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Report: The impact of COVID-19 pandemic on people living with dementia in Ireland

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Corrections and comments are welcome at info@ltccovid.org. This document was last updated on 2 June 2020 and may be subject to revision.

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1. Key points

- 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.
- Public health guidelines will be difficult for many people living with dementia to adhere to and follow due to cognitive impairment.
- Cocooning for people living with dementia will be particularly difficult and people are at significant risk of social isolation, increased anxiety, stress and loneliness.
- The temporary cessation of usual services such as support groups, Alzheimer cafés, day care services and cognitive stimulation therapy will impact significantly on people living with dementia.
- In Ireland, residential care settings have been adversely impacted by COVID-19, where up to 72% of residents are people living with dementia.
- People living with dementia have not featured very much in public policy discussions on the COVID-19 pandemic.
- Public policy has not focused on supporting family caregivers who may be under increased pressure due to the cessation of usual services and supports in addition to the anxiety and stress of living through a global pandemic.

2. Introduction

This preliminary report from Ireland reviews the impact of Covid-19 on people living with dementia and their family caregivers. It builds on an earlier report written by colleagues on COVID-19 in long-term care settings in Ireland¹. The first case of COVID-19 in Ireland was diagnosed on the 29th February². As of May 29th, 25,062 people have tested positive for COVID-19 and 1,650 people have lost their lives³. Age is a significant risk factor for COVID-19 and we now know that 93.4% of all Irish deaths have occurred in people over the age of 65, and 79.82% have occurred in people over the age of 75, with those over 85 years of age having a case fatality ratio of 26.32%⁴.

3. Dementia as a Risk Factor for COVID-19

There is no compelling evidence that dementia per se is a risk factor for COVID-19 or that a cognitively impaired person will have more severe symptoms from COVID-19 than a person of similar age and health profile who is cognitively intact⁵. In Ireland, dementia was not listed as an underlying condition of the first 327 people admitted to ICU with COVID-19⁶, although this may not be surprising since dementia remains under-reported and under-

¹ Pierce, M., Keogh, F., & O'Shea, E. 2020. *The impact of COVID-19 on people who use and provide long-term care in Ireland and mitigating measures*. Country report available at <https://ltccovid.org/>

² <https://www.rte.ie/news/2020/0320/1124382-COVID-19-ireland-timeline/>

³ <https://www.hpsc.ie/news/title-19681-en.html>

⁴ [https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/COVID-19%20Daily%20epidemiology%20report%20\(NPHET\)%20v1_website.pdf](https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/COVID-19%20Daily%20epidemiology%20report%20(NPHET)%20v1_website.pdf)

⁵ <https://www.alz.co.uk/news/adi-releases-position-paper-on-COVID-19-and-dementia>

⁶ <https://www.gov.ie/en/publication/20f2e0-updates-on-covid-19-coronavirus-since-january-2020/#may>

diagnosed in Ireland⁷. An analysis of over 17 million patient records in the UK, found that death from COVID-19 is strongly associated with being male, being older and more deprived, having uncontrolled diabetes and having severe asthma. In addition, people with non-white ethnicity are at a higher risk. This analysis also found that many other comorbidities, including stroke and dementia, were associated with increased risk⁸. One UK based study found that among those over 65, people living with dementia are three times more likely to develop severe COVID-19, but it is uncertain as to whether this is an indirect effect of living in nursing homes where there are high rates of infection⁹. The same researchers found an association between the APOE4 gene and severe COVID-19¹⁰. Many of these studies are preliminary and under-going peer review so it is difficult to come to any concrete conclusions in relation to dementia being a risk factor. Ultimately, given that age is by far the strongest risk factor for dementia¹¹, it is reasonable to assume that the person living with dementia is at heightened risk of developing COVID-19.

Additionally, having dementia may expose the individual to *at risk behaviour* during the COVID-19 pandemic. For example, it will be a lot more difficult for people living with dementia to understand and comply with public health guidelines such as practicing physical distancing and hand hygiene. Cocooning or shielding, where a person is required to remain at home or indoors and avoid face to face contact with others as much as possible will also be difficult for a person living with dementia. The cognitively impaired person is also likely to have difficulties remembering safety procedures, such as wearing masks, or understanding and acting on the public health messages and advice given by others. Ignoring such warnings, lack of sufficient self-quarantine measures and lack of compliance with public health advice will all inevitably increase the risk of infection⁵. In addition older people including those with dementia who are infected with COVID-19 may have an atypical presentation. Only one third are likely to have fever and about 25% will have gastrointestinal symptoms¹². Dementia can also impair language and communication skills and because of this the person may be unable to report symptoms. This may mean that the early detection of COVID-19 may be overlooked.

⁷ O'Shea, E., and Carney, P. (2017). *Dementia: Paying Dividends: A Report on the Atlantic Philanthropies Investment in Dementia in Ireland*. NUI Galway and Centre for Economic and Social Research on Dementia, National University of Ireland, Galway.

⁸ Williamson, E., et al. 2020 OpenSAFELY: factors associated with COVID-19-related hospital death in the linked electronic health records of 17 million adult NHS patients. <https://doi.org/10.1101/2020.05.06.20092999>

⁹ Janice L Atkins, Jane AH Masoli, Joao Delgado, Luke C Pilling, Chia-Ling C Kuo, George Kuchel, David Melzer. 2020. PREEXISTING COMORBIDITIES PREDICTING SEVERE COVID-19 IN OLDER ADULTS IN THE UK BIOBANK COMMUNITY COHORT medRxiv 05.06.20092700; DOI: <https://doi.org/10.1101/2020.05.06.20092700>

¹⁰ Chia-Ling Kuo, PhD, Luke C Pilling, PhD, Janice L Atkins, PhD, Jane A H Masoli, MBChB, João Delgado, PhD, George A Kuchel, MD, David Melzer, MBBCh PhD, APOE e4 genotype predicts severe COVID-19 in the UK Biobank community cohort, *The Journals of Gerontology: Series A*, , glaa131, <https://doi.org/10.1093/gerona/glaa131>

¹¹ Winblad, B. et al. (2016). 'Defeating Alzheimer's disease and other dementias: a priority for European science and society', *The Lancet Neurology*, 15 (5), 455.

¹² Professor Sean Kennelly (April 21st 2020). Morning Ireland, RTE Radio 1 <https://www.rte.ie/radio/radioplayer/html5/#/radio1/21753604>.

4. Public Policy on Dementia in Ireland

It is estimated that there are between 39,272 and 55,266 people living with dementia in Ireland, of whom an estimated 19,530 live in residential care settings¹³. In Ireland, public policy on dementia is guided by the National Dementia Strategy¹⁴, a policy document that aims to heighten awareness and understanding of dementia, support a timely diagnosis and enhance community services to ensure that people with the condition live at home in the community for as long as possible. In this policy document, there is limited discussion of long-term residential care options or of the need for a continuum of care. The National Dementia Office did commission a subsequent report on the continuum of care in 2019 that set out a range of options for people living with dementia, including the future recalibration of care from nursing homes to community-based provision, including housing with care options¹⁵.

Across Europe a gradual recalibration in care settings has been taking place since the late 80's and in many countries, especially the Netherlands and the Nordic countries, long-term care for people living with dementia has been re-organised on a social rather than medical model of care¹⁶. There has been limited evidence of this type of remodelling of long-term care in Ireland¹⁵, and the reality is that most people who have dementia either live at home with the support of family caregivers or in large scale generic nursing homes, many of which are not customised or purpose built to minimise the disabilities and other difficulties associated with this condition.

Like in other countries, in Ireland the main bulk of dementia care is provided by family caregivers of whom there are an estimated 60,000. Many of these caregivers provide around the clock services with limited support from their relatives or from formal/government provided services¹⁷. Many family caregivers continue to remain integrally involved in their loved one's care even after a relative is placed in long-term residential care, visiting daily, supporting their relatives in decision-making, communicating valuable information about their relatives welfare to nursing home staff and caring at a distance¹⁷. There is no automatic entitlement to formal home care support services for people who have dementia in Ireland. Nor does eligibility for services automatically confer entitlement. Broadly speaking, however, formal home support services, home care packages, in-home respite care, day care, dementia advisors and telephone help lines have improved following the publication of the National Dementia Strategy and the establishment of the National Dementia Office. Currently, new legislation is being prepared

¹³ Pierse, T., O'Shea, E., & Carney, P. 2019. Estimates of the prevalence, incidence and severity of dementia in Ireland. *Irish Journal of Psychological Medicine*. 36(2):129-37. DOI: <https://doi.org/10.1017/ipm.2018.31>

¹⁴Department of Health. 2014. *The Irish National Dementia Strategy*. Dublin: Ireland: Department of Health. <https://assets.gov.ie/10870/3276adf5273f4a9aa67e7f3a970d9cb1.pdf>

¹⁵ O'Shea, E., Keogh, F., & Cooney, A. 2019. *The Continuum of Care for People living with dementia in Ireland*. National Dementia Office. Tullamore, Ireland. <https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/The-Continuum-of-Care-for-People-with-Dementia-in-Ireland-2019-.pdf>

¹⁶ Malmberg, B., and Zarit, S. H. (1993). 'Group homes for people living with dementia: a Swedish example', *The Gerontologist*, 33 (5), 682-686.

¹⁷ Brennan, S., Lawlor, B., Pertl, M.M., O'Sullivan, M., Begley, E. and O'Connell, C., 2017. De-Stress: A study to assess health and well-being of spousal carers of people living with dementia in Ireland. Dublin, Ireland: Alzheimer Society of Ireland.

by the Irish government that will see access to home care expanded in Ireland¹⁸. This should improve access and equity significantly, provided resources are made available to give expression to the new rights being initiated for people living with dementia.

5. Public Health Policy on COVID-19 in Ireland

Since the outbreak of COVID-19, in Ireland, the National Public Health Emergency Team (NPHE) has been advising the Minister for Health and the Irish government on the pandemic and the measures required to mitigate its impact and protect the public health of its citizens. At the start of the pandemic, government policy focused predominantly, and perhaps understandably, on emergency planning for the acute care sector. In response to concerns about the potential impact of COVID-19 on nursing home residents and staff, on the 6th March, Nursing Homes Ireland, (the representative body for private and voluntary nursing homes in Ireland), announced visitor restrictions to nursing homes¹⁹. These restrictions stipulated that people could only visit nursing homes in urgent circumstances and children and groups were not allowed visit. In practice, this meant that people living in residential care including those with dementia can no longer see their family and friends in person. On the 12th March, the government closed all schools, colleges and childcare facilities, and on the 24th March more stringent measures were introduced that involved a significant societal lockdown. All shops, pubs, cafes, gyms, and public places, including some social care services were closed down and people were advised to remain at home and only exercise within a 2 kilometre radius of where they lived. In this lockdown strategy, government advice was that all people over the age of 70, including those of that age living in residential care facilities and those listed as medically vulnerable, should cocoon. Interestingly, the list of medically vulnerable people required to cocoon does not include people living with dementia²⁰. Depending on space and the physical lay-out of nursing homes and residential care settings, cocooning for some people living with dementia may be extremely difficult to exercise and monitor¹.

During the COVID-19 pandemic, there has been little emphasis in Ireland on the unique and complex needs of people living with dementia either in the community or in residential care. For example, up to May 12th, there has been no reference to dementia or Alzheimer's Disease in the minutes from the National Public Health Emergency Team meetings nor in their letters to the Minister for Health²¹. For some this may not appear that untoward, but given that in Ireland close to three quarters of all residents in nursing homes are likely to have dementia¹³, the omission is noteworthy. The minutes from the 14th May meeting contain two references to people living with dementia, firstly, they propose repeat testing for people who may have difficulty communicating symptoms, such as people living with dementia. The second reference is to wearing masks and an acknowledgement that this practice may be difficult for some people living with dementia, but do not want this to lead to stigmatisation²¹. The National Dementia Office (part of the Health Service Executive),

¹⁸ The Institute of Public Health in Ireland. (2018). *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation*. Dublin, Ireland: The Institute of Public Health in Ireland.

¹⁹ <https://nhi.ie/COVID-19-coronavirus-nursing-home-care/>

²⁰ <https://www2.hse.ie/conditions/coronavirus/cocooning.html>

²¹ <https://www.gov.ie/en/collection/691330-national-public-health-emergency-team-covid-19-coronavirus/>

have released an excellent collection of online resources for people living with dementia, families and formal carers to support them during the COVID-19 pandemic²².

6. Impact of COVID-19 on people living with dementia living in the community

Precise estimates of the prevalence of dementia in Ireland suggest that there are between 19,742 and 35,736 people living with the condition in the community¹³. The main public services available to support these people to remain living at home include: home help, home care packages, in-home respite care and day care. Residential respite care, where a person living with dementia is admitted to a nursing home for a period of some weeks to enable a family caregiver take a break from caring, is also a service often used by people who have dementia. The provision of each of these services has been significantly impacted by COVID-19.

For example, all residential respite care in nursing homes has been discontinued¹. In Ireland, 245 day centres provide a total of 5,969 weekly places for an estimated 2,879 people living with dementia in the community²³ all of which, under current guidelines, are closed. Many other community based services for example cognitive rehabilitation, cognitive stimulation and psychosocial educational interventions, associated with new range of post diagnostic services for people living with dementia living in the community²⁴, have been temporarily discontinued or the service format has changed as for example it is now available online. All memory technology resource rooms (MTRR) that provide people living with dementia and their carers with advice about assistive technology, safety and quality of life issues have also temporarily closed down during the COVID-19 pandemic.

We do not know precisely how many people living with dementia receive home care support in the community. The Health Service Executive provided over 17.13 million hours of home care to 53,000 older people, including people living with dementia, in Ireland in 2018. This did not include home care packages. They also ran 8 pilot projects providing intensive home care packages to people living with dementia²⁵. Additionally, NGO's such as the Alzheimer Society of Ireland (ASI) play an important role in supporting people living with dementia and deliver in home support services. During the current crisis, home care support in the community has likely been reduced as some home care workers have been redeployed to residential care settings and some care recipients and family caregivers are refusing home care support due to fear of infection¹. There are 20 Alzheimer Cafés in Ireland²⁶ and other services such as support groups and social clubs which are not now

²² <https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/COVID-19-Online-Resource-Hub.pdf>

²³ Pierse, T., Keogh, F., O'Shea, E. *et al.* 2020. Geographic availability and accessibility of day care services for people living with dementia in Ireland. *BMC Health Serv Res* 20, 476. <https://doi.org/10.1186/s12913-020-05341-z>

²⁴ Pierce, M. Keogh, F. Teahan, A. and O'Shea, E. (2019). Report of An Evaluation of the HSE's National Dementia Post-Diagnostic Support Grant Scheme. Tullamore: National Dementia Office.

²⁵ <https://www.hse.ie/eng/services/publications/corporate/hse-annual-report-and-financial-statements-2018.pdf>

²⁶ Teahan, Á., Fitzgerald, C., & O'Shea, E. 2020. Family carers' perspectives of the Alzheimer Café in Ireland [version 1; peer review: 2 approved, 2 approved with reservations]. *HRB Open Res* 3:18. <https://doi.org/10.12688/hrbopenres.13040.1>

running because of COVID-19 restrictions. One Alzheimer café has moved online²⁷. The ASI continues to provide online and telephone support, a service that may benefit family caregivers more so than the individual with dementia. The ASI has expanded their helpline to include being able to book a 1:1 session with a Dementia Nurse or Dementia Advisor, run an online family caregiver support group and provide a list of useful resources on their website²⁸.

6.1. Living alone in the community

In Ireland, there are an estimated 6,000 to 10,000 people living with dementia who live alone in the community²⁹. During this pandemic, these are a group of people who are extremely vulnerable. In addition to in-home service restrictions in some areas and being unable to stay connected with people face to face, or attend a day centre, a lack of access to the internet or lack of ability to use online resources independently may also heighten a sense of loneliness and abandonment and have a profound psychological impact on these people³⁰. The inability on the part of the person who lives alone to access and understand information and education resources on COVID-19 may also increase their risk of acquiring the infection. Work is required with people living with dementia, people working in the area, and advocacy groups to develop supports and guidelines that can be understood by people living with dementia³¹.

6.2. Living in the community and attending hospitals

A person living with dementia has on average 2.4 co-morbidities and uses 5.1 prescriptive drugs³². The person is also at heightened risk of accidents in the home, including falls. A corollary of this is that hospital presentation is not uncommon for a person who has dementia. As a result of COVID-19, many hospitals have banned accompanying persons and visitors to reduce infection rates⁵, meaning that some people living with dementia may not be allowed to bring a family caregiver with them to accident and emergency (A&E) or when admitted to hospital. In Ireland, each hospital provides its own guidelines on visiting and some hospitals make exceptions for people visiting a person living with dementia. An analysis, carried out for this report, of visitor exceptions in public general hospitals, up to the 22nd May, found that approximately one third (16 of the 44) of public hospitals have made an exception for people accompanying or visiting a person living with dementia. A further 9 of the 44 Irish hospitals allow visitors on a case by case basis³³. This is in contrast to the UK where there is a blanket exception made for people living with dementia, who are

²⁷ <https://engagingdementia.ie/>

²⁸ <https://alzheimer.ie/about-us/coronavirus-COVID-19-update/>

²⁹ Pierce, M., Cahill, S., and O'Shea, E. (2014). *Prevalence and projections of dementia in Ireland, 2011 report* prepared for Genio, Ltd.

³⁰ <http://www.nuigalway.ie/opinion/combating-exclusions-and-ageism-for-older-people-during-the-COVID-19-pandemic.html>

³¹ O'Neill, D. 2020. Protecting Our Longevity Dividend During COVID-19. *Ir Med J.* 113(4):50. <http://imj.ie/wp-content/uploads/2020/04/Protecting-Our-Longevity-Dividend-During-COVID-19.pdf>

³² Schubert, C.C., Boustani, M., Callahan, C.M., Perkins, A.J., Carney, C.P., Fox, C., Unverzagt, F., Hui, S. and Hendrie, H.C., 2006. Comorbidity profile of dementia patients in primary care: are they sicker? *Journal of the American Geriatrics Society*, 54(1), pp.104-109.

³³ <https://www2.hse.ie/services/hospital-service-disruptions/hospital-service-disruptions-covid19.html>

Accessed 22nd May 2020

permitted to have one person accompany them during visits to acute care settings³⁴. A hospital environment is far from ideal for a person diagnosed with dementia and there is a burgeoning body of literature pointing to the adverse outcomes people living with dementia experience once hospitalized^{35,36}. A new unfamiliar environment can lead to increased stress and responsive behaviours. The person with a moderate to severe cognitive impairment may feel even more lonely and frightened and may not understand why they are in an unfamiliar environment and not in close contact with family members. They may also be less able to communicate or adhere to instructions and safety measures. All these factors may lead to them having an increased risk of developing delirium during their hospital stay⁵.

6.3. Research studies in Ireland since COVID-19 pandemic

Since the pandemic commenced in Ireland, a number of small-scale studies have been undertaken to explore the effect the pandemic has had on community dwelling older people including those individuals who have dementia. The ASI conducted an online study of the impact of COVID-19, with a total of 147 respondents, including people living with dementia, family caregivers and dementia community champions³⁷. Many of the respondents identified issues, such as loneliness and isolation, lack of routine and boredom, anxiety, fear and stress. The ASI found that 31% of the people living with dementia they interviewed are comfortable using ICT, however, they added that the particular group interviewed (16 people living with dementia) were younger than the average ASI client. In Ireland, internet access decreases with age with only 38% of people over 80 having access to the internet compared to 86% of those aged 50-59³⁸. In another survey conducted amongst older people by the Central Statistics Office in Ireland, 30% of people over the age of 65 reported feelings of loneliness due to COVID-19³⁹. These findings are in accordance with reports from ALONE, a national organisation supporting older people to age at home, who experienced an increase in calls to their helpline from older people living in the community, concerned with mental health difficulties stemming from cocooning⁴⁰. Helen Rochford-Brennan, the Chairperson of the European Working Group on Dementia and an Irish person living with dementia living in the community, reflects on the impact of COVID-19, cocooning and social isolation, and how it has increased anxiety and stress⁴¹. She talks about the invisibility of

³⁴ https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf

³⁵ George, J., Long, S. and Vincent, C., 2013. How can we keep patients with dementia safe in our acute hospitals? A review of challenges and solutions. *Journal of the Royal Society of Medicine*, 106(9), pp.355-361.

³⁶ Timmons, S., O'Shea, E., O'Neill, D., Gallagher, P., de Siún, A., McArdle, D., Gibbons, P. and Kennelly, S., 2016. Acute hospital dementia care: results from a national audit. *BMC geriatrics*, 16(1), p.113.

³⁷ Alzheimer Society of Ireland. 2020. *COVID-19: Impact & Need for People living with dementia and Family Carers* <https://alzheimer.ie/wp-content/uploads/2020/04/Research-report-Covid19-Final..pdf>

³⁸ Doody et al. 2020 *Internet access and use among adults aged 50 and over in Ireland: Results from Wave 5 of the Irish Longitudinal Study of Ageing*. Tilda. Dublin: Ireland. https://tilda.tcd.ie/publications/reports/pdf/Report_Covid19InternetReport.pdf

³⁹ <https://www.cso.ie/en/releasesandpublications/er/elec19/employmentandlifeeffectsofCOVID-19/>.

⁴⁰ <https://alone.ie/alone-receives-increased-number-of-calls-from-older-people-regarding-mental-health-difficulties-stemming-from-cocooning/>

⁴¹ Rochford-Brennan H and Keogh F. 2020. Giving voice to those directly affected by the COVID-19 pandemic – the experience and reflections of a person living with dementia [version 1; peer review: awaiting peer review]. *HRB Open Res*, 3:29 <https://doi.org/10.12688/hrbopenres.13063.1>

people living with dementia in society and how they may have significant difficulty accessing services during this pandemic.

7. Impact of COVID-19 on people living with dementia living in residential care settings

As noted by Pierce et al., as of December 2018 there were 581 nursing homes registered with the Health Information and Quality Authority (HIQA) in Ireland, providing accommodation to 31,250 people¹. More than three quarters of these nursing homes in Ireland are private or voluntary (not for profit) and the remainder are public. Private nursing homes are significantly more likely to be providing dementia care, but receive considerably less state funding compared with the public sector⁴². As cited earlier, a significant proportion of residents in nursing homes in Ireland, up to about 19,530⁴³, equivalent to 72% of all residents, are likely to be people who have dementia¹³. A small proportion of these people live in older congregated large scale buildings where infection control and the practice of social distancing and self-isolation will be very difficult for front line staff to support.

How exactly the COVID-19 pandemic has affected the day to day lives of older people living with dementia who live in nursing homes in Ireland is really impossible to know and understand since every person's story will be different. We know that within nursing homes social contact, attachment, pleasurable activities, choice, control, and connectivity are so important to people who have dementia⁴⁴. Yet, given the Irish government's cocooning guidelines for those over 70, (who constitute a sizeable proportion of nursing home residents), we can only speculate that 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 also adversely affect well-being. The Alzheimer Society of Ireland have suggested some ways to support people living with dementia in nursing homes such as: putting together a life story book, creating a memory box, sending in pictures, sending audio recordings of messages and if possible having video calls⁴⁵. While, Nursing Homes Ireland launched the comfort words initiative encouraging children to write to people living in residential care⁴⁶. One innovative practice in the UK involves a 'drive through' visiting service to allow visitors to visit care home residents and still maintain physical distancing⁴⁷.

⁴² Cahill, S., O'Nolan, C., O'Caheny, D., and Bobersky, A. (2015). 'An Irish National Survey of Dementia in Long Term Residential Care', The Dementia Services Information and Development Centre, Dublin, http://www.dementia.ie/images/uploads/site-images/DSIDCReport_439721.pdf accessed 8 April 2020.

⁴³ This figure was calculated on the basis that there were 27,125 occupied beds in long-stay care in Ireland in 2016, see footnote 13 for the publication reference.

⁴⁴ Cahill, S., and Diaz-Ponce, A. (2011). 'I hate having nobody here, I'd like to know where they all are': Can qualitative research detect differences in Quality of Life among Nursing Home Residents with different levels of Cognitive Impairment?', *Ageing and Mental Health*, 15 (5), 562-572.

⁴⁵ <https://alzheimer.ie/wp-content/uploads/2020/03/Tips-for-nursing-home-restrictionsv3.pdf>

⁴⁶ <https://nhi.ie/comfort-words-initiative-launched-to-bond-children-and-nursing-home-residents-during-COVID-19/>

⁴⁷ <https://www.bbc.com/news/av/uk-52788453/drive-through-care-home>

Dementia is an extremely frightening condition for the individual and familiarity, a sense of belonging, routine and consistency are so important for good quality dementia care⁴⁸ and for the preservation of personhood⁴⁹. We know that in Irish residential care settings significant staff shortages can occur; for example, the Irish Times newspaper reports on one nursing home operating with less than 60% of their staff⁵⁰. 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-19⁵¹. Fostering a sense of belonging and familiarity with newly appointed staff recruited at short notice to back-fill front line positions is not likely to be easy. 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. On-going communication with friends and relatives inside and outside the nursing home may also be difficult. Technology may be an important resource for maintaining contact with others, but is it possible during an extremely busy pandemic period to teach a person living with dementia to use Skype or Facetime to communicate with family members? Pierce et al. emphasise the need to provide more support to nursing homes to ensure they have sufficient staff and that the well-being of staff is adequately upheld¹.

We also know that some of the behavioural and psychological symptoms of dementia, commonly referred to as responsive behaviours, such as agitation, aggression, apathy, depression wandering can be precipitated by boredom and the absence of multisensory stimulation⁵². As a general rule of thumb, antipsychotic medication should be the last resort in responding to these behaviours as the use of such drugs can have very deleterious consequences⁵³. We do not know if this type of medication may be in more frequent use during pandemic periods in residential care settings.

7.1. Deaths in nursing homes and residential care settings in Ireland

Deaths from COVID-19 experienced by people living with dementia in residential care settings is a complex topic and even more complicated when cross national comparisons are attempted. First, there is the issue of diagnosis and uncertainty about who may have dementia or not¹³. Second, residential care facilities, including nursing homes and care homes, are defined differently within countries. Third, is the issue of whether COVID-19 deaths refer to the death of the person who has already tested positive for COVID-19 or a death of a resident linked to a suspicion of COVID-19. For example, the Health Protection Surveillance Centre (HPSC) in Ireland reports information on deaths in three different

⁴⁸ Aminzadeh, F., Dalziel, W. B., Molnar, F. J., and Garcia, L. J. (2010). 'Meanings, functions, and experiences of living at home for individuals with dementia at the critical point of relocation', *Journal of Gerontological Nursing*, 36 (6), 28-35.

⁴⁹ Hennelly, N., Cooney, A., Houghton, C., and O'Shea, E. (2019). 'Personhood and Dementia Care: A Qualitative Evidence Synthesis of the Perspectives of People living with dementia. *The Gerontologist*.

⁵⁰ <https://www.irishtimes.com/news/health/granddaughter-of-resident-fielded-2-500-calls-when-helping-at-COVID-19-hit-nursing-home-1.4257627>

⁵¹ <https://www.irishtimes.com/news/health/granddaughter-of-resident-fielded-2-500-calls-when-helping-at-COVID-19-hit-nursing-home-1.4257627>

⁵² Brooker, D., and Latham, I. (2016). *Person-centred dementia care: Making services better with the VIPS framework*. London: Jessica Kingsley.

⁵³ Banerjee, S. (2009). 'The use of antipsychotic medication for people living with dementia: Time for Action', A report for the Minister of State for Care Services, *Department of Health*, London, <https://www.icpmh.info/wp-content/uploads/time-for-action.pdf> accessed 8 April 2020.

categories: confirmed, probable or possible⁴. Fourth, figures reported by the HPSC in Ireland refer to deaths *in* residential settings. It we are unclear if people who were transferred to hospital and subsequently passed away are included in these figures. Finally, some nursing homes in Ireland have disputed some of the reported deaths⁵⁴. So the following data needs to be interpreted with caution.

As of May 6th, 62% of all COVID-19 deaths in Ireland occurred in a residential care setting (857/1,375), with 53.8% (740) occurring in a nursing home⁶. The HPSC in Ireland provide information on underlying medical conditions and mortality for 17,135 confirmed cases of COVID-19 up to and including the 20th May. Table 1 taken from this report shows the numbers of people with different underlying conditions. The report does not define chronic neurological disease but it is likely that this category includes people living with dementia, however, it may not include all people with dementia, especially if their dementia is undiagnosed. After those with immunodeficiency (28.13%), those with a chronic neurological condition were the least likely to receive hospital care 30.5% (308/1008) compared to people with chronic kidney disease who were the most likely 49.8%. (235/471). They were also the least likely to receive care in ICU 1.29% (13/1008) compared to people with a BMI >=40 of which 43% (139/244) ended up in ICU.

	Community		Hospital		ICU		All settings	
Chronic heart disease	1536	10.5%	909	35.8%	195	49.7%	2445	14.3%
Chronic respiratory disease	1331	9.1%	497	19.6%	98	25.0%	1828	10.7%
Diabetes	659	4.5%	418	16.5%	94	24.0%	1077	6.3%
Chronic neurological disease	700	4.8%	308	12.1%	13	3.3%	1008	5.9%
Cancer/malignancy	325	2.2%	307	12.1%	43	11.0%	632	3.7%
Chronic kidney disease	236	1.6%	235	9.3%	29	7.4%	471	2.7%
Asthma requiring medication	284	1.9%	146	5.8%	46	11.7%	430	2.5%
Immunodeficiency including HIV	253	1.7%	99	3.9%	24	6.1%	352	2.1%
BMI >=40	139	1.0%	105	4.1%	65	16.6%	244	1.4%
Chronic liver disease	86	0.6%	59	2.3%	12	3.1%	145	0.8%

Source: <https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary%2020052020.pdf>

According to the report, of the 1,245 people who died from COVID-19: 39.8% (n=496) of those had chronic heart disease; 29.2% (n=364) had chronic neurological disease; 16.5% (n=205) had chronic respiratory disease; 13.3% (n=165) had diabetes; and 13.1% (n=163) had cancer/malignancy⁵⁵. The figure of 29.2% in relation to chronic neurological disease aligns in some regards with figures released by the Office for National Statistics for England and Wales. They report that the most common pre-existing condition of a person who died from COVID-

⁵⁴ <https://www.irishtimes.com/news/health/nursing-homes-dispute-accuracy-of-hse-data-on-covid-19-deaths-1.4270145>

⁵⁵ <https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary%2020052020.pdf>

19 was dementia and Alzheimer disease accounting for 6,887 (20.4%) of all deaths⁵⁶. When all pre-existing conditions are taken into account this rises to 8,577 (25.3%) of all deaths⁵⁷. If we are to apply these rates (20.4% - 29.2%) to the numbers of people who have passed away in residential care settings in Ireland up to May 5th (857), then between 175 and 250 people living with dementia have passed away due to COVID-19 in residential care settings. However, this may be a low estimate. If the mortality rate matches the prevalence of dementia in residential care settings in Ireland at 72%¹³, then this figure could be much higher, potentially over twice this number.

There has been significant media coverage about the excessive number of deaths from COVID-19 in long-term residential care in Ireland and some family members of deceased residents have called for enquiries into their relatives' deaths⁵⁸. The impact of COVID-19 on those living in residential care settings has also resulted in several calls for the restricting and/or abolition of such settings^{59,60}. At an Oireachtas (Parliament) Committee meeting on the 26th May, Nursing Home Ireland referenced the following factors in contributing to the spread of the pandemic in nursing homes: the lack of government support available to the private and voluntary sector in the early stages of the pandemic; inadequate PPE and oxygen supply; the transfer of hospital patients to nursing homes without Covid-19 testing and a massive recruitment drive by the public sector (HSE) causing staff exodus from the private sector⁶¹. Two health service professionals, a Geriatrician and Nurse Academic, interviewed on national radio about the crisis in nursing homes, proposed a number of reasons for the huge impact of the pandemic on nursing homes in Ireland. The first was that the asymptomatic spread of COVID-19 was much higher than originally believed. For example, only a third of older people with COVID-19 developed a temperature and so were not fitting the criteria for testing. The second was that COVID-19 is more virulent than anticipated. The nature of care in a nursing home means that staff have consistent and regular close contact with residents, including helping residents with activities of daily living and so it is very difficult to manage physical distancing. The third was where there was a high level of COVID-19 in the community then the chances of it being spread into the nursing home from staff living in the community was much higher. Surprisingly, in many of the nursing homes most affected, single occupancy rooms were common, which would be one way that infection spread could be reduced.

⁵⁶<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deaths-involving-covid-19-england-and-wales/deaths-occurring-in-april-2020#how-many-people-have-died-from-covid-19> accessed 5.06.20

⁵⁷ <https://www.alzheimers.org.uk/news/2020-05-15/ons-figures-show-dementia-main-underlying-condition-covid-19-deaths-alzheimers>

⁵⁸ <https://www.rte.ie/news/coronavirus/2020/0521/1139704-nursing-home-death/>

⁵⁹ <https://www.independent.ie/opinion/comment/exposure-of-latent-ageism-in-virus-response-highlights-need-to-reform-care-systems-for-older-people-39225507.html>

⁶⁰ <https://www.irishtimes.com/opinion/nursing-homes-must-be-made-a-thing-of-the-past-1.4257422>

⁶¹ Oireachtas Committee: Special Committee on Covid-19 response. Tue, 26th May 2020. <https://www.oireachtas.ie/en/oireachtas-tv/video-archive/committees/>

However, one of the speakers, Prof. Sean Kennelly explained that there are other environmental factors that need to be considered⁶².

7.2. Government measures as response to COVID-19 in nursing homes

At the start of the pandemic, government policy focused predominantly on emergency planning for the acute care sector, meaning that like in many other European countries residential care settings were not prioritised¹. With the increase of clusters of cases and deaths in residential care facilities during the month of April, the government later launched a plan to support nursing homes to deal with the virus. This included: screening staff twice a day, prioritising testing for nursing home staff, providing expert advice and training from the Health Service Executive (the Irish health service) providing additional PPE and having a COVID-19 lead in every nursing home. This plan also provided additional funding, of up to a total of €72 million, to support private and voluntary nursing homes to deal with COVID-19⁶³. According to Tadhg Daly, CEO of Nursing Homes Ireland, up to the 25th May, €8.7 million of this fund had been drawn down by nursing homes⁶¹.

On the 23rd May, the Minister for Health announced that the government is setting up a COVID-19 Nursing Home Expert Panel to examine best practice measures in response to COVID-19⁶⁴. There has been controversy certainly in social media over the composition of this committee. While one of the committee members is a former patient advocate, there is no nursing home resident or resident representative, no family caregiver, nor are there any dementia experts on the committee. This absence reflects, in our view, the invisibility of dementia generally in Irish society and the lack of priority given to people living with the disease in nursing homes.

8. Impact of COVID-19 on family caregivers

There are an estimated 60,000 family caregivers to people who have dementia in Ireland⁶⁵, who provide the main bulk of care services. The care delivered by them accounts for 48 per cent of the overall cost of dementia in Ireland⁶⁶. A recent Irish study has shed light on the type of personal and social care services family caregivers deliver to their relatives who have dementia and the type of stress they experience¹⁷. Caring in Ireland has been shown to be

⁶² Sean Kennelly, Consultant Physician in Geriatric Medicine and Corina Naughton UCC Prof of Clinical Nursing, Morning Ireland Radio Interview <https://www.rte.ie/radio/radioplayer/html5/#/radio1/21778593>).

⁶³ <https://www.irishtimes.com/news/ireland/irish-news/coronavirus-72-million-support-package-for-nursing-homes-1.4221194>

⁶⁴ <https://www.gov.ie/en/press-release/81910-minister-for-health-announces-the-establishment-of-a-covid-19-nursing-home-expert-panel/>

⁶⁵ O'Shea E, Cahill S, Pierce M, 2017. Developing and Implementing Dementia Policy in Ireland. Galway, Ireland: NUI Galway and Centre for Economic and Social Research on Dementia; 2017.

⁶⁶ Connolly S, Gillespie P, O'Shea E, Cahill S, Pierce M. Estimating the economic and social costs of dementia in Ireland. *Dementia*. 2014;13(1):5-22.

associated with poor health outcomes for the family caregiver. The prevalence of clinical depression for family caregivers of persons with dementia is noted to be three times the Irish national average¹⁷. In particular the behavioural and psychological symptoms of dementia more commonly known as responsive behaviours such as agitation aggression, anxiety are issues that contribute to caregiver burden.

The COVID-19 pandemic and the resulting lockdown are likely to have contributed to an increase in caregiver burden and to carer ill-health. For example, reports from the ASI reveal that family caregivers are under additional stress due to COVID-19, with the escalation of responsive behaviours probably due to a lack of routine³⁷. Family caregivers' own fears about the effects their own health decline will have on their ability to sustain the care role were other concerns cited. A letter to HRB Open, highlights the essential and challenging role family caregivers play in Ireland and how they have had to react quickly to this pandemic, often without clear guidance or provision of PPE⁶⁷. Family caregivers Ireland, carried out a recent online survey with 1,307 current family caregivers. Their findings show that the withdrawal of services, including respite and other homecare supports, has had a significant impact on family caregivers. A total of 43% of carers were concerned that respite and day care will not return to their previous level after the crisis; 63% of family caregivers were concerned for the well-being of the person they care for and 60% worried about their own mental-health and well-being⁶⁸. It is clear from the report that family caregivers are under significant pressures, which is impacted by the closure of community services such as day care and respite care. Some family caregivers may now have to provide care from a distance, which brings additional challenges especially when their relative may no longer understand why a spouse or adult child is required to keep their physical distance⁶⁹.

9. Access to care

Alzheimer Europe have outlined their concerns in relation to people living with dementia being denied access to medical care because of their diagnosis of dementia⁷⁰. They have called for all treatment to be based on the patient's individual case and not on chronological age or whether they have a particular diagnosis. The United Nations equally express concern, identifying the importance of ensuring that difficult health care decisions are guided by dignity and the right to health⁷¹. The Council of Europe's Commissioner for Human Rights has

⁶⁷ Phillips D, Paul G, Fahy M *et al.* The invisible workforce during the COVID-19 pandemic: Family carers at the frontline [version 1; peer review: awaiting peer review]. *HRB Open Res* 2020, 3:24 (<https://doi.org/10.12688/hrbopenres.13059.1>)

⁶⁸ <https://familycarers.ie/wp-content/uploads/2020/05/Family-Carers-Ireland-Caring-Through-COVID.pdf>

⁶⁹ O'Shea, E. 2020. Remembering people living with dementia during the COVID-19 crisis [version 1; peer review: 4 approved]. *HRB Open Res* 2020, 3:15 <https://doi.org/10.12688/hrbopenres.13030.1>

⁷⁰ <https://www.alzheimer-europe.org/Policy/Our-opinion-on/Triage-decisions-during-COVID-19-pandemic>

⁷¹ United Nations. 2020. *Policy Brief: The Impact of COVID-19 on older persons.*

<https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-The-Impact-of-COVID-19-on-Older-Persons.pdf>

expressed concern at the management of COVID-19 in residential care settings in Europe, questioning the adequacy of the response, the preparedness of such settings and whether people residing in such settings receive equal access to health care. Alzheimer UK have raised ethical issues around discriminatory triage decision-making practices that include access to specialist medical care for people living with dementia⁷². Some European countries have even seen criminal investigations take place into some residential care facilities⁷². In Ireland, the government has published an ethical framework for decision-making in a pandemic in which it emphasises that the allocation of scarce medical resources should be underpinned by the principle of fairness, and prioritisation of care should be made based on health-related benefits⁷³. While this framework may place additional strain on busy practitioners and clinicians, it is to be welcomed as an expression of solidarity in times of crisis.

There are many other access issues that impact on people who have dementia and their family members during a pandemic period that have not been adequately explored in this report. For example, In Ireland, COVID-19 has impacted on diagnostic services (both in general practice and at Memory Clinics) and on post-diagnostic services. The Memory Clinic at St James's hospital, stopped reviewing all new patients for a six week period and during that period developed a virtual clinic for more urgent follow up patients⁷⁴. The implications of getting a diagnosis⁷⁵ of dementia during the pandemic, and delays in starting anti-dementia drugs and in assessments for home adaptation, and assistive technology all add to the distress experienced by some people. Covid-19 will also adversely impact on dementia research⁷⁶ especially in studies where face to face contact is needed to collect data.

10. Conclusion

As COVID-19 is likely to be around for the foreseeable future, policy and practice needs to focus on how people living with dementia and their informal and formal carers can be optimally supported. More innovative ways to keep people socially connected and engaged are needed to ensure that the psychosocial well-being of people living with dementia and family caregivers is maximised. The UN emphasises the importance of hearing the voice of older people during this pandemic, and this also applies to the voice of the person living with dementia⁷¹. Decisions around treatment and care need to reflect the wishes of the person

⁷² <https://www.coe.int/en/web/commissioner/-/lessons-to-be-drawn-from-the-ravages-of-the-COVID-19-pandemic-in-long-term-care-facilities>

⁷³ <https://www.gov.ie/en/publication/dbf3fb-ethical-framework-for-decision-making-in-a-pandemic/>

⁷⁴ <https://dementiaacademy.co/resources/webinars-covid-19/>

⁷⁵ Brown, E. E., Kumar, S., Rajji, T. K., Pollock, B. G., & Mulsant, B. H. 2020. Anticipating and Mitigating the Impact of the COVID-19 Pandemic on Alzheimer's Disease and Related Dementias. *The American Journal of Geriatric Psychiatry*. DOI: [10.1016/j.jagp.2020.04.010](https://doi.org/10.1016/j.jagp.2020.04.010)

⁷⁶ Ousset, P. J., & Vellas, B. 2020. Impact of the COVID-19 Outbreak on the Clinical and Research Activities of Memory Clinics: An Alzheimer's Disease Center Facing the COVID-19 Crisis. *The Journal of Prevention of Alzheimer's Disease*, 1-2. DOI: [10.14283/jpad.2020.17](https://doi.org/10.14283/jpad.2020.17)

living with dementia and their family caregivers. The voice of the person with dementia needs to be stronger not weaker. So far in this pandemic, people living with dementia and family caregivers have remained invisible.

This report has outlined the impact that the Covid-19 pandemic has had on people who have dementia and their family caregivers. It has also detailed the Irish governments' policy response to the pandemic including the complete lockdown it initiated from March 24th. As of May 29th a total of 25,062 people had tested positive for the infection and 1,650 people had died. Although not emerging as an issue of core concern in official government records about Covid-19, a significant proportion of these deaths were of people living with dementia who live in nursing homes or other residential care centres. Unlike many European countries, such as the Netherlands, Germany, Denmark, Sweden and Norway, where a range of small scale living facilities including housing with care, assisted living, group living and sheltered housing are available to people in need of supportive housing because of dementia, in Ireland large-scale generic nursing homes, accommodating in some cases up to 150 residents are the predominant model of care available to people living with dementia who can no longer live at home. Models such as these are not conducive to quality of care during normal times and will undoubtedly have a deleterious impact on people living with dementia during a pandemic crisis such as Covid-19.

11. Lessons learnt so far

11.1. Short-term calls for action

- Given the unique and complex needs of people living with dementia, measures to ease the current restrictions on close family members' visits to nursing homes and care homes should now be reviewed.
- According as the pandemic crisis eases, the restrictions on family members' visits to hospital need to be reviewed.
- There is a need for staff training in relation to delivering personal care tasks to people who have dementia especially given cocooning and physical distancing requirements.
- 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.
- There is a need for counselling services and post-traumatic support to be made available to front-line staff working in nursing homes.

11.2. Longer term policy implications

- 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.
- Like in other European countries legislation must be developed and enacted to ensure that a proportion of all new build nursing homes are designed as small scale domestic dwellings.
- 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.
- The testing 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.

12. Note on data

Many of the reports cited here are updated on a daily or weekly basis, and several of the academic publications are currently undergoing peer-review.