DEMENTIA AND COVID-19 – SCOTLAND'S NATIONAL ACTION PLAN TO CONTINUE TO SUPPORT RECOVERY FOR PEOPLE WITH DEMENTIA AND THEIR CARERS



Update Flash Report – July 2021

The Scottish Government committed to produce Flash Reports on their Dementia and COVID-19 National Action Plan at 6 months after publication and again at 12 months. This is our first flash report detailing progress on some of the 21 commitments in the Plan.

Bringing the voice of lived experience to our work - Commitment 1 focusses on participation and engagement, through strengthening our relationships with people with a dementia diagnosis.

We have started to develop our listening practices, to create and embed a feedback loop, incorporating the expert voice of lived experience across Scotland to play a crucial role in determining the direction of our various subgroups, as well as monitoring and reviewing our progress against the plan's commitments. We have enhanced our network of lived experience stakeholders from one group to four member groups, with the intention of widening this further to involve representation from a greater range of participants, all working together in collaboration. This builds on positive engagement with established and valued national lived experience groups - The Scottish Dementia Working Group, Together in Dementia Everyday, The National Dementia Carers Action Network and Dementia Engagement and Empowerment Project. We will continue to work on being fully accessible to encourage input from seldom heard individuals, and take a Human Rights based approach to policy development and delivery, incorporating and embedding the key themes highlighted within the Equaity Impact Assessment of our Plan.

Equalities and Human Rights Commitment 3 – The comprehensive Equality Impact Assessment (EQIA) of the Dementia and COVID-19 National Action Plan was published in March, including summary, audio and BSL versions. We are now implementing actions identified in that report and progressing work via the additional equalities groups contacts we have made during that process. One particular example is collaborating with Downs Syndrome Scotland (DSS) and Alzheimer

Scotland to look at links between Downs Syndrome and early onset dementia and how we can provide support, through a planned working group (to be established around September 2021).

Dementia Friendly Communities - The value and impact of dementia friendly communities in enabling people to remain connected to the people and places that matter to them is at the heart of **Commitment 11**.

We have established a Communities subgroup which includes people from existing Dementia Friendly Community initiatives. Using the evidence developed by the Life Changes Trust, who co-chair the group, and utilising the expertise of the Age Scotland dementia project, as well as knowledge and experience built in the existing Dementia Friendly Communities, the group is driving forward its priorities to:

- Map existing dementia friendly communities across Scotland.
- Establish a digital 'store' where resources to develop a dementia friendly community are made available to communities across Scotland.
- Maximise the knowledge and skills in the existing communities workforce through an offer of mentoring to new and emerging dementia friendly communities.



Housing and Dementia Forum - Commitment 6 recognises how important home is. Now more than ever people with dementia want to stay in their own homes for as long as possible, connected to what they know and where they know. From design to



adaptations, through to care, the Dementia and Housing Forum has been established to be a catalyst to the delivery of Commitment 6. Cochaired by Lesley Palmer, Chief Architect for the Dementia Services Development Centre at University of Stirling and Ashley Campbell of the Chartered Institute of Housing, the forum is currently gathering evidence from a range of experts via roundtable semi-structured conversations.

Building on existing work such as the Being Home Report (2017), CIH's Housing and Dementia Framework and innovation from Health and Social Care Partnerships and third sector housing providers, the diverse range of people engaged in the forum will help shape proposals that will complement the Housing 2040 plan, as well as local housing initiatives.

Post-Diagnostic Support Commitment 4 - We have been working with COSLA, Alzheimer Scotland and the Chief Officers of Integration

Joint Boards to help assess current provision across Scotland and barriers to further expansion of the dementia post diagnostic support service. We are liaising with stakeholders and our lived experience groups to help ensure that people with dementia and their families get the best support available from services and in their communities.



Physical Rehabilitation Commitment 8 – We are continuing our ongoing commitment to, and funding for, the national dementia/Allied Health workforce framework Connecting People, Connecting Support, to help further strengthen this work across Scotland, to assist the continuing embedding and impact of this work and the crucial role of Allied Health Professionals in dementia care and physical rehabilitation in every territorial health board.

Care Homes Commitment 14 - We are all aware of the impact the pandemic has had on care homes and with up to 80% of care home residents living with dementia in some care homes, we righty have a priority focus on this important care setting. The Dementia in Care Homes working group met more frequently than usual, continuing into 2021, expanding its membership, and has heard testimony from members of Care Home Relatives Scotland and other family members who have been so acutely affected by the loss of physical contact with their loved ones. Minutes from these meetings have fed into on-going Scottish Government priority work in this area, in supporting implementation of the *Open With Care* guidance.

In recognition of the need to help families understand the evolving guidance on going into a care home and navigate the care home's arrangements for visiting, we have been funding a new project - the Alzheimer Scotland's Action on Rights team - which has supported around 150 families to reconnect with their loved ones in care homes. We have also funded Together in Dementia Everyday (TIDE) to produce and implement a project to which is working with partners to help restore the relationship between families and staff in care homes. Both projects have been, and continue to be, valuable additional supports in this key area of dementia care as we move through pandemic recovery.



Review of psychoactive medication in care homes during the pandemic (Commitment 16) will take place with a study carried out by the Care Inspectorate which is under commission. Work has been scoped out between the Scottish Government and the Care Inspectorate and will begin shortly.

We have progressed our work on a **study of excess deaths** of people with dementia during the pandemic for **Commitment 15**. Secondary analytical research is progressing and the results will be published this year to help enhance our shared understanding of the impact of COVID-19 and our on-going response.

On **Commitment 18**, the Dementia Policy team have continued to attend regular meetings on Anticipatory Care Planning, including providing an update at the meeting in May with regards to implementing the **COVID-19 Dementia Anticipatory Care Guide** as part of wider commitments in the National Action Plan. Dementia ACP Guidance has been added to the Essential ACP Online Tool, to ensure wider access to the guidance.

Counselling service - In response to Commitment 13, the Scottish Government has funded Alzheimer Scotland to establish a new national dementia carers counselling service for families and carers who have been adversely affected by the impacts of COVID-19. The team comprises trained professional counsellors who provide professional emotional support to carers and families of people living with dementia, critical to their wellbeing and their resilience. Specifically they are helping families and carers with expert tailored support in response to the death of a loved one under unprecedented circumstances, supporting their mental wellbeing; and supporting people who care for a loved one with dementia with the ability to



continue to provide that care long term. The service began taking referrals from July, running for 2 years and sits alongside Alzheimer Scotland's existing 24 hour helpline offering advice and support.

Supporting the re-opening of adult day services Commitment 9
As many day centres now start to reopen, we are hopeful the relaxing of social distancing rules allow capacities in centres to rise and for use of the services to be extended to allow people with dementia to benefit from the activity and for their carers to receive some respite.

Dementia in acute care Commitment 17 - We have now agreed to extend the established and valued strategic partnership between Scottish Government, Health Boards and Alzheimer Scotland to support the network of Dementia Nurse Consultants, who will continue to lead and support improvements in response to people with dementia in acute care and associated care settings at NHS Board level.

National Dementia Workforce Framework – Promoting Excellence Commitment 19 - In May we published the first refresh of the national dementia workforce framework. We will continue to support NHS Education for Scotland and the Scottish Social Services Council to implement this framework and help ensure that people with dementia and their carers receive care, treatment and support based on our shared human rights principles, including across key areas such as therapeutic support and palliative and end of life care. This includes on-going national funding.

Dementia Prevention, research and Brain Health Commitment 21 July saw publication of Scotland's first national Brain Health and Dementia Research Strategy, supported by the Scottish Government and designed to maximise the collective impact of Scotland's dementia research community and the engagement with, and participation of, people with dementia in clinical research. We are also taking forward work to establish the piloting of innovative Brain Health

clinics, which will begin this year; and we are working with Brain Health Scotland on their planned engagement process which will inform their first national strategy this year.



We are all researchers

scottish Brain Health & Dementia Research Strategy