

DEMENTIA AND INEQUALITY

Care Policy and Evaluation Centre (CPEC) Briefing Note #1

May 2024



1 Introduction


As a progressive neurodegenerative disease with no existing cure, dementia affects around [900,000 people in the UK](#) and [55 million across the world](#).

Dementia is characterised by a range of symptoms including memory loss, confusion, anxiety, problems with speech and understanding, aggression and agitation. These symptoms lead to profound impact such as challenges in communicating, loss of independence, changes in behaviour and self-confidence. The diagnosis of dementia impacts relationships, roles, and responsibilities within families and communities. As such, there is an increased need for treatment, care and support, which impacts the health and social care use of services and their costs. Family members and unpaid carers are crucial in providing support and care for people with dementia which affects carers' health, employment, and wellbeing.

The economic impact of dementia is staggering, with the total estimated [cost in England of £24.2 billion](#) in 2015 and the estimated global [costs of US\\$ 1 trillion in 2018](#). Currently, the cost of dementia in the UK is [£42 billion per year](#), with an estimated costs of £90 billion by 2040. In 2022, dementia and Alzheimer's disease was the [leading cause of death](#) in England and Wales. In England, most of the dementia care costs are met by [unpaid carers](#) and people with dementia and their families through paying for their [social care services](#). The evidence shows a greater [economic impact](#) on social care compared to health care and on people at advance stages of dementia.

Inequality in its various forms is on the rise, and means that increasingly, different people have very different opportunities, standards of living, access to care and support, and experiences navigating health and care systems. Existing inequalities exacerbate the impacts of dementia and ability to access support, and in turn people with dementia and their carers face an additional burden. Disparities related to age, education, socioeconomic status, living arrangements, timely dementia diagnosis, type and severity of dementia, level of deprivation in the localities where people live, access to care and treatment are some of the areas that we at the [Care Policy and Evaluation Centre \(CPEC\)](#) based at the London School of Economics and Political Science (LSE) are working on.

Reading time:

 10 - 15 minutes

Who is this for:

Policymakers, health and social care professionals, researchers, advocacy groups, funders and anyone involved in dementia care and public health policy

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Our research on long-term care inequality based on the data from the English Longitudinal Study of Ageing (ELSA) shows that, compared to people without dementia, those with dementia had [higher care needs and a lower socioeconomic status](#). Further evidence from the [Improving the Experience of Dementia and Enhancing Active Life \(IDEAL\)](#) project found variability in the costs of dementia:

- Costs of services were higher for people with dementia **who lived alone** compared to those who lived with others.
- The cost of care was **higher for men than women**.
- The **type of dementia influenced the cost**, with Lewy body and Parkinson's dementias being associated with higher cost of care at the outset.
- The costs of services for frontotemporal dementia and Lewy body dementias are found to increase at a higher rate compared to the costs of services for Alzheimer's dementia (AD), which means that that [people with rarer dementias](#) require more care and support than people with more common types of dementia.

Some of our work revealed interesting links between levels of [wealth and the costs of hospital care](#) in people with AD where higher levels of wealth were associated with higher health costs prior to AD diagnosis. This evidence of inequalities suggests that wealthier people have better awareness about dementia and seek care earlier.

This briefing paper highlights some of the major work by CPEC in addressing the issues around inequalities in dementia. Not all inequalities are bad: people with greater care needs for more support. But many inequalities are inherently unfair - what researchers would call inequities - and these are the focus of our research, which covers dementia risk, treatment, and stigma.

2 Risk

Approximately [2 in every 100 people aged between 65 and 69](#) have dementia. A person's

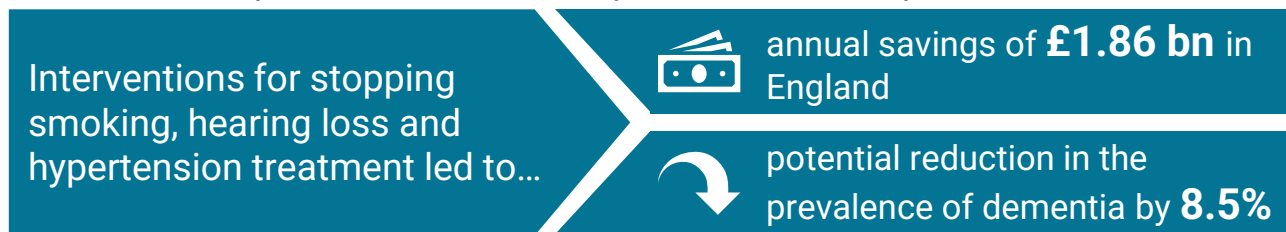


Approximately **2 in every 100 people** aged between 65 and 69 have dementia. Risk then **doubles every five years**. However, not everyone is equally at risk.

risk then increases as they age, roughly doubling every five years. However, not everyone is equally at risk, as certain risk factors mean that some people are more likely to develop Alzheimer's disease and other dementias than other people. [Common risk factors](#) include gender and sex; ethnicity; health conditions; lifestyle, and air pollution. Within CPEC, we have completed a number of studies which shed light on these risk factors and illustrate inequality when it comes to dementia risk.

[Prevention programmes](#) targeting individuals at risk of developing dementia have shown promising results. For example, interventions for dementia like [the Finish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability \(FINGER\)](#) are found to be potentially cost-effective in reducing the risk of dementia. Further evidence on the [economic benefits](#) of intervening earlier in reducing dementia risks comes from the study which constructed the economic model based on the published evidence on the risk-reduction interventions for dementia including diabetes, hearing loss, hypertension, social isolation, obesity, depression, physical inactivity, less early age education, and [smoking](#).

The findings show that the interventions for stopping smoking, hearing loss and hypertension treatment were cost-effective by an **annual saving of £1.86 billion in England** in health, social care, and unpaid care costs. The implementation of these interventions could reduce the prevalence of dementia by 8.5% and would improve health outcomes.






The Quality of Life of people with dementia was found to be influenced by the **type of dementia**. Our work from the Modelling Outcome and cost impacts of interventions for DEMentia ([MODEM](#)) study indicates that [people with non-Alzheimer's dementia](#) were more likely to report a decline in health-related Quality of Life and as such they may need tailored support to maintain their Quality of Life.

Our analysis of the [changes in functional unmet needs](#) among older people with dementia living in the community found an increase in unmet needs over time, and more so in people with higher functional needs at the beginning. **Not having a partner** was found to be a major contributor to higher levels of unmet needs, suggesting that functional decline might be mitigated by intervening at early stages of dementia, especially for people who live alone.

Poorer [Quality of Life experienced by dementia family carers](#) is associated with factors such as **cognitive decline of a care recipient, the increase in hours of providing care, and their levels of stress and depression**. There are also indications that unpaid carers may be more at risk of developing dementia, and this is something we are hoping to investigate through further studies.

3 Treatment

Our research underscores the importance of equitable access to dementia care and treatment. By highlighting disparities, we can advocate for policies that ensure all individuals receive the support they need. [Access to dementia care and support](#) is shaped by a range of interconnected factors across three levels:

-  **Individual**
Personal preferences, values, resources, cognitive, and physical skills
-  **Service**
Eligibility criteria and referral decisions
-  **Policy**
Organisational and commissioning care and support arrangements

A recent mapping study found that primary care-led [post diagnostic dementia support](#) was only available in a few areas, meaning that **certain groups found it more difficult to access services**, including those identifying themselves as Black and Minority Ethnic. Such inequities are evident across the spectrum of dementia treatment, including in psycho-social interventions, digital interventions, and amongst carers.

Psycho-social interventions

People with dementia experience a range of behavioural and psychological symptoms, some of which can be addressed by specially-designed psychosocial interventions. These interventions help with reducing stress, improving memory and thinking, and maintaining relationships.

Our work on effectiveness and cost-effectiveness of psychosocial interventions shows that they can be beneficial in improving the Quality of Life of people with dementia. The evidence on the scalability of non-pharmacological interventions indicates that for example, [Cognitive Stimulation Therapy \(CST\)](#) for people who are newly diagnosed with dementia in England, provides affordable improvements in their health-related Quality of Life. Another one of our studies has also found that a personalised [cognitive rehabilitation intervention](#) at home for people with mild-to-moderate dementia could be implemented at a reasonable cost.

However, despite the promising outcomes of these interventions, access remains unequal. Socio-economic status, health disparities, ethnicity, and other factors significantly influence who can benefit from these psychosocial supports. Implementing more cost-

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effective solutions for dementia care not only improves access to support but also plays a crucial role in reducing inequality by ensuring that essential services are available to a broader range of individuals, regardless of their socio-economic status or background. Addressing these disparities requires not only expanding access to psychosocial interventions, but also tackling the underlying social determinants of health to ensure equitable support for all individuals affected by dementia.

Digital interventions

Digital technology has massive potential to support people with dementia and their carers to address their needs and improve their Quality of Life. Our work on technological tools for people with dementia and their carers found that most technologies were intended to improve [safety and security of people with dementia](#) in the community setting. Other technological interventions aimed to improve memory or were intended to support delivery of care and treatment. Recent evidence on the [use of information communication technology \(ICT\) among unpaid carers](#) of people with dementia suggests that mostly mainstream ICT devices (laptops, smartphones, online applications such as social media platforms, videoconferencing) were used by carers to assist in their daily lives and caring activities.

Although numerous technologies have been identified along the dementia care pathway, the evidence of their widespread use was sparse. The digital divide means that [1.7 million households](#) in the UK have no broadband or mobile internet access. The evidence on the challenges of [scaling up technology](#) in dementia care points at numerous, overlapping factors which widen the digital divide, another mode of inequality which is also related to intersecting inequalities of socio-demographic factors discussed.

The factors which exacerbate the digital divide, and prevent certain populations fully utilising ICT, include:



Carers

The impact of caring on family carers of people with dementia can be profound, affecting various aspects of their lives including emotional and physical health, financial situation, and their overall Quality of Life. Carers themselves are often faced with a multitude of intersecting barriers which influence how they care, and how care affects their well-being. The [DETERMIND](#) project investigated how the Quality of Life for both the caregivers and people with dementia is influenced by a multitude of factors. While the **pandemic** had a major impact on the [QoL of dementia family carers](#), the effects on the QoL of people newly diagnosed with dementia were less evident in that they maintained their QoL during the pandemic. **Family carers of people with more severe dementia symptoms, living in deprived areas, and with fewer number of memory clinic contacts experienced a greater decrease in their QoL.**

[The changes over time](#) (before, during and after the Covid pandemic) showed an overall decline in QoL among carers and a stable QoL in people with dementia, with some reported improvements in their life quality during the post-covid period. **Carers in rural areas reported a faster decline in QoL during the pandemic** and a faster increase in QoL following the pandemic.

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Some interventions for dementia carers have been found to be beneficial such as [the STRategies for RelaTives \(START\)](#) psychological intervention: it is both clinically effective and cost-effective. The evidence from this randomised controlled trial of 260 self-identified family carers, with a follow up of 6 years, shows that START intervention is beneficial for them in terms of their improvement on the primary outcome measure of depression and anxiety. These interventions are important for helping carers tackle the challenges they face. These interventions not only provide tangible support for those directly impacted by dementia but also represent a vital step towards addressing the multifaceted challenges they face. By empowering family carers through effective and cost-effective interventions like START, we not only reduce the burden of depression and anxiety but also contribute to a more equitable landscape of care, ensuring that all individuals, regardless of their circumstances, have access to the assistance they need in navigating the complexities of dementia caregiving.

4 Stigma

Stigma associated with dementia impacts people with dementia, their families and carers significantly. People living with dementia are often looked down upon by society, and treated differently. This needs to be addressed so that people living with dementia and their carers can get the respect and inclusive support they need. This involves increasing awareness of stigma in dementia and developing stigma reduction interventions.

In our work at CPEC and together with partners, we are advancing a body of research to understand and mitigate stigma and discrimination associated with dementia in diverse contexts. This encompasses a multi-faceted approach: characterising the nature of stigma in various settings and developing evidence-based interventions. Through our collaboration with Alzheimer's Disease International, we conducted the largest ever global survey in 2019 with almost 70,000 respondents. [The survey results](#) illustrated that **86 per cent of people living with dementia reported experiencing stigma and discrimination in at least one area of their life** and that this stigma is a huge compounder of the difficulties caused by dementia. Based on this work, we are developing validated measures to assess stigma and discrimination such as [Discrimination and Stigma Scale Ultra Short for People Living with Dementia \(DISCUS-Dementia\)](#) which assesses experience of stigma and discrimination among people living with dementia.



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Together with stakeholders in seven countries around the world, we developed the [Strengthening Responses to Dementia \(STRiDE\) in Developing Countries](#) project. This project focused on strengthening responses to dementia and examining current practice, both at a national level and for individual families in Brazil, India, Indonesia, Kenya, Jamaica, Mexico, and South Africa. Our research in Brazil and Kenya is pioneering in the development and tailoring of anti-stigma interventions. We have co-produced a practical toolkit '[Don't forget I'm human](#)' provides evidence-based approaches to reducing stigma through several case studies on how to tackle stigma in real-world situations with individuals with lived experience across the seven STRiDE countries.

Realising how far-reaching the challenge of inequality and stigma is, our [STRiDE England](#) project is documenting inequalities and experiences of hard-to-reach groups in five sites across the country. The project is using a rigorous qualitative approach to capture the lived experiences of people with dementia and their carers, and the study itself is co-designed with these groups.

We are now also collaborating with Alzheimer's Disease International to run a [second global survey about attitudes towards dementia](#), five years after the 2019 survey. This is the first opportunity we'll get to see how perceptions about dementia have changed over time.

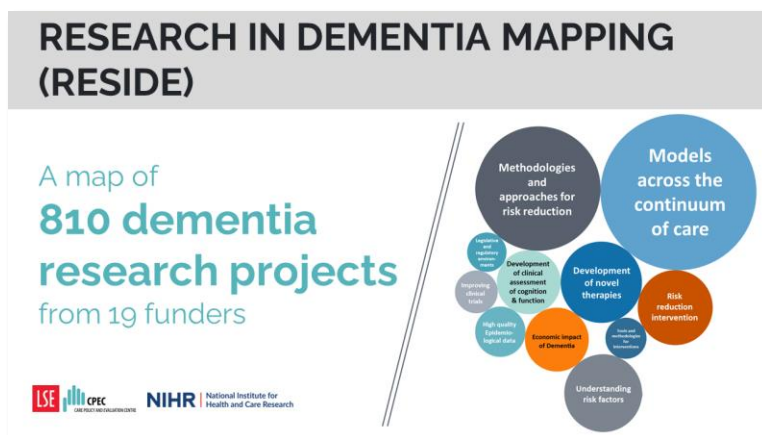
5 Towards equity in dementia care and support

With people living longer and increasing age being the main risk for dementia, the [numbers of people with dementia](#) are expected to more than double in England over the next 25 years. The [costs of care are projected to rise](#) considerably, and based on our simulation model for England, they are expected to reach £80.1 billion in 2040. A model developed by CPEC researchers further shows that [the annual average costs of care per person](#) are projected to increase from £35,100 in 2015 to £58,900 in 2040. The number of [older people with complex care needs](#) in England will increase in the next 20 years due to people living longer and being more dependent, and having more comorbidities and dementia. Furthermore, the projections of [multi-morbidity among older people](#) in England show an increase, with the number of people with four and more diseases almost doubling between 2015 and 2035.

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The increased scale of dementia means that there is urgent need to recognise the diversity of people who live with dementia and their carers – both in terms of the intersecting inequalities related to socio-demographic factors, and in terms of individual preferences and experiences of the system. This is what STRiDE England is exploring. While systemic change and large-scale interventions are critical for ensuring there are adequate support structures in place, should be implemented in a tailored way on a local level to ensure that the specific needs of individuals are also taken into account.

To ensure that this is possible, we need to continue to document the experiences of people living with dementia and their carers, while also mapping the projected needs and associated costs of support. While an increased funding focus on dementia, for example through the [National Institute for Health and Care Research \(NIHR\)’s Three Schools’ Dementia Research Programme](#) is promising, there needs to be concerted effort to ensure



that people with lived experience are at the heart of research, and that research is being translated into tangible improvements in policy and practice. At CPEC, we have developed a map of the existing dementia research ([RESIDE](#)) in the UK, which highlights which areas of dementia research are receiving the most funding, and where the gaps are.

This Dementia Action Week, it’s important to take stock of the progress made so far, but also raise awareness about the continuing inequalities in dementia, and how we can address these through research, policy, and practice.

6 Further resources

Dementia Action Week 2024

- BLOG | [Why tackling stigma is key this Dementia Action Week by Elisa Aguzzoli](#)
- VIDEO | [Why are there such unequal experiences of dementia care and support? | Adelina Comas-Herrera](#)
- VIDEO | [Addressing inequalities in dementia research | Jayeeta Rajagopalan](#)
- VIDEO | [Co-designing dementia research to amplify under-represented voices | Chiara De Poli](#)

Recent publications

- Damant J, Freddolino P, Dangoor M, Hu B, King D, Wittenberg R (2024) **Unpaid carers of people with dementia and information communication technology: Use, impact and ideas for the future.** *Dementia*. <https://doi.org/10.1177/14713012241249793>
- De Poli C, Oyeboode J, Airoldi M, Glover R (2020) **A need-based, multi-level, cross-sectoral framework to explain variations in satisfaction of care needs among people living with dementia.** *BMC Health Services Research*, 20(1). <https://doi.org/10.1186/s12913-020-05416-x>
- Henderson C, Knapp M, Martyr A, Gamble LD, Nelis SM, Quinn C, Pentecost C, Collins R, Wu YT, Yu-Tzu; Jones, Ian R (2022) **The use and costs of paid and unpaid care for people with dementia: longitudinal findings from the IDEAL cohort.** *Journal of Alzheimer's Disease*, 86(1). <https://doi.org/10.3233/JAD-215117>
- King D, Farina N, Burgon C, Feeney Y, Berwald S, Bustard E, Gallaher L, Habibi R, Wittenberg R, Comas-Herrera A, Knapp M, Banerjee S (2022) **Factors associated with change over time in Quality of Life of people with dementia: longitudinal analyses from the MODEM cohort study.** *BMC Geriatrics* 22(1). <https://doi.org/10.1186/s12877-022-03142-z>
- Knapp M, Bauer A, Wittenberg R, Comas-Herrera A, Cyhlarova E, Hu B, Jagger C, Kingston A, Patel A, Spector A, Wessel A, Wong GHY (2022) **What are the current and projected future cost and health-related Quality of Life implications of scaling up cognitive stimulation therapy?** *International Journal of Geriatric Psychiatry* 37(1). <https://doi.org/10.1002/gps.5633>
- Read S, Hu B, Wittenberg R, Brimblecombe N, Robinson L, Banerjee S (2021) **A Longitudinal Study of Functional Unmet Need Among People with Dementia.** *Journal of Alzheimer's Disease*, 84(2). <https://doi.org/10.3233/jad-210724>

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