

From Lord Markham Parliamentary Under-Secretary of State

> 39 Victoria Street London SW1H 0EU

By email

05 February 2024

Dear Noble Lords,

Thank you for your contributions to the debate on 18 January 2024 on what plans the Government has to create parity of esteem between health and social care to address dementia. I am writing to address a number of the questions raised in the debate, which would benefit from a fuller response.

Baroness Browning highlighted a report published by the APPG on Dementia last month entitled Raising the Barriers, which includes recommendations for how Integrated Care Systems (ICSs) may improve dementia services and asked about accountability within ICSs.

It continues to be the case that local leaders are best placed to make decisions about their local populations with fewer top-down national targets, missives and directives. That is why ICSs have greater devolved responsibilities than their predecessors. ICSs are accountable to the individuals and communities they serve. In addition, there are formal accountability arrangements for different partners of ICS that are defined in legislation and other supporting guidance, with local authorities held to account through local democratic processes and NHS organisations accountable to NHS England, which is in turn accountable to government and to Parliament.

Several Lords raised concerns about the costs of care for people with dementia and asked questions relating to NHS Continuing HealthCare (CHC), the implications of Section 117 of the Mental Health Act, and the costs of adult social care.

We want every care user to receive health and social care at the right time and in the right place, which is appropriately joined-up and funded, especially for those with complex and nursing care needs. This includes people with dementia and their families. Eligibility for CHC is assessed on a case-by-case basis taking into account the totality of an individual's needs. It is not determined by age, diagnosis or condition or financial means. Non-eligible individuals may still receive some NHS-funded or NHS-provided services, for example NHS-funded Nursing Care or through a 'joint package of care' with the local authority.

Baroness Greenfield highlighted the importance of strengthening the dementia research landscape and requested further detail on how the Government plans to do this. I assure their Lords that the Government is strongly committed to supporting research into dementia and through partnerships with patients, researchers, funders and charities we continue to play a significant role in global efforts against the disease.

The Government has committed to double funding for dementia research to £160 million per year by the end of 2024/25 and we are making significant progress towards meeting the commitment. We

have instigated momentous new programmes of work, such as the Dementia Translational Research Collaboration Trials Network (D-TRC-TN) which is funded by Government via the National Institute for Health and Care Research (NIHR) and supported by almost £50 million of investment. On Wednesday 24<sup>th</sup> January we publicly announced plans for the D-TRC-TN which include significantly increasing the number of clinical trial sites capable of delivering dementia research in patients, spread regionally, across the whole of the UK. It will offer people with dementia the opportunity to take part in early phase clinical trials irrespective of where they live and widen access to a greater number and diversity of people with dementia or cognitive impairment.

To improve participation in dementia research, as justifiably raised by Baroness Greenfield, the government via the National Institute for Health and Care Research (NIHR) is funding Join Dementia Research with charity partners. The online platform enables the involvement of people with a dementia diagnosis, and their carers to take part in a range of important research. There have been almost 79,000 study recruitments from Join Dementia Research since it was established.

Baroness Berridge asked whether there is data on how many people with dementia are detained under the Mental Health Act. Whilst our current data on the Mental Health Act does contain some information about health conditions and co-morbidities, we do not have data available on the number of people with dementia who are currently detained under Section 117. Latest available data shows that at the end of March 2023, 21,016 people in total were subject to the Mental Health Act.

Regarding Baroness Wheeler's question about the Government's plans to reform the charging system for adult social care, at the Autumn Statement in November 2022 we listened to the concerns of local government and took the difficult decision to delay charging reform. The funding is being retained in local authority budgets to help them meet current pressures. In April 2023 we set out an updated plan for reforming the adult social care system in the Next steps to put People at the Heart of Care plan, backed by up to £700 million.

Baronesses Donaghy and Ritchie discussed dementia diagnosis rates and asked what steps Government is taking to invest in diagnostic infrastructure for dementia, and what plans the Government has for a major conditions strategy.

As I said during the debate, timely diagnosis of dementia is vital to ensure that a person with dementia can access the advice, information, care and support that can help them to live well with the condition and remain independent for as long as possible.

NHS England is committed to improving dementia diagnosis rates and has established a dedicated programme team to prepare the NHS for the potential arrival of new dementia treatments, should they be approved by the Medicines and Healthcare Regulatory Authority and determined to be clinically and cost-effective by National Institute for Health and Care Excellence (NICE). This programme of work includes assessing the additional scanning, treating and monitoring capacity that will be needed, and securing additional diagnostic capacity including MRI, lumbar puncture and PET-CT.

NHS England is also working with partner agencies to support and inform further research into other diagnostic modalities, including blood-based biomarker and digital tests, which will help improve identification and management of Alzheimer's disease.

I wish to highlight that the Government, via the NIHR, has invested nearly £11 million of funding to develop new digital approaches for the early detection and diagnosis of dementia. Alongside charity partners, we are also investing in the Blood Biomarker Challenge which seeks to make the case for blood biomarker tests in a healthcare setting in the UK.

I can also confirm that Government plans to publish a Major Conditions Strategy early this year, covering six conditions including dementia. In August 2023 we published our initial report '*Major Conditions Strategy: Case for change*' and our strategic framework, setting out what we have learned so far, and sharing what we plan to focus on next to develop the final strategy.

Baroness Ritchie asked for an update on Government's plans to prepare the NHS to deliver ground-breaking new treatments, where I wish to give further details to the response I gave during the debate. We are expecting NICE to publish final guidance on the use of lecanemab in July 2024, and on the use of donanemab in September 2024. The NHS in England is legally obliged to fund medicines approved in a NICE appraisal, usually within three months of final guidance. In some cases, an extended funding timeline may be agreed to reflect factors like the complexity of implementation.

I welcome their Lords questions on this important topic, and I assure their Lords that we are committed to improving the lives of people living with dementia. I hope that this letter has provided further clarity on the points raised at the debate.

I will deposit this letter in the libraries of both Houses.

With my very best wishes,

LORD MARKHAM CBE

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