

Dementia Action Week Briefing – 17-21 May 2021

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1. How You Can Help

We would hugely appreciate your support for our campaigning during Dementia Action Week. There are a number of ways you can get involved, including:

- **Wearing an Alzheimer's Society badge throughout the week, particularly in the Chamber during PMQs on 19 May.** Badges are available to collect from your Whips' Office.
- **Raising how social care reform must cater to the needs of people with dementia during PMQs on 19 May.** If you are drawn for a question, we would be very happy to provide suggested text.
- **Becoming a Dementia Friend** by attending one of our online training sessions for MPs (18 May, 3-4pm, or 20 May, 10.30-11.30am). Please email alex.osborne@alzheimers.org.uk to register and receive Zoom joining details.
- **Sharing your support for Dementia Action Week on your social media** using images from our digital pack and the suggested text below.
- **Utilising our template press release**, a copy of which is available in the digital pack.

2. Background

Alzheimer's Society holds Dementia Action Week annually to encourage people to take action to improve the lives of people affected by dementia. This year's theme is **#CuretheCareSystem**.

There are an estimated 850,000 people living with dementia in the UK, with this number set to rise to nearly 1.6 million by 2040.¹ Dementia is a progressive, long-term health condition with huge care costs attached. **It has been estimated that 70% of care home residents and over 60% of home care recipients are people with dementia.**²

The Covid-19 pandemic has devastated the lives of so many of those who rely on social care. It's estimated that 34,000 people with dementia lost their lives to Covid-19.³ **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.

While dementia isn't curable yet, the care system is. That's why Alzheimer's Society is using Dementia Action Week to call on the Government to **#CuretheCareSystem** now.

3. #CuretheCareSystem

People with dementia have been worst-hit by the pandemic, accounting for over a quarter of all Covid-19 deaths.⁴ Tens of thousands more have seen their condition deteriorate at an increased

¹ Wittenberg, Raphael et al. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040. 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.

² Alzheimer's Society. Dementia UK: Update. 2014. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_uk_update.pdf; <https://www.ukhca.co.uk/pdfs/UKHCADementiaStrategy201202final.pdf>.

³ Alzheimer's Society. Pandemic's toll: over 34,000 people with dementia dead; care home deaths third higher than thought. 2021. <https://www.alzheimers.org.uk/news/2021-03-01/pandemics-toll-over-34000-people-dementia-dead-care-home-deaths-third-higher>.

⁴ 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://tccovid.org/wp-content/uploads/2020/08/International-report-on-the-impact-of-COVID-19-on-people-living-with-dementia-19-August-2020.pdf>.

pace over the last 12 months due to limited support and social isolation brought on by repeated lockdowns. **Family carers are also exhausted, with over 40% spending over 100 hours per week caring for a loved one living with dementia.**⁵ All of this has highlighted even further the urgent need for social care reform in the UK.

It doesn't have to be this way. Alzheimer's Society knows that 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 gives them time to recharge and look after their own wellbeing.

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.

Furthermore, Alzheimer's Society believes that care should be person-centred; that informal carers should be recognised as an integral part of the care ecosystem; that there must be greater integration between health and social care, and that there must be a minimum set of national standards. These principles are essential in order to achieve meaningful social care reform.

Achieving this vision will allow people with dementia to best manage their lives *with* dementia, meaning that their families can spend more time in their most important roles as husbands, wives, sons, and daughters.

With this in mind, **Alzheimer's Society is calling on the Governments of England, Wales, and Northern Ireland to commit to:**

- **Publishing a clear, budgeted plan for social care reform, complete with milestones, with reform underway this year.**
- **Ensuring that reforms are attentive not just to funding, but also to improving the quality of care that people receive.**

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.'

The Prime Minister can keep this promise by making the legacy of the pandemic a long-awaited Government plan to rebuild a social care system that we want to grow old in – now and for future generations. It's time to **#CuretheCareSystem**.

4. Suggested Text for Social Media

- 'This Dementia Action Week, I'm calling on the Government to #CuretheCareSystem.'
- 'High-quality, person-centred dementia care must be at the heart of upcoming social care reform. I'm joining with @alzheimerssoc to urge the Government to #CuretheCareSystem.'
- It's time for the Government to provide quality social care that's free and easy to access no matter where you live – just like the NHS. #CuretheCareSystem.'

⁵ 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>.