Casey Commission
Independent Commission on Adult Social Care

Rt Hon Wes Streeting MP
Secretary of State for Health and Social Care

copied to: Stephen Kinnock MP, Minister of State for Care

03 March 2026

Dear Secretary of State,

Subject: Immediate action on safeguarding, dementia and motor neurone disease

One year ago, when you and the Prime Minister asked me to Chair an Independent Commission on Adult Social Care, I made a clear commitment that I would not wait until the end of the Commission to recommend action where I saw fit.

Later this year, I will launch a national conversation with the public and publish my first report. I am grateful to you, Stephen Kinnock the Minister of State for Care and colleagues for all the support and help so far. I consider us on track to meet the terms we agreed and intend to work at a significant pace.

In the short term, I am asking Government to act on three areas: adult safeguarding, dementia and Motor Neurone Disease (the full detail of each of these asks can be found at **Annex A**). These are challenges in themselves but also indicate wider issues of system failure or where fresh thinking is needed. All of these have been discussed with your officials.

Safeguarding

Among all the issues I have considered in the past year, one of the most concerning has been the abdication of responsibility, by successive governments, to protect people who are vulnerable and at risk of abuse. Instead of a robust national safeguarding system, serious safeguarding failures are addressed as isolated local problems, meaning the same concerns are identified repeatedly without national scrutiny, action, or consequences.

That is why I am requesting that the Department of Health and Social Care:

1. **Set up, immediately, a new National Safeguarding Board, chaired by the Chief Social Worker and reporting to the Minister for Social Care, which would have statutory responsibility for adult safeguarding: reviewing Safeguarding Adult Reviews (SAR), identifying national risks, and commissioning thematic reviews.**

2. **Lead an urgent review of existing adult safeguarding statutory duties and powers, to test whether the current framework provides sufficient clarity and leverage in high-risk situations**.

Dementia

Despite the well-known increasing prevalence of dementia and the government's manifesto commitment to put Britain at the forefront of transforming treatment for dementia, I have not found a system set up to tackle this problem with the same energy we have seen in the face of other conditions.

Preparation needs to be made for future clinical breakthroughs. Dementia is currently viewed as an inevitable part of aging or something which should be tackled through prevention only. People with dementia are too often treated as "bed blockers" rather than patients with neurological, health conditions. There is a lack of collective drive on this issue.

I am asking the Government to send a clear signal that dementia and specifically Alzheimer's Disease is a priority and a clinical matter by:

3. **Giving immediate backing to scale up investment in dementia trials. Starting with using funding from the Dementia Goals Programme to trial new dementia drugs, beginning with pilots of 100 people across 2 sites, with an ambition to scale up to 2,000 people across 20 sites within 5 years.**

   It is my view that we should be flooding the system with clinical trials. But as a first step I am asking the Government to fund a small trial that is ready to proceed, using funding that is already available. There is so much more that could be done. This would signal a renewed commitment to get on the front foot.

4. **Making faster progress on the Modern Service Framework for Frailty and Dementia.**

5. **Appointing a new, full-time Dementia Tsar who has national responsibility for driving forward the prevention, treatment and care of dementia, including fulfilling the Government's manifesto commitment to put Britain at the forefront of transforming treatment for dementia.**

Motor Neurone Disease (MND)

You know that I review systems by prioritising looking at how they serve the people who are most in need; those who the public would expect to receive the best care. Motor Neurone Disease (MND) is one of the most horrendous conditions people can face and affects just 5,000 people in the country at any given time. Its progression is fast, and predictable. Despite this, people living with MND are put through the same one-size-fits-all system as everyone else, facing long waits for social care and housing adaptations.

So I am asking the Government to:

6. **Create a new fast-track “passport” for people diagnosed with MND. Mirroring the DWP Special Rules, specialist diagnosis by a consultant neurologist would automatically trigger entitlement to fast track set up of healthcare, care and support, including using an expedited Care Act needs assessment.**

This is not about cutting across or ignoring the Care Act. Instead, this is about making sure people with MND do not have to face long waits or go through repeated, slow assessments.

Separately, I will return to the Care Act as my work continues. I understand the importance of the Act which has changed how we talk about people’s independence and rights. But without money or infrastructure to back it up, no one has truly been able to implement it effectively. They are instead pushed into gatekeeping. This cannot be right: performative legislation brought in by the previous administration without taking responsibility for whether the new ‘rights’ can be fulfilled means people are being failed. These six recommendations are modest changes that point to bigger, more fundamental failings in the system: a one-size fits all approach, a divide between the NHS and social care, pessimism about the lives older people can live and a lack of central accountability and grip.

Taking these immediate actions will not fix those fundamental problems, but they will be an important step forward and offer a vital lifeline to people who do not have time to wait for us to act.

The Baroness Casey of Blackstock, DBE CB
Chair, Independent Commission on Adult Social Care

Annex A

Adult safeguarding

1. **Set up, immediately, a new National Safeguarding Board, chaired by the Chief Social Worker and reporting to the Minister for Social Care,** which would have statutory responsibility for adult safeguarding: reviewing Safeguarding Adult Reviews (SAR), identifying national risks, and commissioning thematic reviews. This Board should be responsible for convening safeguarding professionals and for the accountability of safeguarding across the system at a national level. It will also be required to publish an annual report on its findings and progress. As a first step, the Board should:

- review and update the criteria for what triggers an escalation of safeguarding concerns or patterns beyond the local level – on the assumption that the current framework allows for too high a level of local discretion and too much variation as a result;
- take immediate action on recurring issues already known about, including clearer guidance on coercive control and exploitation and transitions;
- better annual data collection, to track the number of commissioned and completed SARs and track better data on the patterns.

2. **Lead an urgent review of existing adult safeguarding statutory duties and powers, to test whether the current framework provides sufficient clarity and leverage in high-risk situations**. This could include:

- clarifying what triggers the Section 42 duty for local authorities to make inquiries if it is suspected an adult with care needs is experiencing, or is at risk of, abuse or neglect
- considering whether mechanisms such as powers of entry would strengthen safeguarding while remaining consistent with adults' rights;
- strengthening the links between safeguarding, inspection and regulation, potentially through clearer pathways for how SAR findings can inform regulatory action and the focus of inspections.

Dementia

3. **Giving immediate backing to scale up investment in dementia trials. Starting with using funding from the Dementia Goals Programme to trial new dementia drugs, beginning with pilots of 100 people across 2 sites, with an ambition to scale up to 2,000 people across 20 sites within 5 years.**

   Allocating £6million using the Dementia Goals Programme as a vehicle to fund a pilot study would pay for the administration of newly licensed dementia drugs lecanemab and donanemab to 100 people, including staff time, diagnostic tests, MRI scans – using existing capacity so that no investment in new infrastructure is required.

   These pilots would send an important message about treating dementia as a clinical issue, and would allow the NHS to pilot new therapies and collect evidence on how the medicines could be deployed at scale across the country, through the Europe-wide initiative ACCESS-AD.

   Co-led by King's College London, and involving partners like NICE, University of Leicester, University College London and others, ACCESS-AD provides a ready-made model enabling access to newly licensed treatments, collecting vital real world evidence and get the system ready for their rollout. Once this study is supported, the Dementia Goals Programme will use it as a basis to ensure the pilot approach is further scaled to sites across the NHS.

4. **Making faster progress on the Modern Service Framework for Frailty and Dementia.** Although heartened by the commitment to this in the NHS 10 Year Plan, we want government to move more quickly, to publish the MSF in this calendar year. It should be developed in partnership with local government as well as the NHS and look at how dementia can be put on a level playing field with other conditions, for example by setting national standards for dementia diagnosis, including an 18-week referral-to-treatment target.

5. **Appointing a new, full-time Dementia Tsar who has national responsibility for driving forward the prevention, treatment and care of dementia,** including fulfilling the Government's manifesto commitment to put Britain at the forefront of transforming treatment for dementia. Leadership responsibility for dementia is shared across several individuals in NHS England and DHSC. Given the enormity of the problem, a new Dementia Tsar should sit above all existing NHS and DHSC leadership and replicate the role of the Cancer Tsar, providing leadership and accountability to drive progress across different system interests.

Motor Neurone Disease (MND)

6. **Create a new fast-track "passport" for people diagnosed with MND.** Mirroring the DWP Special Rules, specialist diagnosis by a consultant neurologist would automatically trigger entitlement to fast track set up care and support, including using an expedited Care Act needs assessment. This process should not affect the type or quality of care offered; people should still get access to the healthcare, care and support they need, but more quickly, and with more anticipation of how those needs are likely to change.

   The principle is simple: where a condition is severe, predictable and time-limited, people should not be subject to repeated, slow assessments and long waits for support. The system should help them plan for the likely trajectory of those needs, based on the predictable path the condition will take, rather than having to assess them each time the condition progresses. Diagnosis of MND, which affects 5,000 people in the UK at any given time, would therefore passport individuals into a fast tracked setup of healthcare, care, carers' support and housing adaptations.

   This could include:

- Automatic prioritised access to care and support following diagnosis.
- A nationally mandated maximum timeframe (for example, 28 days) from diagnosis to support being in place.
- A clear expectation on health, local authorities and housing authorities to arrange and deliver the full support package within that timeframe.
- Removal of repeated needs assessments and sequential gatekeeping processes.
- Financial assessment would remain. The DFG means test and any care charging assessment would still apply, but these would be combined and would be the only financial tests required.

The fast-track would apply to the whole package of help so that everything is set in motion at once rather than the individual needing to move slowly through separate systems.

If needed, we would support any statutory changes needed to deliver this, for example amendments to social care and housing legislation to create a guaranteed, diagnosis-triggered fast track for people with MND.