



# Detrimental effects of confinement and isolation on the cognitive and psychological health of people living with dementia during COVID-19: emerging evidence

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**Note:** If you notice any inaccuracy in this report, please email [aida.gonzalez@ucl.ac.uk](mailto:aida.gonzalez@ucl.ac.uk)

## 1. Key points

- **3 papers** describing the effects of lockdown on people with dementia living in the community have been published to date<sup>1-2-3</sup>. They show a **worsening of functional independence** and **cognitive symptoms** during the first month of lockdown (31% of people surveyed) and also exacerbated **agitation, apathy and depression** (54%), along with the deterioration of **health status** (40%) and increased used of **antipsychotics** or related drugs (7%). People with frontotemporal dementia (FTD) and their family caregivers seem to be particularly struggling to comply with protective measures.
- Only **2 case studies reporting strategies** to support people with dementia in care homes have been produced so far<sup>4-5</sup>. One describes a quarantine care plan for a person with FTD and the other, a mitigating strategy to ease the distress experienced by a man when his family stopped visiting during the pandemic.
- **People living with dementia in care homes** have experienced a particularly harsh version of lockdown. Although no observational studies on the effects of confinement in care home residents have been published yet, the **ban on visits** from spouses and partners in care is believed to be causing a significant deterioration in the health and wellbeing of residents with dementia<sup>6</sup>. It is worth noting that a study involving 26 care homes proved that it is possible to implement successful infection control measures at the same time that **visits are permitted**<sup>7</sup>.
- COVID-19 infections will continue happening until a vaccine is developed. Learnings from this first COVID-19 wave can help the **home care** and **day care sector** prepare to minimise the disruption of their services in future waves so support can continue for people with dementia in the community. In care homes, **evidence-based compassionate protocols** should contribute to mitigating the detrimental effects of isolation and quarantine in residents with dementia (and their families).

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<sup>1</sup> <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.16644>

<sup>2</sup> <https://onlinelibrary.wiley.com/doi/epdf/10.1111/ene.14339>

<sup>3</sup> <https://pubmed.ncbi.nlm.nih.gov/32517839/>

<sup>4</sup> <https://www.sciencedirect.com/science/article/pii/S1064748120303262?via%3Dihub>

<sup>5</sup> <https://www.sciencedirect.com/science/article/pii/S0165178120307587?via%3Dihub>

<sup>6</sup> <https://www.alzheimers.org.uk/news/2020-06-05/thousands-people-dementia-dying-or-deteriorating-not-just-coronavirus-isolation>

<sup>7</sup> [https://www.jamda.com/article/S1525-8610\(20\)30526-0/fulltext](https://www.jamda.com/article/S1525-8610(20)30526-0/fulltext)

## 2. Introduction

This report contains a short review of the emerging evidence on the impact of COVID-19 on the cognitive and psychological health of people living with dementia and the reported mitigating measures. In an attempt to give a comprehensive and contextualised overview of the state of the topic, the empirical evidence summarised below is combined with other sources of information, such as published letters to the editor and news.

The association between social isolation, higher mortality and poorer health (both physically and psychologically) in healthy individuals was known before the COVID-19 pandemic began<sup>8,9</sup>. In the early days of the COVID-19 crisis, experts warned about the potentially harming effects of confinement in people living with dementia<sup>10</sup> who, besides cognitive difficulties, also experience neuropsychiatric symptoms as part of their clinical syndrome<sup>11</sup> and are particularly vulnerable to changes in routine. Shortly after that, the media began featuring testimonies of people with dementia and their families describing the challenges faced because of lockdown<sup>12,13</sup> and more recently, the first observational studies conducted during the pandemic revealed significant deterioration of cognitive function and psychological symptoms during the first month of lockdown for people living with dementia in the community.

For care homes, where rates of infection and mortality have been large worldwide<sup>14</sup>, confinement measures involved, among others, a ban on visits (including family caregivers and next of kind) and further isolation measures when outbreaks were identified (such as asking residents to stay in their rooms). The challenges that the implementation of these measures of infection control represent for people living with dementia also come with complex ethical implications and associated consequences of incalculable effect on the cognitive and mental health of this population.

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<sup>8</sup> [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(19\)30230-0/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(19)30230-0/fulltext)

<sup>9</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0033350617302731?via%3Dihub>

<sup>10</sup> [https://www.thelancet.com/journals/lanpub/article/PIIS0140-6736\(20\)30755-8/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS0140-6736(20)30755-8/fulltext)

<sup>11</sup> <https://pubmed.ncbi.nlm.nih.gov/31506117/>

<sup>12</sup> <https://ltccovid.org/2020/05/03/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/>

<sup>13</sup> <https://ltccovid.org/2020/04/24/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-spain/>

<sup>14</sup> <https://ltccovid.org/wp-content/uploads/2020/06/Mortality-associated-with-COVID-21-May-1.pdf>

### **3. Negative effects of confinement and compassionate measures to mitigate them**

#### **3.1. People with dementia living in the community**

The majority of people with dementia live in the community<sup>15</sup> and rely on care and support provided by family members.

#### ***Emerging evidence of the impact of confinement on people living with dementia in the community***

Interruption of well-established daily routines, reduction of social interaction, exercise and meaningful activities are among the disruptive changes brought in by COVID-19 to people with dementia living in the community. Disorientation, confusion and exacerbation of behaviours that challenge are expected to appear (or increase if already present) in this context, also increasing the burden on family and professional caregivers. Such hypothetical predictions are being confirmed now by emerging evidence.

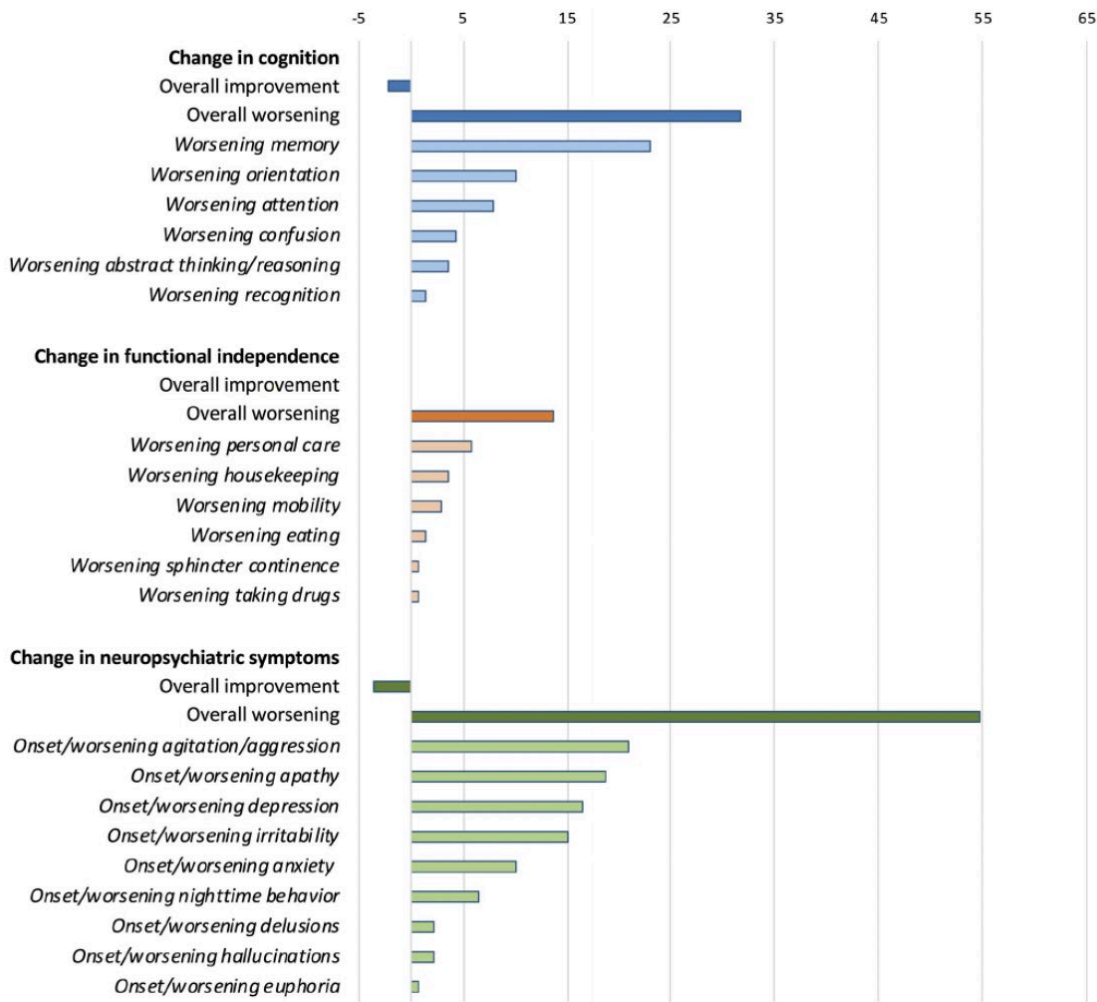
A survey conducted on 139 patients from an Italian Cognitive Disorders Centre in April 2020 asking about their first month of lockdown revealed that 31% of respondents reported worsening of memory and orientation abilities and 54% worsening or onset of agitation, apathy and depression<sup>16</sup> (Figure 1 below). In 7.2% of the patients surveyed, the clinical changes required drug prescription, particularly antipsychotics. 49% of the caregivers reported higher levels of anxiety compared with the period before lockdown.

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<sup>15</sup> [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia\\_uk\\_update.pdf?fileID=2323](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf?fileID=2323)

<sup>16</sup> <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.16644>

Figure 1: Clinical changes reported in *Canevelli et al., (2020)* showed as percentages.



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

In a sample of 40 patients seen in a Spanish Cognitive Disorders Unit, the Neuropsychiatric Inventory (NPI) was administered before and after 5 weeks within lockdown. The authors found that general NPI scores have increased during confinement, with a significant worsening of apathy and anxiety scores. 30% of patients and 40% of caregivers reported a worsening of patient's health status during confinement.<sup>17</sup>

Lastly, another study reported the findings from a survey administered to 12 patients with frontotemporal dementia (FTD) and 12 with Alzheimer's disease (AD). The results showed that people with FTD had more difficulties complying with protective measures to prevent infection by COVID-19 compared to the group with AD, in particular they showed significantly less

<sup>17</sup> <https://onlinelibrary.wiley.com/doi/epdf/10.1111/ene.14339>

adherence to ‘washing hands’ and keeping ‘social distancing’. The authors also described 2 cases of patients with semantic dementia and their struggles to understand the protective rules<sup>18</sup>.

### ***Measures to mitigate the impact of confinement in people living with dementia in the community***

Support in the community has been greatly affected by the removal of social contact (e.g. gatherings with family and friends), activities (e.g. daily walks, attendance to yoga or signing lessons), the disruption of home care and the closure of day care centres during the pandemic.

#### Home care

Lack of Personal Protection Equipment (PPE), testing and clear guidance about effective infection control protocols in the early times of the pandemic resulted in some home care providers disrupting the services offered (e.g. cancelling visits to vulnerable people or users refusing the service for fear of infection)<sup>19-20-21</sup>. These services may however continue (now and in future waves of COVID-19) if the following measures are taken:

- Provision of enough PPE (including access to the supply chain and reasonable prices)
- Guidance on recommended PPE for different scenarios<sup>22</sup>
- Clear guidance and training on correct use of PPE and infection control

#### Day centres

With many countries transitioning now to the ‘new normality’, the services provided by day care centres are progressively being restored. New protective measures to continue services in some places include<sup>23,24</sup>:

- Establishing attendance turns for users, to reduce the number of people in the centre at same time

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<sup>18</sup> <https://www.cambridge.org/core/journals/international-psychogeriatrics/article/behavioral-pattern-of-patients-with-frontotemporal-dementia-during-the-covid19-pandemic/0C9240C27D6F2CDF88A3341883E782EB>

<sup>19</sup> <https://www.bbc.com/news/health-51934034>

<sup>20</sup> <https://ltccovid.org/2020/04/24/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-spain/>

<sup>21</sup> <https://ltccovid.org/2020/05/03/report-the-impact-of-the-covid-19-pandemic-on-people-living-with-dementia-in-uk/>

<sup>22</sup>

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/878750/T2\\_poster Recommended PPE for primary outpatient community and social care by setting.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878750/T2_poster_Recommended_PPE_for_primary_outpatient_community_and_social_care_by_setting.pdf)

<sup>23</sup>

[https://www.infolibre.es/noticias/politica/2020/06/02/los\\_centros\\_dia\\_abordan\\_desescalada\\_ritmos\\_diferentes\\_preocupados\\_por\\_las\\_secuelas\\_deterioro\\_para\\_algunas\\_personas\\_puede\\_ser\\_irreversible\\_107331\\_1012.html](https://www.infolibre.es/noticias/politica/2020/06/02/los_centros_dia_abordan_desescalada_ritmos_diferentes_preocupados_por_las_secuelas_deterioro_para_algunas_personas_puede_ser_irreversible_107331_1012.html)

<sup>24</sup> <https://www.euroweeklynews.com/2020/06/18/temperature-checks-and-screened-tables-the-new-normality-at-day-centres-for-the-elderly-on-spains-costa-blanca/>

- Temperature checks
- Use of masks when physical distance cannot be guaranteed (such in collective transport)
- Schedule flexibility to encourage the use of private transport
- Screened tables for lunchtime
- Provision of enough PPE

It is unclear, however, how these day care services might adjust and prepare to navigate future waves of COVID-19 or what alternative support will be provided in case of users getting infected or having to quarantine.

### **3.2. People living with dementia in residential and nursing care homes**

It has been estimated that 85% of care home residents in England have dementia<sup>25</sup>. People with dementia who live in care homes are usually older, in more severe stages of the disease, show more severe symptoms and require greater support for daily activities than people living in the community. They are, therefore, also more vulnerable to the pernicious effect of confinement and quarantine measures.

#### ***Emerging evidence of the impact of confinement and isolation on people living with dementia in care and nursing homes***

Non-COVID related deaths in people with dementia in care homes in England have increased up 80% in the month of April compared to the previous years<sup>26</sup>. There were 10,000 unexplained extra deaths among people with dementia in England and Wales according to official figures that, in principle, are not attributable to COVID-19 infection<sup>27</sup>. This may be due to a combination of undiagnosed COVID-19 and disruption to normal care for people without COVID-19. The release of this data has drawn attention to the potentially harming effects of confinement and isolation as long as other side effects of the pandemic (e.g. reduced access to usual health services). A survey carried out by the UK leading charity Alzheimer's Society revealed that 79% of the 128 care homes surveyed reported that lack of social contact is believed to be causing a deterioration in the health and wellbeing of their residents with dementia<sup>28</sup>. People with dementia may not understand why their families no longer come to

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<sup>25</sup> <https://pubmed.ncbi.nlm.nih.gov/28794896/>

<sup>26</sup> <https://www.alzheimers.org.uk/news/2020-05-15/ons-figures-show-dementia-main-underlying-condition-covid-19-deaths-alzheimers>

<sup>27</sup> <https://www.theguardian.com/world/2020/jun/05/covid-19-causing-10000-dementia-deaths-beyond-infections-research-says>

<sup>28</sup> <https://www.alzheimers.org.uk/news/2020-06-05/thousands-people-dementia-dying-or-deteriorating-not-just-coronavirus-isolation>

see them. Being removed from strong and grounding emotional bonds may be confusing and emotionally distressing and having a devastating effect on their health.

Velayudhan et al., (2020)<sup>29</sup> paper addresses the mental health of people living with dementia in care homes during the pandemic. The authors warn about the risk for increased use of antipsychotics and other sedatives in residents to ensure compliance with protective measures in a context of staff shortage and need for physical distance. They also advocate for proactive training and support in care homes to avoid these undesirable collateral effects of COVID-19 and promote person-centred care. Not only the use of antipsychotics is associated with higher mortality<sup>30</sup> in people with dementia, but also, COVID-19 is primarily a respiratory disease and the use of practices that might cause respiratory depression (e.g. high doses of antipsychotics or benzodiazepines) may lead to adverse outcomes.

### ***Measures to mitigate the impact of confinement and isolation in people living with dementia in care and nursing homes***

There is only one example in the COVID-19 literature of a compassionate care plan to support people living with dementia through quarantine. Laboni et al., (2020)<sup>31</sup> describe an isolation care plan for a person with frontotemporal dementia that effectively maintained the person safe until her quarantined period ended.

For confinement in care homes, one of the most controversial measures has been the ban on visits and its impact on resident's wellbeing. Padala et al., (2020)<sup>32</sup> reported the case of a man, a nursing home resident, who experienced a significant worsening of confusion, depression, anxiety, apathy, irritability, difficulty sleeping, restlessness and poor appetite since his daughter (very engaged in his care) stopped visiting during the pandemic. The use of video calls to restore contact between the resident and his daughter seemed to have some positive effects on levels of anxiety and appetite. Hado et al., (2020) also advocate for meaningful communication between family caregivers and residents in care homes<sup>33</sup>. As proactive solutions for the ban on visits, the authors suggest strengthening's communication channels (e.g. assigning staff members as primary contacts for families, use of virtual visits, ...), activating family councils (e.g. family councils that advocate for residents quality of care can be supported by using e-mail and Skype instead of usual on-site meetings) and mobilizing gerontological

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<sup>29</sup> [https://www.cambridge.org/core/services/aop-cambridge-core/content/view/C3F930299840D83603C3077377AE462F/S1041610220001088a.pdf/mental\\_health\\_of\\_people\\_living\\_with\\_dementia\\_in\\_care\\_homes\\_during\\_covid19\\_pandemic.pdf](https://www.cambridge.org/core/services/aop-cambridge-core/content/view/C3F930299840D83603C3077377AE462F/S1041610220001088a.pdf/mental_health_of_people_living_with_dementia_in_care_homes_during_covid19_pandemic.pdf)

<sup>30</sup> [https://www.jamda.com/article/S1525-8610\(18\)30728-X/abstract](https://www.jamda.com/article/S1525-8610(18)30728-X/abstract)

<sup>31</sup> <https://www.sciencedirect.com/science/article/pii/S1064748120303262?via%3Dihub>

<sup>32</sup> <https://www.sciencedirect.com/science/article/pii/S0165178120307587?via%3Dihub>

<sup>33</sup> <https://www.tandfonline.com/doi/full/10.1080/08959420.2020.1765684>



social students (e.g. to assist staff to maintain communication with families and provide social support).

### *Lifting the ban on visits*

The consequences of the ban on visits carry a deeper and complex ethical debate. As Alison Rahn<sup>34</sup> points out, continuous interaction with community networks like family and friends serve as bridges with the outside world and contributes to maintaining the sense of self of residents. Some people living in care homes will not outlive the COVID-19 time regardless of whether they contract the virus or not so, are isolation measures the conditions of living that these people will be offered at the end of their lives? Another controversial point is the blanket ban on visitors, with no special allowance to spouses or family caregivers (those actively involved in care and support). Reaching a fair compromise between rights and risks seems feasible, although may require investment in staff and training<sup>35</sup>. Dr Lee-Fay analyses risks and risk reduction for easing lockdowns in care homes in a LTCcovid report published in May<sup>36</sup>. Her report recommends considering the regional prevalence of COVID-19, limiting the number of visitors and visits, screen visitors, and setting up additional infection control measures when planning for an ease on the ban on visits.

The feasibility of implementing successful infection control measures at same time that visits are permitted has eventually been demonstrated by Verbeek et al; (2020)<sup>37</sup>. In this study, 26 Dutch nursing homes enlarged their possibilities for allowing visitors in their facilities following guidelines developed on this purpose. Compliance with guidelines was sufficient to good, no new infections were reported during this time and nursing homes recognized the added value of real personal contact between residents and their families, with a positive impact on their well-being.

Practical examples of how care homes around the world have tried to enabled visits in their facilities include “[window visits](#)” and “[car visits](#)” that, yet still very restrictive, may allow better direct interaction than video calls for many people.

Examples of strategies enabling more meaningful, private and direct interaction between residents and their partners in care:

- [Hug curtains](#)
- [Glass booths](#)

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<sup>34</sup> <https://theconversation.com/banning-visitors-to-aged-care-during-coronavirus-raises-several-ethical-questions-with-no-simple-answers-134663>

<sup>35</sup> [https://theconversation.com/aged-care-visitor-guidelines-balance-residents-rights-and-coronavirus-risk-but-may-be-hard-to-implement-137706?utm\\_source=twitter&utm\\_medium=bylinetwitterbutton](https://theconversation.com/aged-care-visitor-guidelines-balance-residents-rights-and-coronavirus-risk-but-may-be-hard-to-implement-137706?utm_source=twitter&utm_medium=bylinetwitterbutton)

<sup>36</sup> <https://ltccovid.org/2020/05/13/easing-lockdowns-in-care-homes-during-covid-19-risks-and-risk-reduction/>

<sup>37</sup> [https://www.jamda.com/article/S1525-8610\(20\)30526-0/fulltext](https://www.jamda.com/article/S1525-8610(20)30526-0/fulltext)

- [Glass-pod](#)
- Visits in care home open spaces (e.g. [gardens](#), [terraces](#), [purpose-built tents](#) ...)
- [Designated spaces](#) within the care home

Apart from the above strategies, we now know that the correct use of appropriate PPE provides high level of protection against COVID-19<sup>38</sup> even for people being at high risk of exposure. Enough supply of PPE to equip visitors along with updated infection control protocols and training for both staff and families may be a way forward for people with dementia living in care home entering 'new normality' at same time and pace than the rest of us.

#### 4. Lessons learnt and call for action

- A **Minimum Dementia Dataset** is urgently required. The difficulty to access data about people living with dementia, both in care homes and in the community, is hindering our understanding of the effect of the pandemic on this population and limiting and slowing down our response to mitigate its effects.
- Confinement can harm people living with dementia, leading to a worsening of both cognitive and psychological symptoms. Continuity of support and access to therapeutic services may **mitigate the negative effects** of confinement on the cognitive and psychological health of people living with dementia in the community in future waves of COVID-19.
- Enough support to domiciliary care providers and day care centres (e.g. supply of PPE, training in how to use it correctly) and redesign of activities to comply both with the therapeutic and protective requirements may enable **continuity of support in the community**.
- People living with dementia who have contracted COVID-19 or have been in contact with an infected person may have to be quarantined. **Compassionate isolation care plans** for care homes may reduce the deleterious effects of quarantines on this population. **More research is needed** to better understand what the optimal models of compassionate isolation are.

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[https://www.bmj.com/content/369/bmj.m2195?utm\\_source=twitter&utm\\_medium=social&utm\\_term=hootsuite&utm\\_content=sme&utm\\_campaign=usage](https://www.bmj.com/content/369/bmj.m2195?utm_source=twitter&utm_medium=social&utm_term=hootsuite&utm_content=sme&utm_campaign=usage)

- Building capacity to deliver models of care able to diminish the cognitive and psychological effects of quarantine and isolation requires urgent **investment in staffing, training and PPE supply** in the care home sector. Restoring meaningful interaction and communication between residents and their families is a top priority.
- **Guidelines and training for compassionate support and isolation** in care homes need to be rapidly developed and widely shared.