

## General Debate on Dementia Action Week – Thursday 27<sup>th</sup> May

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### 1. Top Lines

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- Dementia Action Week is an annual event held by Alzheimer's Society. In 2021 the focus is on the **need for a clear, budgeted Government plan for social care reform to be brought forward this year**, with a focus not solely on funding, but also on addressing the quality of dementia care.
- After a devastating year for people with dementia, who account for over a quarter of Covid-19 deaths, the **legacy of the pandemic must be a social care system where people can live with meaning, purpose and connection**.
- **Reform of social care must allow people to have choice and control**, for example enabling people with dementia to live where and as they choose, and with control over their daily activities.
- The foundations are in place for the UK to be a world-leader in dementia research, **but Government funding is required to support the realisation of this potential**.

### 2. Background

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#### *Dementia Action Week*

Alzheimer's Society holds Dementia Action Week (17-23 May) annually, seeking to improve outcomes for people affected by dementia.

There are an estimated 850,000 people living with dementia in the UK<sup>1</sup>. Dementia is a progressive, long-term health condition with huge care costs attached. It has been estimated that 70% of care home residents<sup>2</sup> and over 60% of home care recipients are people with dementia<sup>3</sup>.

**People with dementia and their families are struggling to get the person-centred care and support they need and deserve**, while decades of underfunding have led to a care system that's unfair, costly, and difficult to access.

This year, our #CureTheCareSystem campaign is focusing on the need for social care reform to get underway this year with a clear, budgeted plan which not only tackles the devastating cost of dementia care, but is also transformational on care quality.

**While dementia is not curable yet, the care system is**. After a devastating year for people with dementia, who account for over a quarter of Covid-19 deaths, the legacy of the pandemic must be a Government plan to make our social care system one we all want to grow old in.

#### *Dementia Strategy*

Dementia Action Week is also taking place in the context of an emerging Dementia Strategy, which DHSC is consulting on at present. This is a chance to draw together all strands of the Government's dementia activity to form an ambitious strategy with a clear timeline, which must recognise the substantial impact that the pandemic has had on people affected by dementia. The opportunity must not be missed.

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<sup>1</sup> [https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec\\_report\\_november\\_2019.pdf](https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf)

<sup>2</sup> Alzheimer's Society. Dementia UK: Update. [Online] 2014. [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia\\_uk\\_update.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf).

<sup>3</sup> Alzheimer's Society. Dementia UK: Update. [Online] 2014. [https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia\\_uk\\_update.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf).

### 3. Social care reform #CuretheCareSystem

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#### *Impact of Covid-19*

**People with dementia have been worst-hit by the pandemic, accounting for over a quarter of all Covid-19 deaths.**<sup>4</sup> Tens of thousands more have seen their condition deteriorate at an increased pace than would otherwise be the case over the last 12 months due to limited support and social isolation brought on by repeated lockdowns. We know carers are exhausted, too, as a group which has provided millions of hours more care during the pandemic, in the absence of respite provision. 40% of carers have spent over 100 hours a week caring for people with dementia<sup>5</sup>.

#### *Long-term reform*

**During his first speech as Prime Minister, Boris Johnson made a hugely welcome commitment to 'fix the crisis in social care once and for all,'** citing 'a clear plan we have prepared to give every older person the dignity and security they deserve.' We welcome the renewed pledge made by Lord Bethell on 17<sup>th</sup> May to "sustainable improvement of the adult care system" with proposals to be brought forward in 2021.

**The central principle of social care must be that it focuses on what matters to people while acknowledging the importance of care that offers people choice and control;** that supports the individual with choosing and setting their own goals; that recognises the importance of relationships to health and wellbeing; and that improves people's experiences of 'living well,' grounded in research.

**The right care and support services can make a huge difference for people with dementia and their families.** Direct personal care can help with washing, dressing, laundry and meals; extra support helps people with dementia carry on doing activities they love and spending more quality time with the people who matter most in their lives; respite breaks for family carers give them time to recharge and look after their own wellbeing.

Our 'A Future for Personalised Care' paper set out what 'good looks like' for social care for people affected by dementia – highlighting **the need to focus on building and maintaining their relationships and connection to their community, setting their own goals for what matters to them, and having choice and control over personalised care, so that people affected by dementia can best manage their life with dementia,** and families can spend more time in their most important roles: that of husbands, wives, sons and daughters.

#### *Funding*

The Government must provide investment in social care to ensure the 200,000 people with moderate or severe dementia with care needs who receive no formal social care support can access care. A number of feasible solutions to the social care funding have been proposed by think tanks and other organisations. A common theme amongst these suggestions, which Alzheimer's Society supports, is that **risk should be pooled across society. This could be implemented through a mix of general taxation and deferred payment on assets;** however, the exact mechanism for delivering this would best be determined by economic experts.

A cap and floor model, such as proposed by the Dilnot Commission in 2011, would limit exposure to extremely high costs by capping lifetime care fees and increasing the 'floor' to enable people to keep more of their assets before paying for care.

Due to the extremely limited funding available to the sector at present, there is little scope for innovative practice and improvement; a dedicated care innovation and improvement fund could support the sector to improve quality and outcomes.

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<sup>4</sup> González, Livingston et al. Impact and mortality of COVID-19 on people living with dementia: cross-country report. 2020. International Long Term Care Policy Network, Care Policy and Evaluation Centre, London School of Economics. <https://ltccovid.org/wp-content/uploads/2020/08/International-report-on-the-impact-of-COVID-19-on-people-living-with-dementia-19-August-2020.pdf>.

<sup>5</sup> Alzheimer's Society. 'Exhausted' family and friends spent 92 million extra hours caring for loved ones with dementia since lockdown. 2020. <https://www.alzheimers.org.uk/news/2020-10-05/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>.

#### 4. Dementia research funding

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Dementia is one of the greatest healthcare challenges facing the UK, with a cost to the economy of £26bn per year<sup>6</sup>.

Without life-changing treatments, the number of people living with the condition is set to grow to a million people in the next five years. Considered alongside the tragic and disproportionate impact of the pandemic on people living with dementia, there has never been a more critical time to invest in dementia research and social care. Government investment in research will be vital in driving the post-Covid-19 economic recovery: every £1 of public or charity investment in medical research delivers a return equivalent to around 25p every year, forever<sup>7</sup>.

Alzheimer's Society was pleased to see the 2019 Conservative Party manifesto commit to delivering the Dementia Moonshot, which would double funding for dementia research for each of the next 10 years. However, this pledge has not yet been realised.

The Queen's Speech also contained a welcome commitment to invest in research and development. A decade of steady investment has built a foundation for the UK to be a world-leader in dementia research, but this can only be achieved with appropriate support from Government. Additional funding could help us better understand the causes of dementia, providing hope for a cure in the future and exploring best practice in dementia care in the here and now. This is why the Dementia Moonshot must be delivered as soon as possible.

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<sup>6</sup> Alzheimer's Society. How many people have dementia and what is the cost of dementia care? 2019. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers>.

<sup>7</sup> British Journal of Family Medicine Every £1 invested in medical research returns 25p per year, forever. 2018. <https://www.bjfm.co.uk/every-1-pound-invested-in-medical-research-returns-25p-per-year-fore>