

Alzheimer's Society Briefing – 'Worst Hit: Dementia during Coronavirus' Report 29th September 2020

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Summary and key findings

Alzheimer's Society is the UK's leading dementia charity, and in this report, we seek to shine a light on the impact of coronavirus disease (COVID-19) on people who have dementia and those who care for them.

This report demonstrates the growing evidence on the disproportionate impact of COVID on people affected by dementia, considering high death rates, the impact of isolation during the pandemic and the need for long-term care reform, offering recommendations to Government on how people with dementia can be better supported to live well through the pandemic and beyond, and how the Government can ease the on carers and the care system.

Some key findings:

- 27.5% of all those who died of COVID-19 from March to June had dementia. For the same period, dementia was the most common pre-existing condition with for COVID deaths.
- For people who survived the crisis, the effects of social isolation were severe. 46% of people with dementia in our survey reported that lockdown had a negative impact on their mental health.
- 82% reported a deterioration in the symptoms of people with dementia¹.
- 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 health².

Alzheimer's Society recommendations

As we move towards winter, our key recommendations are:

1. The Government must recognise the key role that informal carers play in the lives of people living with dementia by:
 - 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.*
 - Ensuring the delivery of carers' assessments and provision of short breaks for carers.
 - Collecting local authority and health authority data on carer assessments and respite care.
2. The Government must set out plans for long term social care reform, with provision of care to *be universal and free at the point of use.* The additional costs of dementia-specific health and social care should not be funded by individuals but via a *shared pooling of risk across society*, just like education, the NHS, and other public services.

Disproportionately high death rates

People with dementia have never been identified by the Government or its respective health agencies as being at particular risk of contracting COVID-19, yet more than a quarter (27.5%) of people who died with COVID-19 from March to June had dementia. For the same period, dementia was the most common pre-existing condition with for COVID deaths. Moreover, the largest increase in excess non-COVID-19 deaths was in people with dementia. There were 5,049 excess deaths of people with dementia between 4 January and 10 July, in addition to the deaths attributed directly to COVID-19.³

It is estimated that 39% of people with dementia in the UK live in care homes and 70% of care home residents are living with dementia⁴. Although attempts were made to protect care home residents, the support for care homes fell short, which disproportionately affected people with dementia. Social care was not prioritised for COVID-19 testing and personal protective equipment. Public Health England data shows there were four weeks in March to April where more than 800 new

¹ 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>

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>

³ Dataset: Death registrations not involving coronavirus (COVID-19): England and Wales, 02 September 2020. [Online] 2020.

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationsnotinvolvingcoronaviruscovid19englandandwales>.

⁴ Alzheimer's Society. Dementia UK: Update. [Online] 2014. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf.

outbreaks in care homes were reported each week.⁵ Between the start of March and end of April, deaths from any cause in care homes more than tripled above their usual level.⁶

Loss of social contact

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.

Around 97%⁷ of care homes have stopped visits – as infections rise, even more are shutting their doors. If people living with dementia are unable to maintain their skills through socialising, they can quickly lose them. 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%)⁸. 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 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.

Impact on family and friend carers

An Alzheimer's Society investigation has discovered family and friends of people with dementia have spent an extra 92 million hours caring for loved ones with dementia⁹ during the pandemic. But even before lockdown and in the face 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 depressed¹⁰. The Government must put urgent support in place for exhausted carers in the community at the earliest opportunity. We know that carer's psychological health can predict a breakdown in care and therefore the need for the person with dementia to move into a care home, thus improving carers' psychological health and ensuring they receive adequate support may delay the need for placement in a care home¹¹.

Long-term social care reform

Since the outbreak of Covid-19, strategies for protecting people affected by dementia who rely on social care appeared slow and inconsiderate of the complex and varying needs of the people who live with dementia. The social care crisis is a dementia crisis - people with dementia are estimated to make up at least 70% of care home residents¹² and over 60% of home care recipients¹³. The Government must bring forward plans for long-term social care reform in early 2021.

Support provided by Alzheimer's Society

Dementia Connect has been there for anyone needing support during the coronavirus pandemic. It offers personalised support to anyone with dementia, their carers, families and friends. It's free and puts service users in touch with our specialist Dementia Advisers who offer the support they need, from local help to telephone and online advice.

Our support services have helped a huge number of people during COVID-19 and have been accessed over 2 million times between 23rd March and 31st August. 93% of our service users now feel more able to manage after the support they received from us.

⁵Public Health England. COVID-19: number of outbreaks in care homes - management information. [Online] 2020. <https://www.gov.uk/government/statistical-data-sets/covid-19-number-of-outbreaks-in-care-homes-management-information>.

⁶ The Health Foundation. COVID-19 chart series: Care homes have seen the biggest increase in deaths since the start of the outbreak. [Online] 2020. <https://www.health.org.uk/news-and-comment/charts-and-infographics/deaths-from-any-cause-in-care-homes-have-increased>

⁷ ONS. Impact of coronavirus in care homes (released 3rd July 2020)

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

⁸ 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>.

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

¹⁰ 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>.

¹¹ The Fog of Support, Alzheimer's Society, September 2020 (available online: https://www.alzheimers.org.uk/sites/default/files/2020-09/as_new_the-fog-of-support_carers-report_final-compressed.pdf)

¹² Alzheimer's Society. Dementia UK: Update. [Online] 2014. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf.

¹³ United Kingdom Homecare Association. UKHCA Dementia Strategy and Plan: February 2013. [Online] 2013.

https://www.ukhca.co.uk/pdfs/UKHCA_DementiaStrategy201202final.pdf.