

Briefing for Westminster Hall debate on family visit access in health and social care settings during the covid-19 outbreak. Wednesday, 11 November 2020

Contact: Daniela Fernandez Gomora d.fernandezgomora@alzheimers.org.uk

Key points:

- More than 27.5% of all Covid-19 deaths were of people with dementia.
- Since the coronavirus began in March, eight months ago, many families have not been able to see their loved ones who have dementia and live in a care home.
- This is all the more tragic when you consider that half of all care home residents die within 15 months of admission into a care home¹. For people with dementia, a lack of social contact significantly increases the progression of their dementia.
- Family and friends play a significant role in the care of many care home residents with dementia.
- Government care home visitor guidance from 5th November offers little new to enable visits for key family carers, with some measures suggested being impractical for residents, visitors and/or homes.
- Alzheimer's Society calls for the Government to allow for at least one informal carer per care home resident to be designated a key worker, with access to training, COVID-19 testing/ vaccinations and PPE.

About Alzheimer's Society

Alzheimer's Society is the UK's leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland.

Dementia and Covid-19

There are an estimated 850,000 people living with dementia in the UK². Approximately 61% of these people live in the community, with approximately 39% living in care homes or supported accommodation. Around 70% of people living in care homes have dementia, and 97% of care homes have stopped visits since March.³ In September 2020 Alzheimer's Society published the report: '[Worst Hit: Dementia during coronavirus](#)' highlighting the disproportionate impact (more than 27.5% of all Covid-19 deaths) of the coronavirus outbreak on people affected by dementia.

Family visit access in care home settings

Since the outbreak of coronavirus many families have not been able to see their loved ones who have dementia and live in a care home resulting in severe negative effects for both.

Beginning of the outbreak

At the beginning of the pandemic when shielding was introduced, dementia was not considered as being one of those conditions particularly at risk. We understand why governments and care providers took the step to close care homes to visits at that early point. However, this decision was considered to be a temporary measure until a longer-term solution could be found, it has now been 8 months since then and this hasn't yet happened.

The clinical impact on people with dementia

For people with dementia, a lack of social contact is not only bad for their mental health, it also has a significantly negative effect on the progression of their dementia. If people with dementia do not practice their communication and cognitive skills, they run the risk of losing them permanently. Similarly, their dementia symptoms will deteriorate more rapidly than would usually be the case. Sadly, this could ultimately lead to them dying far earlier than they might otherwise have done so. Between January and July of this year, 5,000 more people than we would ordinarily expect died of dementia. This means that dementia deaths were 52% higher for that period than they normally are. Family and friends play a significant role in the care of many people with dementia, whether it's through interpreting their needs or providing personal care. We also know that Covid-19 symptoms are presenting differently in people with dementia and therefore those family and friends are often best-placed to identify if someone is unwell and may require a Covid-19 test.

Effects of social isolation on people with dementia

Some care homes have enabled friends and family members to stay in touch with their loved ones through video or phone calls. For many people with dementia, such technology can be confusing or distressing to use.

¹ <https://eprints.lse.ac.uk/33895/1/dp2769.pdf>

² https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

³ AS survey of 100 care homes April 2020

If people living with dementia are unable to maintain their skills, they can quickly lose them. This includes recognising family members, as well as remembering words and how to form sentences. People living with dementia are also more likely to have depression than the general population (23% against 19% of the whole population) and this lack of contact has the potential to deepen that depression.⁴ In an Alzheimer's Society survey, 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%)⁵.

Care providers insurance

Alzheimer's Society is concerned that anecdotal evidence suggest that some care providers' insurance premiums have been increased significantly if they are admitting visits during this time. *Can the Minister confirm what conversations she has had with insurance representatives to support care providers?*

The rules on visiting

The most recent guidance from 5th November states that indoor visits are possible using Covid-secure visiting areas/pods however these must have floor to ceiling screens and separate entrances to the room for residents and visitors. For many care homes, this is impractical or even impossible to facilitate. The guidance also suggests the use of 'window' visits; however, it stipulates that the windows must remain closed; this approach offers no meaningful contact. There has been no progress in the latest iteration of the guidance to enable loved ones to provide residents with the vital care that they have been missing since March.

Family visit access in healthcare settings

Hospital visits have been significantly restricted since the coronavirus outbreak. Guidance produced on 8 April 2020 suspended visits to hospitals, except if not being present would cause the person with dementia distress or if they are nearing the end of life. Being in an unfamiliar environment can be disorientating and frightening for someone with dementia, therefore having the support of a carer, who can help to reassure and communicate care needs can significantly improve the person's stay in hospital. During the early stages of the pandemic carers told us that they were unable to see loved ones for many weeks, resulting in their condition deteriorating significantly which they felt was due to a lack of visits and care that could have been provided by family members had they been allowed to visit. The new guidance allows visits to inpatient settings, in a very careful and Covid-19 secure way.⁶ In addition, details of visiting restrictions are subject to the local discretion by trusts and other NHS bodies which can result in regional variation and delays to visits of people most at need of care.

Alzheimer's Society calls for the Government

Alzheimer's Society has welcomed the Government's recent announcement of a pilot scheme to enable informal carers to be given keyworker status and are eager to see further detail.

Alzheimer's Society's recommendations to Government are:

- a. Allowing for at least one informal carer per care home resident to be designated a key worker, with access to training, COVID-19 testing/ vaccinations and PPE.
- b. Where care homes are unable to facilitate visits from loved ones, they must be required to notify the CQC and be required to put in place appropriate arrangements to maintain contact between loved ones and residents.
- c. Performance in enabling safe visiting and meeting cultural needs should also form part of the CQC's inspection framework during the pandemic.
- d. DHSC should rapidly co-produce with a small group of care providers and others a highly practical toolkit for care homes on how to implement the Visiting Guidance safely, drawing on best practice.

Debbie Abrahams MP and Jim Shannon MP are co-sponsoring a 90 minutes Westminster Hall debate on Thursday 12th November at 3 pm titled '*The effect of the Covid-19 outbreak on people affected by dementia*'. If you would feel able to add your name in support of the debate, please [contact us](#) and we will be able to provide speaking notes.

⁴ Evans, J., Macrory, I., & Randall, C. (2016). Measuring national wellbeing: Life in the UK, 2016. ONS. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuringnationalwellbeing/2016#how-good-is-our-health>

⁵ 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://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0751-visiting-healthcare-inpatient-settings-principles-131020_.pdf