

Coronavirus – General Debate – Tuesday 13th October

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1. Key points

- A report from Alzheimer's Society, [titled Worst Hit](#) has shown that people with dementia have been disproportionately impacted by the pandemic, and over 1/4 of all coronavirus deaths between March & June were of people with dementia.
- An Alzheimer's Society report recently published, showed that 92 million extra hours have been spent by family & friends caring for loved ones with dementia
- Alzheimer's Society are concerned that dementia diagnosis rates fell again in August and continues to stay under the 66.7% target.
- Alzheimer's Society are concerned that the stopping of visits to care homes is have a detrimental impact on the lives of people with dementia – causing distress and loss of cognitive skills.
- Alzheimer's Society would like to see nominated visitors to care homes classified as 'key workers' and be provided with access to PPE and infection control training on the same basis as care staff.

2. How people with dementia have been affected by Coronavirus

There are an estimated 850,000 people living with dementia in the UK¹. As Coronavirus numbers begin to rise once again, the Government must prioritise protecting those with dementia.

Deaths

People with dementia have been greatly impacted by the coronavirus pandemic. In terms of deaths, dementia has the most frequent pre-existing health condition for people dying with coronavirus². Data from the ONS shows that 27.5% of people whose death certificate mentioned COVID-19 from March to June in England and Wales had dementia. There were 13,840 deaths of people with dementia involving COVID-19 in these four months.³

Dementia Diagnosis

Dementia diagnosis opens the door to emotional, practical, legal and financial advice, support services, and pharmacological and non-pharmacological interventions. Prior to the pandemic there were already long waiting times for a diagnosis in some localities, with data showing waiting times from referral to diagnosis varying between 3-34 weeks in 2019⁴.

Diagnosis data for August shows that the diagnosis rate has dropped to 63.1% - down from 63.2% in July and below the target 66.7%⁵.

How isolation leads to deterioration in dementia

For many people with dementia, their family and friends play a significant role in their care, whether it's through interpreting their family member's needs or providing personal care. If people living with dementia are unable to maintain their skills, they can quickly lose them. This includes basic cognitive skills, such as recognising family members, as well as communication skills, such as remembering words and how to form sentences. For many people with dementia living at home, social distancing guidelines for friends and family combined with the reduction or cancellation of home care services meant they were left without vital social interaction and support.

People living with dementia are 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.⁶ 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%)⁷.

Alzheimer's Society is calling for government to take action by:

- a. Setting out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects of declining cognitive or physical functioning, support for mental and physical health, and speech and language therapy.

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

2 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19englandandwales/deathsoccurringinapril2020>

3 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsinvolvingcovid19englandandwales/deathsoccurringinjune2020>

4 London Dementia Clinical Network (2020). The 2019 national memory service audit. [Online] Available at <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf>

5 <https://digital.nhs.uk/data-and-information/national-indicator-library/dementia-65-estimated-diagnosis-rate#purpose>.

6 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>

7 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>.

- b. Working with national UK health and social care departments to develop and implement a clear recovery plan to ensure that all elements of memory assessment services can re-open and urgently catch up on waiting lists so the freefall in dementia diagnosis rates does not continue.
- c. Ensuring that any communications to, or requirements of, people affected by dementia are clear, consistent, straightforward to understand and reflect the daily lived experience and needs of people affected by dementia.

3. Care Home Visits

We understand the vital public health reasons for removing contact between people in care homes and their loved ones as over half (56%) of care homes have experienced COVID-19 among residents or staff.⁸ Around 70% of people living in care homes have dementia, and 97% of care homes have stopped visits.⁹

In September 2020, Government released updated guidance, which sets out how care home providers, working with local officials in their area can enable safe care home visits. The Government have also published the Winter Plan for Adult Social Care, which stipulates that care home visitors must always be supervised during their visit and visits must be limited. This government guidance states that the process of considering visitors to care homes should be led by the local director of public health. However, the decision on whether to allow visitors, and in what circumstances, is an operational decision and therefore ultimately for the provider and managers of each setting to make.

We recognise that 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 the technology is not accessible or user friendly. 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 provided with.

Friends or family members are often more attuned to changes in mood and wellbeing of someone living with dementia and are often the first to spot when something isn't right. This can be important in ensuring quick action is taken to provide medical help or adjustments made to care to prevent a more rapid decline in health. Through prompting a quick response and testing for someone living with dementia, family members and loved ones are an undervalued link in preventing the further spread of COVID - 19 in the care setting.

Alzheimer's Society has welcomed the commitments from the Government in the Winter Plan to fund a £546m Infection Control Fund and free PPE for care staff until March 2021. Alzheimer's Society would like to see nominated visitors have access to PPE and infection control training on the same basis as care staff.

Alzheimer's Society is calling for the Government to take action by:

- 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 national care inspectorates and seek to put in place arrangements to maintain contact between loved ones and residents.

4. Coronavirus effects on the lives of carers

Statistics show that 61% of people with dementia live at home with most being supported by unpaid carers¹⁰, yet, respite provision – or short breaks - for carers has been substantially restricted during the period of the pandemic. Research also indicates 40% of carers of people with dementia have clinically significant depression or anxiety. This has been shown to be unrelated to the severity of dementia¹¹, which suggests if carers have the right support with their mental health, it could improve their wellbeing and enable them to better cope with caring responsibilities as the condition progresses. We know a carer's psychological health can also predict a breakdown in care and therefore the need for the person with dementia to move into residential Care¹².

Figures from Alzheimer's Society, show that 92 million extra hours have been spent by family and friends caring for loved ones with dementia, and 95% of carers in our survey reported a negative impact on their mental or physical health¹³

Alzheimer' Society is calling for the Government to take action to support carers by:

- a. Ensuring the delivery of carers' assessments and provision of short breaks for carers.
- b. Collecting local authority and health authority data on carer assessments and respite care.

⁸ ONS (2020) *Impact of coronavirus in care homes in England: 26 May to 19 June 2020*,

www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/impactofcoronavirusincarehomesinenglandvivaldi/26mayto19june2020

⁹ Alzheimer's Society [2020] <https://www.alzheimers.org.uk/lockdowncarerhours>

¹⁰ Carers Trust. (2020). Key facts about carers and the people they care for. Available: <https://carers.org/key-facts-about-carers-and-people-they-care>.

¹¹ Livingston, G. et al. (2013) [Clinical effectiveness of a manual based coping strategy programme \(START, STRAtegies for RelaTives\) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial](https://doi.org/10.1192/bjp.2019.160)

¹² Livingston, G., et al. (2020). Clinical effectiveness of the START (STRAtegies for RelaTives) psychological intervention for family carers and the effects on the cost of care for people with dementia: 6-year follow-up of a randomised controlled trial. *British Journal of Psychiatry*, 216(1), 35–42. <https://doi.org/10.1192/bjp.2019.160>

¹³ 2 Alzheimer's Society. Survey: Caring for a person living with dementia during the COVID-19 pandemic. [Online] 2020. <https://www.alzheimers.org.uk/COVID-19-report-news>