Action plan
for dementia

No time to lose.
They can’t wait.

Government support is needed to progress towards a life-changing treatment for dementia by 2025.
Foreword

The clock is ticking to find the first life-changing treatment for dementia.

It is ticking because every three minutes someone develops dementia in the UK, and for every person who gets dementia the impact on them, their family and friends as well as their community and wider society is huge.

It is ticking because the number of people with dementia in the UK is expected to grow to one million in just three years and double to two million by 2050. The cost of dementia is expected to grow rapidly, reaching £30bn by 2021 and more than doubling to £55bn by 2040.

It is ticking because dementia is the leading cause of death in the UK, yet there are currently no treatments to prevent, cure or even slow down the progression of the diseases that cause dementia.

Together, we have the power to change this. Through medical research we will bring about a lasting solution to dementia, but we need to intensify our efforts to end this crisis as soon as possible.

At Alzheimer’s Research UK, we are funding more research than ever before and working tirelessly across the life sciences sector to find the innovation and science that will improve the lives of people living with dementia.

We are making good progress in dementia research, but we must not become complacent. There is much more that must be done. We need renewed political leadership to drive us towards new treatments and get them to the people who need them so urgently.

‘No Time to Lose’ is our action plan for dementia research and outlines five clear goals for government. We need government to invest 1% of the total cost of dementia in dementia research. Just 1% will get more researchers into the field. Just 1% will help us find new ways to detect and diagnose dementia much earlier than we do today so we can widen the search for new treatments. We also need to redefine how we think about brain health so we can help people increase their understanding of how they can reduce their risk of dementia. We must also prepare our healthcare systems for the cost and resources that will be required when a successful treatment is found, so we can get treatments to people without delay.

Taking on these actions will push us towards the goal of bringing about a life-changing treatment for dementia by 2025 – a global ambition set by G8 world health leaders, at a summit during the UK government’s presidency. If we’re going to reach that ambition and begin to help the millions of people living with dementia around the world, we can’t afford to wait.

Hilary Evans
Chief Executive, Alzheimer’s Research UK
It is the leading cause of death in the UK and one in three people born today will develop dementia in their lifetime. Without an effective treatment, one million people will have the condition in the UK in just three years, rising to two million by 2050.

Thanks to political leadership, over the last few years significant progress has been made in dementia research, and the drug development pipeline of new treatments in clinical trials is improving, but research investment still lags significantly behind other major disease areas.

Alzheimer’s Research UK is committed to increasing its investment in dementia research every year so we can one day achieve a world free from the fear, harm and heartbreak of dementia.

We need government to do the same.

Our action plan builds on the foundations already laid and will help us improve outcomes for people with dementia as soon as possible.

**Action plan for dementia**

To improve the lives of people with dementia by 2025, the UK government must:

1. Increase investment in dementia research to 1% of the total annual cost of dementia to the UK economy by 2025 (projected to be £320m in 2025).
2. Double the number of dementia researchers and people participating in dementia research.
3. Prepare the healthcare sector to detect the diseases that cause dementia 10-15 years before symptoms appear.
4. Spearhead dedicated dementia risk reduction and wider brain health campaigns for both the public and health and social care professionals.

To achieve these goals, dementia must be brought to the centre of policy-making and tackled across government departments and silos. The first Prime Minister’s Challenge on Dementia, launched in 2012, demonstrated the unparalleled value political leadership can bring to an issue. This leadership has led to increased focus and funding. It is vital we do not lose momentum or the progress to date will be lost.

The scale and complexity of dementia means we must have a long-term plan to tackle this enormous challenge – the necessary investment, support and incentives must transcend the political cycle.

It is crucial that government extends the Challenge on Dementia in line with the G8 ambition of finding a life-changing treatment by 2025 and improving the lives of people with dementia. Given the scale and impact of dementia, it is also crucial that dementia remains a strategic priority for UK Research and Innovation, the new public funding body, and that we protect future collaboration and scientific alignment as we exit the EU.
Just 1% could save millions of pounds, millions of memories, and millions of lives.
Let’s make it possible.
### We need to:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Increase research investment to 1% of the total cost of dementia</td>
</tr>
<tr>
<td>2.</td>
<td>Double research capacity and get more people involved in research</td>
</tr>
<tr>
<td>3.</td>
<td>Detect and diagnose dementia 10-15 years earlier</td>
</tr>
<tr>
<td>4.</td>
<td>Create government-led campaigns to reduce risk and improve brain health</td>
</tr>
<tr>
<td>5.</td>
<td>Develop and prepare for new treatments</td>
</tr>
</tbody>
</table>

### To deliver:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Better quality of life for those living with dementia</td>
</tr>
<tr>
<td></td>
<td>Fewer people living with dementia</td>
</tr>
<tr>
<td></td>
<td>Swift access to new treatments</td>
</tr>
<tr>
<td></td>
<td>The UK as a world leader in dementia research</td>
</tr>
</tbody>
</table>

### We must:

- Bring about a life-changing treatment for dementia by 2025
- Improve the lives of people with dementia
We must increase investment in dementia research to create the impetus needed to meet the G8 goal of bringing about a disease-modifying treatment by 2025. The government has played a significant role in driving innovation, but we cannot be complacent. In 2016/17 the government, through the National Institute for Health Research and Research Councils, invested £83.1m in dementia research. The investment to date in initiatives such as the UK Dementia Research Institute, Dementias Platform UK and the Dementia Discovery Fund provide excellent mechanisms to push towards the first life-changing treatment, but sustained increases in investment could ensure every opportunity is taken to capitalise on the good progress made to date.

The government currently spends well in excess of 1% of the total cost of cancer on cancer research. Dementia must be given the same priority.

The government must hold UK Research and Innovation and other funders to account and ensure the annual investment for dementia research increases to 1% of the total yearly cost of dementia to the UK economy by 2025 (£260m investment in research in 2018, £320m by 2025).

Medical research charities have evolved strategic funding to reach goals, often catalysing or filling gaps in government and commercial funding. In addition to funding dementia research, government should acknowledge the contribution of these charities to the UK research and development ecosystem. This includes examining the best incentive structures to encourage innovative research investment and ensuring an annual increase to the Charity Research Support Fund.

“When my dad was being diagnosed, we all hoped it was something other than dementia – cancer or anything else that had the possibility of treatment or a cure, however tiny. A treatment for dementia would mean hope for my family. Hope for more milestones shared. And hope for a better future together.”

Sem Moema
Family impacted by dementia

Increase investment in dementia research to 1% of the total annual cost of dementia to the UK economy.

Projected to be £320m in 2025

1. Action plan for dementia
**Why is this a priority?**

Despite progress in dementia research, the diseases that cause dementia are still poorly understood. This makes developing therapeutic interventions difficult. We must widen our fields of inquiry and dig deeper into the most promising areas. Evidence shows that every £1 increase in public funding for medical research precipitates up to £5 in investment by the pharmaceutical industry. Increases in funding would help to:

- Increase understanding of the role of underpinning disease mechanisms (e.g. proteostasis and inflammation).
- Address novel areas of scientific investigation that offer promise for the development of new drug targets.
- Improve accuracy and timeliness of diagnosis, develop new biomarkers for dementia and more sensitive methods to measure cognitive decline.
- Improve understanding of the causal relationship between dementia and key risk factors.

**What we want to see achieved by 2025**

Government invests 1% of the annual cost of dementia in high-quality research, with increased breadth and volume to dramatically increase understanding of the diseases that cause dementia.

Rapid increase in development and throughput of new targets towards drug discovery with more candidates in each phase of clinical development.

UK Dementia Research Institute is established as a world-leader in academic research and collaboration, with a commitment from UK Research and Innovation to continue to fund the Institute beyond the initial investment. This investment must be in addition to increasing overall funding for dementia research.

Government recognises and incentivises charity-led innovative and pioneering medical research investment.

Alzheimer’s Research UK has committed a further £250m towards dementia research.

For every £1 of money from charities and government invested in dementia research at least £6 is invested by the pharmaceutical industry.
Due to increases in funding from government and funders like Alzheimer’s Research UK, between 2008/09 and 2014/15 the number of dementia researchers in the UK almost doubled from 3,209 to 6,141 and with it, research output also doubled. This has positioned the UK as a leading place to conduct dementia research and allowed us to attract international talent.

However, there is still progress to be made: for every dementia researcher there are four cancer researchers, yet at £16.4 billion\(^3\) annually, the cost of cancer is far less than the £26 billion annual cost of dementia.

Government must facilitate increases in the number of dementia researchers in tandem with increases in research funding. Currently, 28% of academic staff in UK universities are non-UK nationals\(^4\). The launch of the UK Dementia Research Institute is an opportunity to attract further researchers to the UK. When fully operational, this institute will house around 700 researchers and a significant proportion of these will need to come from outside the UK. Government must create an environment in which the UK can continue to attract and retain the best global minds, particularly post-Brexit.

Government should also ensure all patients can take part in medical research, so the number of people with dementia enrolled in dementia studies reaches 20% by 2025. Join Dementia Research was set up to support this goal, but, despite good progress, recruitment is far below the target of 25% of people diagnosed with dementia each year signing up. Government must support Join Dementia Research by integrating it into the health system so signing up for dementia research is part of the standard NHS healthcare pathway.

“Dementia is one of the biggest challenges facing society today, and we need top quality research to find effective treatments. This requires good people – both scientists to undertake the research and volunteers to take part in studies, particularly those diagnosed at the early stages of the disease.”

Prof Tara Spires-Jones
University of Edinburgh and Chair of Alzheimer’s Research UK Grant Review Board
Join Dementia Research must also focus on recruiting people with early memory problems (amnestic Mild Cognitive Impairment) and those at higher risk of dementia to progress clinical trials focused on disease-modifying treatments. This will only be possible in conjunction with improved detection.

**Why is this a priority?**

Although the number of dementia researchers in the UK has increased, this is still a small research base in relation to the scale and impact of dementia and compared with other major diseases. This means there is a long way to go in increasing our understanding of basic neurodegeneration mechanisms and translating this into new treatments. It is vital we do not lose the momentum built over recent years, remembering that dementia research started from a very low base. The UK’s action plan for increases in funding and associated increases in research capacity must continue to be ambitious and visionary.

In addition, the number of people taking part in dementia research has increased. If we continue to increase funding and capacity, we need to also ensure there will be enough willing people with dementia to take part in studies. As research focuses on earlier stages of the disease, traditional approaches to clinical trials may not be feasible for the length of time and scale needed to accurately test potential treatments for dementia. Therefore, new approaches, like virtual trial platforms, and the associated capacity and infrastructure to deliver these approaches must be considered.

**What we want to see achieved by 2025**

- Double the number of dementia researchers from around 6,000 in 2015 to 12,000 by 2025.
- 20% of people with dementia participating in research.
- 25% of people diagnosed with dementia each year enrol in Join Dementia Research and this process is embedded in the fabric of the health system.
- A post-Brexit immigration system that allows the UK to attract the best and brightest researchers from across the globe.
- A post-Brexit deal that enables dementia researchers from the UK to access EU funding and be part of international partnerships and collaborations.
- The NHS is a world-leading place to conduct clinical trials for dementia.

**1:4**

For every dementia researcher there are four cancer researchers

**6,000 researchers in 2015**

**We need 12,000 researchers by 2025**
For people with Alzheimer’s and many other dementias, the first signs of disease begin in the brain decades before overt symptoms appear. Detecting the diseases that cause dementia at a pre-symptomatic stage widens the search for new treatments and dramatically improves the chances of success. Early detection is also a key step towards diagnosing Alzheimer’s and the other diseases that cause dementia early in the disease process.

Alzheimer’s Research UK is developing a global platform to detect the diseases that cause dementia 10-15 years before symptoms show. This will establish the UK as a global leader in early detection technology and enable the development of treatments that will work much earlier in disease.

To achieve this, researchers must be able to unlock insights from patient data that are key to improving our understanding of the diseases that cause dementia and developing effective treatments. As well as improving access to cradle-to-grave patient data, the NHS must move towards collecting data on clinical diagnosis and disease severity to understand when people are being diagnosed and how we can detect diseases like Alzheimer’s earlier.

We need support and collaboration from government and NHS so the UK can lead this revolution.

Future treatments are likely to be most effective at the earliest stages of disease, so we must increase public awareness about the importance of early detection. This will encourage people to come forward earlier, enable them to participate in research that accelerates the development of treatments, and, in the future, get the most benefit from disease-modifying treatments.

"Spotting the signs of dementia in a timely way can help GPs and other healthcare professionals to make early diagnoses and ensure that patients and their families are able to get the support they need and the best care possible. New technological initiatives and diagnostics will be key to achieving this, but it will be essential that healthcare professionals are supported to implement them."

Prof Helen Stokes-Lampard
Chair of the Royal College of GPs
GPs and other healthcare practitioners must have the skills and knowledge needed to engage patients with treatment and care pathways as early as possible. Government should work with professional organisations to deliver these resources and training. This includes engaging clinicians early as new detection tools emerge and recognising their potential to change clinical practice.

As outlined in our 2018 report “Thinking Differently”, government should pilot specialist ‘Brain Health Clinics’ to facilitate earlier detection and access to future treatments. By ‘brain health’ we mean ways to protect the brain from neurodegeneration and protect cognitive wellbeing. This would allow the NHS to test an infrastructure that could incorporate developments in diagnostics, prepare the health system for earlier diagnosis in the future, and implement future dementia treatments. The insights from this pilot would help establish best practice as well as the cost and value of treatments.

Why is this a priority?
The current research paradigm suggests that disease-modifying treatments for dementia are likely to be most effective at the earliest stages of disease, ideally pre-symptomatically. Research also suggests late diagnosis may be a contributing factor for a number of recent clinical trial failures. Early detection and ultimately diagnosis also mean people can prepare for the future and develop resilience strategies.

Changing detection in Alzheimer’s disease

| Declining cognitive function | Normal function |
|-----------------------------|-----------------
| Declining cognitive function | Mild Cognitive Impairment (MCI) |
| Declining cognitive function | Dementia |

**Early detection target**

10–15 years

**Current diagnosis**

10–15 years

What we want to see achieved by 2025

Research enables us to detect the diseases that cause dementia at least 10 years before symptoms appear.

Early detection of the hallmarks of diseases like Alzheimer’s is routine in the NHS following improvement in diagnostic tools as well as awareness raising and education for medical professionals.

'Brain Health Clinics' have been piloted, and government is evaluating data to assess whether to roll them out across the NHS.

The NHS publishes data on current dementia diagnosis including specific clinical diagnosis and disease severity.

Government works with charities to increase public awareness of the value of earlier detection of the diseases that cause dementia.

The NHS is a world-leader in scientific and clinical research with an ethical and transparent data system that provides access to cradle-to-grave patient data.
Research estimates that around 33% of dementia cases can be attributed to key risk factors that could be in our power to change, many of which are the same as those for cardiovascular disease. Our understanding of risk is growing rapidly, but it is relatively immature compared to other conditions such as cancer and cardiovascular disease, particularly in terms of understanding the causal relationships between risk factors and an individual’s risk of developing dementia. We need to test which types of interventions work best to help reduce people’s risk of dementia, and how best to communicate these insights to the public. While many of the risk factors for dementia appear to be common to cardiovascular health, there are other possible risk factors, such as hearing loss, which are not well understood.

Therefore further research investment is crucial. Through the Mike Gooley Trailfinders Charity Risk Reduction and Prevention Fund, Alzheimer’s Research UK is addressing these questions, but this must be part of a strategic and coordinated effort, including funding from the UK Dementia Research Institute as part of the increase in research investment towards 1% of the total cost of dementia.

Since the Blackfriars Consensus in 2014, there has been commitment to improve public awareness of dementia risk. Alzheimer’s Research UK has worked with Public Health England to pilot the inclusion of dementia awareness in the NHS Health Check at midlife and this will be rolled out across England. While this is significant progress, public awareness programmes in all parts of the UK are needed to educate people so they can better manage their risk factors.

Spearhead dedicated dementia risk reduction and wider brain health campaigns for both the public and medical professionals.

“Through the inclusion of dementia risk reduction messaging to the NHS Health Check, we are helping more people to understand the common and important risk factors dementia and cardiovascular disease share. It’s vital that we encourage more people to attend an NHS Health Check and, crucially, ensure they are supported to take action to reduce any risk factors identified.”

Prof Jamie Waterall
Public Health England
Why is this a priority?

There is very low public awareness of the potential to reduce risk of developing dementia. Just 34% of UK adults think it’s possible to reduce the risk of dementia, compared to over three quarters (77%) who recognise that the risk of heart disease can be reduced. This lack of understanding must be addressed urgently through a government-led awareness campaign that highlights the risks for dementia and exposes people to dementia-specific messaging.

We must ensure professionals involved in health, care, leisure and broader healthy lifestyle services are fully aware of the potential for reducing the risk of developing dementia. The current dementia skills framework only includes risk reduction for those in regular contact with people with dementia (Tier 2), which is not relevant to many of the practitioners who engage regularly with the midlife population. Novel approaches to engaging with this wider practitioner group must be explored.

What we want to see achieved by 2025

Our understanding of modifiable risk factors is significantly improved through research, including how these factors affect an individual’s risk of developing dementia and a greater understanding of the most effective intervention methods.

All relevant health, care and wider healthy lifestyle practitioners have the knowledge and skills to support the public in reducing their risk of developing dementia.

70% of people understand they can potentially lower their risk of dementia following successful public health messaging.

Dementia awareness and risk reduction continues to be a key priority area for all relevant government departments across the UK.
There are no treatments that can slow the progression of diseases like Alzheimer’s or delay the onset of the disease. Government and the healthcare sector must prepare for the cost and resource implications of a future cost-effective treatment for dementia to ensure those who would benefit from these treatments can access them without unnecessary delay.

The sheer number of people living with dementia in the UK means that future treatments will likely be costly and pose a significant challenge to our healthcare system. Future treatments could also radically change the dementia pathway and require significant upfront investment for the required infrastructure to deliver them, including changes to how we diagnose people.

In the past, we have seen people wait for new treatments when the health system was unprepared to manage the cost, demand and resources needed, as in the case of Sofosbuvir, the drug breakthrough to treat Hepatitis C. We must prepare now to prevent this outcome for people with dementia.

Alzheimer’s Research UK is leading the Dementia Access Taskforce, which focuses on developing recommendations to raise awareness and detect dementia earlier, informing value and pricing models, and preparing for adoption and uptake of new treatments. The taskforce seeks to work with government and other stakeholders to ensure there is the ability and flexibility to propose innovative funding approaches to meet this challenge. This will involve preparation, cooperation and compromise across key stakeholders, including government, the NHS and the pharmaceutical industry.

“*We do not currently have drugs proven to halt or delay the progression of Alzheimer’s disease, but a number of promising medicines are currently in clinical trials. When the first disease-modifying therapies becomes available, it is vital that people are able to access them as soon as possible.*”

Prof Jonathan Schott
UCL Institute of Neurology
The UK is a relatively small market to launch new treatments in but has a favourable position because of the global reputation of the National Institute for Health and Care Excellence (NICE). In addition, our leading role within the European Medicines Agency and ability to receive simultaneous approval with other EU members collectively make the UK a large market for industry. This position is under threat due to Brexit and an increasing focus on managing costs within the NHS, meaning patients could have to wait to benefit from future treatments. We must prevent this by protecting UK alignment with Europe for medicines regulation and developing an enlightened system of access and uptake of new treatments. The Accelerated Access Pathway, which will track adoption of innovative treatments, is a good example of this and could potentially work for future dementia treatments.

Alzheimer’s Research UK is leading the debate on the future impact of new dementia treatments, including plans to build the evidence-base around possible cost implications and develop innovative solutions. Government must work with charities, the NHS, and industry to understand the views of people living with dementia and use this unique insight to understand the implications of new treatments. We need early engagement, innovative thinking, and a willingness to compromise from government and the pharmaceutical industry.

**Why is this a priority?**

The introduction of treatments in other disease areas suggests that patients will see delays to access if we wait to prepare the system until a new treatment is given a licence. There are disease-modifying treatments coming through the drug development pipeline now with about 17 therapeutics currently in phase III trials. We must start to prepare for a new treatment now.

Policy that determines access to new treatments is currently in development and needs to work for future dementia treatments, including the new Accelerated Access Pathway in England. These new approaches need to be sensitive to the specific characteristics of dementia.

**What we want to see achieved by 2025**

- The first cost-effective disease-modifying treatment is available on the NHS.
- Innovative funding models are available to help manage the cost of new treatments.
- The UK remains an early launch market so life-changing treatments can reach people in the UK without delay.
About Alzheimer’s Research UK

Creating a world free from the fear, harm and heartbreak of dementia.

Alzheimer’s Research UK is one of the world’s leading dementia research charities.

Our mission is to bring about the first life-changing treatment for dementia by 2025 and to deliver this our activity is focused on four key goals: understand, diagnose, reduce risk and treat.

Over the last five years we have committed over £118.9m to ongoing dementia research, including:

• The Alzheimer’s Research UK Drug Discovery Alliance, a network of Drug Discovery Institutes, funded at £30m over five years and housed in world-leading academic centres in the UK to focus on translating promising scientific breakthroughs into the clinic.

• Investing £50m in the UK Dementia Research Institute as part of a £290m investment from the UK government and Alzheimer’s Society to create a world-leading hub for dementia research.

• The Mike Gooley Trailfinders Charity Prevention and Risk Reduction Fund, which provides funds for primary prevention and risk reduction research that has the potential to significantly alter the course of cognitive decline in populations that are at risk of Alzheimer’s disease and other dementias.

• The Dementia Consortium, a unique charity and industry collaboration led by Alzheimer’s Research UK, which validates novel dementia drug targets emerging from academia and accelerates the translation of these findings into early-stage drug discovery projects within the pharmaceutical industry.

We have an ambitious plan to drive progress to meet the 2025 goal, including plans to:

• Lead a global platform to enable very early detection of dementia at a population-wide level.

• Lead the Dementia Access Taskforce to ensure that when new treatments are available people with dementia can access them as soon as possible.

• Introduce a Target Robustness Programme to facilitate the translation of new discoveries into early-stage drug discovery.

• Refresh our grant schemes and significantly grow the portfolio of Alzheimer’s Research UK-funded preclinical and clinical research, partnering with other funders when appropriate.

• Sustain investment in the UK Dementia Research Institute and Drug Discovery Alliance to ensure discoveries mature into new medicines tested in clinical trials.

---

1 Office for Health Economics Consulting (2014), ‘The Trajectory of Dementia in the UK – Making a Difference’
2 Alzheimer’s Research Trust (2009), ‘Forward together. Complementarity of public and charitable research with respect to private spending’
3 http://www.ox.ac.uk/news/2012-11-07-cancer-costs-uk-economy-%e2%82%ac158bn-year (Adjusted using GDP deflator)
5 Alzheimer’s Research UK polling, 2018 – All interviews were carried out as part of Ipsos MORI’s regular face-to-face omnibus survey. A total of 2,361 interviews were conducted with a nationally representative sample of adults aged 15 and over in the UK between 15th June and 5th July 2018.
6 Alzheimer’s Research UK (2016), ‘Treatments of Tomorrow: Preparing for breakthroughs in dementia’
7 Source: Alzforum.org. Accessed 16/07/2018
8 ‘A pill too hard to swallow: how the NHS is limiting access to high priced drugs’ Gornall, J et al (2016) BMJ 2016;354:i4117
25,000 Hepatitis C patients receive new treatments by Prof Graham Foster and Peter Huskinson (05/01/2018)
“My mum and dad have been together for what feels like forever, sometimes ganging up on my sisters and I as parents do.

My dad showed symptoms of dementia when he was 58, two years before he planned to retire. My mother was a nurse and knew something was wrong right away. But even with her background and quick referrals, it took two years for dad to be diagnosed with Alzheimer’s.

Because my dad was diagnosed early, he was able to help make decisions and take part in clinical trials. It allowed my family to plan and enjoy the time with dad. I think we all now secretly wish for the days when my parents would gang up on us.

A treatment for dementia would mean hope for my family. Hope for more milestones shared. And hope for a better future together.”

Sem Moema
Family impacted by dementia
Alzheimer’s Research UK is the UK’s leading dementia research charity.

Visit www.alzheimersresearchuk.org to find out more.

3 Riverside
Granta Park
Cambridge
CB21 6AD
UK

Telephone: 0300 111 5555
policy@alzheimersresearchuk.org

Our registered charity number is 1077089 and SC042474.