

Response to Scottish Parliament Covid-19 Committee Call for Evidence, May 2020

About Dementia is a five-year project, funded by Life Changes Trust and hosted by Age Scotland. We bring together people affected by dementia with professionals in the public and third sectors to influence change around policy and practice in Scotland. This response relates to the following points in the committee's call for evidence:

- *How do we maintain public confidence and support in the public sector response to COVID-19 as determined by the Scottish Government whilst easing current restrictions;*
- *How should different interests in civic society and the economy be involved in the decision-making process about amending restrictions and what would enable the final decisions to be widely supported despite any necessary trade-offs that may require to be made;*
- *Could the current decision-making processes used by the Scottish Government to respond to COVID-19 be improved and if so how;*
- *How robust is the current data used to inform the on-going response and are there areas where further development is required;*

The impact of Covid-19 on people living with dementia – the need for robust data

The current crisis has had an unprecedented impact on people living with dementia and they, along with unpaid carers and family members, are understandably concerned about the implications of this for the future. According to the National Records of Scotland 31% of those with pre-existing conditions who have died of Covid19 were living with dementia (National Records of Scotland 2020a). Serious consideration should therefore be given to the potential impacts on this community of lockdown easing as well as any future peaks and waves.

The association between Covid-19 and dementia is not yet well understood. The increased risk may be due to the greater likelihood of residing in a care home where it is estimated that people living with dementia make up 62% of residents in Scotland (Scottish Government 2018). Care homes have been particularly heavily hit by Covid-19, making up 60% of registered deaths at the peak of the crisis (National Records of Scotland 2020b). People living with dementia may also find it harder to understand and comply with social distancing regulations putting them at further risk contracting the disease (Alzheimer Disease International 2020). Research has demonstrated that they may also be prone to deterioration of dementia symptoms following viral infections (Holmes et al 2009 & 2011). A recent study has pointed to a potential increased risk for people living with dementia who contract Covid-19 (Kuo et al 2020). Kuo et al found that the risk of dying from the disease was 39% for those with dementia, compared to 19% with COPD for

instance. The investigation has also suggested an association between the gene believed to predispose individuals to Alzheimer's, and a predisposition to Covid-19.

These are early findings and more research is needed into the association between Dementia and Covid-19 outcomes. In the meantime we urge the committee to consider whether dementia should be added to the conditions for which 'shielding' is recommended. Such a move may further benefit people living with dementia by enabling them to access services that are currently unavailable to them. However, we recognise that this is a delicate balance, and that consideration must also be given to the impact on unpaid carers' experience of isolation and loss of support since the lockdown. Any extension of shielding advice must also therefore include clear guidance and assistance to carers.

People with dementia living in care homes

The impact of Covid-19 on people living in care homes in Scotland and the UK has been profound. We accept that steps must be taken in these circumstances to safeguard the welfare of all residents. However, we also believe that this should not come at a cost to the human rights of people living with dementia. Calls to the Age Scotland Helpline have highlighted instances where care homes have locked residents, including those with dementia, into their rooms, causing significant distress to both residents and their families. There is an urgent need for clear guidance on adopting a rights-based approach to care and infection control, both in the easing of the current lockdown measures, and in preparation for any further peaks and waves.

We are also aware that under the current lockdown many family members have been prevented from visiting their relations in care homes. This separation from familiar faces can be particularly distressing for people living with dementia. We welcome moves in individual homes to enable sustained contact through digital means such as tablets and video conferencing software. However, given the high levels of digital exclusion among the older population in Scotland (Citizens Advice Scotland 2018), this will not be a solution for everyone. People with advanced dementia may also find this a challenging medium through which to communicate. A face on a screen is no substitute for the reassurance of a warm squeeze of a hand or a hug, and the therapeutic benefits of human contact in dementia care are well documented (Doherty et al 2006). In considering moves to ease the current lockdown conditions, About Dementia would welcome consideration of enabling visits from relatives including safe measures to enable the restoration of physical contact. Issues of access to adequate PPE for staff, residents, and visitors will require cooperation between central and local government, the NHS and private providers, and are a vital prerequisite to any easing.

People living with dementia in the community

We are aware that Health and Social Care Partnerships (HSCP) across Scotland have withdrawn or scaled back home care provision in response to staff absences and increased demand on social care as a result of Covid-19 (BBC Disclosure 2020). Conversations with people affected by dementia (those with a diagnosis and

unpaid carers) at About Dementia events and focus groups over the past year have highlighted that even prior to the lockdown people were struggling to access the support they need until after they have reached crisis point. Our recent Human Rights of Unpaid Carers virtual meeting (28th May 2020 N=15) highlighted the profound impact lockdown had on their physical and emotional wellbeing following the sudden and exponential expansion of their roles. Carers reported the loss of services such as home care and respite care, as well as voluntary provision and peer support. This is compounded for those struggling to retain employment during the lockdown, or managing health conditions of their own. The challenges of caring under lockdown are been further complicated for those who do not live with the person for whom they care. Carers have expressed fear of being stopped by police, and anxiety at needing to prove the validity of their status.

For many people with dementia living alone, social care visits are a lifeline, enabling much needed social contact and reducing isolation. The lockdown and enforced isolation has exacerbated this for many, heightening the risk of cognitive decline, and increasing social care needs. We urge HSCPs to reinstate suspended care packages as a matter of urgency, and to commit funds to supporting carers at this time. We urge the committee to examine contingency planning to avoid the curtailing of social care packages in the event of future lockdowns, and to ensure that carers are adequately supported under the commitments of the Carers (Scotland) Act (2016).

Anticipatory care

About Dementia has become aware through calls to the Age Scotland helpline of an increase in the use of DNAR orders for people aged over 70. We are particularly concerned about the way in which some of these conversations have been initiated with people with dementia without their carers or power of attorney present. These conversations have caused considerable distress to both the individuals and their families. Wherever possible conversations about end of life care should take place in advance. In situations where this is not possible medical professionals should conduct these sensitively and in line with existing NHS guidance (NHS Inform, 2020). About Dementia also believes that there is a need for more detailed guidance to support conversations with people living with dementia. Such guidance must include the importance of person-centred care, and respect for human rights as well as the involvement of family members and powers of attorney.

Access to physical activity in public spaces

The availability of public toilets is an important issue for people living with dementia and is frequently raised in discussions around access to public spaces even prior to lockdown. People living with dementia may need to find public toilets quickly but regularly face difficulties in doing so. Inadequate toilet facilities can result in a lower quality of life and increased levels of anxiety for people living with dementia preventing them from playing a full and active role in society (Hyde & Cassidy 2017). We are aware that access to public conveniences such as toilets has been restricted as lockdown has been eased in England. After weeks isolating at

home many people living with dementia will have experienced significant muscle degeneration and loss of strength and balance function, and will need considerable support to become physically active again. Any further delay in this could be detrimental to their long-term recovery. Carers will also be eager to take advantage of opportunities to stray further from home and enjoy the great outdoors. We would urge that consideration be given to enable the safe reopening of public toilets in tandem with the easing of lockdown to enable people to enjoy public spaces with dignity. We would also urge that allied health professionals such as Physiotherapists, Speech and Language Therapists, and Occupational Therapists many of whom have been redeployed to other roles during the crisis, be prioritised for resumption of normal duties.

Accessible information – Maintaining public confidence and involving civil society

The introduction of lockdown in Scotland has resulted in considerable uncertainty for people affected by dementia, and the wider population of older people in Scotland. The Age Scotland helpline received the equivalent of a year's worth of calls in the first four months of this year, many of which were requests for advice on how to respond to the regulations. The citizens of Scotland have a right to information that will keep them safe during this pandemic. We urge the committee, the Scottish Government and other public bodies to produce information and advice in a clear and accessible format. While we understand that guidance must be standardised and applicable to the whole population, this can make it harder to interpret if it does not reflect people's lived realities. We welcomed concessions given to individuals with mental health problems and those with learning disabilities to enable them to maintain routines safely, and would urge dementia to be considered in any further guidance. There is much to be learned from lived experiences of the Covid-19 pandemic, and it is important that this learning is swiftly integrated into existing practice. We would welcome the involvement of people affected by dementia in the production of tailored rights-based and person-centred guidance on supporting people affected by dementia during lockdown.

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