

Written evidence submitted by Alzheimer's Society (ASC0043)

Executive Summary

This evidence is submitted on behalf of Alzheimer's Society, who are the largest dementia charity in England, Wales and Northern Ireland working directly with people living with the condition. We are a leading voice on the issues that matter most to people living with dementia, from working with academics and commissioning robust, evidence-based research to influencing decision makers locally and nationally through our campaigns. We would be happy to give oral evidence should it be of assistance to the committee.

Dementia is now the UK's biggest killer¹, with one in three people born today in the UK expected to develop the condition in their lifetime². The impact of rising dementia prevalence on social care will be significant:

- There are around 982,000 people living with dementia in the UK today, a figure set to rise to 1.4m by 2040 (and associated economic costs of £42bn today rising to £90bn by 2040).³ Unpaid care and social care account for 50% and 40% of the total cost spent respectively.⁴
- The average costs per person associated with dementia range from £28,700 to £80,500 for severe dementia due to an increased need for complex care.⁵
- By 2040, 76,000 more people with dementia will need residential care, and 30,000 more will require nursing home care.⁶
- Around 60% of people drawing upon adult social care services at home have dementia,⁷ as do 70% of residents in older age care homes in England.⁸

However, neither the Government, nor our health and care systems have yet made dementia the political and, therefore, policy priority that it needs to be. For example, over one third of people with dementia do not even have a diagnosis – a totemic example of Government and NHS failings on dementia.⁹ Similarly, the failure to reform social care (with those living with dementia making up a very significant proportion of those who draw on social care) indicates a serious lack of awareness and action on dementia. The numbers of people with dementia and their need for social care are so significant that it is not possible to successfully reform social care (or indeed the health system) without also specifically reducing the impact of dementia on these systems.

Inaction on social care reform by successive governments has led to heavy costs for people living with dementia, within a care system that is not set up to deliver the care people living with dementia require or deserve. The following issues are of particular concern:

- The quality of social care is not good enough.¹⁰ This is unsurprising when data suggests only 29% of care workers in England have received any dementia training,¹¹ and a recent inquiry by a cross-party group of MPs found that only 44% of people affected by dementia rated care staff's understanding of dementia positively.

¹ Office for National Statistics (2023), [Death registration summary statistics, England and Wales: 2022](#).

² Lewis, F (2015), [Estimation of future cases of dementia from those born in 2015](#).

³ Alzheimer's Society and Carnall Farrar (2024). [The economic impact of dementia](#). p.3.

⁴ *Ibid.*, p.37.

⁵ *Ibid.*, p.11.

⁶ *Ibid.*, p.12.

⁷ UKHCA/Homecare Association (2015), [Dementia and Homecare: Driving Quality and Innovation](#). p.8.

⁸ Wittenberg, R (2018), The Costs of Dementia in England, *Int J Geriatric Psychiatry*, Vol 34, Iss. 7, pp.1095-1103.

⁹ Alzheimer's Society and Carnall Farrar (2024). [The economic impact of dementia](#).

¹⁰ CQC (2024), [The state of health care and adult social care in England 2023/24](#).

¹¹ Skills for Care (2024), [The state of the adult social care sector and workforce in England](#).

- The lack of support for unpaid carers means too many are reaching breaking point.¹² Half of carers Alzheimer’s Society surveyed recently had not received any support at all, and only 9% had accessed dementia-specific respite care.¹³
- There has been insufficient long-term sustainable investment from successive governments in social care. This has resulted in systems that are not meeting people’s needs, and current funding models that place the financial burden too heavily on individuals. For example, someone with dementia currently spends an average of £100,000 over their lifetime on care costs.¹⁴

These issues with social care significantly reduce the quality of life of people with dementia and their unpaid carers. Problems with social care also have a wider impact on our health system. For example, good social care can help prevent emergency hospital admissions.¹⁵ With one in six hospital beds today occupied by someone living with dementia,¹⁶ government action on social care would not only improve the lives of people living with dementia and their unpaid carers, but could also have a significant positive impact on our health system, reducing costs and pressures on the NHS.

Throughout the response, we have included quotations from people affected by dementia and their unpaid carers to illustrate their experiences. These are taken from an unpublished analysis of survey answers, commissioned by Alzheimer’s Society, and carried out by Walnut Unlimited.¹⁷

Question 1 - How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?

- 1.1 Successive governments’ failure to reform adult social care and to ensure people with dementia can receive high quality care that meets their needs, has led to inconsistency across the country and multiple negative impacts, both to the NHS and to patients. Firstly, it has increased pressure on the NHS. Secondly, it has meant that too many people with dementia do not receive the right care in the right place.
- 1.2 Social care that does not meet the needs of people living with dementia can lead to increased healthcare utilisation. Data shows that people living with dementia attend A&E almost a million times a year, and that people living with dementia also account for using one in six hospital beds at one time.¹⁸ Better quality social care that meets the needs of people living with dementia could prevent some of these A&E attendances and hospital admissions. For example, a recent Age UK report suggests that in 2019/20 alone, 855,000 emergency admissions to hospital of older people could have been avoided with the right care at the right time.¹⁹
- 1.3 As well as increasing pressures on the NHS, this means that people with dementia are not receiving the right care in the right place. The average length of a hospital stay, for someone living with dementia, for a non-elective admission, is 18 days (of which 3 days represent excess length of stay – ie. people who remain in hospital beyond the expected length of

¹² APPG on Dementia (2022), [Workforce Matters](#). p.17.

¹³ Alzheimer’s Society and Walnut (2024), [Personal Experiences of the Dementia Journey: The True Picture](#). p.36.

¹⁴ Alzheimer’s Society (2018), [Dementia the true cost: fixing the care crisis](#). p.16.

¹⁵ Age UK (2023), [State of Health and Care of Older People in England](#). p.2.

¹⁶ Alzheimer’s Society and Carnall Farrar (2024). The economic impact of dementia – Module 2: Dementia’s contribution to health metrics. p.12.

¹⁷ Alzheimer’s Society and Walnut (2024) Raising the awareness of Alzheimer’s through storytelling. As yet unpublished.

¹⁸ Alzheimer’s Society and Carnall Farrar (2024). The economic impact of dementia – Module 2: Dementia’s contribution to health metrics. p.10.

¹⁹ Age UK (2023), [Age UK issues clarion call for a big shift towards joined up home and community-based health and social care services for older people](#).

stay).²⁰ We have also found that the length of a hospital stay increases as dementia severity increases, with someone with severe dementia spending around one month in hospital for a non-elective admission (of which 8.1 days on average represents the excess length of stay).²¹ Lengthy hospital stays are known to lead to a range of negative outcomes for people with dementia, including a decline in physical and cognitive function.²² Avoiding hospital admissions is particularly important for older adults living with dementia, with evidence suggesting that they often experience more adverse outcomes, having been admitted, than people without the condition.²³ For example, the functional skills of people with dementia can quickly deteriorate during stays, leaving them more vulnerable.²⁴

1.4 Not only could better adult social care help reduce these numbers, but beds could be made available again more quickly if more suitable social care packages were provided, allowing for quicker hospital discharge processing. In April 2024, [data published by NHS England](#) shows that the combined waits for care home beds and home-based care accounted for an average of 45% of delayed discharges from acute hospital of people who had been in hospital for 14 days or longer.²⁵

1.5 With dementia prevalence predicted to increase by 43% between now and 2040,²⁶ pressures on our health system are only likely to increase, further underscoring the need for better social care. To achieve better social care, wide reform is needed. However, one area where action could be taken relatively quickly is to ensure care staff are trained in the right skills to provide high-quality care that meets the specific needs associated with dementia. We expand on this further under Question 3 below. However, we also reference this point here, since high quality dementia training, in addition to improving individuals' quality of life, could also reduce costs to the wider health and care system.

1.6 A recent report by Alzheimer's Society highlights a best practice example of high-quality dementia training, WHELD (Well-being and Health for People with Dementia).²⁷ WHELD has shown to be effective in reducing inappropriate prescribing of anti-psychotic medication and helpful in managing agitation.²⁸ WHELD has also shown to result in improvements in care and quality of life for people living with dementia, and has also led to reduced GP and hospital visits. This intervention shows savings of £2,000 per care home, per year, after accounting for the costs of implementing the training, to the wider health system, due to reduction of use, therefore, showing a return on investment.²⁹ If all care staff were required to undertake high quality dementia training, the savings to the wider system through reduced primary and emergency care contacts could be significant.

Question 3 - What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

A. Cost of inaction to individuals

²⁰ Alzheimer's Society & Carnall Farrar (2024), [The economic impact of dementia – Module 2: Dementia's contribution to health metrics](#), p.11.

²¹ Ibid., p.25.

²² Fogg et al (2018), Hospital outcomes of older people with cognitive impairment: An integrative review, *Int J Geriatr Psychiatry*, 2018 Jun 26;33(9):1177–1197.

²³ Alzheimer's Society (2022) [Left to cope alone](#), p.37.

²⁴ Ibid.

²⁵ CQC (2024), [The state of health care and adult social care in England 2023/24](#) p.8..

²⁶ Alzheimer's Society and Carnall Farrar (2024), [The economic impact of dementia](#), p.12.

²⁷ Alzheimer's Society (2024) [Because we're human too: Why dementia training for care workers matters, and how to deliver it](#), p.23.

²⁸ Ibid.

²⁹ Ibid.

2.1 Failure by successive governments to prioritise, invest in and reform adult social care means that: (i) too many people living with dementia are not getting high quality social care that meets their needs; (ii) unpaid carers are not getting support they need to continue caring; and (iii) the financial costs of dementia social care falls too heavily on individuals. The human cost to individuals with dementia and their unpaid carers is enormous, resulting in a reduced quality of life due to the huge emotional and financial strain.

Quality of social care

2.2 A 2022 inquiry by the APPG on Dementia found that less than half (44%) of people living with dementia rated care staff's understanding of dementia positively, and two in five (39%) people said their care plans were not personalised.³⁰ A recent survey of 3,476 people who are close to someone with dementia, or are living with symptoms, across England, Wales and Northern Ireland, suggests the situation has not improved since 2022.³¹ It found that:

- Less than four in 10 are satisfied with the support available for people living with dementia; and
- When asked what would best help to improve the lives of people living with dementia, 65% of people said more care workers who are skilled in caring for those with dementia.³²

2.3 These findings are borne out in the 2024 CQC State of Care report, which found that the ability and behaviours of staff "did not always meet the additional and complex needs of people living with dementia, especially when their condition deteriorates."³³ Care providers, as part of this report, acknowledged that they were facing challenges with being able to recruit and retain staff "with the appropriate skills and experience to provide consistent care for people living with dementia."³⁴ A recent report by Nuffield Trust also found that people with dementia in England are not consistently receiving good quality social care.³⁵

Unpaid Carers

2.4 Already, there are approximately 1.8m people providing some form of care for people with dementia in England,³⁶ with evidence suggesting that the need for unpaid care could rise significantly by 2040³⁷. The contribution of these unpaid carers is enormous: unpaid carers of people living with dementia report spending up to a third of their year supporting their loved ones, with 16% having had to give up work to care.³⁸ In financial terms, Alzheimer's Society's research suggests that the value of unpaid care, together with the opportunity cost of hours of work foregone, is now £21.1bn across the UK.³⁹

2.5 Despite the invaluable work carried out by unpaid carers, their contributions are not sufficiently recognised by the government. Instead, unpaid carers have been consistently left without enough support.

³⁰ APPG on Dementia (2022), [Workforce matters](#), p.17.

³¹ Walnut (2024), [Personal Experiences of the Dementia Journey – The True Picture](#).

³² Ibid., p.41.

³³ CQC (2024), [State of healthcare and adult social care in England 2023/24](#), p.120.

³⁴ Ibid., p.121.

³⁵ Nuffield Trust (2024), [What needs to improve for social care to better support people with dementia?](#)

³⁶ Centre for Economic Business Research (2019), [Economic cost of dementia to English businesses](#), p.4.

³⁷ Alzheimer's Society and Carnall Farrar (2024). [The economic impact of dementia](#), p.12.

³⁸ Ibid.

³⁹ Ibid.

“I was locked in a Perspex box hammering on the walls screaming for help and the world outside just walked on. I was a prisoner too! That's Dementia for a carer without help.”⁴⁰

2.6 In Alzheimer’s Society’s recent survey of people living with dementia and their carers, one in five unpaid carers had not heard of any sources of support from health or social care professionals. Over half of carers said their mental or physical health had been negatively affected by their caring responsibilities, and 25% said that by being an unpaid carer, they felt more socially isolated.⁴¹

2.7 Considering the challenges that carers face, having access to respite care would allow for carers to spend time resting, recuperating, and spending time doing activities they enjoy. However, only 9% of those we surveyed had been able to access dementia-specific respite breaks.⁴² It is not surprising, therefore, that Dementia Carers Count data indicates that 89% of unpaid carers of people living with dementia have reached “crisis point” at least once, with over a quarter trying to manage crises often.⁴³

2.8 Without dementia-specific respite care, carers will often overlook their own needs, with nearly two thirds reporting they’re suffering from their own health conditions whilst providing care, and one in five sharing that they’re neglecting their own health.⁴⁴ This is borne out by the CQC’s recent State of Care report, where the organisation shared that whilst “unpaid carers play an essential role in supporting people with dementia ... their own needs often appear neglected.”⁴⁵ This is especially likely if they are not receiving a high-quality, regular needs assessment or are not being signposted to local services and groups.

“I am a carer 24/7 and a Jack of all trades. A nurse, a doctor, a social worker, a dietitian, a pharmacist working 75 hours per week, all unpaid.”⁴⁶

Cost of care

In the UK, the annual cost of social care for people living with dementia is over £17.2bn,⁴⁷ with costs projected to rise to £40.7bn by 2040.⁴⁸ Unfortunately, the social care system, due to government inaction, is now under significant pressure, and as a result, the financial burden now falls too heavily on individuals. 50% of all people who draw on social care have to fully fund it,⁴⁹ which, if they have dementia, can cost an average of £100,000 over their lifetime.⁵⁰ This is unacceptably high. For reference, in an unpublished survey of 3,278 Alzheimer’s Society campaigners, 82% of respondents

⁴⁰ Alzheimer’s Society and Walnut (2024) Raising the awareness of Alzheimer’s through storytelling. As yet unpublished. p.13.

⁴¹ Alzheimer’s Society and Walnut (2024), [Personal Experiences of the Dementia Journey: The True Picture](#). p.18.

⁴² Ibid., p.36.

⁴³ Dementia Carers Count (2024) [Invisible: 2023 Dementia Carers Count Survey Findings](#). p.3.

⁴⁴ Alzheimer’s Society and Carnall Farrar (2024). [The economic impact of dementia](#). p.12.

⁴⁵ CQC (2024), [The state of health care and adult social care in England 2023/24](#). p.119

⁴⁶ Alzheimer’s Society and Walnut (2024) Raising the awareness of Alzheimer’s through storytelling. As yet unpublished. p.14.

⁴⁷ Alzheimer’s Society and Carnall Farrar (2024), [The economic impact of dementia](#). p.12.

⁴⁸ Ibid.

⁴⁹ Ibid.

⁵⁰ Alzheimer’s Society (2018), [Dementia the true cost: fixing the care crisis](#). p.16.

stated that introducing a cap on the cost of care should be the government's top social care priority.⁵¹

"The estimated cost of her care was just over £208,000. Like so many other people have shared, she worked all her life and paid her taxes. She certainly wasn't rich. She had very little help from the NHS. What other illness is treated like this? It's just with dementia you have to sort out your care."⁵²

B. What reforms are needed, and how might people's lives change as a result

2.9 Significant and long-term reforms are needed to improve social care for people living with dementia. Alzheimer's Society is focused on three key changes that will make a tangible difference for people living with dementia:

Quality of social care

2.10 In order to improve the quality of care, Alzheimer's Society is calling for the government to introduce a funded statutory duty for CQC-registered care providers to ensure care staff undertake high-quality evidence-based dementia training, mapped to the Dementia Training Standards Framework.⁵³ The government should also implement a long-term workforce strategy to foster a sustainable and supported workforce to deliver high-quality, personalised care. Strategies should include fair pay and a clear career development pathway. A similar recommendation was made in 2022 by the APPG on Dementia.⁵⁴

2.11 Alzheimer's Society's recent report 'Because we're human too: *Why dementia training for care workers matters, and how to deliver it*', demonstrates the significant benefits that dementia training can bring for people who draw on care, for care staff and for the wider health and care system.⁵⁵

2.12 Alzheimer's Society's 2024 report shows that:

- For people with dementia, well-trained social care staff means improvements in their day-to-day quality of life – and best practice examples of training have been shown to reduce use of antipsychotic medication and physical restraints.
- For care staff, being trained in dementia can lead to increased confidence and job satisfaction – and could potentially help address an urgent national imperative, namely reducing staff turnover. Evidence from Skills for Care, suggests that social care staff who receive regular training (not dementia specific) in their role have a lower turnover rate (31.6%) than those who do not (40.6%), with learning and development being one of the top three retention factors.⁵⁶
- For care providers, benefits can include increased staff engagement, improved relationships with families and enhanced reputations with regulators and local commissioners.

⁵¹ Alzheimer's Society (2023), Survey of 3,278 people living with dementia, conducted during January-February 2023.

⁵² Alzheimer's Society and Walnut (2024) Raising the awareness of Alzheimer's through storytelling. As yet unpublished. p.8.

⁵³ Skills for Health (2021) [Dementia Training Standards Framework](#).

⁵⁴ APPG on Dementia (2022). [Workforce Matters: Putting people affected by dementia at the heart of care](#).

⁵⁵ Alzheimer's Society (2024) [Because we're human too: Why dementia training for care workers matters, and how to deliver it](#). p.21.

⁵⁶ Skills for Care (2024) [What data tells us about how learning and development supports retention](#).

- For our wider health and care system, there can be significant savings: one long-running study of a dementia training intervention showed savings of £2,000 per care home, per year.⁵⁷

Unpaid carers

2.13 To address the issues facing unpaid carers, Alzheimer’s Society is calling for the government to introduce a National Carers’ Strategy to help meet the needs of unpaid carers of people living with dementia. This strategy must ensure that unpaid carers are receiving the statutory needs assessments to which they are entitled; and that they have sufficient access to dementia-specific respite care.

2.14 Prioritising the wellbeing of unpaid carers, by providing individuals with the statutory assessments, to which they are entitled, and signposting them to sources of support and to respite care opportunities, will allow unpaid carers to continue playing their vital role in the care of their loved ones.

Cost of care

2.15 Alzheimer’s Society, and the people it supports, believes that significant, long-term investment in social care is long overdue and would pay dividends if provided. A move to sustainable, multi-year funding settlements would enable long-term planning and innovation, helping people with dementia to receive the high quality care they deserve; as well as relieving the increasing pressure for the individuals who care for them.

2.16 The government should also ensure that the funding model for social care pools the risk of care costs across society, easing financial burdens on individuals and their families. One example of risk-pooling is a cap on total care costs that someone pays in their lifetime and a generous means test (the lower the cap and the more generous the means test, the greater the risk pooling). Alzheimer’s Society was disappointed when the UK Government decided, in July 2024, not to proceed with the proposed charging reforms set out in *People at the Heart of Care*.⁶⁸

2.17 In conclusion, it is crucial that the government acts now to transform social care. Alzheimer’s Society’s response has identified the cost of government inaction in three areas: quality of care, pressures on unpaid carers, and the cost of care. We have set out what needs to change and the positive impact that recommended changes would have. With the predicted increases in dementia prevalence, there will be an estimated additional 106,000 people with dementia who will require residential or nursing care,⁵⁸ not to mention the additional people who will require domiciliary care. It is, therefore, essential that the government addresses the issues we have identified and develops a social care system with robust foundations for the future. The social care system of the future should act not just as a safety net, but also as a means for people with dementia to live as well as possible at each stage of the condition. Without undergoing the required improvements, however, the cost to individuals and society will only continue to grow.

December 2024

⁵⁷ Alzheimer’s Society (2024) [Because we’re human too: Why dementia training for care workers matters, and how to deliver it](#). p.23.

⁵⁸ Alzheimer’s Society and Carnall Farrar (2024). [The economic impact of dementia](#). p.12.

