



Impact and mortality of the first wave of COVID-19 on people living with dementia in Spain

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Corrections and comments are welcome at info@Itccovid.org. This document was last updated on 9th August 2020 and may be subject to revision.

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Note: If you notice any inaccuracy in this report, please email aida.gonzalez@ucl.ac.uk

1. Key points

- Between **11,941-14,877 people with dementia may have died** with COVID-19 in care homes in Spain (see section 3 – National level mortality figures for people living with dementia).
- 8 out of the 17 Autonomous Communities (AACCs) in which Spain is administratively divided are making data related to the **impact of COVID-19 on care homes** for old people publicly available in the official websites of the corresponding regional governments. We have not found this information for the remaining 9 AACCs.
- 1 out of the 17 Spanish AACC has reported data of COVID-19 deaths in **people living with dementia** (Asturias, **43% of total deaths** occurred in people with dementia¹). The different approaches used by the different Spanish regions to record and publish care home and dementia COVID-19 related information makes any attempt of extracting national-level data impossible.
- **Visits in care homes** have restarted since the lockdown came to an end but are subject to many limitations in terms of frequency, duration and number of people visiting. The rules vary substantially across care homes and AACCs. The prolonged separation from their families arising from this ban on visits is believed to be causing **devastating and long-lasting damage** in the cognitive and psychological health of people living with dementia in care homes.
- Many dementia clinics have **continued to offer outpatient care** during the pandemic, either by phone or face to face under appropriate measures of infection control.
- **Day-care centres are now reopening** under new infection control protocols and protective measures.

¹ <https://ltccovid.org/2020/06/14/new-report-the-covid-19-long-term-care-situation-in-asturias-spain/>

2. Introduction

On 31st of January 2020 the first COVID-19 case in Spain was confirmed in the Canary Island of La Gomera². On the 24rd of February the first inland cases were identified in Madrid, Catalonia and Valencia. The state of emergency was declared on 14th of March and the country was put under nationwide lockdown³. As per 9th August 314,362 COVID-19 cases have been confirmed in Spain, 28,503 of whom have died⁴. However, the excess of deaths between 13th of March and 22nd of May is 44,006⁵. It has been reported that 69 % of all COVID-19 related deaths have occurred in residential care settings⁶.

Recent epidemiological studies suggest that the average prevalence of dementia in people aged 65 and over in Spain is around 5%^{7,8,9, 10}, ranging between 4%-9%¹¹. Considering that there are 9,28 million people aged 65 and over in Spain¹², that would mean that between 371200-835000 people live with dementia in the country. This is a conservative estimate, since young-onset dementias (with onset before age 65) which account for 5-15% of all dementia cases¹³, would not be included in these figures. Prevalence in those over 90 ranges between 31 and 45%¹⁴.

3. National-level mortality figures for people living with dementia

Figures from 28th June showed that 19,576¹⁵ care home residents have died with confirmed or probable COVID-19. Given that between **61%¹⁶ and 76%¹⁷** of care homes residents in Spain have dementia, proxy estimates would suggest a share of between **11,941 and 14,877 deaths of people with dementia in care homes in the country**. This is likely to be a conservative estimate, as total excess mortality is 58%¹⁸ compared with the previous year (44,543 excess deaths compared to the official 28,343¹⁹ deaths reported) and current real 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 dementia²⁰. Lastly, this estimate does not include people with dementia who lived in the community and died of COVID-19.

² <https://www.redaccionmedica.com/secciones/sanidad-hoy/coronavirus-infectados-espana-y-evolucion-covid19-desde-origen-4148>

³ <https://english.elpais.com/politics/2020-03-13/spanish-government-declares-state-of-alarm-in-bid-to-combat-coronavirus-spread.html>

⁴ <https://www.rtve.es/noticias/20200721/mapa-del-coronavirus-espana/2004681.shtml>

⁵ https://momo.isciii.es/public/momo/dashboard/momo_dashboard.html#nacional

⁶ <https://www.rtve.es/noticias/20200805/radiografia-del-coronavirus-residencias-ancianos-espana/2011609.shtml>

⁷ <https://pubmed.ncbi.nlm.nih.gov/30881138/>

⁸ <https://europepmc.org/article/med/24147055>

⁹ <https://pubmed.ncbi.nlm.nih.gov/19832772/>

¹⁰ <https://pubmed.ncbi.nlm.nih.gov/25444413/>

¹¹ <https://www.elsevier.es/es-revista-neurologia-295-avance-resumen-informe-fundacion-del-cerebro-impacto-S021348531730350X>

¹² <https://es.statista.com/estadisticas/630678/poblacion-de-espana-mayor-de-65-anos/>

¹³ <https://innp.bmj.com/content/74/9/1206>

¹⁴ <https://www.elsevier.es/es-revista-neurologia-295-avance-resumen-informe-fundacion-del-cerebro-impacto-S021348531730350X>

¹⁵ <https://www.rtve.es/noticias/20200628/radiografia-del-coronavirus-residencias-ancianos-espana/2011609.shtml>

¹⁶ <https://www.sciencedirect.com/science/article/abs/pii/S0211139X08000024>

¹⁷ <https://pubmed.ncbi.nlm.nih.gov/19237032/>

¹⁸ https://momo.isciii.es/public/momo/dashboard/momo_dashboard.html

¹⁹ https://www.msrebs.gob.es/profesionales/saludPublica/ccaves/alertasActual/nCov-China/documentos/Actualizacion_150_COVID-19.pdf

²⁰ <https://pubmed.ncbi.nlm.nih.gov/32706392/>

4. Regional-level rates of infection and mortality figures for people living with dementia

Spain is divided in 17 Autonomous Communities (AACC) with devolved governments. Regional provision of healthcare relies on the government of each AACC, while social care provision is shared between the autonomous/regional governments and the local authorities or townhalls. Different AACC have different systems of information and different approaches to data recording, reporting and where (and whether) they make the data public. Even within the same Autonomous Community, different provinces may have different systems to register and manage datasets. Some approaches and metrics that differ between regions are:

- The type of COVID-19 cases included (confirmed, suspected or both) is not always clearly described when data is reported for some regions.
- It is unclear in some regions (e.g. Madrid and Catalonia) whether data covers deaths of care homes residents or only deaths in the care home (this is, people who lived and died in the care home versus people who lived in the care home but died in hospital).
- In some regions, the figures publicly available about the rate of COVID-19 infections and deaths in care homes do not distinguish between care homes for older people and for younger people with disabilities.
- A register of COVID-19 deaths in people living with dementia is absent in the data shared by the majority of Spanish regions, with only Asturias providing percentages of deaths among people with a diagnosis of dementia.
- Approaches to reporting information changed over time as the pandemic progressed and new guidance was issued from the central government. This means that the data available earlier in the pandemic may be different than the data available now.

This variability, along with the lack of publicly available data from some regions, is one of the main barriers to extracting figures for Spain. Table 1 summarises total COVID-19 cases and related deaths in each of the 17 AACCs for which data is available. The sources used by the authors to compile the data in Table 1 were:

- Number of care homes and number of care home beds are from recent statistics published by the *Centro Superior de Investigaciones Científicas* (CSIC) <http://envejecimientoenred.es/estadisticas-sobre-residencias-2019/>. We have also added the official figures provided by official regions when available (there can be discrepancies between sources).
- The rest of the figures corresponds to **data released by the local governments** in their official websites. Some data “not found” in the website of the AACC is available in the media, in particular in the website of the state-owned Spanish Radio and Television Corporation (RTVE). We decided not to use these data for the sake of consistency, to avoid mixing sources and also because figures provided by RTVE and the websites of some AACC did not always match.

Table 1. Number of people who test positive for COVID-19 in care homes, mortality and place of death, by Autonomous Community

Autonomous Community (data updated)	Number of older people living in care homes ¹	Number of care homes with COVID-19 cases (over total of care homes for old people in the AACC) ²	Total COVID-19 cases in the AACC	Total COVID-19 cases in care homes	Total deaths in the AACC	Total deaths of care homes residents (older people only)	% share of deaths of care home residents (compared to total deaths in the AACC) ³	Residents who died in care home/in hospital
Cataluña (07/07/2020)	62,015 (beds)	<i>not found</i>	66,462 (confirmed)	15,059 confirmed (51,572 confirmed + probable)	12,606	4,099	<i>NA</i>	<i>not found</i>
Madrid (18/06/2020)	48,768 (beds)	<i>not found</i>	71,845 (confirmed)	<i>not found</i>	15,034 (confirmed + probable)	<i>not found</i>	<i>NA</i>	<i>not found</i>
Castilla y Leon (18/06/2020)	42,575 (48,547 beds)	<i>not found</i>	26,182 (confirmed + probable)	7,141	<i>not found</i>	2,591 (there are 2,563 additional deaths)	<i>NA</i>	<i>not found</i>
Castilla La Mancha (17/06/2020)	26,649 (beds)	239/473	17,845	6,605	3,019	1,298	43%	<i>not found</i>
Valencia (6/5/20)	26,810 (beds)	156/328	10,537	2,148	1,302	485	37%	<i>not found</i>
Aragon (17/06/2020)	18,424 (beds)	113/275	5,901 confirmed + 2,780 probable (over 99,488 cases being investigated)	2,871	905	760	84%	<i>not found</i>
Extremadura	13,751 (beds)	<i>not found</i>	<i>not found</i>	<i>not found</i>	<i>not found</i>	<i>not found</i>	<i>not found</i>	<i>not found</i>
Navarra (23/06/2020)	5,835 (6149 beds)	<i>not found</i>	10,211 (confirmed)	1,676 (confirmed) (all care homes, no old people only)	528*	432 (268 confirmed + 164 probable)	81%	<i>not found</i>
Cantabria (25/06/2020)	6,024 (beds)	20/64	3,017 (2,345 confirmed + 672 probable) *	766	209	152 (143 confirmed + 9 probable)	72%	46 (32%)/92 (64%)

Asturias (25/06/2020)	12,313 (beds)	69/240	2435 (confirmed)	683	335	228	68%	52 (23%)/ 176 (77%)
La Rioja (25/06/2020)	2,576 (3209 beds)	19/32 *	4073 (confirmed)	576 (confirmed)*	365	211	57%%	not found
Galicia	21,179 (beds)	not found	not found	not found	not found	not found	NA	not found
Andalusia (25/06/2020)	42,585 (beds)	not found	17,844	not found	1,434	not found	NA	not found
Murcia (25/06/2020)	5,192 (beds)	not found	3278 (confirmed)	not found	150	not found	NA	not found
Basque Country (25/06/2020)	20,534 (beds)	not found	20820	not found	1609	not found	NA	not found
Balears (25/06/2020)	5,110 (beds)	not found	2189 (confirmed)	not found	226	not found	NA	not found
Canary Islands (25/06/2020)	7,327 (beds)	not found	2426	not found	162	not found	NA	not found
¹ If not available, number of beds in the AACC, obtained from most recent CSIC report - not always coincide with numbers provided by the AACC regional governments ² Number of care homes obtained from most recent CSIC report - not always coincide with numbers provided by the AACC regional governments ³ Calculated by the authors *calculated by the authors from the historic series								

Table 2 shows the estimated COVID-19 related mortality of people with dementia for all AACCs. The data has been compiled from the following sources:

- In the absence of epidemiological data for each AACC we have relied on estimates provided by local authorities, non-governmental organizations and the media for the figures regarding **number of people living with dementia in each AACC**.
- The estimates of people with dementia living in care homes used for these calculations correspond to the reported **share of people with dementia living in care homes in Spain (currently 61-76%)²¹**.
- The estimated number of people with dementia who died in care homes in each AACC is calculated assuming same likelihood of death with COVID-19 across care home residents (assuming that 61-76% of total deaths in care homes may correspond to people with dementia, as that is the share of care home residents that are estimated to have dementia). We are aware this may be an underestimate since people with dementia may have a higher probably to die from COVID-19 than people without dementia and

²¹ <https://pubmed.ncbi.nlm.nih.gov/19237032/>

also, it is likely that the prevalence dementia among people living in care homes is higher than reported.

The following AACCs make data about the share of COVID-19 deaths in care homes available in their official websites: Castilla y Leon, Castilla la Mancha, Valencia, Aragón, Navarra, Cantabria, Asturias and La Rioja. The rest, either do not provide data or the quality is too poor for the data to be useful (e.g. providing figures with no clarification of what they correspond to).

Table 2. Estimated COVID-19 related mortality of people with dementia, in each of Spain's Autonomous Communities

Autonomous Community (AACC)	Estimated figures of people with dementia who live in the AACC	Total deaths of care homes residents (care homes for old people only)	Estimated number of residents with dementia who died (calculation based on a prevalence of dementia of 61-76% in care homes residents)	% of total deaths in the AACC occurring in people with dementia
Cataluña	123,000 ¹	<i>not found</i>	<i>NA</i>	<i>not found</i>
Madrid	52,873 ²	<i>not found</i>	<i>NA</i>	<i>not found</i>
Castilla y Leon	63,000 ³	2,591	1,580-1,969	<i>not found</i>
Castilla La Mancha	50,000 ⁴	1,298	791-986	<i>not found</i>
Valencia	70,000 ⁵	485	295-368	<i>not found</i>
Aragon	10,000 ⁶	760	463-577	<i>not found</i>
Extremadura	21,000 (diagnosed) ⁷	<i>not found</i>	<i>NA</i>	<i>not found</i>
Navarra	5,500 (diagnosed) ⁸	432 (268 confirmed + 164 probable)	263-328	<i>not found</i>
Cantabria	8000 ⁹	131	92-115	<i>not found</i>
Asturias	25,200 ¹⁰	228	139-173	43%
La Rioja	3,300 ¹¹	211	128-160	<i>not found</i>
Galicia	70,500 ¹²	<i>not found</i>	<i>NA</i>	<i>not found</i>
Andalusia	123,695 ¹³	<i>not found</i>	<i>NA</i>	<i>not found</i>
Murcia	11,100 ¹⁴	<i>not found</i>	<i>NA</i>	<i>not found</i>
Basque Country	60,000 ¹⁵	<i>not found</i>	<i>NA</i>	<i>not found</i>
Baleares	31,000 (10,500 diagnosed) ¹⁶	<i>not found</i>	<i>NA</i>	<i>not found</i>
Canary Islands	24,000 ¹⁷	<i>not found</i>	<i>NA</i>	<i>not found</i>

1<https://www.lavanguardia.com/vida/20160921/41472614304/86000-personas-sufren-la-enfermedad-del-alzheimer-en-catalunya.html>

2<https://www.sciencedirect.com/science/article/pii/S0213485314001777> ((estimación a través de prescripciones, 2011))

3<https://www.elnortedecastilla.es/castillayleon/dependientes-region-padecer-20190917173528-nt.html>

4<https://ahoraclm.com/2019/02/24/en-castilla-la-mancha-hay-50-000-pacientes-con-demencia/>

5http://publicaciones.san.gva.es/publicaciones/documentos/AlzheimerVtot_171205.pdf

6<https://www.ceafa.es/es/que-comunicamos/noticias/mas-de-100-000-personas-sufren-demencia-en-aragon>

7<http://www.juntaex.es/comunicacion/noticia&idPub=19980#.XvXyqpNKjPA>

8<https://www.navarra.es/es/noticias/2019/09/20/en-navarra-hay-diagnosticadas-5.500-personas-de-demencia-cuya-causa-principal-es-la-enfermedad-de-alzheimer#:~:text=En%20Navarra%20viven%20en%20la,est%C3%A1%20pendiente%20de%20aprobaci%C3%B3n%20%2D>

- 9 <https://www.eldiariomontanes.es/cantabria/alzheimer-mata-veces-20190920142515-nt.html#:~:text=En%20Cantabria%20hay%20118.000%20personas,es%20la%20enfermedad%20de%20Alzheimer.>
- 10 <https://www.lne.es/sociedad-cultura/2013/09/18/asturias-hay-25200-personas-demencia/1470590.html>
- 11 <https://www.larioja.com/la-rioja/201702/08/rioja-punta-lanza-contr-a-20170208010044-v.html#:~:text=Prevalencia%20de%20la%20enfermedad.&text=Se%20estima%20que%20el%20n%C3%BAmero,m%C3%A1s%20de%202.000%2C%20sufrir%C3%ADa%20alz%C3%A9imer.>
- 12 https://afaco.es/alzheimer_cifras_es.html#:~:text=En%20Galicia%20hay%20cerca%20de,a%20la%20que%20pertenece%20AFACO.
- 13 http://ibdigital.uib.es/greenstone/collect/portal_social/index/assoc/jandaluc/ia0040.dir/jandalucia0040.pdf
- 14 <https://www.murciasalud.es/pagina.php?id=191821#:~:text=Teniendo%20en%20cuenta%20los%20resultados,Murcia%20padecerian%20EA%20o%20EAECV.>
- 15 <https://www.lavanguardia.com/local/paisvasco/20190920/47500397777/un-millar-de-personas-pediran-mas-medios-para-la-investigacion-en-la-ix-marcha-del-dia-mundial-del-alzheimer-en-bilbao.html>
- 16 <https://www.diariodemallorca.es/mallorca/2017/11/22/65-poblacion-demencia-padece/1265977.html>
- 17 <https://www.canarias7.es/sociedad/el-numero-de-afectados-de-alzheimer-se-duplica-cada-15-anos-BX5536560>

5. Impact of COVID-19 on people living with dementia in care homes

80% of all people with dementia in Spain live in their private homes in the community (between 296,960-668,000) and rely on family care,²² while the rest live in residential setting (74,240-147,000). It is estimated that around 61% of all care home residents in Spain (around 333.920 residents in total in the country²³) have some form of cognitive impairment²⁴, that would make around 200,000 people with cognitive impairment living in institutions.

Autonomous Communities (AACCs) are currently responsible for issuing preventive and infection control guidance for care homes. The guidance documents include measures such as²⁵:

- keeping physical distancing
- supply of hydroalcoholic gel in entrances, exits, common areas and every bedroom
- use of face mask by all care workers and visits
- isolation of suspected cases
- establishment of turns to use common areas such as living rooms and dining rooms to avoid crowds
- a 'COVID lead' in every centre, trained in surveillance, prevention and infection control
- protocols for effective sectorisation of the care home in the face of a variety of COVID-related epidemiological scenarios should be in place (e.g. isolation areas, areas to handle infected material, etc.
- provision of enough PPE and training on its correct use.

²² <https://content.iospress.com/articles/journal-of-alzheimers-disease/jad01258>

²³ <http://envejecimientoenred.es/una-nueva-estimacion-de-poblacion-en-residencias-de-mayores/>

²⁴ <https://www.elsevier.es/es-revista-revista-espanola-geriatria-gerontologia-124-articulo-prevalencia-demencia-pacientes-institucionalizados-estudio-S0211139X08000024>

²⁵ https://www.comunidad.madrid/sites/default/files/doc/servicios-sociales/fase_3_protocolo_centros_socio_sanitarios_personas_mayores.pdf

- new residents should show a negative RT-PCR performed 72 hours before admission

Apart from the mortality rates in care homes described in previous sections of this report, people living with dementia in care homes have gone through exceptional challenges. First, daily routines got interrupted as a consequence of COVID-19 (e.g. therapies, communal living, etc.); second, all visits, including those of family and partners in care homes were banned since the pandemic started; and third, isolation measures in care homes with COVID-19 outbreaks also affected people living with dementia. Altogether these measures may be **leaving lasting damage in the cognitive and mental health of people living with dementia** as it has been extensively documented in the media and, more recently shown in emerging scientific evidence²⁶.

Visits in care homes were allowed in all regions in Spain with the start of ‘new normality’ period, with the exception of care homes with active COVID-19 cases and care homes in geographical areas with severe new outbreaks. In this regard, recent outbreaks (from 15th July 2020) in several regions or the fear to new cases have led to new restrictions in family visits^{27,28,29}. The conditions of these visits vary substantially across care homes and are subjected to many limitations in terms of frequency, duration and number of people visiting^{30,31,32}. The degree of implementation of the new preventive measures specified above and their success in the prevention of new cases in care homes is unknown. In the recent outbreak in the region of Aragon in late July, many care home residents have been infected³³.

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

The majority of people living with dementia live in the community. Multiple aspects of life in the community have been disrupted by the pandemic (e.g. home care, day centres).

In the early days of the pandemic, experts had warned about the particular challenges of people with dementia living under lockdown^{34,35,36} and the media have featured the challenges of people living with dementia and their families as result of confinement measures in

²⁶ <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/>

²⁷ https://www.eldiario.es/politica/calatayud-cierra-parques-y-la-residencia-municipal-por-los-brotos-de-covid-19_1_6117530.html

²⁸ https://www.eldiario.es/madrid/comunidad-madrid-residencias-detectar-positivos_1_6066789.html

²⁹ https://www.elconfidencial.com/espana/2020-07-19/madrid-extrema-la-vigilancia-en-residencias-y-restringe-visitas-para-evitar-un-rebote_2686875/

³⁰ <http://www.lexnavarra.navarra.es/detalle.asp?r=52782>

³¹ https://docm.castillalamancha.es/portaldocm/descargarArchivo.do?ruta=2020/06/22/pdf/2020_3981.pdf&tipo=rutaDocm

³² https://www.amavir.es/sites/default/files/guia_de_actuaciones_en_las_residencias_y_centros_de_dia_publicos_y_privados_de_personas_mayores_y_de_personas_con_discapacidad_de_castilla.pdf

³³ https://www.abc.es/espana/aragon/abci-multiplican-contagios-residencias-aragon-infectados-mas-100-internos-45-centros-202007291750_noticia.html

³⁴ https://www.abc.es/familia/mayores/abci-afecta-covid-19-hogares-enfermos-alzheimer-202004120212_noticia.html

³⁵ <https://www.lavozdeasturias.es/noticia/asturias/2020/04/05/cadena-solidaria-ayudar-memoria/0003158608630405656772.htm>

³⁶ <https://www.elmundo.es/cataluna/2020/04/19/5e9b326821efa0e2558b45de.html>

Spain^{37,38}. Interruption of previously well-established daily routines, reduction of social interaction, access to support, exercise and pleasant and stimulating activities are among the disruptive changes brought in by the current situation. Disorientation, confusion, exacerbation of behaviours that challenge and neuropsychiatric symptoms (delusions, hallucinations and agitation) emerge as result of this changes.

Home care

Home care services have varied in their response to COVID-19 depending on the region and city³⁹. For instance, the widespread lack of PPE in the beginning of the pandemic led many home care providers to suspend their services. In other cases, where services were maintained, users refused them upon fear of infection and in some areas of the country services continued as usual⁴⁰. We have not found data corresponding to the number of people living with dementia whose home care services were suspended or interrupted during the pandemic.

Day centres

All day centres in Spain were ordered to shut down to prevent infection risk at the start of the pandemic on 13th March (some Autonomous Communities had already proceeded to the closure on centres on early March), leaving thousands of people with dementia and their families without an essential source of support.

During phase 1 of the de-escalation process, that started in Spain on Monday 11th May, some regions gave priority to the restoration of face to face activities in day care centres for people living with dementia (up to a maximum of 30% of the centre capacity initially, and increasing as the country entered in 'new normality') while others opted for delaying the opening of the centres⁴¹. Currently protective measures to continue services in day centres include^{42,43}.

- Establishing attendance turns for users, to reduce the number of people present in the centre at same time
- Temperature checks
- Use of masks when physical distance cannot be guaranteed (such in collective transport)
- Regular administration of COVID-19 questionnaire to check presence of symptoms
- Schedule flexibility to encourage the use of private transport
- Screened tables for lunchtime
- Provision of enough PPE
- Disinfection protocol for every centre

³⁷ https://sevilla.abc.es/andalucia/cordoba/sevi-confinamiento-memoria-vida-paciente-alzheimer-202004180808_noticia.html

³⁸ <https://www.rtve.es/noticias/20200318/confinamiento-para-enfermo-alzheimer-trastorno-mental-teneis-encerrada/2010344.shtml>

³⁹ <https://ltccovid.org/wp-content/uploads/2020/05/LTCCovid-Spain-country-report-28-May-1.pdf>

⁴⁰ <https://ltccovid.org/2020/04/24/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-spain/>

⁴¹ https://www.infolibre.es/noticias/politica/2020/06/02/los_centros_dia_abordan_desescalada_ritmos_diferentes_preocupados_por_las_secu_elas_deterioro_para_algunas_personas_puede_ser_irreversible_107331_1012.html

⁴² <https://www.madrid.es/UnidadesDescentralizadas/Mayores/Descriptivos/ficheros/PROTOCOLO%20CORONAVIRUS%20CENTROS%20DE%20IA%20FASE%203.pdf>

⁴³ <https://www.europapress.es/comunitat-valenciana/noticia-asi-abriran-centros-dia-mayores-valencia-forma-gardual-grupos-reducidos-turnos-20200618143916.html>

- Protocols to transport users in place, requiring temperature checks, hand washing, use of masks, social distancing, disinfection of seats and door handles.

7. Measures to support people living with dementia during the pandemic

Measures to support unpaid carers issued by the central government

As well as the disruption in community-based long-term care services such as day care centres and home care provision in Spain, at the start of the pandemic hundreds of families decided to remove their loved ones from care and nursing homes over concerns of infection⁴⁴. Overall, this has led to a significant increase in burden care for families, who became the main care providers of care home residents that returned to live in private homes. Four days after the announcement of the state of emergency, the Spanish Government issued a decree comprising the following measures to support unpaid carers:

1) **MECUIDA plan**. People with long term needs, many of them with dementia have lost an important source of daily support with the closure of day care centres. This support has come to be provided by families instead. A decree published on 18 March 2020 by the Spanish government establishes that workers able to prove new caring duties derived from the COVID-19 situation (e.g. closure of day care centres) are **entitled to request that their working conditions get adjusted or reduced**, with proportional adjustments in their salaries.

2) **Mortgage debt moratorium** for those who qualify as financially vulnerable, including: people unable to afford the payment of their mortgages as result of COVID can apply for a moratorium and families looking after relatives as a consequence of COVID-19 who needed to apply for the above plan MECUIDA, and experienced a substantial loss of income that made it difficult to afford the costs of the mortgage can benefit from this protection measure.

Therapeutic outings

Spain was in strict lockdown since 14th March to 4th of May 2020 when a phased de-escalation plan came into place and progressively lifted the confinement measures. During lockdown, citizens were only allowed out to go to work, getting supplies or medicines, however, the Spanish Ministry of Health announced, a few days later, exceptions to this rule, one of them applying to people with mental health conditions or disabilities who may experience worsening of symptoms due to confinement. People living with dementia were included within this exception and **were allowed out for 'therapeutic outings'**.

Third sector

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https://www.infolibre.es/noticias/politica/2020/07/23/familias_que_sacaron_sus_mayores_residencias_denuncian_presiones_para_reingreso_bajo_amenaza_perder_plaza_109218_1012.html

Many **local Alzheimer Associations** and charities have continued providing support to carers, mostly by phone or videoconference and the National Alzheimer Association (CEAFA) launched a section with support resources in their website.

Provision of COVID-19 and dementia-specific information

Some institutions and professional societies, like the Spanish Neurology Society issued **advice and guidelines for families and people living with dementia** and some neurology departments launched new online resources to also support their patients with dementia during the pandemic, as the Hospital Universitario Central de Asturias.

8. Impact of COVID-19 on the access to medical care of people with dementia

8.1. Admission to hospital

In some regions the rates of admission to hospital of people living in care homes (and therefore those residents with dementia) did not seem to have been affected by the pandemic⁴⁵. In the worst hit regions such as Madrid, controversial events have taken place during the peak of the pandemic, coinciding with a surge of infections that overwhelmed the health and care system. As it is widely known, initial guidance (March 2020) from the regional Department of Health in Madrid⁴⁶, the epicentre of the pandemic in Spain, established that people living in care homes with moderate cognitive impairment (as per score in Global Deterioration Scale > 6) and with potential COVID-19 should not be sent to hospital for care. This guidance was inspired in ICU protocols of triage in situations of catastrophe (for admission to ICU, not to hospital). This guidance was later amended after receiving criticisms from patient associations and the regional Department of Social affairs⁴⁷. The admission of people from care home to hospitals in this Autonomous Community remains controversial: recent media reports (12th June) confirm that between 25th and 30th of March 1,364 care home residents died in Madrid, of which only 13% were transferred to hospital⁴⁸ but also, official data shows that 10.300 care home residents were transferred to hospitals from 1st March to 5th June⁴⁹. The referral from care homes to hospitals is a topic under current investigation in Madrid.

8.2. Intensive Care Units

Guidance issued by the Spanish Society of Intensive Care on March 2020⁵⁰, establishing criteria for admission to ICU in situation of scarcity of resources, literally stated “any patient with cognitive impairment, either due to dementia or any other degenerative condition, will not be

⁴⁵ <https://ltccovid.org/2020/06/14/new-report-the-covid-19-long-term-care-situation-in-asturias-spain/>

⁴⁶ https://www.elespanol.com/espana/madrid/20200325/polemico-documento-madrid-ancianos-discapacidad-no-derivaran/477453553_0.html

⁴⁷ <https://www.elmundo.es/madrid/2020/03/26/5e7c5d7d21efa081408b45e5.html>

⁴⁸ https://www.infolibre.es/noticias/politica/2020/06/05/los-seis-documentos-que-desmontan-version-ayuso-sobre-orden-no-trasladar-en-fermos-residencias-hospitales-107433_1012.html

⁴⁹ <https://www.segg.es/media/descargas/Carta-geriatria-residencias-Madrid.pdf>

⁵⁰ <https://www.fesemi.org/sites/default/files/documentos/publicaciones/etica-semicyuc-covid-19.pdf>

eligible to receive mechanical ventilation". This protocol did not specify the level of cognitive impairment and in principle it denies mechanical ventilation to all people living with cognitive difficulties regardless the level of severity (e.g. people with mild Alzheimer's disease, who may have more than a decade of life expectancy ahead of them). This protocol has been now published in the journal of *Medicina Intensiva*⁵¹, the official journal of the Spanish Society of Intensive care.

The practical implementation of these recommendations is, however, unknown, since the predominant practice is that hospitals usually developed their own protocols. For example, the Hospital Clinic in Barcelona used a triage protocol based on ethical principles by which no person was excluded based on a diagnosis of dementia and a global assessment of the person was considered instead^{52,53}. There is also confirmation about the implementation of the ICU protocol used in IFEMA hospital in Madrid (the worst-hit COVID-19 region in country) that did guarantee access to ventilators to people living with dementia, excluding only those severe cases unlikely to benefit from admission to ICU (the protocol specifies GDS \geq 6)⁵⁴. Both Barcelona and Madrid were at the epicentre of the pandemic and faced a severe surge of infections in a short period of time.

8.3. Dementia Clinics

Clinics through phone and videoconference

Spain has around 220 highly specialised dementia clinics⁵⁵ within its public health system. Neurologists and geriatricians across the country have **continued consultation, mostly over phone** as common practice⁵⁶. A variable proportion of medics were, however, redeployed to COVID-19 services, which may have reduced the staffing availability to attend outpatient clinics⁵⁷. The degree of involvement of clinical neurologists in COVID-19 teams was variable according to each region and hospital. In Madrid, 95% of departments of neurology had neurologists reallocated to care for patients with COVID-19, according to a recent survey⁵⁸. It is unknown, however, to what extent this impacted in the attention of patients with dementia.

As the pandemic situation improved, face to face clinics commenced again. This process is happening differently across different regions, with final decisions being made by local teams. For instance, in the ACE Foundation in Barcelona, the visits of patients to the Memory Unit dropped by 60% following the suspension of face-to-face activity in mid-March. However, by 24rd of April they were able to perform 78% of visits by using videoconference or phone calls⁵⁹.

⁵¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7158790/>

⁵² <https://tallerdederechos.com/wp-content/uploads/2020/03/AET-UCI-COVID-19-V.1-20-03-20-Cl%C3%ADnic3.pdf>

⁵³ <http://www.bioeticayderecho.ub.edu/es/el-obd-presenta-sus-recomendaciones-para-la-toma-de-decisiones-eticas-sobre-el-acceso-de-pacientes>

⁵⁴ https://www.madrid.es/UnidadesDescentralizadas/Emergencias/Samur-PCivil/Samur/ApartadosSecciones/COVID-19/data/ProtocoloCOVID_HospitalIfema.pdf

⁵⁵ <https://www.elsevier.es/es-revista-revista-espanola-geriatria-gerontologia-124-articulo-mapa-enfermedad-alzheimer-otras-demencias-S0211139X17301725>

⁵⁶ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7151454/>

⁵⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7166024/>

⁵⁸ <https://pubmed.ncbi.nlm.nih.gov/32563566/>

⁵⁹ <https://content.iospress.com/articles/journal-of-alzheimers-disease/jad200547>

Although there is no national agreement about how to move forward in continuing outpatient face to face dementia clinics, there is general agreement about maintaining current infection control measures, encouraging the use of telemedicine and continuity of phone clinics and allowing very few people in waiting rooms⁶⁰.

The reorganization of primary care services⁶¹ and neurology departments may have potentially led to a lower rate of admission of new patients and therefore, a delay in diagnosis, although there is no proof that this had been the case.

9. Lessons learnt and calls for action

- **Need for a Dementia Minimum Dataset.** The absence of reliable and real-time data about the number of people living with dementia and their characteristics (cognitive status, place of residence, level of independence, co-morbidities, carer needs, etc), hampers the evaluation of the actual impact of the COVID-19 in this population. The implementation of a Dementia Minimum dataset⁶², would provide valuable data, both for the current situation and for more general clinical practice and planning of health and care policies.
- One of the main issues and controversies during the pandemic has been the heterogeneity in the data collected and ways to share it across the country. A **common information system for all AACCs** would be of great value in the near future to develop joint actions against COVID-19 and other challenges.
- People living with dementia have experienced a double hit of the pandemic: on the one hand, COVID-19 infections have been especially frequent and severe in people with dementia; on the other hand, lockdown and quarantine measures have negatively impacted the cognitive and psychological health of this population. A **national consensus strategy for dementia care during COVID-19** deems necessary.
- Dementia clinics should adapt to the new situation. Easier access to the specialists taking care of patients and remote consultations should be promoted.
- Measures to **mitigate the impact of COVID-19 in community-based services** (including home care services and day centres), should be adopted rapidly: ensure enough PPE,

⁶⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7165283/?report=classic>

⁶¹ <https://www.redaccionmedica.com/secciones/medicina-familiar-y-comunitaria/coronavirus-la-crisis-sanitaria-cierra-700-centros-de-atencion-primaria-5168>

⁶² [https://geriatrics.ucsf.edu/minimum-data-set-mds-data#:~:text=The%20Minimum%20Data%20Set%20\(MDS,homes%20in%20the%20United%20States.](https://geriatrics.ucsf.edu/minimum-data-set-mds-data#:~:text=The%20Minimum%20Data%20Set%20(MDS,homes%20in%20the%20United%20States.)

staffing, training and contingency protocols are in place to guarantee continuity of care during a new wave. A comprehensive analysis of care home facilities and protocols is warranted to evaluate whether the current model of long-term care should be modified in the middle term.

- There is a pressing need for relatives of people with dementia in care homes to be considered at the level of keyworkers and an essential part of care and ensure that **care homes have enough resources to enable safe visits.**

NOTE FOR READERS: THE AUTHORS OF THIS REPORT WOULD WELCOME HELP TO COMPLETE DATA FOR TABLES 1 AND 2. IF YOU THINK YOU CAN CONTRIBUTE WITH RELIABLE INFORMATION, PLEASE SEND AN EMAIL TO aida.gonzalez@ucl.ac.uk