

For the attention of the Special Committee on Covid-19 Response,

On behalf of The Alzheimer Society of Ireland, I present a submission for the Special Committee on Covid-19 Response. I would appreciate your consideration of the issues and concerns enclosed.

Yours sincerely,

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Submission to the Special Committee on Covid-19 Response

- **Dementia & COVID-19 Mortality**

Dementia is a complex neurological condition and public health guidelines are difficult for many people living with dementia to adhere to due to cognitive impairment. Age is by far the strongest risk factor for dementia and for COVID-19, meaning that many people living with dementia are likely to contract and die from COVID-19.

In Ireland, residential care settings have been adversely impacted by COVID-19, where up to 72% of residents are people living with dementia. It has been argued that many people living with dementia have comorbidities that are counted and as a majority of nursing home residents have dementia they are included in a way by association. The public health framing of dementia has only recently begun to be embraced by policy makers in Ireland. Dementia is not considered the key cause of death; another disease present would be named instead. It is deeply concerning that data has not captured the mortality rate of COVID-19 among people with dementia in both nursing homes and in the community. Yet, data from the UK Office for National Statistics reveals dementia to be the main underlying condition for 1 in 4 Covid-19 deaths. The omission of this disease by Irish officials in their considerations seems, therefore, concerning and alarming.

- **Complexity of Dementia**

Among people with dementia social contact, attachment, pleasurable activities, choice, control, and connectivity are all very important. Yet, given the Irish government's cocooning guidelines for those over 70, the latter will have a profound impact on quality of life. This coupled with the cessation of group recreational activities in nursing homes, group outings from nursing homes to familiar places and the absence of regular visits from family members and exposure to familiar faces of close relatives will all adversely affect well-being. Many of the restrictions introduced to nursing homes to cope with COVID-19 are having detrimental emotional and psychological effects on people with dementia in terms of social isolation and loneliness, according to ongoing ASI research. Many people with dementia do not understand COVID-19 advice relating to social distancing and visiting restrictions and do not understand why family members stopped or limited visiting. Our research shows this causes confusion, distress and can even lead to deterioration in the person's symptoms (<https://alzheimer.ie/wp-content/uploads/2020/04/FINAL-Research-survey-results-on-need-1st-April-2020.pdf>). The cognitively impaired person is also likely to have difficulties remembering safety

procedures, such as wearing masks. In the nursing home setting, the wearing of PPE by staff can cause confusion and distress among people with dementia.

Family members play a vital role in supporting the person with dementia in nursing such as offering companionship, helping with meals, taking the person outside for a walk, observing their needs etc. When visiting restrictions were implemented in early March, it was not clear how individuals with dementia were being supported in nursing homes, how their needs were being met, and how the support provided by family members was being addressed.

While some visiting restrictions have been lifted, the existing restriction needs to be considered from the perspective and complex needs of people with dementia. There is also a need to understand how people living with dementia in nursing homes have been affected by Covid-19 restrictions and how their needs can be addressed. In the short to medium term, the immediate needs of people with dementia, arising from recent restrictions in nursing homes needs to be understood and addressed. Special and appropriate safeguarding measures, both short and long-term, are critical to safeguard this cohort.

- **Technology**

Visiting restrictions mean that on-going communication with friends and relatives inside and outside the nursing home may be difficult. Technology may be an important resource for maintaining contact with others, but is it challenging during an extremely busy pandemic period to teach a person living with dementia to use technology to communicate with family members. There is a need for more innovative practices including careful use of assistive technologies to support the psychosocial well-being of people living with dementia while maintaining physical distancing.

- **Staff Training**

In Irish residential care settings significant staff shortages have occurred. It is difficult for an individual's personhood to be preserved when regular staff are no longer available to provide care due to their own infection from Covid-19. Fostering a sense of belonging and familiarity with newly appointed staff recruited at short notice to back-fill front line positions is not easy for people with dementia. Some of these staff may have had little or no training in dementia and may be unfamiliar with residents' life stories. The use of masks and face visors add another layer of complexity to the relationship between staff and the person with

dementia. There is an immediate need to provide dementia specific training to staff and to ensure nursing homes have sufficient staffing ratios and that the well-being of staff is adequately upheld.

- **Person-Centredness**

Every effort should be made to preserve the choice, autonomy and needs of people with dementia during a pandemic, and public health measures should reflect these principles. People with dementia are a vulnerable cohort and restrictions that are implemented need to be aligned with a person-centred approach. Public health measures for nursing homes should give more significant consideration to the role of families, and the voice of people with dementia and family carers should be included in developing public health measures for nursing homes.

Dementia can be an extremely frightening condition for the individual, and familiarity, a sense of belonging, routine and consistency are crucial for good quality dementia care and for the preservation of personhood. Recent ASI research shows that some of the behavioural and psychological symptoms of dementia, commonly referred to as responsive behaviours, such as agitation, aggression, apathy, wandering have been widely reported by family carers during COVID-19. Antipsychotic medication should be the last resort in responding to these behaviours as the use of such drugs can have very deleterious consequences. We do not know if this type of medication may be in more frequent use during pandemic periods in residential care settings, an issue that should be investigated.

- **Addressing Short- & Long-Term Need**

The immediate need of people with dementia that are presenting now, arising from recent restrictions in nursing homes needs to be understood and addressed. This includes investigating the impact of restrictions for people with dementia, identifying strategies to support engaging remotely in care, and ensuring adequate PPE and oxygen supplies to cope future outbreaks of COVID-19.

Nursing homes should be part of a continuum of care that includes Intensive Home Care Packages, which have been shown to offer significant benefits to people with dementia. The current model of long-term care in Ireland needs to be urgently reviewed with reference to a number of already recently published policy documents on housing for older people and the continuum of care for people living with dementia. In addition, the testing and development of the new statutory home care scheme for older people

proposed to be introduced during 2020 should not be delayed because of the current pandemic. It is vital that this statutory scheme is developed immediately and without further delay.

- **Integrated Care**

Nursing home care should be viewed broadly in terms of the wider spectrum of all available services and supports operating in an integrated way, and should also include the role of family members, many of whom provide care to their loved ones in nursing homes. Nursing homes, including private facilities, should be integrated into the wider framework of health and social care and considered part of integrated care pathways to include nursing homes visits. Allied health care professional should also be involved in older people's care in nursing homes, as they are in communities. There should be clear responsibility and oversight for all care facilities for older people at both regional and national level.

- **Oversight**

The role of the COVID-19 Lead in nursing homes should be continued, and this role should include dementia training and awareness of the complexity of dementia. While HIQA currently address and approach nursing homes in a generic way, dementia should be taken into account as a disease area in itself that requires a particular response due to the complex nature of the disease and its challenges. HIQA inspection procedures should include new standards to safeguard older people in nursing homes including those with dementia in the event of a further pandemic. Increasing the frequency of thematic inspections and a focus on dementia care in standard inspections should also be considered in order to support the needs of this vulnerable cohort.

- **Visibility of Dementia**

Throughout this pandemic, people with dementia have been rendered invisible. Data on COVID-19 mortality in nursing homes and communities among people with dementia has not been collected, and the experience of this cohort has been largely overlooked. People with dementia should be given particular consideration in relation to public messaging around COVID-19. The Alzheimer Society of Ireland is calling for the omission of dementia in many realms such as public health guidance, research investment, policy development and general media in the area of Covid-19 to be immediately addressed. The recently published report "*The impact of COVID-19 pandemic on people living with dementia in Ireland*", by Niamh Hennelly and Suzanne Cahill, describes the precarious situation in Ireland for people living with dementia and their carers during the pandemic. The report concludes that "*policy and practice needs to focus on how people living with dementia*

and their informal and formal carers can be optimally supported". As we move beyond the "emergency" planning for Covid-19, dementia should be given the consideration it warrants and deserves in terms of public health policy, research into the impact and future planning of it with regards to Covid-19 in both residential settings and communities.