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Longevity Centre UK

Living well with dementia through care and support: it's not rocket science



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In short

Dementia is the leading cause of death in the UK. The risk of dementia increases with age and as we live longer lives, more and more of us will live with the condition ourselves and/or as carers. However, dementia is not an inevitable consequence of ageing, and much more can be done to prevent, delay or lessen its impact on daily lives.

Dementia remains woefully underdiagnosed across the country. And this has to change as diagnosis unlocks the care, support and treatment that people living with dementia need to manage their condition. We must improve post-diagnostic support, as without the guarantee of proper care pathways many people are left to cope alone. For example, even after a dementia diagnosis, in England only two-thirds - and in Scotland less than half - of people have a care plan.

For too long, government has relied on families and friends to fill these gaps. But, in an ageing society, our informal support systems, local government, the formal care sector and health service can't continue to sustain the status quo.

Treatments to slow, stop, or even reverse the disease process are currently out of reach for most people living with dementia. So, we need to redouble efforts both in prevention and delaying onset, and in ensuring every dementia diagnosis is followed up with access to formal care and support services enabled by a comprehensive, personalised care plan. All people living with dementia should have access to quality care suited to their individual needs and the PriDem model highlighted in this booklet illustrates what a holistic primary care pathway looks like.

“Living better with dementia is not rocket science. Whilst one day we might find a cure, to help people living with dementia now, resources must be directed towards improving the dementia care ecosystem to ensure everyone affected by dementia gets access to the care and support they need.”

Professor Dame Louise Robinson, Professor of Primary Care and Ageing at Newcastle University and PriDem Project lead

Why dementia matters

The World Health Organization reports more than 55 million people live with dementia worldwide, with nearly 10 million new cases every year.

Globally, by 2030:



An estimated 78 million people will live with dementia.

Exceeding the entire populations of the UK and Ireland combined.



\$2.8 trillion are projected in dementia costs.

This is equivalent to the current GDP of France or Italy.

In the UK:



An estimated 982,000 people are living with dementia.

By 2040, 1.4 million will be.



One in three people born in the UK today will develop dementia in their lifetime.



Over nine out of ten people living with dementia are aged 65+.

An estimated 7.5% are living with young onset dementia with symptoms occurring under the age of 65.



Dementia is the most common cause of death in women over 65.

On average women diagnosed at 65 live around nine years with dementia.



65% of people living with dementia are women.

Two out of three dementia carers are women.



41% of informal carers of people living with dementia experience financial difficulties.

Around 20% are unable to work due to caring responsibilities.



In 2024, dementia cost £42 million.

63% of these costs are borne by people with dementia, their families and friends, with unpaid care accounting for 50% (£21.1 billion) of the total cost.



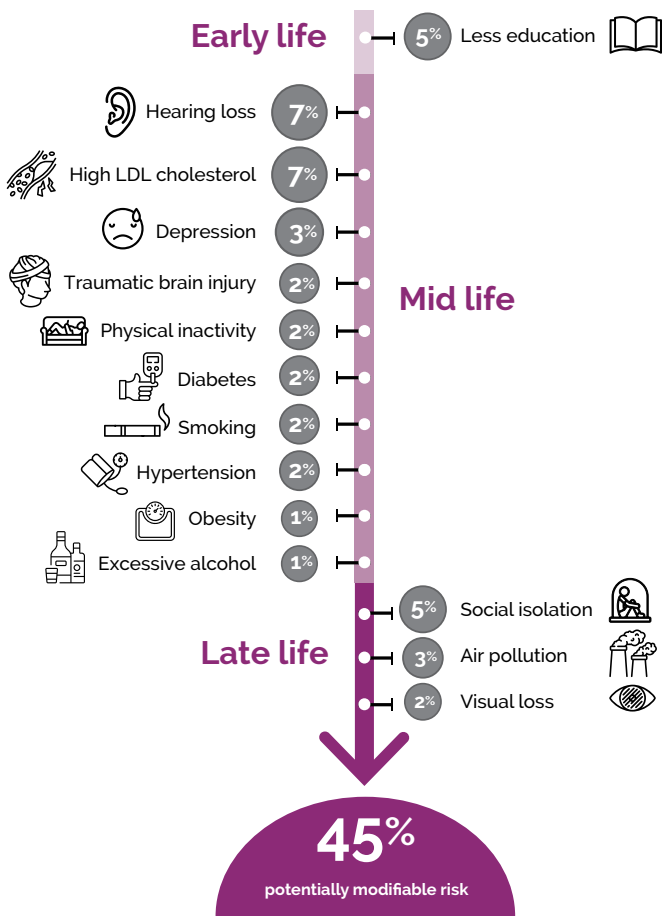
By 2040, total dementia-related costs are projected to increase to £90-£95 billion annually.

The case for prevention and a primary care approach

The good news is there is much more that can be done to prevent, delay or lessen the impact of dementia on daily lives.

According to research conducted by the Lancet Commission on dementia prevention, intervention, and care, up to 45% of dementia cases globally could be prevented or delayed by addressing 14 modifiable risk factors.

Percentage reduction in cases of dementia if these risk factors are modified over the life course



Source: Information based on infographic by Livingston, et al, in Lancet Commission 2024

Targeted interventions, from education to healthcare, could dramatically reduce dementia incidence. Emerging evidence also suggests that wider disease prevention efforts – such as shingles vaccination and the use of statins to lower cholesterol – may offer additional benefits by helping to reduce the risk of dementia.

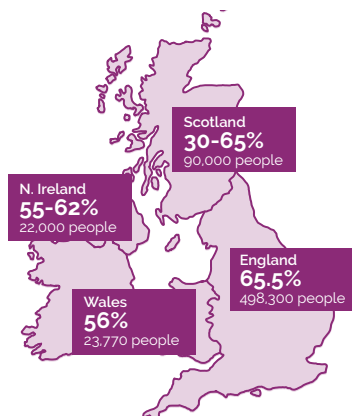
And we could look after ourselves better. For example:

- Those of us aged between 40 and 74 without a pre-existing condition are eligible for an NHS health check every five years. But half of us don't take up the invitation and an estimated 6.5 million in England have undiagnosed high cholesterol.
- In the UK, 18 million adults are impacted by hearing loss. Over half of people aged 55 plus and 80% of those over 70 have some form of hearing loss. An estimated eight million adults could benefit from hearing aids but only about two million people use them.

Good dementia care starts with a diagnosis

More than a third of people living with dementia in the UK don't have a diagnosis. Spending on diagnosis and treatment for dementia is equivalent to just 1.4% of dementia healthcare costs; by contrast, unplanned hospital admissions make up almost a third of all dementia healthcare costs.

Estimated diagnosis rates by UK nation



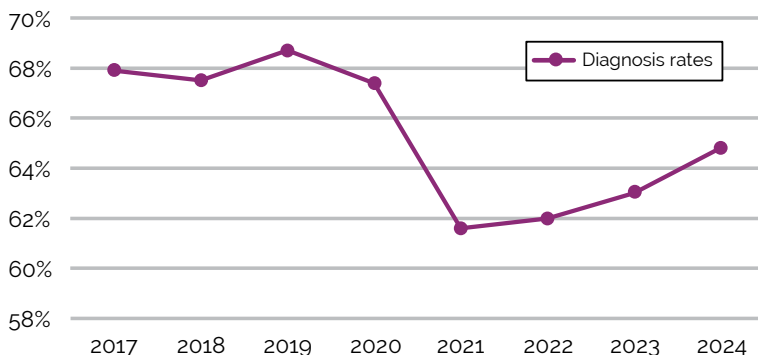
England regions	Diagnosed	Estimated Total	Diagnosis Rate %
North East	25,454	36,135	70.4
North West	65,321	94,251	69.3
Yorkshire & the Humber	48,035	71,019	67.6
East Midlands	44,339	65,491	67.7
West Midlands	50,025	79,041	63.3
East of England	56,915	89,153	63.8
London	51,659	76,816	67.2
South East	83,389	132,342	63.0
South West	55,604	90,919	61.2

People with undiagnosed dementia attend A&E **1.5 times** more than someone who is diagnosed and three times more than a person without dementia.

In 2022, **over three in five (61%)** people affected by dementia felt they hadn't received enough support – with **one in five carers** saying the lack of support meant their loved ones ended up in A&E.

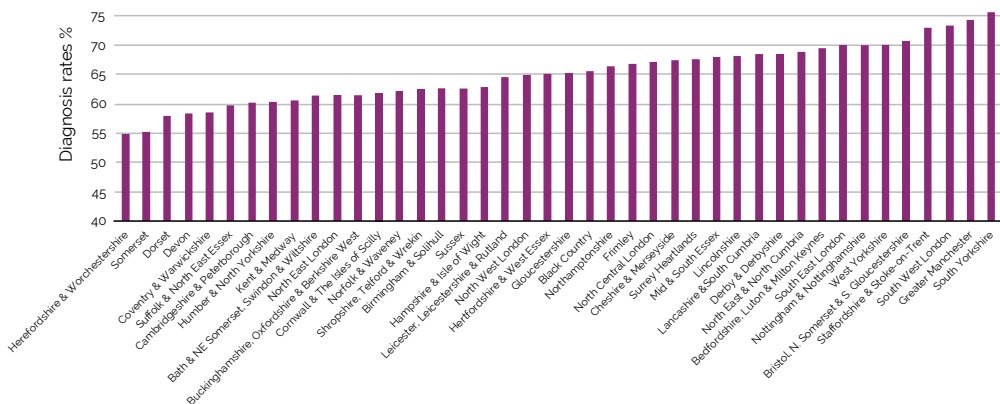
Nine in ten people agree that people living with dementia need more support than they currently receive. Yet, only half of the people affected by dementia know who to contact if they need healthcare or social care support.

Dementia diagnosis rate (people aged 65+) in England



Pre-pandemic, the NHS in England had achieved the national target of diagnosing two-thirds of people living with dementia and started to focus on reducing regional variation.

Estimated dementia diagnosis rate by NHS Integrated Care Boards (ICBs) in England (February 2025)



Post-pandemic England boasts one of the highest dementia diagnosis rates globally (65%). But progress has slowed and as the graph above illustrates, access to diagnosis, and to care and support is far from equal. For example, an Office of Health Economics (OHE) report, *Inequalities in Dementia*, found that diagnosis rates are between five and eight percentage points lower in rural areas, with this gap increasing since 2020.

We must support all people post-diagnosis

"But what's even harder is the lack of immediate help to live well with dementia, because you can live well with dementia. Yet that concept isn't really part of our narrative at all, is it? It just feels like a really dark place at times, where people don't have the support or practical help they need when that journey begins."

Andy Burnham, Mayor of Greater Manchester, speaking about his father who has been diagnosed with Alzheimer's Disease at ILC's Future of Ageing Conference in February 2025.

Many of us can live well with dementia with the right support. But, even post-diagnosis, care and support for people with dementia and their carers is limited. In England, just two-thirds of people diagnosed with dementia receive any kind of care plan, and access to formal care is limited. There's an expectation that family and friends will shoulder the burden. But as more of us age and our support networks shrink, we will be even further from meeting the care and support needs of those who have been diagnosed – let alone those who have not.



Nearly one million people are living with dementia – two thirds at home in the community.



Fewer of us have children. More of us are single.

40% of over-75s live alone.



In England, 68.2% of those with a recorded diagnosis of dementia on 31 January 2025 received a care plan or care plan review in the preceding 12 months.

This means that over half of the total numbers estimated to be living with dementia don't have any form of care plan.

Comprehensive national data on those referred for post-diagnostic support following a dementia diagnosis is not readily available.

But research evidence as reviewed by the OHE highlights multiple inequalities linking location, deprivation, socioeconomic status, age, culture, and ethnicity of people living with dementia with access to and experience of diagnosis and healthcare, A&E attendances and hospital admissions, inclusion in clinical trials, and drug prescribing.



In Scotland, just 47.7% of those people estimated to be newly diagnosed with dementia in 2021/22 were referred for post-diagnostic support.



In 2023, there were 340,000 care home beds available to people with dementia.

Just three-quarters were rated good and above by Care Quality Commission inspectors.



Fewer than one in three care workers in England have received any dementia training.

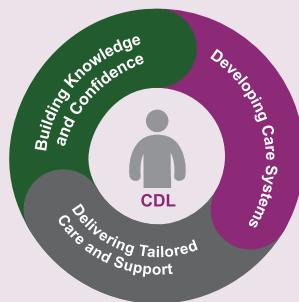
Dementia is one of the NHS's six major conditions; people living with dementia deserve high-quality care just as much as those with cancer or diabetes. Despite national guidance, dementia care remains fragmented, with a postcode lottery of support. According to the Carnell Farrar report on the economic impact of dementia, healthcare accounts for only 14% of total dementia expenditure, with nearly half (£3.5 billion) allocated to secondary care – limiting the role of primary care. General Practitioners (GPs) are reimbursed for annual dementia reviews, but both the quantity and quality of these vary widely.

Following the new NHS neighbourhood care strategy, there is an urgent need to shift resources to enable more cohesive, primary and community care-led approaches to ensure better outcomes for everyone affected by dementia, and care closer to home.

Case study: The PriDem model (led by Newcastle University and University College London)

PriDem is an evidence-informed, holistic primary care model led by a Clinical Dementia Lead (CDL), such as an Admiral Nurse, to co-ordinate services and to improve the care and support of people living with dementia and their carers.

It focuses on three key areas:



- **Direct patient care** via personalised care planning, also addressing daily living, activities, and interests. In PriDem, post-intervention, the proportion of patients with tailored care plans increased from 37.4% to 64.7%.
- **Staff training and support:** Clinical Dementia Leads delivered training and developed local service maps to streamline referrals.
- **Integrated services and multidisciplinary collaboration:** Innovative models, such as "One-Stop Shop Dementia Review Clinics", that enable patients and carers to engage with multidisciplinary teams in a single visit.

Despite the positive outcomes, the PriDem project illustrated familiar challenges such as funding constraints and staff capacity, highlighting the need for systemic changes to support primary care services effectively.

The full study report can be found on the ILC website here:

<https://ilcuk.org.uk/primary-care-led-post-diagnostic-dementia-care/>

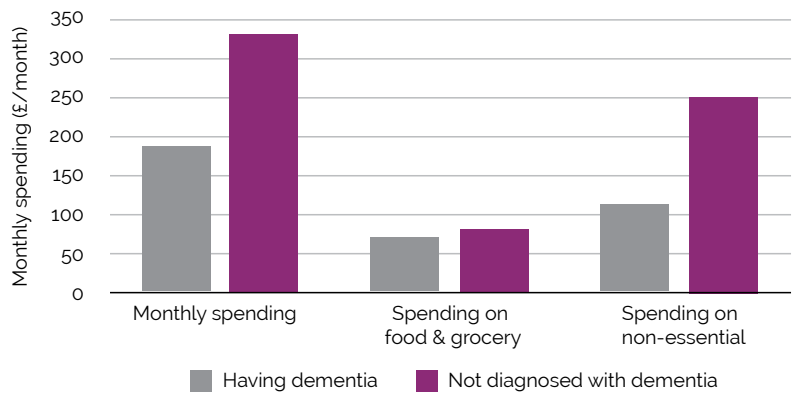
And we can do more beyond healthcare to support people with dementia



One in four people with dementia give up shopping post-diagnosis.

Around 63% believe shops aren't doing enough to help them.

Consumer spending could see a boost of **£948 million each year** if our spending environments were more welcoming to people living with dementia.



What needs to happen next

- **Be ambitious about prevention:** increase spend as a proportion of the overall health budget to enable active treatment of, for example, mid-life hypertension, high cholesterol and hearing loss – as well as promoting education, exercise, and social engagement, and address lifestyle risk factors.
- **Introduce measures to ensure every diagnosis is followed up by GP/community based review:** ensure each person has a personal care plan, with a named lead professional to co-ordinate care; tailor care to individual needs, cultural preferences, and priorities.
- **Protect and support carers with:** family carers face high risk of mental and physical ill health. Interventions like PriDem alongside other initiatives, such as UCL's STrAtegies for RelaTives (START) programme, should be scaled up to ensure comprehensive support for family carers.
- **Introduce midlife brain health assessments** to help identify risk factors, encourage behavioural change and raise awareness of dementia symptoms to encourage early diagnosis.
- **Plan for the future:** clinicians should support families in planning for future decisions, including financial and legal preparations.
- **Ensure better data collection and data sharing** across all parts of the UK to inform sustainable, scalable models that enhance dementia care quality over time.

Conclusion

Many of us could be living for many years with dementia – and we should not just accept that those years will become increasingly difficult and miserable.

“My feeling is we could do so much better if we rethought what's possible for people with dementia, rather than focusing on what isn't.”

Andy Burnham, February 2025

By adopting a more positive, holistic and personalised approach and integrating models like PriDem, we can ensure a better quality of life for individuals with dementia and their families.

About the PriDem Project

The PriDem intervention was created to address the need for change by improving post-diagnostic support of people living with dementia and their carers. Research was conducted by a multi-disciplinary team led by Professor Dame Louise Robinson at Newcastle University, in collaboration with a number of partner organisations: University College London; Kings College London; University of Sussex; University of Manchester; Dementia UK; London School of Economics and Political Science; International Longevity Centre UK; University of Exeter. The project was supported by the Alzheimer's Society and the Peter Sowerby Foundation.

Further information and the full study report can be found on the ILC website here: <https://ilcuk.org.uk/primary-care-led-post-diagnostic-dementia-care/>



Further/useful information

Alzheimer's Society – one of the leading dementia charities in the UK, offering practical advice and resources for people living with dementia and their carers www.alzheimers.org.uk

Dementia UK – in addition to helpful advice for carers, the charity provides specialist dementia support through Admiral Nurses. www.dementiauk.org

Dementia Platform UK Data Portal brings together records of over 3 million people in a free-to-access research resource. [DPUK Data Portal](https://dpuuk.org/)

References

Official data shows dementia and Alzheimer's disease continued to be the top leading cause of death in England and Wales in 2023, with 66,876 deaths registered (11.6% of all deaths). Office for National Statistics (ONS), released 10 October 2024, ONS website, statistical bulletin, [Deaths registered in England and Wales: 2023](#)

The infographic on modifiable risk factors is adapted from the work by Livingston et al. (2024). [Dementia prevention, intervention, and care: 2024 report of the Lancet Commission](#)

Information on the NHS Health Check and numbers of people with high cholesterol from the National Audit Office report [Progress in preventing cardiovascular disease](#) (Nov 2024)

Figures on hearing loss from RNID, the hearing loss charity rnid.org.uk

Data on the costs of dementia from Carnall Farrar's report commissioned by the Alzheimer's Society [The economic impact of dementia](#) (May 2024)

Figures on carers facing financial difficulties and involuntary economic inactivity due to caring responsibilities are from the Office for Health Economics (OHE) report [Inequalities in Dementia: Unveiling the Evidence and Forging a Path Towards Greater Understanding](#) (June 2024)

Representations of the numbers diagnosed and the estimated dementia diagnosis rates in England are based on data from [Primary Care Dementia Data, January and February 2025 - NHS England Digital](#)

Figures on the numbers diagnosed and the estimated dementia diagnosis rates in England are taken from the [General practice disease registers: interactive dashboard | GOV.WALES](#)

Figures on the numbers diagnosed and the estimated dementia diagnosis rates in Scotland and N. Ireland are from a report by [Future Health Are UK health systems dementia ready? Comparing dementia policy across the four nations of the UK](#) (April 2024)

Figures on impact of lack of post-diagnostic support on carers taken from a 2022 Alzheimer's Society reports [Left to Cope Alone: The unmet support needs after a dementia diagnosis](#) (June 2022) and [Personal Experiences of the Dementia Journey – The True Picture](#) (March 2024)

Data on spending with dementia taken from ILC's report [Retail therapy: helping people with dementia enjoy spending](#) (October 2022)

About ILC

ILC is the UK's leading authority on the impact of longevity on society. We combine evidence, solutions and networks to make change happen.

We help governments, policy makers, businesses and employers develop and implement solutions to ensure we all live happier, healthier and more fulfilling lives. We want a society where tomorrow is better than today and where future generations are better off.

ILC wants to help forge a new vision for the 100-year life, where everyone has the opportunity to learn throughout life, and where new technology helps us contribute more to society.



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