

Westminster Hall Debate on Social Care Reform & Workforce – 18 March 2021

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1. Suggested Questions to Ministers

- Will the Minister commit to announcing a timetable for the Government's planned reform of the social care system?
- Can the Minister provide an update on progress on the Government's planned reform of the social care system?
- How does the Minister plan to ensure the needs of people affected by dementia are addressed in the Government's long-term social care reform proposals?

2. Key Messages & Background

- With more than 30,000 people with dementia dying of Covid-19 (a large number of whom were living in residential care), and tens of thousands more seeing their condition deteriorate at an increased pace due to limited support, the pandemic has exposed how the social care system fails to support people with dementia.
Alzheimer's Society believes that the need for social care reform is clear and urgent: the Government must clarify its timetable for reform as soon as possible.
- **The social care crisis is a dementia crisis.** People with dementia are estimated to make up at least 70% of care home residents and over 60% of home care recipients.¹ Any proposed changes to adult social care – positive or negative - will undoubtedly have a significant impact on people with dementia and their families. **If you get social care right for people with dementia, you get it right overall.**
- Until action is taken to reform the social care system, people with dementia will continue to struggle to get the care, funding and skilled support they need to live well.
The legacy of the pandemic must be a social care system that provides every person with dementia with quality care that is free at the point of use.

There are an estimated 850,000 people living with dementia in the UK.² Dementia is a progressive, long-term health condition with huge care costs attached.

There are currently about 770,000 people with dementia in England. Almost half a million of that number have severe dementia. By 2040, more than 1.3 million people in England will have dementia, with just over 900,000 of those having severe dementia.³ **Dementia is currently the biggest single killer of people in the UK.⁴**

People living with dementia face higher charges for care than those with other conditions. Alzheimer's Society research shows that care for people with dementia on average costs

¹ Alzheimer's Society. Dementia UK: Update. [Online] 2014. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf; United Kingdom Homecare Association. UKHCA Dementia Strategy and Plan: February 2013. [Online] 2013. <https://www.ukhca.co.uk/pdfs/UKHCA-DementiaStrategy20120final.pdf>.

² Wittberg, Raphael et al. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040. [Online] 2019. Care Policy and Evaluation Centre, London School of Economics and Political Science. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

³ Ibid.

⁴ Office for National Statistics. Monthly mortality analysis, England and Wales: January 2021. [Online] 2021. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/monthlymortalityanalysisenglandandwales/january2021#leading-causes-of-death>.

15% more than care for those without the condition, and **that typical overall costs for dementia care are approximately £100,000.⁵**

3. Covid-19 Context

People with dementia have been worst hit in the pandemic. **At least 27% of all Covid-19 deaths have been amongst people with dementia.⁶** Deaths of people with dementia, not including those where Covid-19 was present, have also been significantly higher than normal. The Covid-19 pandemic has emphasised failings in the social care system, highlighting the urgent need to prioritise the Government's planned reforms.

Throughout the pandemic, the families and friends of people with dementia have had to pick up where the social care system has failed to support them. **People with dementia – whether they live in a care home or in the community – have seen increased levels of deterioration of their condition over the last 12 months.**

An Alzheimer's Society survey over the summer of 2020 saw many say that their caring responsibilities had increased because of the deteriorating symptoms of the person they care for. **Alzheimer's Society estimates that family and friends spent an extra 92 million hours caring for loved ones with dementia in the 20 weeks after the start of lockdown.⁷** This rise in caring responsibilities for formal and informal carers occurred while usual support systems, such as respite care and carers assessments, were unavailable.

Increasing numbers of families are hesitant to make use of care homes due to high death rates and issues with visiting during the pandemic. This may be an irreversible attitude, leading to an increase in use of domiciliary care or informal carers in the years ahead.

4. Long-Term Social Care Reform

During his first day in office, the Prime Minister made a commitment to fix social care and to find a more equitable solution to funding dementia care. Progress, however, has been slow: now is the time to clarify the Government's timetable for reform.

With Dilnot proposals and the White Paper on the future of health and care laying the foundations for these plans, **it's vital that any reforms are not just transformational with regard to cost and funding, but also in terms of the quality of services and the ability of people to access them.** Proposals must be coupled with a workforce plan (akin to the NHS' 10-year plan) and a long-term plan on improving the quality of services.

Alzheimer's Society is calling for care (including specialist dementia 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.

Alzheimer's Society believes that any proposals for long term reform need to address these basic principles: care should be person-centred and include an element of choice; informal carers should be recognised as an integral part of the care ecosystem; there must be greater integration between health and social care.

⁵ Alzheimer's Society. People with dementia spend almost £15bn of their own money waiting for Government care reforms. [Online] 2019. <https://www.alzheimers.org.uk/news/2019-07-15/people-dementia-spend-almost-ps15bn-their-own-money-waiting-government-care-reforms>.

⁶ Alzheimer's Society. Worst Hit: Dementia During Coronavirus. [Online] 2020. <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>.

⁷ Alzheimer's Society. Lockdown isolation causes shocking levels of decline for people with dementia, who are rapidly losing memory, speech, and ability to dress and feed themselves. [Online] 2020. <https://www.alzheimers.org.uk/news/2020-07-30/lockdown-isolation-causes-shocking-levels-decline-people-dementia-who-are-rapidly>.