrewshire) provided an update on his Impact of Scams presentation at the last Cross Party Group meeting. Paul has met with head of fraud at TSB, who will refund all money that people lose to scams. Paul would like to see other banks follow suit. Maurice Corry MSP also chaired a parliamentary debate regarding scams.
- There was a request for data on the prescribing of anti-psychotic drugs for people with dementia. David Berry from the Scottish Government will provide this information if it is held centrally and therefore available.

Richard highlighted that we need to look at what is being done and what progress has been made. Richard reinforced his commitment to drive policies forward and also reminded attendees of the Parliamentary debate in May, the outcomes from which can be discussed at the next meeting.

6. Date of next meeting

The date of the next Cross Party Group meeting has not been set, but will take place in August, after Parliamentary recess.