

Meeting Minutes

APPG on Dementia: Annual General Meeting 2026

The Modern Service Framework for Frailty and Dementia

March 2026, Room B, 1 Parliament Street

Overview

The APPG on Dementia was formally reconstituted at this Annual General Meeting (AGM) to ensure continued compliance with Parliamentary rules. Members elected the Group's officers and confirmed its mission and governance arrangements for the year ahead. The meeting was joined by Stephen Kinnock MP, Minister for Care (who holds responsibility for dementia), and Fiona Carragher, Chief Research and Policy Officer at Alzheimer's Society. Both provided insights and ambitions around the development of the Modern Service Framework (MSF) for Frailty and Dementia, followed by a Q&A with the Minister and an open discussion.

Attendees

Guest speakers

Stephen Kinnock MP, Minister for Care

Fiona Carragher, Chief Research and Policy Officer, Alzheimer's Society

APPG members

Debbie Abrahams MP (Chair), Lord David Blunkett, Baroness Christine Crawley, Freddie van Mierlo MP, Joe Robertson MP, Lord Peter Weir

Alzheimer's Society

Kieran Winterburn, Head of National Influencing, Tyler Bennington-Poulter, National Influencing Officer

Dementia UK

Charlotte Lillford-Wildman, Head of Policy and Public Affairs

Alzheimer's Research UK

Ryan McCullough, Senior Public Affairs and Campaigns Manager

Eli Lilly

Dr Caroline Casey, Public Affairs Manager

Minutes

Formalities of the AGM (Debbie Abrahams MP)

Debbie Abrahams MP opened the AGM by welcoming all attendees and formally re-establishing the All-Party Parliamentary Group (APPG) on Dementia. She confirmed the group's name as the **All-Party Parliamentary Group on Dementia** and read its mission statement: *"To raise awareness of dementia in Parliament and promote policy solutions that reduce the devastation caused by this condition."* Members confirmed their agreement with both the name and the mission statement.

Debbie Abrahams MP then outlined the process for electing Officers, noting that elections would proceed in the order of Vice Chairs, Co-Chair, and Chair. Baroness Ritchie and Joe Robertson MP were proposed and elected as Vice Chairs of the APPG, followed by Baroness Browning, who was proposed and elected as Co-Chair. Joe Robertson MP proposed Debbie Abrahams MP as Chair, and members confirmed her election. Debbie Abrahams MP expressed her honour at serving as Chair and

reaffirmed her commitment to working with all members to drive meaningful change for people living with dementia.

Membership of the APPG was confirmed, with the required 20 members across both Houses secured. Membership represents a diverse range of political parties, including Labour, Conservative, Liberal Democrat, Plaid Cymru, and the DUP, as well as Independent MPs and Crossbench Peers. Debbie Abrahams MP formally acknowledged Alzheimer's Society for continuing in its role as Secretariat for the APPG.

Pre-meeting session for APPG members (All members)

Debbie Abrahams MP framed the discussion, highlighting the APPG's opportunity to engage on the development of the Modern Service Framework (MSF) for Frailty and Dementia. She outlined the framework's significance, announced as part of the 10 Year Health Plan, which sets long-term national outcome goals and identifies key interventions to achieve them. This is the first national service framework to include dementia, offering a chance to address persistent challenges such as long waits for diagnosis, uneven access to support, and limited post-diagnostic follow-up.

Debbie emphasised that the APPG's role extends beyond welcoming the framework: members should ensure its ambition and delivery mechanisms reflect the scale and urgency of dementia as a national challenge. Key areas identified for focus included improving diagnosis rates and recording, ensuring NHS readiness to adopt innovations and disease-modifying treatments, and strengthening post-diagnostic care and workforce training. Members were encouraged to coordinate contributions to cover the full dementia care pathway, from diagnosis and waiting times to treatment readiness, NHS capacity, post-diagnostic support, and workforce development.

During the session, members shared priority areas for discussion with the Minister. Joe Robertson MP thanked attending dementia charities and stressed the importance of collaborative working. Baroness Christine Crawley expressed interest in upcoming NICE guidance, disease-modifying treatments, and public engagement to reduce stigma around dementia diagnosis. Lord Peter Weir highlighted the recently announced dementia tsar role, while Freddie van Mierlo MP discussed ambitions for dementia to become treatable or curable, raised concerns about NHS preparedness and diagnostic capacity, and raised questions regarding NICE reforms and how they value medications.

Chair's speech (Debbie Abrahams MP)

Debbie welcomed the Minister for Care, Stephen Kinnock MP, and Fiona Carragher, Chief Research and Policy Officer at Alzheimer's Society, to the meeting. She noted that the APPG had formally reconstituted, elected its officers, and confirmed its mission and governance for the year ahead. Debbie introduced the session's focus on the Modern Service Framework (MSF) for Frailty and Dementia, emphasising that, as the first framework of its kind for dementia, it has the potential to be transformational for people affected by the condition. She highlighted the opportunity to bridge the longstanding divide between health and social care, particularly in the context of the ongoing Casey Commission on adult social care reform.

She underlined the central role of the workforce, referencing the APPG's Workforce Matters report, which recommended that all care providers ensure staff receive high-quality, evidence-based dementia training. Debbie noted that too few staff currently receive such training, despite modelling suggesting around 70 per cent of residents in older people's care homes live with dementia. She stressed that equivalent ambition is needed across the NHS, ensuring sufficient specialist capacity and embedding dementia expertise across primary, community, and acute care settings.

Reflecting on previous APPG discussions, Debbie highlighted personalised care interventions such as NIDUS-Family and the GRACE programme, which demonstrate the benefits of preventative,

personalised approaches designed to address health inequalities. She emphasised the importance of translating research, diagnostics, and treatment advances into real-world benefits, ensuring that high-quality dementia care is accessible nationally. She also noted the need for clear MSF goals to improve care and support for people living with dementia and unpaid carers, citing that over a third of people diagnosed in mid-2025 had not received a care plan or review in the preceding twelve months.

Concluding her remarks, Debbie reaffirmed the APPG's ambition to ensure dementia receives the same seriousness, investment, and long-term planning as other major diseases. She then invited Fiona Carragher to speak on the challenges and opportunities in dementia, followed by the Minister, who would outline the Government's ambitions for the MSF.

The Government's ambition for the MSF (Minister for Care)

The Minister thanked the APPG for the invitation to speak and welcomed the opportunity to discuss the development of the MSF for Frailty and Dementia. He highlighted the significance of recent contributions to the national conversation on dementia, including Baroness Casey's letter to the Secretary of State and her speech at the Nuffield Trust Summit, which emphasised dementia within broader health and social care reform.

He outlined the purpose of the MSF, explaining that it will define aspirational long-term outcome goals, identify the best-evidenced interventions to drive progress, and provide a clear strategy to support adoption by clinicians and providers. A key aim is to reduce unwarranted variation in care and improve consistency through clearer standards and metrics. The Minister emphasised the importance of incorporating the perspectives of people with lived experience. He referenced the Dementia World Cafe co-hosted with Alzheimer's Society, which brought together over 30 people living with dementia to contribute directly to policy development.

He confirmed the appointment of the MSF co-chairs: Dr Jeremy Isaacs, National Clinical Director for Dementia and Older People's Mental Health at NHS England; Sarah McClinton, Chief Social Worker for Adult Social Care, DHSC; and Professor Jugdeep Dhesi, President of the British Geriatrics Society. The Minister stressed that the framework must deliver tangible progress and be underpinned by practical implementation considerations.

Looking ahead, he noted that insights from Phase 1 of the Casey Commission on adult social care reform will inform further development. The Minister reiterated the Government's commitment to restoring the dementia diagnosis rate to the national ambition of two-thirds, highlighting that the January rate reached 66.1 per cent. He also noted alignment with the wider Health Mission, with a commitment for 92% of people referred for dementia assessment to be seen within 18 weeks. He expressed hope that the MSF will support improvements in care planning and empower people to use digital tools such as the NHS App.

The Minister described ongoing engagement with partners to ensure the framework delivers the best outcomes, including reviewing existing guidance and care pathways, such as the Dementia 100 Pathway Assessment Tool and the Dementia Care Pathway, which cover all elements of the Well Pathway from prevention to end-of-life care. He highlighted the Dementia Intelligence Network's diagnostic support tool, which allows local systems to analyse population factors such as rurality and socio-economic deprivation to address variation in diagnosis rates.

Turning to research and innovation, he highlighted DHSC's investment in dementia research through the NIHR, including nearly £50 million for the Dementia Trials Network and £20 million for the Dementia Trials Accelerator to support early- and late-phase clinical trials. He also referenced the Dame Barbara Windsor Dementia Goals Programme and the Neurodegeneration Initiative, a public-private partnership designed to accelerate progress in dementia research. The Government has recently committed over

£100 million to the dementia research ecosystem and intends to co-invest in the initiative alongside other partners.

Challenges and opportunities in dementia (Fiona Carragher)

Fiona Carragher noted the timeliness of the discussion, referencing Baroness Casey's recent address to the Nuffield Trust Summit, in which dementia was highlighted as central to reforms in adult social care. Baroness Casey emphasised the challenges faced by people living with dementia and the pressures these create across health and social care, calling on the Secretary of State to take immediate action. Fiona welcomed the Secretary of State's subsequent response, which included renewed commitments on dementia research, national leadership, and an update on the Modern Service Framework's (MSF) delivery timeline, with an interim product expected in September and the full Framework by year-end.

Fiona emphasised that early and accurate diagnosis remains the most effective intervention to unlock access to treatment, support, and research participation. She highlighted that a third of people living with dementia in the UK remain undiagnosed, and that three in ten of those diagnosed do not have a recorded dementia type. Referral-to-diagnosis waiting times have increased from 13 weeks in 2019 to 22 weeks, with significant regional variation. Fiona noted that diagnostic science, including blood biomarkers, advanced neuroimaging, and digital tools, is advancing rapidly, but the UK currently lags behind other European countries in adoption. She underlined the opportunity for the Framework to set ambitious goals on diagnosis, including reducing waiting times, increasing diagnosis rates, and ensuring consistent recording of dementia type and stage, thereby addressing the postcode lottery and improving early access to care and treatment.

Fiona also highlighted the importance of ensuring access to treatment and interventions. She noted that only six per cent of primary care prescriptions for people with dementia are for dementia-specific NICE-approved treatments. She referenced the forthcoming emergence of disease-modifying therapies, with over 130 Alzheimer's drugs currently in clinical trials, and stressed the need for the UK to be prepared to deliver these therapies at scale. Fiona noted limitations in access to specialist diagnostics, with only 2.1 per cent of patients at memory services receiving PET or CSF tests, and low levels of scanners and dementia specialists compared to other G7 countries. She also highlighted that up to 45 per cent of dementia cases globally are linked to modifiable risk factors, demonstrating the potential impact of prevention and public health interventions.

Fiona reminded members that the MSF will define aspirational long-term outcome goals and identify the best-evidenced interventions to drive progress. She stressed that the ambition for dementia should match other frameworks, such as the MSF for Cardiovascular Disease, which sets explicit goals on reducing mortality. With broad support across the dementia sector, Alzheimer's Society is proposing that the MSF adopt the following long-term goals: an agreed reduction in age-standardised dementia-related mortality by 2035, aligning with the 10 Year Plan; and a complementary goal on compression of morbidity, so that people live with dementia as late as possible in life, including through delayed progression.

Fiona concluded by outlining six enabling conditions proposed by Alzheimer's Society and partner charities for inclusion in the Framework: early and accurate diagnosis; clear end-to-end care pathways; access to tailored and personalised support; sufficient workforce and multidisciplinary team capacity; access to treatments and innovation; and access to clinical trials. She emphasised that implementing these conditions is essential to translate ambition into tangible improvements for people living with dementia and their families, and noted the urgency of action as other countries are already preparing.

2:45pm–3:00pm: Q&A session with the Minister

Baroness Christine Crawley raised the role of public awareness campaigns and engagement in encouraging earlier diagnosis and reducing stigma. She asked how the Modern Service Framework (MSF) could improve attitudes towards diagnosis rates and ensure people receive clear post-diagnostic support following diagnosis. Lord Peter Weir welcomed the recent announcement of a Dementia Tsar and asked how the Government intends to ensure that the role drives improvements across the system and addresses inequalities in dementia care and outcomes. Freddie van Mierlo MP asked what steps the MSF would take to support national and local readiness for disease-modifying treatments (DMTs), including workforce planning, diagnostic capacity, and infrastructure, noting the long-term ambition that dementia may become treatable or curable.

Fiona Carragher emphasised the importance of consistent implementation of existing NICE guidance on dementia care. She noted that adherence to current guidance on both drug and non-drug treatments provides an opportunity to improve equity and deliver better value through earlier diagnosis and effective condition management. She highlighted evidence indicating that approximately six per cent of primary care prescriptions for people living with dementia are for dementia-specific NICE-approved treatments and that only 31 per cent of patients attending memory assessment services are offered cognitive stimulation therapy, a recommended non-drug intervention. Fiona Carragher suggested the need for strengthened accountability for guideline delivery and updating guidance to reflect the growing pipeline of DMTs.

The Minister welcomed the questions and reiterated the Government's commitment to improving dementia diagnosis and access to care. He emphasised that timely diagnosis is critical, serving as the gateway to advice, support, and potential treatments for people living with dementia and their families. He confirmed the Government's commitment to restoring the dementia diagnosis rate to the national ambition of two-thirds, noting that the rate had reached 66.1 per cent in January, representing a steady increase over the preceding eighteen months. He also highlighted the Health Mission target for NHS waiting times, with a commitment that 92 per cent of patients referred for specialist care, including dementia assessment, should be seen within 18 weeks.

In response to questions on leadership and accountability, the Minister welcomed the appointment of a Dementia Tsar. While the role's responsibilities and remit are still being finalised, he suggested the Cancer Tsar model as a useful reference for national leadership and system-wide improvements. He noted that the MSF is intended to reduce unwarranted variation in care and establish clearer national standards across the dementia pathway.

Regarding diagnosis and service variation, the Minister referenced the work of the Office for Health Improvement and Disparities' Dementia Intelligence Network, which has developed a diagnostic support tool for local systems. The tool enables analysis of variation in diagnosis rates based on population characteristics such as rurality and socio-economic deprivation and supports local action to improve rates.

The Minister acknowledged concerns about low levels of prescribing for dementia-specific treatments and noted his particular interest in these figures. He highlighted that the MSF will provide opportunities to review existing pathways, strengthen accountability for NICE guideline implementation, and ensure that the health system is prepared to adopt new treatments and innovations as they become available.