




Dementia: a manifesto

General Election 2024



One in two of us will be directly affected by dementia. As our population ages, it will be the defining health and social care challenge of our time.



One in two of us will be directly affected by dementia, either through being diagnosed with it, caring for a family member or friend or both. However, despite what many people believe, dementia is not an inevitable part of ageing.

Dementia is the UK's biggest killer, and, as our population ages, it will be the defining health and social care challenge of our time.

Living with dementia can mean fear and confusion, not only for the person with the condition but also for the people caring for them and their wider family and friends. Every day and every moment can throw up new and complex challenges – and trying to support someone with dementia can be exhausting and overwhelming.

Yet more than a third of people with dementia are currently undiagnosed, and so unable to access the care and support that a diagnosis can unlock. For those who are diagnosed, there remains no cure – only care, which is often disjointed and inaccessible. This must change for those living with dementia today, alongside all those who will be diagnosed with dementia over the course of the next Parliament and beyond.

The scientific field is now at a critical tipping point. For the first time, two new drugs have shown that Alzheimer's

disease can be slowed, unequivocally demonstrating that the diseased brain can be treated. With further breakthroughs and potentially game-changing diagnostics also on the horizon, there is reason for hope. The only question is whether the UK will be at the forefront of progress, or a late adopter. Now is the time to make the UK a world leader in dementia research and attract global investment.

Investment in dementia is investment in the UK and its population. The total cost of Dementia in the UK is £42bn a year and is predicted to rise to £90bn by 2040¹. A person with dementia spends an average of around £100,000 on care during their lifetime².

We come together as organisations not to say that the challenge will be easy, nor that the recommendations will solve every issue that someone with dementia faces. But a new Government has a unique chance to make long overdue but significant and tangible progress - we urge you not to miss it.

The scale of the challenge, the daily struggles that people living with dementia and their families face, and the opportunity for new treatment options and scientific breakthroughs are why the next Government must make dementia a political priority.

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The next Government must:

Prevent



Preventing, reducing and delaying dementia

1 Create a cross-governmental ‘Brain Health’ National Prevention Strategy for dementia to address the health and lifestyle factors that affect our risk of developing dementia – those that are modifiable but particularly those beyond individuals’ control, like air pollution.

Diagnose



A revolution in dementia diagnosis

2 Invest to scale up the most promising research programmes developing accurate, deliverable diagnostic tools, including blood tests, to ensure the NHS can diagnose dementia at scale and deliver treatments to the people who need them.

3 Commit to a series of ambitious diagnosis rate targets, including the specific type of dementia. This will ensure accurate diagnosis is the norm for people with dementia, providing a gateway to much-needed support, care and treatments. This new diagnosis target should be agreed, and the first in the series met within three years.

Support



Post-diagnostic support that leaves no one facing dementia alone

4 Deliver improved dementia support in primary care for families affected by dementia by ensuring greater access to a named point of contact, both clinical such as a dementia specialist nurse, and non-clinical advisors, navigators and support workers; comprehensive annual health, care and wellbeing reviews for people with dementia and their carers; and joined-up data sharing between all professionals.

5 Introduce a young onset dementia national framework for England, to include timely and accurate diagnosis, age-appropriate and immediate post-diagnostic support, and a coordinated care plan.

Care



A care system that works for everyone

6 Deliver a sustainable funding model for quality personalised care which pools the risk of care costs; provides the investment necessary for a social care workforce strategy that delivers for people living with dementia; and provides improved support for unpaid carers through assessments and appropriate breaks.

7 Urgently review the NHS continuing healthcare (CHC) process so there is greater understanding and recognition of the health needs of people with dementia. This includes a specific focus on how cognitive and behavioural needs are assessed, and ensuring dementia specialists are involved in the CHC assessment process.

Research



Investing for the future

8 Increase real-term investment into dementia research over the next Parliament to accelerate new treatments, attract investment, and protect public services.

9 Publish a long-term, strategic approach to dementia research, directing investment strategically to maximise research outputs. Implement policy across Government to support and grow the dementia research workforce.

10 Develop a plan to embed and promote dementia research into routine health and social care across the UK. Ensure research principles are integrated into dementia diagnostic services to increase participation in dementia research.



Prevent

Preventing, reducing and delaying



The impact that risk factors like air pollution, hearing loss, high blood pressure and wider social determinants of health can have on the brain is stark. Up to 40% of dementia cases could potentially be prevented or delayed by addressing a range of medical, socioeconomic, nutrition and environmental factors that affect brain health³. Good brain health is essential for better and longer living, yielding social and economic benefits and reducing the burden of neurological disease on society, which is estimated to cost the UK around £111bn a year⁴.

1 Establish a ‘Brain Health’ National Prevention Strategy for dementia

Understanding the diverse factors affecting brain health and how they impact on dementia is crucial. Some factors are within our control, such as maintaining physical and mental fitness and staying socially active. Others, like education, the affordability of a healthy lifestyle and air quality, require attention from politicians and policymakers. Many of these are also risk factors for other major health challenges such as heart disease.

We need action to enable people to look after their brain health while reducing dementia risk in the whole population. A key element of this is reaching groups at the

highest risk, which includes communities that experience the greatest health inequalities, whether that is due to poverty, ethnicity, locality, or living with multiple health conditions.

The next Government must: create a cross-governmental ‘Brain Health’ National Prevention Strategy for dementia to address the health and lifestyle factors that affect our risk of developing dementia – those that are modifiable but particularly those beyond individuals’ control, like air pollution.

Diagnose

A revolution in dementia diagnosis



Early and accurate diagnosis is the gateway to essential support, care and treatments. As of late 2023, more than half of local authorities in England are failing to meet England's current target dementia diagnosis rate of 66.7%. Only 2% of people diagnosed with dementia go on to receive specialist tests to confirm the underlying cause⁵. Emerging treatments will only be effective if we can detect dementia at the earliest possible stage of disease, and precisely identify the underlying disease, such as Alzheimer's.



2 Deliver the diagnostic tools needed for accurate and early dementia diagnosis

There is an urgent need for new, accurate and scalable diagnostic tools to improve the diagnostic pathway and ensure that new treatments can be delivered to the people that need them most. For Alzheimer's disease, for example, the two current methods of confirming a diagnosis are expensive and resource-intensive positron emission tomography (PET) scanning or an invasive lumbar puncture. These existing diagnostics will be needed to confirm eligibility for potential new treatments, but neither can be scaled to the level required to determine treatment access. However, blood tests for neurodegenerative

conditions are being developed by UK scientists, whilst other UK research programmes are developing sophisticated methods of measuring genetic risk and leveraging digital technology to detect changes that signal the onset of disease.

The next Government must: invest to scale up the most promising research programmes developing accurate, deliverable diagnostic tools, including blood tests, to prepare the NHS to deliver new treatments to the people who need them.

3 Ambitious new targets in dementia diagnosis

Urgent and equitable improvement is needed to ensure more people receive a timely and accurate dementia diagnosis. Regional variation in diagnosis is stark and even where the current 66.7% target is being met, a third of people living with dementia remain cut off from the support they desperately need.

Too often, diagnosis is delivered without details of the condition that causes dementia, therefore limiting access to both appropriate care and to existing and innovative new treatments. Inequalities such as rurality and deprivation have a major impact on access to diagnosis as well as other factors. Stigma can stop people from accessing help, increasing inequalities in access to and experience of diagnosis⁶.

Innovation is key, and Integrated Care Systems (ICSs) should be supported to implement the emerging brain health

clinic model, address regional variation in diagnosis rates, and place a specific focus on reaching underserved communities, such as people in deprived and rural areas.

The next Government must: commit to a series of ambitious national diagnostic targets to get to a place where diagnosis is the norm for people with dementia. These must be agreed, implemented and the first target met by the end of the next Parliament to ensure that no one misses out on a diagnosis. The new diagnosis target must commit to providing the type of dementia within the diagnosis, with comprehensive national prevalence statistics published on an ongoing basis. It must roll out a pilot of brain health clinics to deliver equitable, high-quality services, commissioned by regional or local health boards.

Support

Post-diagnostic support that leaves no one facing dementia alone



Every three minutes someone develops dementia, and for most people GPs remain the first port of call. Receiving a diagnosis can be life-changing and overwhelming for the person and their family and should be the entry point to the support they need. Yet too many families face a dementia diagnosis alone, falling between the gaps in overstretched and disconnected services.



4 Improve dementia support in primary care

Too many families are left to face dementia alone. GPs remain the first port of call for those who require post-diagnostic support yet primary care practitioners face issues with time, capacity, a lack of specialist dementia knowledge, and fragmented systems, leaving them unable to meet many of the complex challenges faced by families before and after diagnosis.

Research from 2022 has found that following a diagnosis, only 25% of people affected by dementia reported that they or their loved one had had their annual dementia review within the past year. Two out of five (39%) said it was at least two years ago. Yet, support to navigate wider health and care systems can make all the difference to a family facing dementia.

A study of 1,000 individuals impacted by dementia revealed that 54% of family caregivers experienced a crisis due to being unaware of the available support services⁷.

The next Government must: deliver improved dementia support in primary care for families affected by dementia by ensuring that people have greater access to named points of contact, both clinical, such as a dementia specialist nurse, and non-clinical, such as advisors, navigators and support workers; that people with dementia and their carers have comprehensive annual health, care and wellbeing reviews; and that there is joined-up data sharing between all professionals.

5 Introduce a young onset dementia national framework

33,000 people in England are recorded as having young onset dementia, when symptoms occur before the age of 65, but the actual number is much higher. The true scale is unknown due to poor diagnosis rates and recording of data. A hidden and distinct population of people in midlife are affected by dementia, with their specific needs – including changes in family roles, the loss of social identity, and the impact on dependent children and work – largely unmet.

With people aged under 65 not included in national dementia diagnosis targets, they often struggle for years. For many, it takes twice as long as older people to be diagnosed with dementia, with countless false starts across NHS clinical specialties

and misdiagnosis common. They also face the financial consequences of leaving employment early. At their most vulnerable, they must navigate complex social care systems designed for older people living with dementia which take no account of midlife family responsibilities such as dependent children.

The next Government must: extend the national dementia diagnosis targets to include those aged under 65 and create a national mandate for every ICS to establish a Young Onset Dementia Pathway that will provide a timely and accurate diagnosis, age-appropriate immediate post-diagnostic support, and a coordinated care plan for those affected.

Care

A care system that works for everyone



With no cure for dementia, quality social care is a lifeline to people with dementia and their families. People with dementia make up around 60% of people drawing on care at home in the UK⁸ and 70% of residents of older age residential care in England⁹. With a 45% increase in new cases of dementia projected by 2040¹⁰, the situation will only continue to increase pressure on the social care system.

6 Create a social care system that can support everyone affected by dementia

The majority of dementia costs in the UK fall under either formal social care or unpaid care, with over 1bn hours spent each year on unpaid care for people living with dementia¹¹. Decades of underfunding and neglect by successive governments have resulted in care that is costly, difficult to access, and not personalised to meet people's needs.

Long-term and sustainable investment into affordable social care for people living with dementia is required to ensure good quality, affordable social care for people with dementia. Improving social care provision would also reduce the number of avoidable hospital admissions and winter pressure on the NHS. 65% of emergency hospital admissions for people living with dementia were for avoidable illnesses or injuries caused by failures in care¹², leading

to worse health outcomes and poor and inappropriate discharge routes back into the care system.

Whether through unpaid and informal care or through social care packages, measures are desperately needed to improve the care that people receive and support the overwhelming burden that is falling on families of people living with dementia.

The next Government must: deliver a sustainable funding model for quality personalised care that pools the risk of care costs; invest in a social care workforce strategy that delivers for people living with dementia; and provide improved support for unpaid carers through assessments and appropriate breaks.



7 Ensure that NHS continuing healthcare (CHC) funding recognises the long-term complex health needs of dementia

NHS continuing healthcare (CHC) funding is a package of care that is fully funded by the NHS for people with long-term and complex health needs, covering costs such as domiciliary or residential care. CHC can be a lifeline for people with long-term and complex health needs who are facing soaring care costs. However, the CHC process is fundamentally flawed for people with dementia, and families are missing out on this vital funding because the system fails to recognise the complex health needs of people with dementia.

Dementia is a complex, challenging and progressive condition. Individuals have unique health needs but too often, these are misunderstood, underestimated and incorrectly assessed during the CHC process. Assessments often take place without the involvement of dementia specialists who can share essential knowledge and expertise of the health

needs of people with dementia. This leads to a failure to recognise the impact of the person's behavioural and cognitive needs and complexities.

As a result, people with dementia who may be eligible for CHC are denied this crucial funding. This can lead to increased and unmanageable caring responsibilities and serious financial worries for families, who are left to foot the cost of care themselves.

The next Government must: urgently review the CHC process so there is greater understanding and recognition of the health needs of people with dementia. This includes a specific focus on how cognitive and behavioural needs are assessed, and ensuring dementia specialists are involved in the CHC assessment process.

Invest

Investing for the future



The UK has the potential to be a world leader in neurodegeneration research, thanks to its unique combination of strengths in discovery science; world-class digital data and unrivalled cohorts; biomedical and care research charities; and the research capacity of the NHS. Action is needed to capitalise on these strengths and realise the UK's full potential.

8 Invest in dementia research to benefit our nation's health and wealth

Investment in dementia research benefits our economy, with an estimated £2.59 of economic benefit resulting from every £1 invested in 2019-20. However, if the Government's current £160m commitment is realised, this will increase to £3.96 per £1 invested – increasing further still with the arrival of new treatments¹³.

Dementia research is now at a tipping point, with scientific breakthroughs heralding new treatments and diagnostic tools. With the right investment, the field is poised to move from description of disease to precise prediction, personalised prevention and targeted treatment. This requires collaborative, data-driven and human-relevant research. The UK has the assets to deliver this, which will secure health and economic benefits.

Other complex disease areas, such as cancer, offer a blueprint for success, where strategic investment over time has yielded

vital breakthroughs for patients, attracted billions of pounds in investment from industry, and created thousands of jobs¹⁴.

The next Government must: ensure increased real-term spending on dementia research over the next Parliament to accelerate new treatments, boost the economy, create jobs and protect public services.



9 Develop a long-term, strategic approach to dementia research funding across the whole research pipeline

Research funding must be directed strategically to maximise research outputs, prevent the diseases that cause dementia, and develop new diagnostics and treatments. We need to see a holistic, long-term strategy for sustained investment in dementia research that capitalises on the UK's existing research strengths, including in discovery science; data and cohorts; biomedical charities; and the research potential of the NHS¹⁵.

This approach should include more emphasis on strategic initiatives such as the Dame Barbara Windsor Dementia Mission and the UK Dementia Research

Institute, accompanied by 'end-to-end' investment in infrastructure to strengthen the quality and capacity of research efforts, and cross-Government policy to support and grow the dementia research workforce.

The next Government must: publish a long-term, strategic and funded approach to dementia research to maximise research outputs and capitalise on the UK's research strengths. It must also implement policy across Government to support and grow the dementia research workforce, now and into the future.

10 Develop a plan to embed and promote dementia research across the UK

Greater diversity in our research workforce is essential, as is opening up opportunities to participate in research across the whole population, to ensure that research is truly representative and accessible. Research needs to be embedded into routine health and social care, building on the development of new service models such as brain health clinics. The current memory assessment service in the NHS can limit clinical research activity and patient participation in research. We need to see new models of care within the NHS which better enable research to be embedded more fully in clinical practice.

The next Government must: develop a plan to embed and promote dementia research across the UK, ensuring that research principles are integrated into dementia diagnostic services to increase research participation.

Key statistics about dementia



Dementia is an umbrella term for a condition that spans more than 200 sub-types with a wide variety of causes, symptoms and needs



More than a third of people living with dementia in England²⁰ and Northern Ireland²¹, and half of people living with dementia in Wales²², do not have access to a diagnosis and the care and support it unlocks



Dementia is now the UK's biggest killer, according to ONS classification¹⁶



Around 700,000 people in England and Wales are unpaid carers for a loved one with dementia²³, and 1.1bn hours are spent each year on unpaid care for people living with dementia²⁴



There are currently around one million people with dementia in the UK, set to rise to 1.4million by 2040¹⁷



There are currently no treatments available in the UK to cure, stop, or even slow down the progression of the diseases which cause dementia. There are exciting disease-modifying treatments for dementia in the pipeline, but (if approved) people will only be able to benefit from these with an early and accurate diagnosis and an NHS ready to deliver them



Dementia is set to become the most expensive health condition in the UK by 2030¹⁹

One in three people born today will develop dementia in their lifetime¹⁸

About Us



Dementia UK is the specialist dementia nursing charity that is there for the whole family. Our nurses, known as Admiral Nurses, provide free, specialist advice, support and understanding to anyone affected by dementia, whenever it is needed. We are here to make sure no one faces dementia alone.



Alzheimer's Society is help and hope for all people living with dementia, and we vow to end the devastation caused by dementia. We are working to improve dementia diagnosis, increase funding and participation in dementia research, shape the next steps of social care reform, and make dementia a political priority.



Alzheimer Scotland is Scotland's national dementia charity and our aims are to prevent, care and cure dementia. We raise awareness of dementia and campaign for the rights of people affected by the condition, providing services and supports to improve the lives of people living with dementia, their families and carers.



Alzheimer's Research UK is the UK's leading dementia research charity. We are working to revolutionise the way we treat, diagnose and prevent dementia. But we will not stop there. We will keep going until every person is free from the heartbreak of dementia. We exist for a cure.



The UK DRI is the UK's leading biomedical research institute dedicated to neurodegenerative diseases. Our 900+ researchers are working to fill the dementia knowledge gap, and transform that knowledge into real-world tools, diagnostics and treatments. Established in 2017 by principal funder the Medical Research Council (MRC), in partnership with Alzheimer's Society and Alzheimer's Research UK, the UK DRI has become one of the most cited institutes in the field.

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