

Health and Social Care Alliance Scotland (the ALLIANCE)

Briefing: Dementia Carer Voices' response to third National Dementia Strategy, July 2017



The third [National Dementia Strategy](#) was published on 28 June 2017, coinciding with a range of activity in the Scottish Parliament related to the ALLIANCE's Dementia Carer Voice programme, including a Member's Debate on dementia in the name of James Kelly MSP, a parliamentary reception and the launch of our latest report – [Dementia Carer Voices – Rights and the Carer Voice](#).

Dementia Carer Voices was represented on the National Strategy Group and welcomes the publication of the strategy. Below we have detailed a number of our initial views on the strategy.

- In general, the ALLIANCE welcomes the more flexible approach laid out in Commitment 1 of the National Dementia Strategy – that good quality care should not be prevented by time constraints and instead focus on increasing “personalisation and personal outcomes in post-diagnostic treatment”. Indeed, we argued for the need to move away from a time and task culture towards one defined by care and compassion in our recent publication.
- From information gathered in our [carer survey](#) and other engagement we know the value that carers place on accessing services locally. In light of this we particularly welcome Commitment 2 which focuses on testing and independently evaluating the relocation of post-diagnostic dementia services in primary care hubs. Not only does this serve to provide services locally, but also, in housing services within primary care it has the potential to decrease stigmatisation and improve awareness raising of issues faced by people living with dementia.
- The ALLIANCE is fully committed to the ‘What Matters to You?’ programme and over the last two years across a range of our projects we have supported the principle of constructive conversations which are person-centred and ask, “What Matters to You”. In light of this we welcome the focus given to conversations in the strategy and the highlighting of the House of Care model. It is worth noting that the House of Care Adopter Programme in Scotland, led by the ALLIANCE, British Heart Foundation, Year of Care Partnerships and Scottish Government, was initiated in September 2014 and works in partnership with five Adopter sites in Lothian, Greater Glasgow & Clyde, Tayside, Ayrshire & Arran and Lanarkshire.
- Dementia Carer Voices' work has demonstrated how particularly distressing it can be for families when an adult with dementia goes missing even for short

periods of time. We therefore especially welcome that the new strategy has identified this issue and commits to consider the recommendations of Police Scotland's recent report on this issue (Commitment 16). We look forward to having more information about how this can be taken forward and implemented.

- We note the content of Commitment 21 that a national policy governance structure for monitoring and implementing the third national dementia strategy will be established. The ALLIANCE would welcome representation on this group to ensure that the lived experience of people living with dementia plays a role in the implementation of the strategy.
- We welcome Commitment 8 to continue the National Group on Dementia in Care Homes which will help to ensure that the ongoing modernisation of care homes takes into account the experiences of families living with dementia. We look forward to an agenda, programme and timetable for taking this commitment forward.

We also note areas where encouraging progress is being made, but where there is a need for ongoing monitoring to ensure the strategy fulfils its potential for people living with dementia and their carers.

- In general terms, the ALLIANCE has long argued for reducing the gap between policy and implementation and we hope that in the next three years the new strategy will allow us to focus on high quality, personalised services tailored to individual needs.
- How the strategy is communicated will also be very important. For carers and people living with dementia language can be a barrier and we look forward to hearing more about how the Scottish Government intends to communicate its policy direction and commitments in a user-friendly way.
- It is clearly the intention for the strategy to cover the next three years and it is important that where there is clear evidence that policies are having an impact, or not, that precipitous action is taken to address this.
- In relation to an evidence base for future care we note the evaluation in England around Admiral Nurses and wonder if there may be scope for a short pilot/test of this in Scotland. Our carer survey further noted high levels of satisfaction with the Admiral Nurse experience.
- We note the range of activities that contribute to dementia friendly communities. We believe that the work of Dementia Carer Voices demonstrates a commitment to ensuring that those living with dementia are valued part of our communities. To

this end we were disappointed that our work was not acknowledged, but look forward to future partnership activity with key stakeholders.

- The Scottish Government and the Scottish Parliament have always supported the principles contained within the Charter of Rights for People with Dementia and their Carers. Dementia Carer Voices would welcome further visibility around the UN PANEL approach contained within the Charter. In particular ensuring that people living with dementia and those who care for them are fully familiar with the contents of the 'Charter of Rights for People with Dementia and Their Carers'.

About the ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE has over 1,900 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards and Community Health and Care Partnerships are associate members.

The ALLIANCE's vision is for a Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well.

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