

Joint Committee on Human Rights - The Government's response to covid-19: human rights implications of long lockdown

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This briefing includes:

1. Suggested questions
2. The effects of a lack of social contact on people with dementia in care homes.
3. The impact of lockdown on the loved ones and carers of people with dementia
4. Current care home visitor guidance

1. Suggested questions

“Alzheimer’s Society and other organisations have been previously advocated for care home resident’s loved ones to receive ‘key worker status’, these had briefly been implemented in some parts of the country before the new, more contagious strain took hold. What measures do you think could be reasonably be introduced to enable meaningful visits to happen again?”

“Family and friends often provide an important element of care when visiting their loved one’s in care homes. Could you share with the Committee what care you provide when visiting and whether you feel this has been replicated by staff during lockdown?”

“I have been contacted by Alzheimer’s Society who shared with me a study they conducted of care home managers in August 2020 which found that 79% of care home managers reported that a lack of social contact was causing deterioration in health and wellbeing of their residents with dementia. Is this deterioration in health and wellbeing something you recognise and how has this manifested?”

2. The effects of a lack of social contact on people with dementia in care homes.

Throughout the course of the pandemic Alzheimer’s Society has been working with Government to ensure that people living in care homes can receive visits from their loved ones. Family and friends provide an important element of care to people with dementia living in care homes and findings from Alzheimer’s Society studies have shown the devastating impact the stopping of visits has had on residents with dementia.

The nature of dementia means that needs often vary from person to person. Social stimulation and regular face to face contact with loved ones often not only helps people living with dementia to feel secure and improve mood, but also helps them to maintain cognition and communication skills.

We know that some care homes have enabled friends and family members have been able to stay in touch with their loved ones through video or phone calls. However, for many people with dementia, such technology can be confusing or distressing to use. A digital ‘visit’ only allows for certain interactions to take place and family members can’t be involved or check on the care their loved ones are being provided with.

Many care homes have closed their doors to visitors during the pandemic. Around 97%¹ of care homes had closed to visitors during the first wave, according to the latest ONS data from July. If people living with dementia are unable to maintain their skills through socialising, they can quickly lose them. An Alzheimer’s Society survey found that the most common symptoms that people living with dementia reported having increased since lockdown began were difficulty concentrating (48%), memory loss (47%), and agitation or restlessness (45%)². Furthermore, an Alzheimer’s Society survey from August 2020 found that 79% of care home managers reported a worsening of symptoms amongst care home residents with dementia during lockdown. The Government must recognise that family carers are an integral part of the care system. They help with practical elements of care, they support communication, and they provide companionship. When

¹ ONS. Impact of coronavirus in care homes (released 3rd July 2020)

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/impactofcoronavirusincarehomesinenglandvivaldi/26mayto19june2020>

² Alzheimer’s Society. Alzheimer’s Society online survey: The impact of COVID-19 on People Affected by Dementia. [Online] 2020. <https://www.alzheimers.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-decline-people-dementia-who-are-rapidly>.

family carers are unable to provide that vital care, the health and wellbeing of people with dementia can seriously decline, leading to premature deterioration of dementia symptoms and therefore premature death.

International academics looking at risks associated with care home visits during COVID-19 published a paper on 1st November stating that “we found no scientific evidence that visitors to care homes introduced COVID-19 infections³”.

3. The impact of lockdown on the loved ones and carers of people with dementia

A recent Alzheimer's Society survey found that family and friends of people with dementia have spent an extra 92 million hours caring for loved ones with dementia⁴ during the pandemic. But even before lockdown, and in the context of a struggling social care system, more than 40% of family and friend carers of people with dementia were reporting providing more than 100 hours a week of care to their loved ones.

Caring for a loved one with dementia can be hugely rewarding, but it can also be very challenging without the right support. 95% of carers we surveyed reported that the increased caring responsibilities had an impact on their mental or physical health; 69% reported that they feel constantly exhausted, 64% feel anxious, 50% have developed problems sleeping and 49% feel depressed⁵.

4. Current visitor guidance

The most recent iteration of guidance, published in [National Lockdown Guidance](#) on 4 January 2021, contains statements which are contradictory and unclear and Alzheimer's Society is seeking urgent clarification from Government on this. The guidance gives two opposing statements on care home visits, which Alzheimer's Society are concerned will cause confusion amongst the sector and public.

- 1) The guidance states that “*you can also leave home to visit someone who is dying or someone in a care home (if permitted under care home guidance)*”⁶. Current care home guidance allows indoor close-contact visits if the visitor has been tested and wears suitable PPE.
- 2) However, the National Lockdown Guidance later states that “*close-contact indoor visits are not allowed. No visits will be permitted in the event of an outbreak.*”⁷

Alzheimer's Society would like the Government to provide care homes, residents and families some clarity on whether they can see each other in person and on what basis.

The blanket ban on care home visits is a violation of their fundamental rights under the Human Rights Act 1998 (Article 2: Right to life; Article 8: Respect for your private and family life, home and correspondence) and the United Nations Convention on the Rights of Persons with Disabilities (Article 19: Living independently and being included in the community). It is imperative therefore that any future guidance needs to be ensure that peoples' rights are recognised, respected and upheld.

Alzheimer's Society welcomed the Government's commitment in October 2020 that by December 18th, resident's loved ones will be given Key Worker status, with access to PPE and testing which would allow them to safely visit in care homes – in line with Alzheimer's Society's calls. Care home visiting guidance from Government should be enabling for care homes and local authorities to find solutions in partnership with carers and family members that meet the needs of individual residents. We are concerned that this guidance moves the focus away from the continued lack of progress on testing and PPE and Alzheimer's Society is particularly concerned that the commitment to ensure that resident's loved ones will be given 'key worker status' is not being upheld.

³ Comas-Herrera A, Salcher-Konrad M, Baumbusch J, Farina N, Goodman C, Lorenz-Dant K, Low L-F (2020) *Rapid review of the evidence on impacts of visiting policies in care homes during the COVID-19 pandemic*. Pre-print published in LTCcovid.org.

⁴ Alzheimer's Society [2020] <https://www.alzheimers.org.uk/lockdowncarerhours>

⁵ Alzheimer's Society. Alzheimer's Society online survey: The impact of COVID-19 on People Affected by Dementia. [Online] 2020. <https://www.alzheimers.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-decline-people-dementia-who-are-rapidly>.

⁶ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/949536/NationalLockdownGuidance.pdf

⁷ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/949536/NationalLockdownGuidance.pdf