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Impact and Mortality of COVID-19 on People Living With Dementia: Cross-Country Report

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INTERNATIONAL
LONG TERM CARE
POLICY NETWORK

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Itccovid.org

This document is available through the website Itccovid.org, which was set up in March 2020 as a rapidly shared collection of resources for community and institution-based long-term care responses to Covid-19. The website is hosted by CPEC at the London School of Economics and Political Science and draws on the resources of the International Long Term Care Policy Network.

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Note: If you notice any inaccuracy in this report or would like to contribute to future versions, please email aida.gonzalez@ucl.ac.uk

1. Key findings

- We have collected **data on impact and mortality of COVID-19** in people living with dementia in **9 countries**: The United Kingdom (UK), Spain, Ireland, Italy, Australia, the United States (US), India, Kenya and Brazil.
- The share of people whose deaths were linked to COVID-19 in care homes who had dementia **ranges from 29% to 75% across those countries**. Within countries, people with dementia account for 25% of all COVID-19 related deaths in England and Wales, 31% in Scotland and 19% in Italy. We **did not find nation-level data** for the rest of the countries. The high rates of deaths in people living with dementia seem to be **linked to death rates in care homes**, where many residents have dementia.
- Direct comparison between countries is not possible due to **differences in systems of information**: the types of data collected and ways in which they are reported, metrics used and varying definitions of COVID-19 cases and care home facilities. The different approaches to collecting and reporting data across different administrative or autonomous regions within the same nation also hinders the extraction of national-level figures in some countries (e.g. the 4 countries in the UK, the 17 Autonomous Communities in Spain and the different administrative regions in Italy).
- In many places, the **basic human rights of people with dementia may have been compromised** during the pandemic. These rights include access to Intensive Care Units, hospital admissions, health care and palliative care. The controversial **ban on visits** (including spouses and care partners) to care homes across the world, have kept people with dementia detached from essential affective bonds and provision of family care for many months. There is now a pressing need and also an **opportunity for innovation**, looking at new ways of providing services such as allowing visits to care homes and access to healthcare. Excellent examples of both are contained in this report.
- **Guidelines and tools** to support institutions and practitioners to respond better to the needs of people with dementia during the pandemic are needed as a matter of urgency. Confinement, isolation and many of the challenges brought about by the pandemic are detrimental to the cognitive and mental health symptoms in people with dementia across the world, both those living in the community and care homes¹.
- This report offers a list of short-term and long-term actions needed to ensure that **people with dementia are not being left behind in this pandemic or future ones**.

¹ <https://ltccovid.org/2020/07/01/detrimental-effects-of-confinement-and-isolation-on-the-cognitive-and-psychological-health-of-people-living-with-dementia-during-covid-19-emerging-evidence/>

2. Introduction:

This report brings together international evidence on the impact of the COVID-19 pandemic on people living with dementia and an overview of international policy and practice measures to mitigate the impact of COVID-19 among people living with dementia.

This work is part of a voluntary international effort to facilitate learning on the impact of COVID-19 on people who use and provide long-term care ([LTCcovid.org](https://lccovid.org)). This is a “living report” which the authors will continue to update and expand as more data and evidence become available. Offers to join the collaboration and improve this report are very welcome, please email aida.gonzalez@ucl.ac.uk if you would like to contribute.

3. Dementia and vulnerability to severe impacts of COVID-19 infections

Dementia is an umbrella term used to describe a range of progressive syndromes affecting the brain and impairing high level cognitive functions such as memory, language and thinking, and accompanied by a deterioration in the ability to perform everyday activities or impairment in social functioning^{2,3}. It has been estimated that around 50 million⁴ people are living with dementia worldwide, 60% of whom live in low- and middle-income countries (LMICs). The most common form of dementia is Alzheimer’s disease (AD), accounting for up to 70% of all dementia cases in the world, followed by vascular dementia, dementia with Lewy bodies and frontotemporal dementia⁵. Although dementia is a condition related to older age, around 5% of all people who develop dementia have early- or young-onset dementia [before the age of 65]^{6,7,8}. The most common young-onset dementia is typical and atypical forms of AD followed by frontotemporal dementia⁹. People living with dementia may experience a wide range of non-cognitive symptoms such as delusions, depression, anxiety, apathy, sleep disturbance and agitation that may be influenced by biological, psychological, environmental and social factors, as well as behaviours produced by unmet needs (responsive behaviours). These limitations in performing activities of daily living progress from mild (e.g. the person only needs support with finances) to moderate (e.g. requiring support with activities like getting dressed) to severe (e.g. needing support to have a meal or walk). A recent report suggests that 85% of the people living with dementia in the United Kingdom (UK) are living with moderate to severe dementia¹⁰.

² <https://www.psychiatry.org/psychiatrists/practice/dsm>

³ <https://www.who.int/classifications/icd/en/>

⁴ <https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Rates%20of%20dementia,is%20between%205%2D8%25.>

⁵ <https://www.who.int/news-room/fact-sheets/detail/dementia>

⁶ <https://pubmed.ncbi.nlm.nih.gov/30707186/>

⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4356853/>

⁸ <https://pubmed.ncbi.nlm.nih.gov/19478230/>

⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2947856/>

¹⁰ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

People living with dementia may also experience social stigma due to discriminatory policies and the poorly informed perceptions and attitudes of others to dementia. These negative attitudes adversely impact on people living with the condition and were the topic of the World Alzheimer Report 2019¹¹. In the COVID-19 era, the vulnerability of the individual has increased exponentially with the new challenges brought by the pandemic^{12,13}.

The majority of people with dementia live in the community, especially in LMICs¹⁴. However, as dementia progresses, a large proportion of people will require 24 hour care, many people will continue to live in their own home, with family and sometimes formal care (such as home help, day care) and others may move into nursing and other residential care homes or facilities. Available data suggests that the majority of care home residents have dementia, estimates range from 85% in Austria¹⁵, 70% in Canada¹⁶, 61% in Spain¹⁷, 56% in the Czech Republic¹⁸ and 47% (of nursing home residents) in Switzerland¹⁹. In Ireland, where there are over 30,000 people living in nursing homes (including both private, voluntarily and public), it is estimated that between 15,000 and 20,000 of them have dementia^{20,21}. An estimated 86% of care home residents in England have dementia²². Where people with dementia live is particularly relevant when describing the impact of the COVID-19 pandemic on this population, since up to half or more of COVID-19 related deaths²³ in many countries have occurred in care/nursing homes^{24,25,26}. These data should however be interpreted cautiously since definitions of ‘nursing home’ and ‘care home’ differ across countries and there is no universally accepted definition for the different long-term-care services.

3.1. Dementia and COVID-19 infection

The majority of COVID-19-related deaths (around 86%) have been reported among people aged 65 and over, with 39% of these occurring in the over-85 age group in the UK²⁷ (this statistic varies across different countries). Although there is no clear evidence that dementia itself increases the risk of COVID-19 infection, the cognitive difficulties associated with the condition

¹¹ <https://www.alz.co.uk/research/world-report-2019>

¹² <https://www.bmj.com/content/369/bmj.m2463/rr-0>

¹³ <https://www.bmj.com/content/369/bmj.m2489>

¹⁴ <https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf>

¹⁵ <https://link.springer.com/article/10.1186/s12877-018-0870-8>

¹⁶ https://ltccovid.org/wp-content/uploads/2020/05/LTCCovid-country-reports_Canada_Hsu-et-al_May-10-2020-2.pdf

¹⁷ <https://www.elsevier.es/es-revista-revista-espanola-geriatria-gerontologia-124-articulo-prevalencia-demencia-pacientes-institucionalizados-estudio-S0211139X08000024>

¹⁸ <https://link.springer.com/article/10.1186/s12877-018-0870-8>

¹⁹ [https://www.alzheimer-europe.org/Policy/Country-comparisons/2017-Standards-for-Residential-Care-Facilities/Introduction/Prevalence-and-regulation/Dementia-in-nursing-homes-in-Switzerland/\(language\)/eng-GB](https://www.alzheimer-europe.org/Policy/Country-comparisons/2017-Standards-for-Residential-Care-Facilities/Introduction/Prevalence-and-regulation/Dementia-in-nursing-homes-in-Switzerland/(language)/eng-GB)

²⁰ <https://ltccovid.org/wp-content/uploads/2020/05/Ireland-COVID-LTC-report-updated-13-May-2020.pdf>

²¹ <https://www.cambridge.org/core/journals/irish-journal-of-psychological-medicine/article/estimates-of-the-prevalence-incidence-and-severity-of-dementia-in-ireland/8A8BA41B1FC348E5233ACB50497E522D>

²² <https://pubmed.ncbi.nlm.nih.gov/28794896/>

²³ <https://ltccovid.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/>

²⁴ <https://ltccovid.org/wp-content/uploads/2020/06/Mortality-associated-with-COVID-among-people-who-use-long-term-care-26-June-1.pdf>

²⁵ <https://es.jamanetwork.com/journals/jamanetworkopen/fullarticle/2768539>

²⁶ <https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.16669>

²⁷ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19roundup/2020-03-26#coviddeaths>

may make it more difficult for the person with dementia to understand and comply with protective measures. People living with dementia also tend to be older as age is the main risk factor for dementia. They often have hypertension and diabetes which are risk factors for dementia, as well as cardiovascular disease, and chronic obstructive pulmonary disease; all of these increase the risk of complications and death in the case of an infection^{28,29}. In addition, people with dementia who develop infections are more likely to develop delirium, which complicates management and compromises the future cognitive health of the person. People with dementia also experience greater functional loss during hospital stays³⁰ and are likely to experience worse post-discharge functional recovery than those without dementia³¹. People with dementia who are admitted to hospital may not return home but instead may be discharged to a care home or transferred to a different part of the care home. Some may be discharged to a quarantine centre or to a step-down facility after hospitalization. These changes in environment may increase cognitive and functional impairment as people with dementia find it particularly difficult to take on new learning and manage new environments.

A study examining COVID-19 deaths in the electronic health records of 17 million adults in the UK's National Health Service (NHS) suggests that people with dementia were at a higher risk of COVID-19 hospital deaths³². The likelihood that more severe COVID-19 presentation might be increased in people living with dementia has been suggested by a UK Biobank community cohort examining the predictive value of pre-existing comorbidities on the development of severe COVID-19³³. A UK biobank study (N = 322,948, of whom 622 were COVID-19 positive) found that the ApoEε4 allele increases the risk of severe COVID-19 infection³⁴, independent of pre-existing dementia, cardiovascular disease, and type-2 diabetes. ApoEε4 is a well-established genetic risk factor for dementia. In addition, in one of the earliest cohorts studies undertaken in Italy, the authors describe a significantly higher mortality rate of 62% among those living with dementia and COVID-19 compared to 26.2% in those without dementia³⁵. Mortality increased with dementia severity but the rate of mortality on those in stage 1 (or mild dementia according to the Clinical Dementia Rating Scale [CDR]) was already 41%. A diagnosis of dementia was independently associated with higher mortality regardless of age³⁶.

3.2. Neurological impact of COVID-19 which might worsen dementia or increase risk

Emerging evidence suggests that COVID-19 infections often affect the brain, producing neurological symptoms and increased risk of stroke. Overall the most common neurological symptoms are loss of sense of smell, or taste and headache³⁷. However, a retrospective case

²⁸ <https://bmccgeriatr.biomedcentral.com/articles/10.1186/1471-2318-14-10>

²⁹ <https://www.ncbi.nlm.nih.gov/books/NBK344387/>

³⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6099229/>

³¹ <https://pubmed.ncbi.nlm.nih.gov/29723848/>

³² <https://www.medrxiv.org/content/10.1101/2020.05.06.20092999v1.full.pdf>

³³ <https://www.medrxiv.org/content/10.1101/2020.05.06.20092700v1>

³⁴ <https://academic.oup.com/biomedgerontology/article/doi/10.1093/gerona/glaa131/5843454>

³⁵ <https://link.springer.com/article/10.1007/s12603-020-1389-1>

³⁶ <https://link.springer.com/article/10.1007/s12603-020-1389-1>

³⁷ <https://jamanetwork.com/journals/jamaneurology/fullarticle/2766766>

series of 214 COVID-19 patients from Wuhan, China reported neurologic symptoms in 36% of patients with mild COVID-19 infection, and 45% of patients with severe infection³⁸, although part of these symptoms are non-specific (e.g. headache, muscle pain). A retrospective analysis of data from 107 Italians hospitalised with COVID-19 who had MRI or CT scans found that the main neurological hallmark was acute ischemic infarcts (31%)³⁹. This may be one of the reasons for people with dementia who have had COVID-19 to deteriorate further, and those without dementia might be at increased risk of future dementia⁴⁰. In addition, a potential role of SARS-CoV-2 as a trigger for neurodegeneration is under debate^{41,42,43}.

3.3. Presentation of COVID-19 in people living with dementia

Clinical presentation of COVID-19 in older persons may be atypical, as indicated by a summary of recent evidence by the British Geriatrics Society⁴⁴ and this also applies to people living with dementia. In a retrospective study⁴⁵ describing a series of patients from 2 acute hospitals in Brescia, Italy, delirium was the most frequent symptom onset among people with dementia and COVID-19 accounting for 67% of all cases. Fever was only present in 47% of patients, dyspnoea in 44% and a cough in 14%. When it comes to care home settings, data from 4 nursing homes in London⁴⁶ (UK), showed that 43% of infected residents were asymptomatic and 18% had atypical symptoms such as ‘newly’ altered mental status or behaviour, anorexia, diarrhoea or vomiting. In the early days of the pandemic, the asymptomatic presentations of COVID-19 in older people made it difficult for clinicians and care home staff to identify the condition and minimise or engage in infection control.

4. International evidence of impact: mortality figures

4.1. Mortality figures

Since the highest proportion of COVID-19 deaths occur in care homes/nursing homes where a large proportion of residents have dementia, it is not surprising that the numbers of COVID-19 related deaths among people with dementia is also large. In table 1 below we summarize available mortality figures from several countries, also describing where data is missing. Some methodological aspects to consider include:

³⁸ <https://jamanetwork.com/journals/jamaneurology/fullarticle/2764549>

³⁹ <https://pubs.rsna.org/doi/pdf/10.1148/radiol.2020201933>

⁴⁰ <https://www.clinicalkey.com.au/#/content/playContent/1-s2.0-S0889159120303573?returnurl=https%3F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS0889159120303573%3Fshowall%3Dtrue&referrer=https%3F%2Fpubmed.ncbi.nlm.nih.gov%2F32240762%2F>

⁴¹ <https://pubmed.ncbi.nlm.nih.gov/32396710/>

⁴² <https://onlinelibrary.wiley.com/doi/full/10.1002/mds.28084>

⁴³ <https://alzres.biomedcentral.com/articles/10.1186/s13195-020-00640-3>

⁴⁴ <https://www.bgs.org.uk/blog/atypical-covid-19-presentations-in-older-people-%E2%80%93-the-need-for-continued-vigilance>

⁴⁵ <https://link.springer.com/article/10.1007/s12603-020-1389-1>

⁴⁶ <https://www.medrxiv.org/content/10.1101/2020.05.19.20105460v1>

- There is wide variation in definitions of care homes across different countries and how long-term care systems are organised. For the purpose of the current report, when referring to ‘care homes’ we include any kind of long-term care facility that is not home-based. This includes nursing homes, skilled nursing facilities, assisted living facilities, residential facilities and residential long-term care facilities for people who are unable to live independently in the community (excluding those with disabilities or mental health problems)⁴⁷ .
- There is also substantial variation in the way data is collected across and within countries. For instance, the majority of data we have from the UK so far only covers England and Wales; while the data from US comprises all 50 states but only includes data from nursing homes.
- We have drawn on official governmental sources for most of our data but in some cases, where this was not possible we either relied on other sources such as NGO’s or the authors themselves have generated their own devised estimates (details about how these estimates were arrived at are documented and referenced with superscripts across the table).

Table 1. Estimated COVID-19 related mortality of people with dementia in 9 countries.

Country (date update)	Estimated number COVID-19 deaths/ COVID-19 cases in the country	Total deaths of care homes residents/number of care home residents in the country (care homes for old people only)	Estimated number of people with dementia in the country	Percentage of care home residents that have dementia in the country (%)	Proportion or number of residents with dementia who died (% of all COVID deaths in care homes) /infected cases	COVID-19 deaths of people with dementia in the country (% of all COVID-19 deaths in the country)
United Kingdom (06-08-	46,413/308,134 (confirmed) ⁴⁸	19,394 ⁴⁹ / <i>not found</i> (England and	850.000 ⁵⁰ (UK)	86% ⁵¹	49% ⁵² / <i>not found</i> (England	12, 869 (25% ⁵³ England and Wales

⁴⁷ https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1

⁴⁸ <https://coronavirus.data.gov.uk/>

⁴⁹ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedinthehealthsectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional>

⁵⁰ <https://www.england.nhs.uk/mental-health/dementia/>

⁵¹ <https://pubmed.ncbi.nlm.nih.gov/28794896/>

⁵² https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedinthehealthsectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional?WT.mc_id=f5e0eb1233c5d2a1a4a1b591e46fecbd&hootPostID=1376c0e546f27d0e33d8ce1e242a810f

⁵³ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvedinthehealthsectorenglandandwales/deathsoccurringinJune2020#pre-existing-conditions-of-people-who-died-with-covid-19>

2020)		Wales only)			and Wales only)	only) (31% ⁵⁴ Scotland only)
Spain (06-08-2020)	28,500/309,855 (confirmed) ⁵⁵	19,576 ⁵⁶ / <i>not found</i>	371200-835000 ^a	61% ⁵⁷ - 76% ⁵⁸	11,941 - 14,877 ^a (61-75%)/ <i>not found</i>	<i>not found</i>
Ireland (06-08-2020)	1,510/26,303 (confirmed) ⁵⁹	967 ^{60*} / <i>not found</i>	39,272 - 55,266 ⁶¹	72% ⁶²	250 ^c (29%)/ <i>not found</i>	<i>not found</i>
Italy (04-08-2020)	34,211/246,428 (confirmed) ⁶³	<i>partial data</i> ^d	1,000,000 ⁶⁴	<i>not found</i>	<i>not found</i>	19% ^b
Australia (09-08-2020)	295/ 21,084 (confirmed) ⁶⁵	203 / 299,000 ⁶⁵	459,000 ⁶⁶	53%	108 (53%) / (669 cases were people w dementia, out of total 1263) ⁶⁷	<i>not found</i>
United States (10-08-2020)	161,284/4,974,959 (confirmed) ⁶⁸	43,231 ⁶⁹ / 1,246,079 ⁷⁰	5,800,000 ⁷¹	47.8% ⁷²	<i>not found</i>	<i>not found</i>
India (11-08-2020)	45,257/2,223,418 ⁷³ (confirmed)	<i>not found</i>	5,290,000 ⁷⁴	<i>not found</i>	<i>not found</i>	<i>not found</i>
Kenya (13-08-2020)	456/28,104 ⁷⁵	<i>not found</i>	<i>not found</i>	<i>not found</i>	<i>not found</i>	<i>not found</i>
Brazil (13-08-2020)	105,463/3,224,876 ⁷⁶ (confirmed)	<i>partial data</i> ^e	2,000,000 ⁷⁷	<i>not found</i>	<i>not found</i>	<i>not found</i>

⁵⁴ <https://www.nrscotland.gov.uk/covid19stats>

⁵⁵ https://www.msccbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov-China/documentos/Actualizacion_179_COVID-19.pdf

⁵⁶ <https://www.rtve.es/noticias/20200806/radiografia-del-coronavirus-residencias-ancianos-espana/2011609.shtml>

⁵⁷ <https://www.sciencedirect.com/science/article/abs/pii/S0211139X08000024>

⁵⁸ <https://pubmed.ncbi.nlm.nih.gov/19237032/>

⁵⁹ [https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/COVID-19_Daily_epidemiology_report_\(NPHET\)_06082020%20-%20Website.pdf](https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/COVID-19_Daily_epidemiology_report_(NPHET)_06082020%20-%20Website.pdf)

⁶⁰ <https://www.gov.ie/en/publication/72d92-updates-on-covid-19-coronavirus-from-april-june-2020/>

⁶¹ <https://pubmed.ncbi.nlm.nih.gov/31187725/>

⁶² <https://doi.org/10.1017/ipm.2018.31>

⁶³ https://www.epicentro.iss.it/coronavirus/bollettino/Bollettino-sorveglianza-integrata-COVID-19_28-luglio-2020.pdf

⁶⁴ <https://demenze.iss.it/epidemiologia/>

⁶⁵ <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-current-situation-and-case-numbers>

⁶⁶ <https://www.dementia.org.au/statistics>

⁶⁷ <https://www.gen-agedcaredata.gov.au/Resources/Reports-and-publications/2011/May/Dementia-among-aged-care-residents-first-informat>

⁶⁸ <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html>

⁶⁹ <https://data.cms.gov/stories/s/COVID-19-Nursing-Home-Data/bkwz-xpvg/>

⁷⁰ <https://www.kff.org/other/state-indicator/number-of-nursing-facility-residents/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

⁷¹ <https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12068>

⁷² <https://www.cdc.gov/nchs/fastats/alzheimers.htm>

⁷³ <https://www.mohfw.gov.in/>

⁷⁴ <https://ardsi.org/pdf/annual%20report.pdf>

⁷⁵ <https://www.worldometers.info/coronavirus/country/kenya/>

2020)						
<p>All data is official data provided by government websites agencies unless specified.</p> <p>a Estimates calculated by the authors based on figures of prevalence of dementia in care homes</p> <p>b Author calculations. Estimates based on reported comorbidities on available data: www.epicentro.iss.it/en/coronavirus/bollettino/Report-COVID-2019_22_july_2020.pdf</p> <p>c Authors estimation. Details of how this figure has been calculated can be found in https://ltccovid.org/wp-content/uploads/2020/06/COVID-19-and-Dementia-Ireland.pdf</p> <p>d Partial data from a survey conducted on 1,356 out of the 3,292 contacted care homes in Italy, reporting 9,154 deaths out of 97,521 residents⁷⁸</p> <p>e Partial data from a survey conducted on 1,802 contacted care homes where 42,216 people lived and 458 have died of Covid-19⁷⁹</p> <p>*data from 6th of May 2020</p>						

United Kingdom (England and Wales)

25.6% of all deaths recorded as COVID-19 between March and June 2020 in England and Wales were in people living with dementia, and dementia was also the most common pre-existing condition among people whose deaths involved COVID-19⁸⁰. Half of all COVID-19 related deaths in care homes in England and Wales (49.5%) were in people living with dementia⁸¹. In addition to those figures, there has been an increase of 52.2% excess deaths due to dementia⁸² between March and June. Considering that around 86%⁸³ of care home residents in England have dementia, these excess death rates may be explained by a combination of factors. Many may be missed COVID-19 diagnosis, as people who were not admitted to hospital were not tested. In addition, there may be COVID-19 indirect deaths if there has been lack of appropriate care due to staff shortages in care homes, difficulties in accessing medical care during the hardest weeks of the pandemic and the deleterious effect of confinement and isolation and the measures to manage it (e.g. hypothesised increases in use of antipsychotics or benzodiazepines)⁸⁴. A proportion of deaths were in the community among recipients of home care services. Between April to June 2020, 3,628 excess death (50% of total 6,523 deaths) were registered in England among recipients of domiciliary care⁸⁵.

Spain

Figures on 28th June showed that in Spain 19,576⁸⁶ care home residents have died of confirmed or probable COVID-19. Given that between 61%⁸⁷ and 76%⁸⁸ of care homes residents in Spain

⁷⁶ <https://covid.saude.gov.br/>

⁷⁷ <https://sbgg.org.br/em-dia-mundial-do-alzheimer-dados-ainda-sao-subestimados-apesar-de-avancos-no-diagnostics-e-tratamento-da-doenca>

⁷⁸ <https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf>

⁷⁹ <https://preprints.scielo.org/index.php/scielo/preprint/view/1032>

⁸⁰ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvedwithcovid19englandandwales/deathsoccurringinJune2020#pre-existing-conditions-of-people-who-died-with-covid-19>

⁸¹ https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedwithcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional?WT.mc_id=f5e0eb1233c5d2a1a41b591e46fecbd&hootPostID=1376c0e546f27d0e33d8ce1e242a810f

⁸² <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/analysisofdeathregistrationsnotinvolvingcoronaviruscovid19englandandwales28december2019to1may2020/technicalannex#deaths-due-to-dementia-and-alzheimer-disease>

⁸³ <https://pubmed.ncbi.nlm.nih.gov/28794896/>

⁸⁴ <https://www.heraldscotland.com/news/18591144.sedation-linked-dementia-deaths-rise-scotland/>

⁸⁵ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedwithcovid19inthecaresectorenglandandwales/deathsoccurringupto12june2020andregisteredupto20june2020provisional#deaths-of-recipients-of-domiciliary-care-in-england>

⁸⁶ <https://www.rtve.es/noticias/20200628/radiografia-del-coronavirus-residencias-ancianos-espana/2011609.shtml>

⁸⁷ <https://www.sciencedirect.com/science/article/abs/pii/S0211139X08000024>

have dementia, proxy estimates would suggest a share of between 11,941 and 14,877 deaths of people with dementia in the country⁸⁹. This is likely to be a conservative estimate, as total excess mortality is 58%⁹⁰ compared with previous year (44,543 excess deaths compared to the official 28,343⁹¹) and current reported deaths are therefore likely to double official figures. Moreover, this calculation is based on the assumption that people with dementia in care homes are as likely to die of COVID-19 as those without dementia, whereas there is emerging evidence pointing towards increased vulnerability to COVID-19 for those with dementia⁹². Lastly, people with dementia who lived in the community and died of COVID-19 would not be factored in this estimation neither.

United States

A national sample of 10,000 COVID-19 cases in US nursing homes found a higher prevalence of COVID-19 as well as deaths from COVID-19 amongst residents living with dementia⁹³. Residents living with dementia made up 52% of all COVID-19 cases; yet, accounted for an astonishing 72% of all deaths from COVID-19 in this sample.

Ireland

In Ireland, while there is currently no dementia specific data on COVID-19 related deaths, it was reported (up to and including August 8th), that among people with an underlying chronic health condition, 34.1% (498/1,459) of deaths from COVID-19 were of people who had a chronic neurological disease, which might include people with dementia⁹⁴. Up to the 27th June, approximately 63% (1,088/1,735) of all deaths have occurred in residential facilities, this includes nursing homes, community hospitals, long-stay units and other residential institutions such as mental health facilities, prisons and centres for those seeking asylum in Ireland⁹⁵. The majority of these deaths were related to nursing homes as 56 % (967/1,735) of all deaths have occurred in nursing homes. The figure for total deaths includes confirmed, possible and probable cases of COVID-19^{96,97}. As it is estimated that up to 72% of residents in nursing homes in Ireland have dementia⁹⁸, it is highly likely that a significantly higher proportion of people with dementia have died from COVID-19 in such settings. An earlier report estimated that between 175 and 250 people with dementia have died from COVID-19 in nursing homes in Ireland⁹⁹. However, it is also important to note that there have been inconsistencies in methodologies

⁸⁸ <https://pubmed.ncbi.nlm.nih.gov/19237032/>

⁸⁹ <https://ltccovid.org/2020/08/10/updated-report-impact-and-mortality-of-the-first-wave-of-covid-19-on-people-living-with-dementia-in-spain/>

⁹⁰ https://momo.isciii.es/public/momo/dashboard/momo_dashboard.html

⁹¹ https://www.mschs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov-China/documentos/Actualizacion_150_COVID-19.pdf

⁹² <https://pubmed.ncbi.nlm.nih.gov/32706392/>

⁹³ <https://careporthealth.com/wp-content/uploads/2020/05/COVID-19-Report-3.pdf>

⁹⁴ <https://www.hpsc.ie/az/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary%2020052020.pdf>

⁹⁵ <https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/june2020/> (29 June 2020)

⁹⁶ https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid-19_response/reports/2020/2020-07-31_interim-report-on-covid-19-in-nursing-homes_en.pdf

⁹⁷ [https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/june2020/COVID-19_Daily_epidemiology_report_\(NPHET\)_v1.15_final.pdf](https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/june2020/COVID-19_Daily_epidemiology_report_(NPHET)_v1.15_final.pdf)

⁹⁸ <https://pubmed.ncbi.nlm.nih.gov/31187725/>

⁹⁹ <https://ltccovid.org/wp-content/uploads/2020/06/COVID-19-and-Dementia-Ireland.pdf>

used to report overall mortality figures. An analysis of excess mortality in Ireland between the 11th of March and the 16th of June 2020 found a significantly lower figure (1,073) than the officially reported COVID-19 related mortality (1,709). This, according to the authors may be due to the inclusion of people who contracted COVID-19 at end-of-life stage, or whose cause of death may have been due to other factors, despite the fact the individual had COVID-19¹⁰⁰.

Italy

Of the 34,142 COVID-19 positive deceased patients in Italy (as of July 23rd 2020), 756 (of a total of 3,952 cases with data available) had a diagnosis of dementia and 418 of stroke¹⁰¹, representing two of the most common comorbidities in COVID-19 deaths (19.1% and 10.6% of all comorbidities respectively). There is no consistent data on people living with dementia in care or nursing homes in Italy, as the organizations are extremely heterogeneous throughout the territory. It estimated that in 2016, 2,909,090 people over the age of 65 (including people with dementia) were not self-sufficient, but only 273,204 of them were living in residential care facilities (287,328 if including the social residential facilities)¹⁰². This makes recording the COVID-19 deaths in this population even more difficult. There is only a survey¹⁰³ from the National Institute of Health (*Istituto Superiore di Sanità*, ISS) that specifically investigates the high number of deaths registered in residential centres for older people¹⁰⁴. The survey collected data through a questionnaire sent to 3,292 residential homes between February 1st and May 5th 2020. These facilities (which represent 96% of the total Italian territory) are listed among the dementia services by the ISS Dementia Observatory, and these include residential health and social-health facilities, public and private, which host predominantly people with dementia (but not exclusively). Only 1,356 facilities took part in the survey. When considering both patients tested positive for COVID-19 or showing symptoms compatible with SARS-CoV-2 (such as cough, dyspnea, fever, pneumonia or respiratory failure), the mortality rate among the residents was 3.1% in Italy and 6.5% in Lombardy, with the Italian region being the most badly hit by the virus¹⁰⁵.

Low and Middle-Income Countries (LMICs)

In LMICs such as India, there is currently no data available on COVID-19 related deaths in persons with dementia. However, approximately 50.5% of all deaths from COVID-19 have been in those aged 60 years and above and 73% of total deaths have been among individuals with underlying co-morbidities (as of May 21st, 2020)¹⁰⁶. No data had been identified for Brazil and Kenya at the time of writing (August 2020).

5. Impacts on people with dementia living in care homes

¹⁰⁰ <https://www.hiqa.ie/reports-and-publications/health-technology-assessment/analysis-excess-all-cause-mortality-ireland>

¹⁰¹ https://www.epicentro.iss.it/en/coronavirus/bollettino/Report-COVID-2019_22_july_2020.pdf

¹⁰² https://www.cergas.unibocconi.eu/wps/wcm/connect/73024a58-4ae1-4ccf-9280-47b58ea2e448/Cap5OASI_2019.pdf?MOD=AJPERES&CVID=mWPGsIR

¹⁰³ <https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf>

¹⁰⁴ <https://ltccovid.org/wp-content/uploads/2020/04/LTC-COVID19-situation-in-Italy-22-April-2020.pdf>

¹⁰⁵ https://ltccovid.org/wp-content/uploads/2020/06/Mortality_Italy-25-June.pdf

¹⁰⁶ <https://pib.gov.in/PressReleasePage.aspx?PRID=1625744>

For people living with dementia in care homes or nursing homes, the measures introduced to prevent and control the spread of infection may pose particular challenges as they require new learning and adjustment to everyday routine. This in turn can contribute to a deterioration in symptoms and quality of life.

The high level of dependence of people living with dementia on caregivers makes it very difficult to maintain social distancing especially when a person needs more intimate support with personal care. Providing care while wearing personal protective equipment (PPE) comes with its own challenges too, since residents may find it difficult to recognise their usual carers through the masks and protective attire and will find it more difficult to understand and communicate with them. If PPE supply is scarce or insufficient (and only allocated to COVID-19 cases or primarily directed to hospitals) this will increase the risk of exposure to infection for both residents and care staff. If care home staff who are positive continue to work, they will infect others not only in the facility, but also at home and in communities. In Ireland, for instance there were concerns that agency staff, (where care staff may work in several different long-term care settings), would increase the risk of spreading COVID-19 from one setting to the next¹⁰⁷. In places where staff members became infected and stopped working, staff shortages placed a further strain on other staff members, threatening quality of care and residents' safety. For instance, it has been noted that the "confinement disease" - the effect of leaving people alone in their rooms due to staff shortages with no assistance for drinking and eating – may have proven to be even more deleterious than the virus itself¹⁰⁸.

When asked about the major issues encountered during the crisis 77.2% of respondents in Italian nursing homes stated that it was the lack of PPE, 52.1% the difficulty in getting tested, 20.9% mentioned weak guidelines given to limit the spread of the disease (only about half received dedicated training), 33.8% lack of care workers, and 26.2% difficulty in isolating patients testing positive^{109,110}. In particular, only 48.1% of the nursing homes have the facilities to isolate a positive or suspected case in a separate room, 30.7% grouped positive (confirmed or suspected) patients and isolated them from the other residents, and 7.7% could not isolate the patients. 21.1% declared that they had at least a member of the staff who tested positive for COVID-19.

A study conducted in a care home in the south of France that accommodated a total of 140 residents found that 24 deaths¹¹¹ were due to hypovolemic shock (severe condition resulting from losing more than 1/5 of body's fluid supply). This was attributed to a 40% staff absenteeism that caused residents' needs to be neglected. This "confinement disease", as described, may be particularly lethal for people living with dementia¹¹². Anxiety, depression and overall quality of life may be adversely affected as result of confinement. The latter may also lead to the cessation of eating. 5.7% of nursing homes in Italy reported an increased in

¹⁰⁷ <https://ltccovid.org/wp-content/uploads/2020/04/Ireland-COVID-LTC-report-updated-28-April-2020.pdf>

¹⁰⁸ [https://www.jamda.com/article/S1525-8610\(20\)30354-6/pdf](https://www.jamda.com/article/S1525-8610(20)30354-6/pdf)

¹⁰⁹ <https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf>

¹¹⁰ <https://ltccovid.org/wp-content/uploads/2020/04/LTC-COVID19-situation-in-Italy-22-April-2020.pdf>

¹¹¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7196427/>

¹¹² <https://www.abebooks.co.uk/9780335198559/Dementia-Reconsidered-Person-Comes-First-0335198554/plp>

prescription of benzodiazepine and antipsychotics among residents¹¹³. In addition, the absence of scope to mobilise and the requirement to remain within the same room can lead to “deconditioning”, muscle tone loss and mobility loss.

Data from the UK Office for National Statistics reported that between March 2020 to 1st May 2020 there was an increase both in deaths registered as involving COVID-19 and deaths not involving COVID-19 among care home residents¹¹⁴. From a more recent survey on 969 new cases of COVID-19 between May 25th and June 23rd 2020 in Italy, 35.1% were infected in a care home or nursing home compared to 24.6% who got the infection from family members and 6.6% in hospital or in a surgery¹¹⁵.

The ban on visitors such as close family members, including spouses and adult children, has been a widely used measure to contain the spread of COVID-19. This has meant that many people with dementia who were used to having visits and care from family and friends, have stopped receiving these visits. For people living with dementia it may be very hard to understand and remember why their families no longer come to visit and provide care¹¹⁶ and this may lead to feelings of abandonment and to changes in mood and behaviour. Also, even within care and nursing home facilities, residents with dementia can develop new friendships and bonds with each other and the restrictions on social interaction between residents, or the death of another familiar resident is likely to have an additional deleterious impact on the individual.

A person with a moderate to advanced dementia is unlikely to be able to use a mobile phone independently or sometimes at all, and during periods of high risk of infection spread, staff will have less time to assist residents to use phones to talk to their relatives. The ISS survey in Italy, found that 68.6% of nursing homes had introduced alternative ways of communication between residents and family members: 19.4% only video calls and 6.5% only phone calls¹¹⁷. Apart from that, phone and video call contact may be unsuitable for some and insufficient for others. In China, after a month-long full lockdown, residents in care homes¹¹⁸ were described as becoming more socially isolated as a result of the measures to lessen the chance of infection (e.g. ban on visitors, prohibition of group activities), and the levels of anxiety of staff increased and they began to show signs of exhaustion and burnout.

6. Impacts on people living with dementia in the community

Across the world today, most people who have dementia live at home in the community where they are generally supported by family members (WHO, 2012). For example, in LMICs, it is

¹¹³ <https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf>

¹¹⁴ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvedwithcovid19inthecaresectorenglandandwales/deathsoccurringupto1may2020andregisteredupto9may2020provisional>

¹¹⁵ https://www.epicentro.iss.it/coronavirus/bollettino/Bollettino-sorveglianza-integrata-COVID-19_30-giugno-2020.pdf

¹¹⁶ <https://www.sciencedirect.com/science/article/pii/S0165178120307587?via%3Dihub>

¹¹⁷ <https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf>

¹¹⁸ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)30755-8/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30755-8/fulltext)

estimated that 95% of people with dementia live at home, compared to 69% in high-income countries¹¹⁹. In the UK, 61% of people who have dementia are living in the community¹²⁰ and in Ireland the figure is similar at about 63%¹²¹. In the United States, 70% of all people with dementia live in the community¹²². In Italy, it is estimated that 90% of non-self-sufficient older persons (included those with dementia) live at home with family and carers¹²³. Some of these people with dementia will be living alone and will be especially vulnerable during a pandemic crisis.

6.1. Disruption in life routines and effects on cognitive and psychological health

Residing in confinement may present particular challenges for people living with dementia¹²⁴. Interruption of previously well-established daily routines, reduction in stimulating or therapeutic activities, decreased social interaction with family and friends, and lack of access to support services may have a negative impact on both the cognitive function and quality of life of people with dementia^{125,126}. There is also emerging evidence showing the detrimental effect of confinement on the cognitive and psychological health of people living with dementia. A Spanish cohort study found that after five weeks of lockdown, people with cognitive difficulties experienced a worsening in apathy, agitation and wandering behaviour¹²⁷. An overall worsening of cognitive symptoms, reduced levels of independence and worsening or onset of behavioural disturbances/responsive behaviours was also described in an Italian cohort, with half of caregivers also reporting higher levels of stress and exhaustion¹²⁸. A study conducted in South India found that most caregivers reported non-cognitive symptoms (changes in behaviour and psychological) among their relative with dementia, with some reporting issues such as distress caused by wearing masks or anxiety from watching the news¹²⁹.

A comprehensive review of the detrimental effect of confinement and isolation in people living with dementia can be found [here](#)¹³⁰. Family caregivers of people with dementia are also likely to experience adverse effects during a pandemic crisis like COVID-19. The family carer is likely to experience isolation and will have difficulties accessing external sources of support and respite.

In Kenya, the COVID-19 lockdown has resulted in more psychological issues for persons with dementia due to feelings of being abandoned (there are limited visits by family members), the legal implications arising from being found outdoors during curfew hours, and fear of losing a

¹¹⁹ <https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf>

¹²⁰ https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf?fileID=2323

¹²¹ <https://www.lenus.ie/handle/10147/215312>

¹²² <https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12068>

¹²³ https://www.cergas.unibocconi.eu/wps/wcm/connect/73024a58-4ae1-4ccf-9280-47b58ea2e448/CapSOASI_2019.pdf?MOD=AJPERES&CVID=mWPGsIR

¹²⁴ <https://www.bbc.com/news/uk-england-52062256>

¹²⁵ <https://www.politicshome.com/members/article/alzheimers-society-launches-emergency-appeal>

¹²⁶ <https://inews.co.uk/news/health/coronavirus-lockdown-dementia-patients-access-vital-support-networks-2549727>

¹²⁷ <https://onlinelibrary.wiley.com/doi/full/10.1111/ene.14339>

¹²⁸ <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.16644>

¹²⁹ [https://www.ajgponline.org/article/S1064-7481\(20\)30405-X/fulltext](https://www.ajgponline.org/article/S1064-7481(20)30405-X/fulltext)

¹³⁰ <https://ltccovid.org/wp-content/uploads/2020/07/LTCCovid-1-July-Detrimental-effects-confinement-on-people-with-dementia.pdf>

family member to the outbreak. The spatial distancing requirement (without physical contact) has also been perceived as disrespectful to persons with dementia as in Kenya, waving, closed fists, elbow greetings or keeping physically distant from a close relative is considered to be culturally inappropriate. In other circumstances, the increase in the time spent between together the person with dementia and the carer has caused more tension, contentions and conflicts while giving care.

6.2. Disruption of home care services

Some people living with dementia may rely heavily on external formal support services that may have been interrupted since the pandemic started. The provision and continuity of care and support services for people living with dementia have been disrupted in places where home care providers were not able to equip staff with PPE or where users refused the services because of the threat of infection. For instance, a survey of 1,307 family carers in Ireland (not specific to dementia) found that 14% of carers surveyed had cancelled home care provision to reduce the risk of infection and 47% were unable to access PPE¹³¹. In Ireland home care staff became scarce since they were redeployed to strengthen the response of the care home sector¹³².

Inadequate staffing or the replacement of staff on sick leave with untrained staff or staff unfamiliar with residents' life stories may adversely impact on the support that people received in relation to eating, washing, taking medication and other activities of daily living. On the other hand, if services continue without proper infection-control measures, this may also put the care recipient at risk. It is suspected that some older persons have died alone in their homes during confinement¹³³ without anyone noticing until days or weeks after. It is still unknown whether some of them were people with dementia.

Surveys have shown that family carers report increased stress at having to provide more support for people living with dementia as day care centres and other group services are not available¹³⁴. There are reduced opportunities to interact with others in their family and community, and increased responsibility to ensure that the person with dementia has satisfactory hygiene and adhering to physical distancing requirements. The UK charity Alzheimer's Society, has reported a 600% increase in people joining their online community since the pandemic started and launched an Emergency Appeal¹³⁵ to support vulnerable people affected by dementia who may be isolated and not receiving the basic support to help them eat, wash and take medication during the pandemic. Similarly, another UK based charity, Dementia UK, reported a 44% increase¹³⁶ in calls to their Admiral Nurse helpline during lockdown.

¹³¹ <https://familycarers.ie/media/1394/caring-through-covid-life-in-lockdown.pdf>

¹³² <https://itccovid.org/2020/04/15/the-impact-of-covid-19-on-people-who-use-and-provide-long-term-care-in-ireland-and-mitigating-measures/>

¹³³ <https://www.theguardian.com/world/2020/jun/07/uk-coronavirus-victims-have-lain-undetected-at-home-for-two-weeks>

¹³⁴ <https://alzheimer.ie/wp-content/uploads/2020/04/Research-report-Covid19-Final..pdf>

¹³⁵ <https://www.alzheimers.org.uk/news/2020-04-02/alzheimers-society-launches-emergency-appeal-support-vulnerable-people-dementia>

¹³⁶ <https://news.sky.com/story/coronavirus-dementia-charity-sees-44-increase-in-calls-during-covid-19-lockdown-11985503>

A study of 93 people living with dementia or mild cognitive impairment enrolled in a Spanish trial of a television-based assistive integrated service found that most participants did not report negative impacts on accessing food or healthcare during lockdown¹³⁷. Specific negative experiences reported included fear of becoming infected with COVID-19 or infecting family members, frustration and boredom due to not being able to take part in daily activities, loss of usual routine, and social isolation. Participants living alone reported worse wellbeing, more anxiety and sleeping problems. The television-based assistive group (n = 47) did not report better wellbeing than the usual care control group (n = 46). A study by the Alzheimer Society of Ireland of people living with dementia, family carers and dementia community champions found several ways in which participants had been negatively impacted by COVID-19. In particular, people with dementia (n=16) spoke about the impact of loneliness and isolation, feeling bored and a lack of routine, and feelings of anxiety and fear. Family carers (n=95) cited several challenges including how a lack of routine led to responsive behaviours and boredom in the person with dementia they supported. Family carers also spoke about anxiety, stress and fear, loneliness and isolation, and the impact of being housebound, not being able to shop and having no respite care. The dementia community champions (n=36) surveyed identified all of the same issues as the other two groups¹³⁸.

6.3. Closure of therapeutic centres

Non-pharmacological therapies such as behavioural activation, cognitive rehabilitation, cognitive stimulation therapy, psychosocial interventions, reminiscence, occupational therapy, physiotherapy and speech and language therapy, among many others, are mainly delivered through social contact. These interventions are likely to be suspended in many countries during confinement or transferred online. However, not every person living with dementia understands or feels comfortable with online interactions.

7. Impacts in terms of access to healthcare for people living with dementia

7.1. Dementia diagnostic services

Diagnostic, post-diagnostic services and general medical care for people living with dementia may have been compromised in some places because of the pandemic crisis. In Ireland for example, the national Memory Clinic service at St James' hospital stopped seeing all new patients for a six-week period and develop a virtual clinic for more urgent referrals¹³⁹. In

¹³⁷ <https://www.jmir.org/2020/5/e19434/>

¹³⁸ <https://ltccovid.org/wp-content/uploads/2020/07/LTCcovid-1-July-Detrimental-effects-confinement-on-people-with-dementia.pdf>

¹³⁹ <https://dementiaacademy.co/resources/webinars-covid-19/>

Australia, all public memory clinics also stopped seeing patients except for urgent assessments¹⁴⁰.

7.2. Admissions to hospital

People with dementia living in care homes may experience difficulties in accessing hospital care for a variety of reasons as revealed through media reports in some countries.

Spain (Madrid)

In Madrid, care home directors complained about ambulance services being overwhelmed and unable to turn up in the most critical days of the pandemic when rates of infection and ICU admission were at their highest¹⁴¹.

United Kingdom (England and Wales)

Care home providers in the UK also shared with the media complaints about their residents being refused hospital admission. There were also complaints cited of mass signing of do-not-attempt-resuscitation (DNAR) orders in several geographical areas across the country, by people who did not have the capacity to consent to them¹⁴².

Ireland

In Ireland it was noted that only 7% of residents of private and voluntary nursing homes with COVID-19 were referred to the acute care sector¹⁴³.

Singapore

In Singapore, care home residents who had been isolated in hospital had higher rates of falls and use of restraints. Challenges related to care due to cognitive impairment and behaviour were also noted¹⁴⁴.

We do not have information about the access to health care services of people living with dementia living in private homes.

Italy

From the ISS survey¹⁴⁵, 5,292 patients (including those with dementia) in the 1,342 responding nursing homes were hospitalised (an average of 4 in each facility): 956 of them (18.2%) were tested positive for COVID-19 and 2021 (38.2%) showed symptoms compatible with COVID-19. However, there was neither data recorded on the diagnosis of patients nor on the reason for hospital admission, as cases were included for any elective or emergency admission to hospital

¹⁴⁰ https://www.australiandementianetwork.org.au/wp-content/uploads/2020/04/PERSPECTIVE-PAPER_Managing-Memory-Clinics-during-COVID-19_Final_20200420.pdf

¹⁴¹ <https://elpais.com/espana/madrid/2020-03-26/por-que-no-va-la-ambulancia-a-la-residencia-los-cuatro-criterios-en-madrid-para-seleccionar-quien-es-hospitalizado.html>

¹⁴² <https://www.manchestereveningnews.co.uk/news/greater-manchester-news/greater-manchester-care-homes-coronavirus-18083994>

¹⁴³ <https://nhi.ie/opening-statement-by-tadhg-daly-ceo-nursing-homes-ireland-for-oireachtas-special-committee-on-covid-19-response/>

¹⁴⁴ <https://onlinelibrary.wiley.com/doi/10.1111/jgs.16447>

¹⁴⁵ <https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-finale.pdf>

for at least one day. The ISS report shows that most compromised COVID-19 positive cases were treated in nursing homes, without hospitalization and 12.5% of responding nursing homes stated they had difficulties promptly transferring COVID-19 positive patients into hospitals¹⁴⁶. The Regional degree on March 30th, 2020 in Lombardy reads “if a resident is older than 75 years old, frail and with comorbidities, care should be provided at the same facility to avoid further worsening risks due to transportation and waiting in the A&E room”¹⁴⁷.

7.3. Access to intensive care

During a pandemic of this magnitude, when resources are scarce, sensitive decisions must be made regarding the provision of costly treatments and interventions. Restricting access to Intensive Care Units (ICU) to very frail people is ethically justifiable if the individual is unlikely to benefit from critical care organ support and in cases where medical action may be more harmful than helpful. However, concerns have been raised by some, about how in the context of dementia, the notion of frailty is defined and interpreted during a pandemic in different countries and how access to ICU has been ensured.

Italy

In a letter published in The American Journal of Geriatric Psychiatry two doctors from Versilia Hospital disagreed with the guidelines issued by the Italian College of Anaesthesia, Analgesia, Resuscitation and Intensive Care. These guidelines recommended that the identification of age as a criterion for access to intensive care during the pandemic¹⁴⁸. In the letter, they expressed their particular concern about the discriminatory treatment this would mean for people living with dementia given their general age profile. The suggested guidelines explicitly mention the necessity to evaluate the overall functional status of the patient, as frail, older patients with comorbidities are more likely to have longer recovery time than healthier and/or younger people and therefore these population might be ‘resource consuming’ for the National Health System.¹⁴⁹

United Kingdom (England and Wales)

Similar concerns have been expressed in the UK in response to the National Institute for Health and Care Excellence (NICE) ICU admission guidelines, where ostensibly all people living with dementia (regardless of disease severity) could potentially be labelled as ‘frail group’ using the Rockwood criteria and therefore unlikely to benefit. However NICE amended their guidance at the end of April to include a special mention of dementia, asking clinicians to consider involving relevant specialists if needed, such as for people with dementia, when completing the Clinical Frailty Scale¹⁵⁰.

Spain

¹⁴⁶ <https://ltccovid.org/wp-content/uploads/2020/04/LTC-COVID19-situation-in-Italy-22-April-2020.pdf>

¹⁴⁷ https://www.sicp.it/wp-content/uploads/2020/04/DGR-3018-Lombardia_gestione-emergenza-covid-in-RSA-e-RSD_30-mar-20_cprd.pdf

¹⁴⁸ <https://www.sciencedirect.com/science/article/pii/S1064748120302931?via%3Dihub>

¹⁴⁹ <http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid19%20-%20Raccomandazioni%20di%20etica%20clinica.pdf>

¹⁵⁰ <https://www.nice.org.uk/guidance/ng159/chapter/1-Admission-to-hospital>

Similarly in Spain, although the ICU protocol implemented in the IFEMA hospital (Madrid largest COVID-19 hospital) guaranteed equity in access to ICU for people living with dementia¹⁵¹, a guide issued by the Spanish Society of Intensive Care, recommended a diagnosis of dementia (without detailing level of severity) an exclusion criteria for accessing ICU in case the health system became overwhelmed¹⁵². It is however unknown whether this protocol was ever used and what hospital might have considered it since it is common practice that hospitals apply their own triage criteria based on fragility and chances of benefiting from ICU admission.

Switzerland

Swiss ICU guidance established an age limit of 85 to access ICU¹⁵³. Since prevalence of dementia increases with age and reaches rates of 1 in 6 people affected among those above the age of 80¹⁵⁴, this criterion would particularly affect access to ICU to people living with dementia.

Ireland

The Irish government issued an ethical framework to guide decision-making during the pandemic. This states that the allocation of scarce medical resources should be made on the basis of fairness and health-related criteria. A report from the Health Protection Surveillance Centre showed that, up to August 1st, 4.6% of people treated in Irish ICUs had an underlying chronic neurological disease. Of the overall total number of people with a chronic neurological disease who contracted COVID-19 (n=1,206), only 20 were treated in ICU¹⁵⁵.

8. Overview of international policy and practice measures to mitigate the impact of COVID-19

7.1 Health care sector

7.1.1. Clinics by phone or videoconference and provision of information

Specialist clinics for people living with dementia have continued **over the phone or by videoconference** in many countries^{156,157,158}. In the Netherlands, for instance insurance companies lifted restrictions and agreed to cover the cost of the telemedicine, enabling more clinicians to access patients and conduct follow-on visits. In addition, hospitals in many countries issued their own COVID-19 information packages for their patients with dementia.

7.1.2. Measures to support people with dementia in hospital

¹⁵¹ https://www.madrid.es/UnidadesDescentralizadas/Emergencias/Samur-PCivil/Samur/ApartadosSecciones/COVID-19/data/ProtocoloCOVID_Hospitalfema.pdf

¹⁵² <https://www.medintensiva.org/es-recomendaciones-eticas-toma-decisiones-dificiles-avance-S0210569120301108>

¹⁵³ <https://ccforum.biomedcentral.com/articles/10.1186/s13054-020-02927-1>

¹⁵⁴ https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf?fileID=2323

¹⁵⁵ <https://www.hpsc.ie/a->

z/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary_04082020.pdf

¹⁵⁶ <https://www.australiandementianetwork.org.au/2020/04/17/managing-memory-clinics-during-covid-19/>

¹⁵⁷ <https://itccovid.org/2020/04/06/report-the-impact-of-the-covid-19-pandemic-on-people-with-dementia-in-india/>

¹⁵⁸ <https://itccovid.org/2020/08/10/updated-report-impact-and-mortality-of-the-first-wave-of-covid-19-on-people-living-with-dementia-in-spain/>

At the beginning of the pandemic, and in order to prevent the spread of the virus, some countries published guidance banning visitors to hospitals. This has led to ongoing calls from families and advocates for visitation rights of partners in care to support people with dementia particularly in cases of delirium or end of life¹⁵⁹.

In England, people living with dementia were included under the list of exceptional circumstances where **one visitor would be permitted to visit**¹⁶⁰ in April 2020. Wales soon followed suit, also allowing one visitor for a person with dementia and/or someone reaching end of life¹⁶¹. In Ireland, the visiting policy adopted was more variable and each public hospital issued its own guidelines in relation to visitors. A total of 36% (16/44) of hospitals allowed one person to accompany or visit a person with dementia, and another 20% (9/44) made decisions on visitors on a case by case basis¹⁶².

7.2 Community-based long-term care services

7.2.1. Home care services

In many countries, the main barrier to continued provision of home care services in many countries has been the lack of PPE and different countries and regions and came up with different approaches around this issue. For instance, in Australia, the government created a register to facilitate access to PPE including aged sector providers¹⁶³.

7.2.2. Closure of therapeutic centres

In India, Alzheimer's and Related Disorders Society of India (ARDSI) had to close all of their day care centres throughout the country at the start of the pandemic¹⁶⁴. Families who had been using these services reported increased agitation, boredom, and behavioural changes in their relatives living with dementia. This prompted ARDSI to initiate virtual support through video calls using cognitive stimulating activities. To support family carers, ARDSI developed staff rotas to provide regular calls with one-to-one counselling, information about infection control, and to coordinate access to clinicians to ensure access to necessary medications. As restrictions were lifted and day centres have re-opened again, ARDSI hopes to continue providing support and services using adequate PPE and to make COVID-19 testing available for people with dementia, their family members and staff.

In Malaysia, all adult day care centres were instructed to close and remain so indefinitely¹⁶⁵. Virtual support is now taking place, provided by staff to clients via video calls and other activities including exercise videos¹⁶⁶.

¹⁵⁹ <https://www.statnews.com/2020/03/29/hospitalized-adults-need-their-caregivers-they-arent-visitors/>

¹⁶⁰ https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0030_Visitor-Guidance_8-April-2020.pdf

¹⁶¹ <https://gov.wales/hospital-visiting-during-coronavirus-outbreak-guidance>

¹⁶² <https://tccovid.org/wp-content/uploads/2020/06/COVID-19-and-Dementia-Ireland.pdf>

¹⁶³ <https://www.amgc.org.au/covid-19-manufacturer-response/>

¹⁶⁴ <http://ardsi.org/>

¹⁶⁵ <https://tccovid.org/wp-content/uploads/2020/05/Malaysia-LTC-COVID-situation-report-30-May.pdf>

¹⁶⁶ <https://tccovid.org/wp-content/uploads/2020/05/Malaysia-LTC-COVID-situation-report-30-May.pdf>

In Hong Kong, some Non-Governmental Organizations (NGOs) are offering remote activities and counselling through video links to people living with mild and moderate dementia¹⁶⁷. The interactive activities offered weekly include cognitive stimulation to arts and crafts, with the goal of enhancing physical, mental, cognitive and self-management skills during isolation at home¹⁶⁸.

In Kenya, although dementia care has not yet been recognised as a national priority, it is becoming an increasing concern in a context where dementia care is predominantly provided by family carers. As an alternative to face-to-face meetings, carers are receiving virtual support through NGOs, but the frequency of attending meetings has reduced due to the financial cost of online discussions. Those who are able to participate, often experience difficulties in internet connectivity with beg-pardon conversations e.g. “please go ahead”, “can you hear me” statements, and this has led to online fatigue and more distress¹⁶⁹. The Strengthening Responses to Dementia in Developing Countries (STRiDE) team in Kenya (led by the Africa Mental Health Research and Training Foundation¹⁷⁰ and Alzheimer’s Dementia Organization, Kenya¹⁷¹) is exploring ways to cushion the effects of COVID-19 on carers and care recipients through the identification of culturally appropriate coping strategies.

In Ireland, in response to the closure of day care centres and social groups, an initiative, developed in one health service area, was the development and delivery of a ‘Golden Moments’ pack, providing different activities to support people with dementia in their own homes¹⁷².

7.3 Care homes: measures to support residents

Technology adaptations: Assistive technology, surveillance technology and home adaptations have been used to promote safety and more independent living for those affected by dementia and some technologies have been used to mitigate the effects of isolation¹⁷³. In the US, for people with dementia and in quarantine¹⁷⁴, the risk of increased stress has led to the US government agencies issuing an emergency waiver to suspend the requirement of the Health Insurance Portability and Accountability Act (HIPAA) to allow permission to use popular applications for video chats, such as Face Time and Facebook Messenger video chat, which are not HIPPA compliant. This has facilitated the use of these applications to support people with dementia living in care homes remaining in touch with their family and friends. Siette et al., (2020) provide solutions towards integrating traditional and new social digital support

¹⁶⁷ <https://www.scmp.com/news/hong-kong/society/article/3076378/coronavirus-online-day-care-keeping-elderly-hongkongers?fbclid=IwAR3Cad5Tdq6v1f2eIGzLDZA4QN71R85RHlvLNtgCLVimtVEhVd1mEroARDM>

¹⁶⁸ <https://itccovid.org/wp-content/uploads/2020/04/Hong-Kong-COVID-19-Long-term-Care-situation-27-April-2020-1.pdf>

¹⁶⁹ <https://itccovid.org/2020/06/02/new-country-report-the-covid-19-long-term-care-situation-in-kenya/>

¹⁷⁰ <https://africamentalhealthresearchandtrainingfoundation.org/>

¹⁷¹ <https://alzkenya.org/>

¹⁷² https://www.hse.ie/eng/about/our-health-service/making-it-better/golden-moments-packs-re-connect-older-persons.html?fbclid=IwAR160KIamdMuexy6TtWGiaOjPfxFts3h7AhDzwfEYAvw7o91BsQ9Wt0HR0#utm_source=FACEBOOK&utm_medium=social&utm_term=ourhealthservice&utm_content=29052020

¹⁷³ <https://www.tandfonline.com/doi/full/10.1080/08959420.2020.1771237>

¹⁷⁴ <https://www.sciencedirect.com/science/article/pii/S0165178120307587?via%3Dihub#bib0001>

structures to make sure that spatial distancing can be included in social routine without harming and leaving behind disadvantaged populations (e.g. those with little access to technology or little understanding or ability on how to use it)¹⁷⁵.

Redesign of activities to comply with social distancing requirements: Other innovations to allow safe ways of maintaining social, cognitive and physical activities include group activities at a distance (e.g. hallway bingo, doorway exercise classes).

Window, garden, car visits and window therapy: Organised window and garden visits allow families to connect with residents with dementia at same time that safety protocols are in place to minimise risk during these visits. Window or courtyard therapeutic visits with trained artists who can engage residents through music, humour, art, and creative writing can increase cognitive and social engagement and counteract boredom¹⁷⁶. Some care homes in the UK had a 'drive-through' facility to allow family and friends visit residents¹⁷⁷ and others in the Netherlands crafted visiting cabins made of glass so residents can meet family and friends in a safe environment through a wall of glass¹⁷⁸.

Isolation care plans: Laboni et al., (2020) described an isolation care plan for a person with frontotemporal dementia that effectively maintained the person safe until her quarantined period came to an end¹⁷⁹. Another useful example of creative thinking comes from India, where the Nightingales Medical Trust (NMT)—that provides residential care for people with dementia— it has assigned specific rooms for isolating residents that develop influenza like symptoms¹⁸⁰.

Testing and infection control policies: Most countries have developed infection control guidance to prevent infections and, although initially care home residents and staff were excluded from testing in many countries in the early part of the pandemic, increased recognition of the disproportionate impact of the pandemic on people living in care homes has led to efforts to increase testing and infection control processes in most countries. The World Health Organization has published a policy brief outlining key recommendations¹⁸¹.

7.4 Voluntary sector and non-governmental organisations

Globally, volunteers, NGOs and charities play a key role in providing supporting and lobbying for the rights of people living with dementia and their families. Almost uniformly, this sector was quick to respond to the COVID-19 pandemic, providing essential information, filling gaps in services, and advocating for the rights of people affected by dementia. At a global level,

¹⁷⁵ [https://www.jamda.com/article/S1525-8610\(20\)30333-9/pdf](https://www.jamda.com/article/S1525-8610(20)30333-9/pdf)

¹⁷⁶ <https://journalofdementiacare.com/the-joy-of-bringing-outside-in/>

¹⁷⁷ <https://www.bbc.com/news/av/uk-52788453/drive-through-care-home>

¹⁷⁸ <https://www.reuters.com/article/us-health-coronavirus-netherlands-elderly/dutch-elderly-home-builds-glass-sided-cabin-for-safe-coronavirus-visits-idUSKCN21R2VS>

¹⁷⁹ <https://www.sciencedirect.com/science/article/pii/S1064748120303262>

¹⁸⁰ <https://itccovid.org/wp-content/uploads/2020/05/LTC-COVID-situation-in-India-30th-May-1.pdf>

¹⁸¹ https://www.who.int/publications/i/item/WHO-2019-nCoV-Policy_Brief-Long-term_Care-2020.1

organisations such as Alzheimer’s Disease International (ADI)¹⁸², Dementia Alliance International (DAI)¹⁸³, and HelpAge International¹⁸⁴ took the lead to share breaking information and resources, offer guidance, and challenge and advocate for people living with dementia and their families. At local levels, NGOs galvanised their support, and this community-level response has provided an important sense of solidarity and support to enable better well-being during the crisis¹⁸⁵.

One of the first organisations to lead out on the response to the pandemic was Alzheimer’s Disease Chinese (ADC) which released, in collaboration with the Chinese Society of Geriatric Psychiatry, expert recommendations and key messages on mental health and psychosocial support during COVID-19¹⁸⁶. As the pandemic spread beyond China, other NGOs followed suit, quickly adapting their services and support during a rapidly changing and uncertain time.

Below is a sample of the support provided worldwide by this sector, listing some of the key areas of innovative care, support, and resources that have been developed as a response to the pandemic.

7.4.1. Information/guidelines

Guidelines have been developed in different countries that include practical and easy to understand information to advice and support people living with dementia and their families. These include:

- The Taiwan Alzheimer Disease Association (TADA)¹⁸⁷ developed a Handbook of dementia care responding to COVID-19¹⁸⁸ which they shared with the Ministry of Health and Welfare and was quickly disseminated to the department of health of local governments.
- One of the teams involved in the Strengthening Responses to Dementia in Developing Countries (STRiDE) project¹⁸⁹, STRiDE-Jamaica, developed the ‘COVID-19 In Summary Series’¹⁹⁰ in which they distil information from government digital town halls into bite size and digestible information for lay people. This is shared via social media and e-news.
- Other examples of guidelines from other organisations include: **Australia:** [Dementia Support Australia](#), **Austria:** Promez, **Brazil:** [Brazilian Association of Alzheimer](#), **Germany:** [Deutschen Alzheimer Gesellschaft](#), **Hong Kong:** [Christian Family Service Centre](#), **India:** [Alzheimer’s and Related Disorders Society of India](#), **Italy:** [Federazione Alzheimer Italia](#),

¹⁸² <https://www.alz.co.uk/news/adi-offers-advice-and-support-during-covid-19>

¹⁸³ <https://www.dementiaallianceinternational.org/covid-19-resources/>

¹⁸⁴ <https://www.helpage.org/>

¹⁸⁵ <https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-The-Impact-of-COVID-19-on-Older-Persons.pdf>

¹⁸⁶ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)30755-8/fulltext?dgcid=hubspot_email_newsletter_tlcoronavirus20&utm_campaign=tlcoronavirus20&utm_source=hs_email&utm_medium=email&utm...](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30755-8/fulltext?dgcid=hubspot_email_newsletter_tlcoronavirus20&utm_campaign=tlcoronavirus20&utm_source=hs_email&utm_medium=email&utm...)

¹⁸⁷ <http://tada2002.ehosting.com.tw/eng/Default.htm>

¹⁸⁸ <https://www.alz.co.uk/sites/default/files/pdfs/TADA%27s-Reference-Handbook-of-Dementia-Care-COVID-19%20.pdf>

¹⁸⁹ <https://stride-dementia.org/>

¹⁹⁰ <https://www.alz.co.uk/sites/default/files/pdfs/STRiDE-Jamaica-COVID-19-Summary-Series-No.1.pdf>

Spain: [Matia Fundazioa](#) and [Confederacion Espanola de Alzheimer \(CEAFA\)](#), **United Kingdom:** [Alzheimer's Society](#), [Dementia UK](#), and [Rare Dementia Support](#), **Ireland:** [The Alzheimer Society of Ireland](#), [The National Dementia Office](#) and [the Dementia Services Information and Development Centre](#).

7.4.2. Awareness raising

As argued in this report, people living with dementia have been hit hard by the COVID-19 pandemic and an important role of NGOs is around raising awareness of dementia and heighten understanding of how best to support people affected by the condition during the pandemic.

- Alzheimer's Indonesia¹⁹¹ shared with the press and had a half page article in the Jakarta Post on how to keep older persons and those with dementia at home and healthy during COVID-19¹⁹².
- Iran Dementia & Alzheimer's Association (IDAA)¹⁹³ has been translating information and key messaging from Alzheimer's Disease International (ADI) and the World Health Organisation (WHO) into Farsi, producing videos on COVID-19, and posting on their website, Instagram and the Telegram channel.
- Madagascar Alzheimer is running short radio programmes twice weekly to the public, providing tips and advice around COVID-19 for older persons, especially those living with dementia and their carers.
- A webinar on the impact of the COVID-19 pandemic on geriatric health, Alzheimer's and dementia was recently held by the Field Outreach Bureau of Mysore, Ministry of Information and Broadcasting in association with many organizations including ARDSI Mysore and around 350 participants were in attendance¹⁹⁴
- Alzheimer's and Related Disorders Society of India (ARDSI) Mumbai chapter has launched an online dementia awareness campaign to encourage families to remain positive during the COVID-19 pandemic¹⁹⁵.
- The Alzheimer Society of Ireland are engaged in an extensive advocacy programme highlighting concerns about the impact of COVID-19 on people living with dementia and their family caregivers¹⁹⁶.

7.4.3. Practical tips

It is important for carers and those assisting people with dementia to have clear and easy to follow practical tips around hygiene and handwashing, infection control, and the correct use of face masks. The following information kits on these topics along with other topics have been developed:

¹⁹¹ <https://alzi.or.id/>

¹⁹² <https://www.thejakartapost.com/news/2020/04/16/how-elderly-can-stay-healthy-active-connected-during-covid-19-pandemic.html>

¹⁹³ <http://www.iranalz.ir/>

¹⁹⁴ <https://www.youtube.com/watch?v=OK87BK8Ex88>

¹⁹⁵ <https://twitter.com/ardsi/status/1287257680487178241/photo/1>

¹⁹⁶ <https://alzheimer.ie/about-us/coronavirus-covid-19-update/>

- The US Alzheimer’s Association developed Tips for Dementia Caregivers at Home supporting carers with how to help people with dementia remember important hygiene practices¹⁹⁷.
- Regional Alzheimer’s Societies in Germany have developed materials (e.g., documents, podcasts and videos) to support people living with dementia and their family carers during the pandemic¹⁹⁸. The organisations also provide telephone helplines.
- The Taiwan Alzheimer’s Association (TADA) developed creative guidance for carers on how to encourage their relatives with dementia to wear a face mask.
- Alzheimer’s and Related Disorders Society of India (ARDSI) has developed tips to help support family members and caregivers of people with dementia during the pandemic¹⁹⁹.
- Alzheimer’s Italy shared 10 tips to help family members while caring for their relatives living with dementia at home²⁰⁰.

7.4.4. Virtual support

The vast majority of NGOs, charities and health agencies responded quickly to the pandemic situation by repurposing their services to supply virtual support to people with dementia and their families. A few selected examples include:

- **Music, exercise, movement and dancing:** TADA’s exercise videos - Warm up, Aerobic exercise; ALZI music therapy, Poco-Poco dancing, yoga and Pilates; the Alzheimer Society in the UK provides Singing for the Brain sessions online²⁰¹.
- **Cognitive Stimulation:** The University of Hong Kong, in collaboration with University College London, is running a pilot program using cognitive stimulation therapy for people with dementia online²⁰². As the social interactive aspects of cognitive stimulation may be as important as the intervention itself, it remains to be seen how well these virtual interventions will perform on evaluation.
- **Support groups for people living with dementia and/or carers:** Dementia Alliance International (DAI) provides peer to peer support for people living with dementia²⁰³; Fundación Alzheimer de Venezuela provides online carers groups and personal zoom calls to people living with dementia²⁰⁴. Alzheimer’s and Related Disorders Society of India (ARDSI) provides support to caregivers via telephone, video conferencing and social media platforms²⁰⁵.
- **Education:** The Social Care Institute for Excellence (SCIE) offers dementia-specific courses on providing support during COVID-19 for care homes²⁰⁶.

¹⁹⁷ [https://alz.org/help-support/caregiving/coronavirus-\(covid-19\)-tips-for-dementia-care](https://alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care)

¹⁹⁸ https://itccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-26-May-2020.pdf

¹⁹⁹ http://ardsi.org/downloads/Dos_and_Donts_COVID19.pdf

²⁰⁰ http://www.alzheimer.it/to_attivita_covid_19.html

²⁰¹ <https://www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain>

²⁰² <https://www.ucl.ac.uk/global/news/2020/may/ucl-and-hku-working-deliver-dementia-therapy-virtually>

²⁰³ <https://www.dementiaallianceinternational.org/services/online-support-groups/>

²⁰⁴ <https://alzheimervenezuela.org/>

²⁰⁵ <https://itccovid.org/2020/04/06/report-the-impact-of-the-covid-19-pandemic-on-people-with-dementia-in-india/>

²⁰⁶ <https://www.scie.org.uk/care-providers/coronavirus-covid-19/dementia>

It is also important to note that in places where internet connectivity is unavailable or unstable, many organisations have been contacting people with dementia and their carers using calls and messages.

7.4.5. Helplines

Many NGOs and charities have extended their existing helplines to 24 hours, while others have put ‘hotlines’ in place for emergencies. Some NGOs, especially in LMICs, are run by volunteers and don’t have capacity to run a helpline – with some resorting to using their own personal mobiles to ensure 24-hour support to the dementia community during the pandemic.

Advocacy for human rights and protection from penalties

- After the Taiwan government initiated epidemic prevention regulations and introducing penalties for individuals taking public transport without wearing a mask, TADA advocated to protect people with dementia from the penalty by press release and a formal letter to Premier of the Executive. Within weeks, it was announced that people with dementia will not be penalized for violating these measures, but this would need to be accompanied by certification of disability²⁰⁷.
- Alzheimer and Dementia Organisation Kenya (ADOK)²⁰⁸ collaborated with other NGOs on a petition through the Kenya Human Rights Commission and presented to Senate seeking support for people living with dementia around access to specialised care from home, a reduction or subsidy for the cost of incontinence supplies, continued supply of medications, and protection for individuals who may wander away from home.

8. Ageism and discrimination towards people living with dementia

The COVID-19 pandemic has highlighted some existing structural inequalities in society as it is those most socially disadvantaged, such as ethnic minority groups, migrant workers and older people that are most severely affected by the pandemic and in many countries age discrimination (ageism) remains rife^{209,210}. For people living with dementia, a double whammy effect may be experienced due to ageism and pervasive stigma (including witchcraft attribution) attached to their condition²¹¹.

Ageism is, according to the World Health Organization (WHO)²¹², the most socially “normalized” of any prejudice: it involves a normalisation of marginalisation and discrimination through an unconscious message communicated that aging devalues life. Negative and prejudicial attitudes towards older people explain why precarious and at times sub-optimal care support for older people has been considered acceptable, for instance, under resourced and under funded social

²⁰⁷ <https://www.alz.co.uk/sites/default/files/pdfs/ADI-Webinar-1-COVID-19-and-dementia.pdf> (slide 21)

²⁰⁸ <https://alzkenya.org/>

²⁰⁹ <https://unsdg.un.org/sites/default/files/2020-05/Policy-Brief-The-Impact-of-COVID-19-on-Older-Persons.pdf>

²¹⁰ <https://academic.oup.com/psychsocgerontology/article/doi/10.1093/geronb/gbaa051/5820621>

²¹¹ <https://www.alz.co.uk/research/WorldAlzheimerReport2019.pdf>

²¹² <https://www.who.int/ageing/ageism/en/>

care services, including home care and care home sectors. As demonstrated in this report, people living in care homes account for half of COVID-19 related deaths in many countries. Yet, care homes were left in the shadows for some time during the pandemic, with by far the main bulk of resources being deployed to health care/hospital systems. This included failing to provide care homes with adequate PPE, access to testing and additional support to replace absent staff. The loss of human lives of older people living in care homes was not treated as a priority and was not even visible until newspapers and researchers across the world commenced publishing grim figures of deaths.

As argued in this report, confinement measures both in the community and in care homes have detrimental effects on the physical, social, cognitive and psychological health of people living with dementia. For instance, the requirement to self-isolate and the ban on visits from close family caregivers (including spouses) to care homes; being forced to stay in one's own room indefinitely; the probable increase in use of physical and chemical restraints; along with a requirement that people with dementia comply with physical distancing when in contact with staff and others may be a violation of their human rights. Equally, depriving a person from accessing the therapies administered in day and therapeutic centres without providing an alternative indicates that these services are not a priority in COVID-19 contingency plans.

A fear of contracting the infection and risks associated with stigma can result in the avoidance or denial of healthcare, which is particularly detrimental at a time of potential scarcity of life-saving resources²¹³. ADI's World Alzheimer Report 2019 reported that 42.9% of people living with dementia in LMICs experienced unfair treatment by health or medical staff (23.8% for high and 25% for upper-middle income countries)²¹⁴. Specific to COVID-19, for instance in the UK, there have been numerous reports of people living with dementia being denied access to hospital or being told that they have to sign "do not attempt resuscitation (DNAR)" orders²¹⁵. In many countries, care home staff have encountered barriers when attempting to refer people with dementia to hospital. This paper has already referenced the UK's NICE guidelines for clinicians for admissions to critical care²¹⁶, including the algorithm²¹⁷ that also uses a Clinical Frailty Scale (CFS)²¹⁸. Based on the CFS, as noted, people living with dementia would most likely register as 'frail' automatically which, based on the algorithm, could impact their access to ongoing treatment²¹⁹. ICU triage protocols discriminating against people with dementia may have been issued in many countries. Equally important to consider during the pandemic is ensuring people with dementia have access to fair palliative and end of life care. In the light of evidence of care homes being overwhelmed and under-resourced, some governments having had to deploy military units to assist them (e.g. Spain, Canada, Belgium, Sweden) and the overwhelming rise in deaths in care homes across the worlds, it is unlikely that many people with dementia at the end of life, had received appropriate palliative care.

²¹³ <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html>

²¹⁴ <https://www.alz.co.uk/research/WorldAlzheimerReport2019.pdf>

²¹⁵ <https://itccovid.org/2020/05/03/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/>

²¹⁶ <https://www.nice.org.uk/guidance/ng159/chapter/2-Admission-to-critical-care>

²¹⁷ <https://www.nice.org.uk/guidance/ng159/resources/critical-care-admission-algorithm-pdf-8708948893>

²¹⁸ https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/rockwood_cfs.pdf

²¹⁹ <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>

9. Short-term calls for action

Systems of information

- We need better data to fully understand the overall impact that COVID-19 has had on the lives of people diagnosed with dementia. At present, there is a lack of comparable data across countries, gaps in data and insufficient data or poor-quality data within countries. In particular, given that people with dementia form a very sizeable proportion of all residents in care homes and given that COVID-19 has had an unprecedented effect on many of their lives, a Minimum Dementia Data Set across nursing homes/care homes, needs to be introduced and maintained in as many countries as possible as soon as possible. This would allow for a better understanding and more effective response to the needs of people living with dementia, particularly in the COVID-19 era²²⁰.

Support in Care homes

- Governments must ensure that all care homes are guaranteed a sufficient supply of PPE stock.
- Care homes need to train all staff on infection prevention and control. This training must not be a once off educational initiative but rather should be on-going. Specialist dementia training in COVID-19 must be undertaken in all care homes. This type of training needs to include topics such as how best to implement spatial distancing, safety manage visitors, and use of masks and another PPE. Training should include creative approaches for staff to use to help reduce fear, anxiety, apathy, depression and boredom many residents with dementia will experience during a pandemic.
- Care home standards must ensure that all care home facilities have immediate access to medical specialists such as Geriatricians or General Practitioners.
- Even after the person with dementia being admitted to a care home, close family members often continue to deliver care in partnership with paid staff. Special protocols need to be developed to enable close family members to continue to visit and support their family members with dementia in care homes. Appropriate screening and safeguards need to be established in care homes, nursing homes, and other residential care settings to facilitate safe and pleasurable visits.
- Staff in care homes are usually not well paid and are under enormous physical and emotional strain during a pandemic of this magnitude. There is a need for greater financial recognition of the frontline caregiving work they undertake. There is also a

²²⁰ <https://www.bmj.com/content/369/bmj.m2463/rr-0>

need for greater recognition of the psychological support including counselling they may require for coping with the trauma sometimes experienced.

- Testing policies that consider that visitors, care home residents and staff can be COVID-19 positive and asymptomatic. Regular and repeated testing in all residents and staff is recommended. COVID-19 status should be confirmed before admission of all new residents to a care home and of all people being discharged from hospitals to care homes. Quarantine and step-down facilities should also be provided.

Support in the community

- For many family carers of people living with dementia, the closure of services such as day care or reduced access to home help, as well as reductions on care provision by other family members who live outside the household, have resulted in the amount of care they provide and reduced their opportunities for respite. For carers employed in the labour market and who live in the same household as a relative (spouse or parent) who has dementia, new 'work from home' arrangements may have resulted in additional stress. Additional support, either financial or through replacement care services, need to be considered to ensure that the additional efforts by family carers of people with dementia are not detrimental to their own mental, physical and financial health.
- As social distancing restrictions ease, guidelines need to be developed to enable organisations (e.g. day centres) to safely restart therapeutic activities for people living with dementia. In addition, people living with dementia and their families will need to be supported to 're-enter' and re-engage with programs and society. These guidelines would also include advice and recommendations for care home and community services staff about the provision of programmes and services while maintaining spatial distancing.
- Community awareness programs, while applying physical distancing measures, are an important aspect to reduce stigma (e.g. age discrimination and witchcraft attribution) around dementia.

Support in Hospital

- Special guidance can be applied in hospitals for visitors of people with dementia to reduce spread of COVID-19. This guidance should enable people with dementia to be accompanied while staying on hospital or being seen at A&E.
- COVID-19 hospital wards with people living with cognitive impairment may benefit from having access to a dementia liaison specialist team (e.g., Geriatricians, old age

psychiatrists, neurologists, nurse specialists) to consult with and support staff with behaviour management.

Research

- To mitigate a loss of research momentum, national government, voluntary sector, and private sector, investment in research on dementia must continue and protocols must evolve that allow research to continue in the COVID-19 era.

10. Long-term dementia policy implications of the pandemic

For health care services

- There are many advantages associated with obtaining a timely diagnosis of dementia. A backlog of people awaiting assessment and diagnostic services due to the pandemic is likely to result in the absence of a timely diagnosis of dementia for many people. This may in turn lead to a delay in accessing medical and non-medical treatments including engaging in advanced care planning. Furthermore, the pandemic context may change the priorities scale of people, reducing requests for medical appointment for symptoms that often fluctuate and are insidious in the first stages of neurodegenerative disorders (e.g. memory complaints, apathy, etc.). Governments need to review and ensure there is a policy (and appropriate funding) in place that supports and protects people living with dementia and ensures equal access to health and long-term care systems that are integrated and coordinated.
- There is emerging evidence on the role of telehealth in the assessment and management of dementia^{221,222}. This is an area for further investment, particularly in developing countries²²³ where smartphones are increasingly common. Standardisation and validation of online and/or unsupervised batteries for neuropsychological assessment is necessary²²⁴. Research also needs to progress in developing psychosocial interventions that can be delivered remotely in the home of the individual (e.g., cognitive stimulation) to reduce cognitive decline and encourage continued independence, should there be further waves of infection or a future pandemic²²⁵.
- COVID-19 has precipitated rapid shifts to telehealth and wider use of online technologies for connection. People living with dementia and their families need to be supported to make sure they are not 'left behind' in terms of use of technology to

²²¹ <https://link.springer.com/article/10.1007/s13670-019-00297-3>

²²² <https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5219>

²²³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6618173/>

²²⁴ <https://pubmed.ncbi.nlm.nih.gov/27266677/>

²²⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7165101/>

access healthcare, social services, and other aspects of online community life (e.g., exercise lessons, virtual artistic activities, etc).

- The rapid crisis of COVID-19 has brought ethical dilemmas and complex and difficult decisions around triage and resources allocation, particularly for older frail people and those with dementia. In future, governments need to consider transparent processes in which people living with dementia and their families and carers, patient organisation and the public work alongside clinicians and care providers to agree protocols around medical decision making and provision of care. A specific practical application of this would be in the advance decision of preferences regarding medical care and planning of care home visits.

For care homes

- The design of care homes should be ‘re-imagined’ to future proof them and enable better and safer management during pandemic situations. For instance, models of nursing homes such as The Green House²²⁶, where people can live together in small group settings, enjoying at all times the privacy of their own unsuited bedroom could help minimise risk of transmission across a home.
- All nursing homes/care homes that provide multiple bed occupancy accommodation should be re-configured to ensure that single rooms are available to all residents. Better integration between care homes and public health services to facilitate co-operation around public health issues such as during a pandemic, heat waves, extreme pollution, etc.

NOTE FOR READERS: the authors would greatly appreciate any help to complete the missing data in the tables, data and information about other countries, and any comments and corrections about inaccuracies that this report may contain. Please email aida.gonzalez@ucl.ac.uk

²²⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5338211/>