

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), Emma Harper MSP and Maurice Corry MSP.

Organisations

Alliance Scotland (Matthew Hilferty), Alzheimer Scotland (David Beyt, Jim Pearson, Carleen Smith), Association of the British Pharmaceutical Industry (Graeme Rose), Caritas Neuro Solutions (Leigh Fell), DEEP (Agnes Houston), Dementia UK (Bob Cochrane), Healthcare Improvement Scotland (Stephen Lithgow), Life Changes Trust (Arlene Crockett, James McKillop, Maureen McKillop), MECOPP (Jennifer Paton), Paths for All (Carl Greenwood), Parkinson's UK (Tanith Muller), Presbytery of Stirling (Bonnie McDowell), Queen Margaret University (Clare Bates), Royal College of Speech & Language Therapists (Rebecca Kellett), Scam Prevention – East Renfrewshire Council (Paul Holland), Scottish Government (David Berry, Linsey Oughton), Scottish Parliament (Hailey Hannigan), Shared Lives Plus (Ben Hall), TIDE (Natasha Hamilton, Amanda McCarren, Beau Nieuwenhuijs, Alison Reynolds)

Individuals

James Sandison, Judith Sandison

1. Welcome and apologies

The group welcomed Emma Harper MSP who joined the group.

The following apologies were received: Margaret Ann Beggs, Amanda Britain, Margaret Brown, Charlotte Clarke, Lucy Clarke, Anne Connor, Susanne Forrest, Rachael Hamilton MSP, Elaine Hunter, Alison Keir, Donald Macaskill, Emma MacLean, Tilda McCrimmon, Michelle Miller, Sue Northrop, Lucy Richards, Andrew Senew, Helen Skinner, Colin Smyth MSP, Maureen Taggart, Paul Thomas, Debbie Tolson, Karen Watchman, Tommy Whitelaw, Nicola Wood

2. Approval of Minutes

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

3. Annual General Meeting and Re-election of Office Bearers

The group was advised that the AGM needed to take place to elect office bearers. Richard Lyle MSP resigned the chair of the meeting for the election of the group's convener. Emma Harper MSP chaired, nominating Richard Lyle MSP as convener, seconded by Agnes Houston. Members agreed.

Finlay Carson MSP and Colin Smyth MSP had both indicated to the secretariat their willingness to put themselves forward again for as co-deputy conveners. Emma Harper MSP nominated them as deputy conveners. Natasha Hamilton seconded. Members agreed.

Richard Lyle MSP then resumed as chair of the meeting.

4. The Impact of Scams on People Living with Dementia and the Simple, Practical, Preventative Solutions – East Renfrewshire Scams Prevention

Paul Holland of Scams Prevention in East Renfrewshire Council presented to the group on the impact of scams on people. The East Renfrewshire's Scam Prevention programme is in its third year funded by the Life Changes Trust. It operates in East Renfrewshire, Angus and South Ayrshire.

Paul said £9 billion is lost each year to scams in the UK. Examples of scams include doorstep calls for small jobs and home maintenance in which the caller then invents larger problems with the house that require more money to fix. Scam mail includes lottery prizes and false cures for illnesses. Paul said nuisance and scam phone calls not only cost vulnerable people money, they also increase the risk of accidents as people rush to catch the phone and cause unnecessary anxiety and a lack of confidence over phone harassment. He mentioned online fraud is a growing area and an extremely challenging one as it's constantly evolving. He also mentioned pension and investment fraud and said social isolation and loneliness make people more susceptible to romance scams.

In response to these, the East Renfrewshire Scam Prevention programme promotes simple, preventative solutions. In working with social care and the police, they realised prevention is easier and more successful than policing. Examples of simple prevention strategies include 'No cold calling' stickers, which help people to say no when somebody shows up at their door. They also provide a list of trusted traders to prevent people from being scammed by home services. To people being scammed by mail, they recommend diverting the post to someone who can take care of it. Reducing isolation helps to prevent romance scams, so Paul recommended referring people to services such as befriending, the Silverline or man sheds.

The scam prevention programme also engages heavily with professionals in the area. They deliver pop up prevention events and work with schools.

To block nuisance calls they use a True Call device, in which a person can key in the numbers they want to receive on their landline. If a phone number that isn't keyed in calls them, the caller gets a recorded message with an alternative phone number to dial -leading them to a carer or family member who can deal with the phone call. True Call devices cost the programme £100, which pay via funding and are able to install in people's houses for free. A video on the devices can be found here: <https://www.eastrenfrewshire.gov.uk/callblockers>

While safe online practice was too large a subject for Paul to cover in the meeting, he stressed using a credit card for all online transactions over £100. He said this is much safer than a debit card. He also recommended putting an 'at risk' flag on a vulnerable person's bank account or talking to the bank about helping to protect that person's money. A note on the account that someone has a diagnosis of dementia gives the bank an enhanced duty of care.

Currently, they have over 900 scam prevention packages in place and have blocked roughly 800,000 nuisance calls. 35% of people supported by the programme had been previous victims of scams. The programme has reduced anxiety, not just for the people it supports, but their carers as well.

What individuals and groups can do to prevent scams:

- Raise awareness of them
- Encourage reporting
- Protect people with simple, practical solutions
- Become a friend against scams: <https://www.friendsagainstscams.org.uk/>
- E-learning scam awareness training for practitioners and professionals -link in the slides **ACTION:** Secretariat to share the presentation's slides with attendees.
- Reduce loneliness and isolation.
- Raise awareness amongst decision makers.
- Discuss the scale of scams in the Scottish Parliament – consumer protection lies with Westminster, but community safety is a devolved matter.

Richard suggested holding a Members Debate on scams prevention. **ACTION:** The CPG's secretariat to link East Renfrewshire Scams Prevention with the office of Richard Lyle MSP.

Presentation Question and Answer

A question and answer session followed, which included:

- The availability of trueCall, which can be requested from the Prevention team in East Renfrewshire, Angus and South Ayrshire. Outside of those areas, it can be purchased online at <https://www.truecall.co.uk/>. Consumer Advice Scotland (03454 040 506) can also link people to the local Trading Standards for a scam prevention referral if necessary.

- Availability of the service in other areas. Each council is autonomous and makes their own commissioning decisions. Due to financial constraints, it can be challenging even to deliver statutory services, so many local authorities don't feel they have the resources for preventative programmes. They don't always see the cost savings these services result in. Attendees can contact their council to ask if they are aware of this service and considering investing in it.
- An impact evaluation for this service will be coming out later this year.

5. Forging New Frontiers in Dementia Research – Kenneth Davidson, University of Edinburgh

Kenneth Davidson of the University of Edinburgh and NHS Lothian presented on dementia research and an event hosted at the University of Edinburgh last year. Kenneth is part of the Edinburgh Centre for Research on the Experience of Dementia (ECRED), which meets monthly to discuss their work and the broader future of clinical research into dementia.

Kenneth referenced a 2015 report on a review of the dementia research landscape and workforce capacity in the united kingdom, which can be found here:

https://www.rand.org/content/dam/rand/pubs/research_reports/RR1100/RR1186/RAND_R1186.pdf

The report states that roughly 20% of PhD authors remain in dementia research careers. Kenneth stated that most of the people he knows focus on lecturing even when they don't want to as it is felt it offers more job security whereas research is more likely to be contract to contract. He also expressed the view that dementia research is underfunded and undervalued compared to other areas.

Last year, the ECRED hosted an event with PhD students to consider the dementia research landscape and how it might successfully be influenced and navigated. The event included an appreciative inquiry that envisioned a desired future in which:

- The evidence base for dementia is embedded in policy and strategy,
- Measures are established to incorporate the voice of people with dementia and carers,
- Peer support is available for researchers via an online network and database, and
- An operational database exists for practitioners to turn research into practice.

The inquiry then arrived at several key actions to make this desired future into reality:

- **Stakeholder engagement**
 - Create an online network, which ECRED is now working on with NHS Lothian.
 - Public engagement.
- **Involvement in what is already happening**
 - Collect and analyse patient experience data.

- Older People in Acute Hospital (OPAH) Project – to create a care assurance standard for people with dementia
- **Make something new**
 - Create a Lothian Dementia Strategy – meeting with NHS Lothian and the Integration Joint Board in February to begin work on this.

Presentation Question and Answer

A question and answer session followed, which included:

- The extent to which people with dementia and carers are looking for practical ideas and support to everyday problems, such as putting clothes on and crushing pills.
- Increasing access to published research and facilitating turning best practice into standard practice. Kenneth is interested in professionals having access to research databases in order to find solutions to their common problems.
- Linking quality improvement work going on in professional settings to academic research.
- The extent to which technological solutions can replace paid and unpaid carers.
- The extent to which research requires political or monetary backing, and the importance of making it needs-led rather than financially led.

6. Delivering Fair Dementia Care for People with Advanced Dementia – Jim Pearson, Alzheimer Scotland

Jim Pearson of Alzheimer Scotland spoke about the recently published report of the Fair Dementia Care Commission, chaired by Henry McCleish:

https://www.alzscot.org/assets/0003/2746/McCleish_Report_updated_24.01.19_Web.pdf

The commission sought to:

- Determine how advanced dementia is defined and recognised in practice
- Estimate the size of the population of people living with, and dying from, advanced dementia in Scotland
- Examine and describe the current charges and cost framework of advanced dementia care

The report found that advanced dementia produces complex health and nursing care needs, but people with advanced dementia do not currently have equality of access to health care compared to people in the advanced stages of other illnesses. Instead, care for advanced dementia remains essentially a social care response. This means people with advanced dementia are disproportionately subject to social care charges for what are primarily health and nursing care needs.

The report found that people with advanced dementia are paying an estimated £50.9 million per year in social care charges for care which doesn't provide the health or nursing care they require (however, it is difficult to estimate accurate costs given the lack of precise recording of the prevalence of dementia in all settings and exact recording of social care charging). It also found the current system of social care charges is complex, lacks transparency and is variable across Scotland.

The report makes a series of recommendations for supporting people with dementia as they go through the advanced stages of the illness and their dementia becomes much more physical in nature. Among them, it asks that the Scottish Government commits to recognising that the needs of people with advanced dementia are health care needs and ensure equality of access to appropriate health and nursing care, which is free at the point of delivery. It also asks that the Scottish Government commits to investigating the costs of implementing appropriate and free health care for those living, and dying, with advanced dementia.

Presentation Question and Answer

A question and answer session followed, which included:

- The fact that, a few decades ago, all dementia care was free.
- The role people with dementia and carers played in this work.
- Misinformation surrounding charges and the impacts that has on people with dementia and carers.
- The extent to which a person's property is or can be used to pay for care.
- The figures in the report do not include the estimated cost of unpaid care provided to people with advanced dementia.

David Berry from Scottish Government said the Cabinet Secretary has looked at the report this week and would like to meet with its authors. Scottish Government also wants to take a bit of time to look over the report's contents and its definition of advanced dementia and to consider the implications of advanced dementia for residential care as that's where much of the £50.9 million goes.

Richard commented that it's possible to have a member debate on this issue, but Scottish Government needs to lead the debate on this report. He suggested the Cross-Party Group devote more time to continuing this discussion. **ACTION:** The commission's report and charges for care to be on the agenda for the next meeting of the CPG.

7. Open Discussion and Any Other Committee Business

The group had an open discussion, particularly taking time to hear from people with dementia and carers. The group discussed different cases in which accommodation may or

may not be factored into charges for social care. The group also discussed the potential of technology to support people with dementia.

8. Date of next meeting

The next meeting of the CPG is confirmed for 24 April at 5:45pm in Committee Room 6, the Livingstone Room.

Future dates are being identified for June and September.

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