



Westminster Hall Debate – Impact of the COVID-19 outbreak on people affected by dementia

Thursday 12th November, 3pm

About One Dementia Voice

One Dementia Voice is a partnership of organisations working in the field of dementia, including Alzheimer's Society, Alzheimer Scotland, Dementia UK, YoungDementiaUK, John's Campaign, Lewy Body Society, Innovations in Dementia and Together in Dementia Everyday. The group was formed during the pandemic to campaign jointly for the needs and rights of people affected by dementia.

Key points

- Alzheimer's Society has found that people with dementia have been disproportionately impacted by the pandemic; more than 27% of all coronavirus deaths between March and June were of people with dementia.
- Over half of care home residents die within 15 months of moving into a care home¹. Many residents have now spent more than 8 months without any visits from loved ones, with huge consequences for their wellbeing.
- Care home visiting guidance from Government should be focussed on enabling care homes and local authorities to find solutions in partnership with carers and family members that meet the needs of individual residents recognising and upholding their individual human rights including 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).
- Alzheimer's Society urges an acceleration of the pilot keyworker status scheme, and One Dementia Voice organisations urge the Government to enable family carers to be recognised as keyworkers with access to regular testing and PPE to be able to visit safely and to provide care that people with dementia so desperately need.
- National UK governments must set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.
- National UK governments must guarantee that, where care was stopped due to coronavirus precautions (particularly domiciliary care), it will be reinstated when deemed safe, without the need for unnecessary further formal assessment.
- National UK governments need to set out a clear strategy and resources to develop culturally competent dementia prevention, health promotion programmes and access to culturally appropriate dementia support, working with local grassroots BAME community organisations.

Disproportionately high death rates

There are an estimated 850,000 people living with dementia in the UK.² Alzheimer's Society's impact report '[Worst Hit: dementia during coronavirus](#)', published on 29th September 2020, reflects our ongoing concern about the impact of COVID-19 on people affected by dementia in a variety of ways. The report sought to shine a light on the growing body of evidence that demonstrates a disproportionate impact of coronavirus disease (COVID-19) on people who have dementia and those who care for them. 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-19 deaths. Moreover, the largest increase in excess non-COVID-19 deaths was in people with dementia. There were more than 5,000 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. 70% of all care home residents are living with a form of 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 outbreaks in

¹ Forder, J and Fernandez, J-L (2011) Length of stay in care homes, Report commissioned by Bupa Care Services, PSSRU Discussion Paper 2769, Canterbury: PSSRU

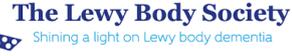
² Wittenberg et al [2019] Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040

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

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.



care homes were reported each week.⁵

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

Alzheimer's Society recommends the following:

- 1) The NHS and local authorities must set out how they will involve social care providers and care homes in winter pressure planning to ensure that social care is placed on an equal footing with the NHS, and that their situation is understood, accounted for and supported. This must include the provision of regular and timely testing and PPE.
- 2) The UK Government must ensure that the Infection Control Fund remains in place until at least April 2021 and care providers should be able to use that fund flexibly, including for infection control, technology and supporting visits.

Care home visits

Lack 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.

We know that some care homes have enabled friends and family members 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%⁷ 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%)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.

Government guidance

There have been several iterations of care home visit guidance from the Government since it was first published in mid-April. The [latest guidance from DHSC](#) on visits to care homes, published on 5th November, suggests options for visits including through Perspex screens, outdoors and further virtual 'visits'.

One Dementia Voice believe the Government must do more to preserve contact between families affected by dementia in a way that is sensitive to the condition, and that this guidance does not acknowledge the vital role played by family and friend carers in the care and wellbeing of people affected by dementia.

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.

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/impactofcoronavirusingcarehomesinenglandvivaldi/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>.



John's Campaign would like to see the Government go further than the proposed pilot scheme. A campaign organisation founded in 2014 for the right of people with dementia to be supported by family carers and for carers to be with people with dementia, John's Campaign is engaged in a judicial review process into the Government's visiting guidelines, fail to sufficiently acknowledge the individual needs of people with dementia and encourage blanket visiting bans by local authorities which potentially breach human rights for care home residents. The Secretary of State is due to formally acknowledge the review by 11th November.

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 infections"⁹.

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 pilot work on key worker status for family carers is lagging.

Alzheimer's Society calls for the government scheme to enable family carers with access to regular testing and PPE to be able visit safely and to provide care that people with dementia so desperately need.

We recommend:

- 1) *Recognising the key role that informal carers play in the lives of people living with dementia, national UK governments must take action to support people in this role by:*
 - a. *Allowing 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. *Ensuring the delivery of carers' assessments and provision of short breaks for carers.*
 - c. *Collecting local authority and health authority data on carer assessments and respite care.*
- 2) *Where care homes are unable to facilitate visits from loved ones, they must be required to notify national care inspectorates (CQC/CSSIW/RQIA) and seek to put in place suitable alternative arrangements to maintain appropriate contact between loved ones and care home residents who have dementia.*
- 3) *National UK governments must set out a clear strategy to enable people affected by dementia to recover from the effects of the pandemic, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.*
- 4) *National UK governments should commit to ensuring that any communications to, or requirements of, people affected by dementia (both in the community and in care homes) are clear, consistent and straightforward to understand. Any guidelines should reflect the daily lived experience and particular needs of people affected by dementia.*

Impact on family and friend carers

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 dementia¹⁰ 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 depressed¹¹.

Dementia UK reports that Admiral Nurses, dementia specialist nurses, have seen a rise in the number of complex clinical cases, including an increase in safeguarding issues. 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

⁹ 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.

¹⁰ Alzheimer's Society [2020] <https://www.alzheimers.org.uk/lockdowncarerhours>

¹¹ 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>.



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 home¹².

Alzheimer's Society recommends the following:

- 1) *National UK governments must guarantee that where care was stopped due to coronavirus precautions (particularly domiciliary care), it will be reinstated when deemed safe, without the need for unnecessary further formal assessment.*

Long-term social care reform

Since the outbreak of COVID-19, strategies for protecting people affected by dementia who rely on social care did not adequately consider 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 residents¹³ and over 60% of home care recipients¹⁴.

The Government must bring forward plans for long-term social care reform in early 2021 which addresses the unfairness people affected by dementia face in the system. Alzheimer's Society believes the legacy of the pandemic must be a universal social care system, free at the point of use, that provides every person with dementia with the quality care they need. This would see social care put on equal footing with the NHS, and no longer the poor relation. Alzheimer's Society would welcome the opportunity to feed into this process.

Dementia diagnosis rates

There has been a steady fall in national dementia diagnosis rates since February 2020, and they have now fallen well below the – already low - target of 66.7%. The latest figures show a diagnosis rate of 63%.¹⁵ This means that more people are living without a diagnosis of dementia, and are unable to access emotional, practical, legal and financial advice as a result.

Whilst memory services are adapting to open virtually which is a welcome interim measure, memory assessment services must re-open in person at the earliest opportunity.

Alzheimer's Society recommends that:

- 1) *National UK health and social care departments must 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.*

COVID-19 and dementia in the BAME community

The Public Health England Report (PHE) highlighted COVID-19 did not create health inequalities, but rather the pandemic exposed and exacerbated longstanding inequalities affecting BAME groups in the UK¹⁶. The PHE Report further highlights that the death rates from COVID-19 in some BAME communities (people of Bangladeshi ethnicity) compared to White British Communities, after accounting for the effect of sex, age, deprivation and region, people of had around twice the risk of death of people from White British communities. People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British.

Half of all deaths of Black (54%) and Asian (49%) people in care homes were related to COVID-19, compared to just 44% for White people¹⁷.

In the same way that dementia – and its different forms – affect people in different ways, carers of people living with the condition face unique challenges and have differing needs. Black, Asian and Minority Ethnic (BAME) groups and those with

¹² 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)

¹³ Alzheimer's Society. Dementia UK: Update. [Online] 2014. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf.

¹⁴ United Kingdom Homecare Association. UKHCA Dementia Strategy and Plan: February 2013. [Online] 2013. https://www.ukhca.co.uk/pdfs/UKHCA_DementiaStrategy201202final.pdf.

¹⁵ NHS Digital Recorded Dementia Diagnoses [2020] September https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/september-2020_stakeholder_engagement_synthesis_beyond_the_data.pdf

¹⁶ Mohammed, Shahid Mohamed (2020) South Asian Carers of People with Dementia during Lockdown. Together in Dementia Everyday. <https://www.tide.uk.net/south->

¹⁷ Mohammed, Shahid Mohamed (2020) South Asian Carers o17 CQC (2020) CQC publishes data on deaths in care settings broken down by ethnicity <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-care-settings-broken-down-ethnicity>

17 CQC (2020) CQC publishes data on deaths in care settings broken down by ethnicity <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-care-settings-broken-down-ethnicity>



English as an additional language have been often described as under-served and under-represented. Since the start of the pandemic, there has been growing concern that these groups will become 'harder to reach' and more isolated¹⁸.

Together in Dementia Everyday (TIDE) has noted that certain BAME groups experience greater levels of isolation, particularly Pakistani and Bangladeshi carers. BAME carers face the same challenges as all carers, but also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion¹⁹. Building on the success of its existing Dementia Dekh Bhaal project, tide has set up a Whatsapp Group for South East Asian carers of people with dementia, provided Covid -19 information in six different languages , delivered health messages via local community radio and also hosted Zoom sessions for South East Asian carers.

Alzheimer's Society research has found that BAME groups were more likely to use BAME-led services and found the need for interventions to be more culturally competent, including the use of interpreters.²⁰ Similarly TIDE's outreach campaigns found the need for accessible information on dementia for BAME groups as well as tools and information to empower BAME carers to be able to self-help, support and link with other carers²¹.

COVID-19 now needs to be a turning point in how as a society we recognise, respect and work with carers of people with dementia as equals to professionals. It has never been more important that governments as well as employers, policymakers and commissioners, take action to recognise that carers of people with dementia are individuals in their own right, equal to professionals and need to be respected for their invaluable contribution to society as a whole and provided with the designated status of a keyworker.

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¹⁸Mohammed, Shahid Mohamed (2020) South Asian Carers of People with Dementia during Lockdown. Together in Dementia Everyday. <https://www.tide.uk.net/south-asian-carers-of-people-with-dementia-during-lockdown/>

19 Dementia Dekh Bhaal™ Project - South Asian Carers of People with Dementia during Lockdown – October 2020

20 Clare, L., Wu, Y.-T., Jones, I. R., Victor, C. R., Nelis, S. M., Martyr, A., ... Matthews, F. E. (2019). A Comprehensive Model of Factors Associated With Subjective Perceptions of "Living Well" With Dementia. *Alzheimer Disease & Associated Disorders*, 33(1), 36–41.

<https://doi.org/10.1097/WAD.0000000000000286>

²¹Mohammed, Shahid Mohamed (2020) South Asian Carers of People with Dementia during Lockdown. Together in Dementia Everyday. <https://www.tide.uk.net/south-asian-carers-of-people-with-dementia-during-lockdown/>