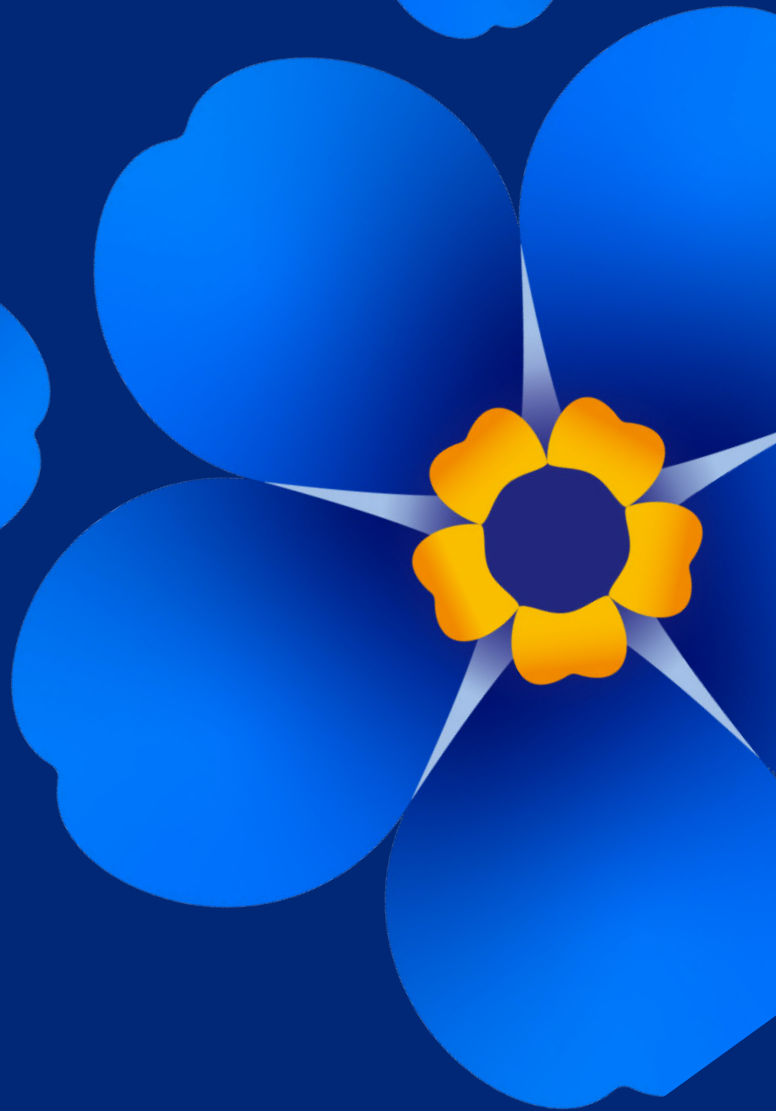
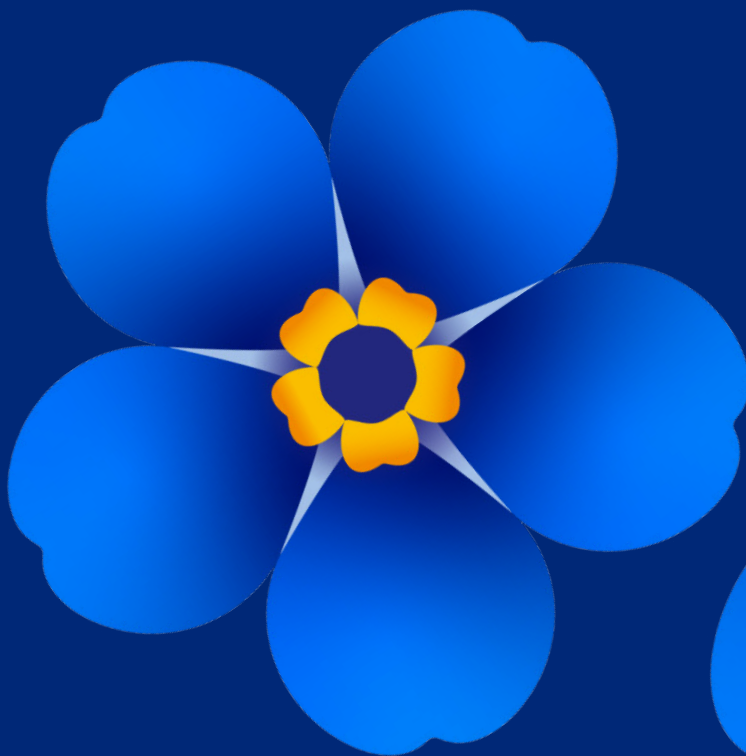
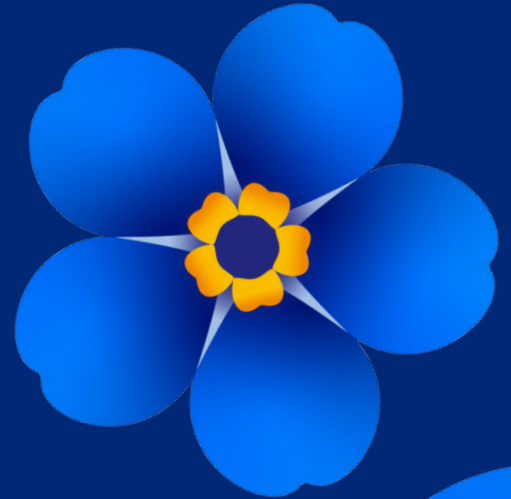


# World Café Report

## Alzheimer's Society

*From discussions with people affected by dementia and the Department of Health and Social Care*



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia

July 2026

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# Forewords

## Kieran Winterburn, Head of National Influencing, Alzheimer's Society

Dementia is one of the greatest health challenges of our time, affecting around one million people in the UK - and touching the lives of millions more.

Alzheimer's Society were pleased to welcome the Government's 10 Year Health Plan last year, which introduced the first ever Modern Service Framework (MSF) for Dementia and Frailty. This framework - which is currently being developed - has the chance to turn the tide on dementia.

But this will only happen if the MSF is shaped by the realities of those living with the condition and informed by the evidence and data we have on the experiences and outcomes of people living with dementia today.

That is why we were proud to host a World Café event on behalf of the Department of Health and Social Care - bringing together people living with dementia, carers, and loved ones to speak directly to policymakers.

This report captures their voices and sets out five key themes and recommendations that can transform dementia care. It also highlights the long-term outcome goals which should provide us with the north star we must now work towards.

As Head of National Influencing at Alzheimer's Society, I know the devastating impacts dementia has on those with the condition, as well as for our health and care systems. For too long, dementia has been overlooked by successive Governments leading to extended waiting times for a diagnosis, care which isn't personalised, and a lack of support throughout the dementia pathway.

But despite the devastating impact of dementia and years of underinvestment, there is now hope. Advances in

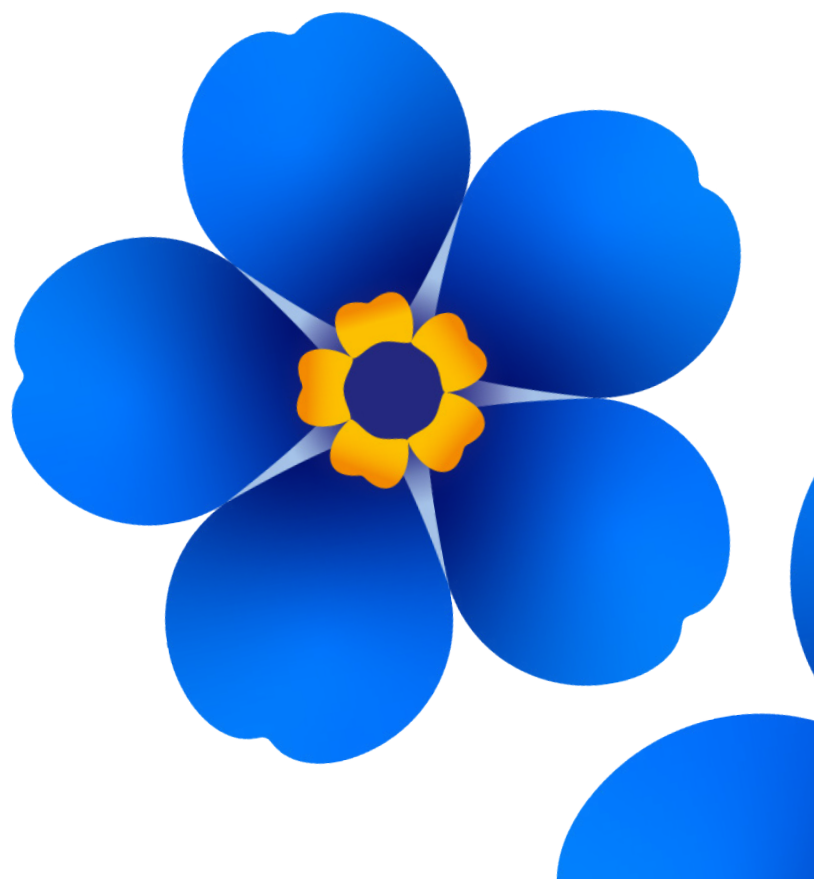
research, technology, and treatment offer new possibilities, and people living with dementia are determined to use their experiences to shape a better future.

Dementia impacts everyone uniquely - with specific barriers and challenges facing different communities. The MSF must address inequalities head-on, ensuring that dementia policy works for everyone, regardless of background or circumstance.

I thank those who joined us at the World Café event for their determination to make a difference and the honesty and hope which they shared.

The World Café was an opportunity to embed the voice of lived experience in policy creation, and I hope this engagement continues throughout the development of the MSF. Alzheimer's Society remains committed to working with the Government to ensure that the MSF is an aspirational framework which seeks to truly transform dementia policy.

With dementia prevalence set to rise by 43% by 2040 to 1.4 million people, and costs soaring to £90 billion, we cannot afford half-measures or a tinkering around the edges. The recommendations in this report, and a truly ambitious set of outcome goals, must be embedded in the MSF if we are to deliver real change and end the devastation caused by dementia.



## Trevor Salomon, Carer

Taking part in Alzheimer's Society's World Café event, held as part of the development of the Modern Service Framework for Dementia and Frailty, was a real privilege. It's not every day you get the chance to speak directly to the Department of Health and Social Care, and this report and its recommendations are a testament to the rich contributions that were made on the day by over 30 people with lived experience of dementia.

When my wife Yvonne was diagnosed with young-onset Alzheimer's in 2013, our lives changed in ways we could never have imagined. We were suddenly trying to understand a condition we knew very little about whilst attempting to get to grips with a system that was hard to navigate. Yvonne had always been very capable and active, caring for family and friends, tending a beautiful garden, and working as a bookkeeper. Watching this change was very hard and, like many carers, I adapted as best I could to support her.

Over time, I became her primary carer, as small changes in daily life grew into a full-time responsibility. Like many others, I had to learn on the job with little guidance and often felt like I was left to cope alone. Caring slowly became my whole world.

By 2019, I'd reached a point where I realised Yvonne needed 24/7 professional care. Her needs had grown, especially around incontinence support, and I made the difficult, but right decision, to move her into a care home. It meant she could receive the care she required round the clock, and it gave me space to breathe whilst always remembering that I was still ultimately responsible for decisions about her care. The biggest benefit has been the consistency of personalised care alongside clinical support. Yvonne's care staff understand her routines and what she enjoys, creating a place that feels safe and familiar. I know not everyone is so fortunate.

My story is just one of the many poignant and sometimes very difficult experiences that were shared at the World Café. People described long waits and uncertainty in getting a diagnosis and a lack of support once that diagnosis is given. Many spoke about being left to navigate complex systems alone and raised concerns about health and care staff who, through no fault of their own, don't always have the knowledge, training or understanding of dementia that's needed to deliver high-quality care.

That's why this report makes clear calls for earlier and more accurate diagnosis, better post-diagnostic support and a workforce with a deeper understanding of dementia, enabled by safe use of technology. These are not abstract ideas or guesses about what might make a difference. They are insights drawn directly from lived experience. This report is vital because it captures in people's own voices the action that's needed via the Modern Service Framework to make dementia the priority it needs to be.

The Modern Service Framework represents a once-in-a-generation opportunity to properly tackle the greatest health and care challenge of today. It must be at the same time both bold and ambitious, offering genuine hope for a future where dementia no longer devastates lives, where people can live for longer and keep doing the things they love, and ultimately where fewer people die from dementia.

We must make the most of this moment and this report is the blueprint. Now is the time to think differently about dementia.

# Executive Summary

**Dementia care has long been one of the NHS's most pressing challenges, yet it has not received the prioritisation it needs. In his Independent Review of the NHS, Lord Darzi highlighted the critical need to improve both the quality and quantity of care for people with dementia, arguing that getting diagnosis, treatment, and support right is central to the NHS's long-term sustainability.**

In July 2025, the Government responded by publishing the 10 Year Plan, committing to develop the first Modern Service Framework (MSF) for Frailty and Dementia. This framework aims to close urgent gaps in diagnosis, treatment, and post-diagnostic support identified by Lord Darzi.

To shape the MSF, Alzheimer's Society convened a Dementia World Café in October 2025 on behalf of the Department of Health and Social Care (DHSC), bringing together people with lived experience. Five priorities emerged:

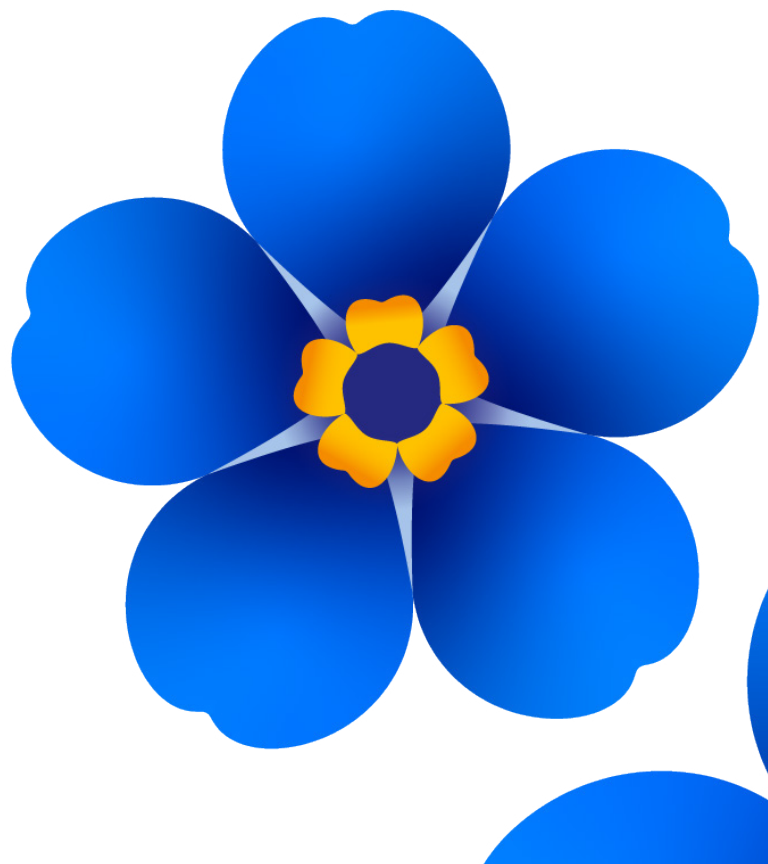
- **Early and accurate diagnosis is essential to improve outcomes.**
- **Post-diagnostic support must be guaranteed – and currently is absent in far too many cases.**
- **Families and unpaid carers need recognition and support, with the Casey Commission driving change in its first phase.**
- **Workforce training on dementia is inconsistent and must improve, especially for GPs and care home staff.**
- **Technology can help but is not a silver bullet; many people struggle to engage with technology as dementia progresses.**

These insights underline the urgency for action. As the MSF is developed, the voices of people living with dementia, their families, and carers must be central. The Government now has a clear mandate to turn these findings into meaningful change for the one million people living with dementia in the UK today. Alzheimer's Society looks forward to continuing to contribute to this work.

To deliver this change, Alzheimer's Society recommends that the MSF sets two bold, long-term outcome goals:

- **Reducing age-standardised dementia-related mortality by an agreed percentage by 2035, aligning with the 10 Year Plan and beyond.**
- **Achieving a compression of morbidity, so that people are living with dementia as late as possible in life, including through delayed progression.**

These goals will provide a clear, measurable ambition to galvanise action across the health and care system.



# Key recommendations

**1**

## Set bold outcome goals for dementia by establishing two overarching system-wide targets

- a. A measurable reduction in age-standardised dementia-related mortality by 2035.
- b. Compression of morbidity, delaying onset and progression of dementia.

These goals will align the MSF with the ambition of the 10 Year Plan and provide a clear focus for investment and innovation.

**2**

## Early and accurate diagnosis

Increase the national dementia diagnosis target and require diagnoses to include type and stage as early as possible.

**3**

## Post-diagnostic support and care

Guarantee structured post-diagnostic support for all people with dementia, including annual care plan reviews and personalised interventions to maintain quality of life.

**4**

## Workforce training

Make high-quality dementia training mandatory for all health and social care professionals, ensuring they have the skills to deliver consistent, compassionate care.

**5**

## The role of technology

Use technology and data-driven approaches to improve diagnosis, care planning, and prevention, and support public health campaigns that reduce stigma and encourage early intervention.

# What people told us

## Early and accurate diagnosis

Discussions showcased the wide variety in experience of a dementia diagnosis. It was clear that people want a diagnosis early on, as this is effectively the gateway to understanding symptoms, planning, and accessing support.

Attendees shared that the journey was complex and that they were referred in numerous directions before finally getting their diagnosis. Attendees said they would like to see current diagnostic pathways made faster, clearer, and more consistent across the country.

This is particularly the case in rural areas and for younger people. They want a system where they do not have to fight to be assessed, or rely on unrelated health events to trigger investigations and discover a dementia diagnosis.

### PARTICIPANT REFLECTIONS

- “Early diagnosis gives people extra years of independence and the ability to make their own decisions. A late diagnosis means faster decline and missed opportunities for support”
- “Diagnosis is everything. Living in a rural area, there was only one Memory Assessment Service for a huge geographic area. I was initially refused an appointment and literally had to turn up and wait outside to be seen”
- “I had multiple scans, but none would have been offered if I hadn’t first had a stroke. The system is slow, confusing, and leaves people in distress”.
- “Doctors are often unaware that younger people can have dementia, which leads to misdiagnosis and poor support”
- “The diagnostic pathway felt random and chaotic. People need clear, structured processes, not to fight the system to be seen”

## Post-diagnostic support and care

The discussions highlighted that having access to the right kind of support post-diagnosis is key. People want diagnosis pathways that do not end with a phone call or letter, but instead provide immediate, structured support, information and follow-up contact.

Attendees discussed the shock they felt upon receiving their diagnosis and then the journey of trying to process what this means and being unsure where to turn for support or to ask questions.

In addition, they wanted routine monitoring to be embedded so that families are not left to manage alone or rely on their own research during moments of panic and uncertainty.

Attendees told us that they had mixed experience in accessing an annual care plan review – given the changing nature of the condition, a consistent check in on an individual is vital to ensure the right kind of care and support.

### PARTICIPANT REFLECTIONS

- “I was diagnosed over the phone by a secretary, with no explanation, no follow-up and no written information. Five years later, I have never had a single review”
- “After diagnosis I only received a 30-minute phone call and was told to update my will and arrange a Power of Attorney. I never got any information about Lewy body dementia and had to search online, which left me terrified”
- “Every newly diagnosed person should get a consistent package of information, helpline access, and ongoing support. Families also need counselling”

## Workforce training

Attendees wanted professionals - from general practitioners (GPs) and consultants to social care providers and wider public services - to have stronger dementia knowledge.

They felt that greater education and understanding would help remove stigma and prevent misdiagnosis.

At present, a lack of understanding leads to inaccessible services and poor communication, and a lack of recognition of different types of dementia, for example young onset dementia.

They believe brief, one-day courses for professionals are inadequate and want meaningful, ongoing dementia education to be embedded in continued professional development.

### PARTICIPANT REFLECTIONS

- “Many carers and staff in care homes lack training, which leads to misinterpretation of symptoms and inappropriate responses”
- “Local dementia hubs are vital and should be available everywhere. Integrated health and social care can help people remain living at home for as long as possible”
- “Care staff should have a proper, recognised qualification in dementia, and all GPs should receive strengthened dementia training”
- “Every GP surgery should have a dedicated dementia advisor to provide continuity and support”
- “People with dementia should have regular check-ins with a named healthcare professional, at least every six months”

## The role of technology

Attendees had mixed opinions on the use of technology. Some felt it could improve their lives if it played a role in supporting them with travelling to different places, or in helping to keep them safe.

However, it was also clear that there are risks in technologies not being accessible due to cost, regional variation in what innovations are available, and general capacity to utilise technology as dementia progresses.

Technology should be personal, simple, and respectful, designed around what people living with dementia want.

An overarching theme was also that technology must work hand in hand with human support to improve care – not replace it.

### PARTICIPANT REFLECTIONS

- “Technology should be universal and user friendly. People do not want lots of different apps for different things”
- “AI could act as a friend, learn about you, detect signs of decline, and give reminders, but it needs to be introduced properly, not cold”
- “Smart home technology that picks up changes in speech or behaviour could link to health and social care systems to encourage timely diagnosis”
- “Technology should help people enjoy life, such as playing music they love, and support independence”
- “My husband isn’t able to use technology. He would remove any wearables almost immediately, and he no longer uses his phone. I have to hide an AirTag in his pocket to track his location”

# What this means

## **The MSF for Dementia and Frailty is an opportunity to turn these findings into meaningful change for the one million people living with dementia in the UK today.**

Its purpose is to close critical gaps in diagnosis, treatment and post-diagnostic support, creating a consistent and equitable approach nationwide. At the heart of this vision is early and accurate diagnosis - because it unlocks access to treatment and support, helps people live independently for longer and gives families time to plan. People told us clearly: early diagnosis is everything.

To truly seize this opportunity, the MSF must not only address immediate priorities but also set aspirational outcome goals. Reducing dementia-related mortality and compressing morbidity will ensure that improvements in diagnosis, care, and support translate into longer, healthier lives.

Diagnosis must become faster and more consistent. We need national leadership and investment to end the postcode lottery and make timely diagnosis a reality for everyone.

People told us they want clear, structured processes and professionals who understand dementia, including younger onset and cultural differences. That means investment in diagnostic tools such as MRI and PET scanners, specialist staff, and culturally relevant approaches, alongside initiatives like DiADeM to improve care home pathways.

Participants also highlighted the need for new approaches such as blood tests and peri-diagnostic monitoring to identify dementia earlier and prevent crisis. Collecting staging and biomarker data through a national registry and expanding audits will help drive quality and equity.

But support is required following a diagnosis, to ensure people can have the best quality of life possible. We need to see a structured post-diagnostic pathway where people can access the right kind of support, clinical trials, treatment to support with symptoms and annual reviews. Participants shared that too often they are diagnosed and then left with leaflets, with a need to seek out support themselves but no idea where to start.

Dementia does not discriminate – it affects people of all cultures and backgrounds from diagnosis to end of life. Yet international studies reveal that care staff currently have low confidence in their ability to deliver quality care, lack dementia-specific knowledge, and feel unable to support the complex care and communication needs of people with dementia. However, high-quality training around dementia can build the confidence of the workforce and promote better quality relationships, as well as enabling culturally sensitive care (helping to address inequality). These factors play a large part in someone's overall experience of receiving care and living a more fulfilling life, therefore their importance should not be overlooked. As people progress with the disease it is vital that strong connections between the health and social care system are made. This should happen as early as possible to support people living in their homes for longer, and then to support them with whatever type of care may be appropriate in future. This will be critical both for the Government's ambitions for neighbourhood health and the shift from hospital to community.

A skilled workforce is essential to make this vision real. Dementia training must become mandatory, backed by clear commissioning and investment. People told us that one-day courses are not enough and that GPs and care staff need proper qualifications and ongoing education. Too few care staff in England are recorded as having had some form of dementia-specific training.

Technology offers real opportunity. But people want technology that is simple, personal, and complements human care, not replaces it. There is huge potential in smart home systems to detect changes, AI tools to support early diagnosis, and integrated platforms for care plans and hospital passports.

But technology must remain affordable, inclusive, and respectful – and always used alongside human connection. Embedding these approaches will ensure consistent, high quality support wherever people live.

# Conclusion

**The voices captured through the Dementia World Café make clear that early diagnosis, guaranteed post-diagnostic support, skilled professionals, and appropriate use of technology are essential to improving lives. We would like to take the opportunity to thank everyone that participated in the Dementia World Café, and for sharing their experiences.**

**To turn these priorities into lasting change, the MSF must be bold - setting clear, measurable goals such as reducing dementia-related mortality and achieving compression of morbidity. By embedding these ambitions alongside practical reforms, the Government can deliver a future where people live well for longer and families receive the support they deserve.**

**Alzheimer's Society stands ready to support the next phase of this vital work.**

