

Layla Moran MP
Chair of the Health and Social Care Committee
Health and Social Care Committee
House of Commons
London
SW1A 0AA

Sent by email to: hscocom@parliament.uk

10/12/2024



Alzheimer's Society
Suite 2, 1st Floor East Wing,
Plumer House, Tallyour Road,
Plymouth PL6 5FS

alzheimers.org.uk

Re: 10 Year Health Plan Inquiry | Ensuring the inclusion of people living with dementia.

Dear Layla Moran MP,

I am writing on behalf of Alzheimer's Society to express our concerns and provide insights into the inclusion of the dementia patient group in the development of the 10-Year Health Plan. As the leading cause of death in the UK, dementia devastates the lives of individuals and families, and presents the greatest challenge to our healthcare system. We respectfully request you as Chair of this influential committee, to urge the Secretary of State for Health and Social Care at the Oral Evidence Session on the 18th of December to engage with people affected by dementia as a central focus of the consultation process.

There are around 1 million people living with dementia in the UK, a number expected to grow to 1.4 million by 2040. The economic burden of dementia is equally profound. It is already the most expensive health condition to the economy at £42 billion per year, although this figure is projected to rise to £90 billion by 2040. In addition to the scale and financial cost of dementia, it places significant strain on our National Health Service: people living with dementia occupy one in six hospital beds and are three times more likely to visit the GP than those without dementia. Given the urgency of this issue, it is vital that the consultation for the 10-Year Health Plan reaches the often-marginalised dementia patient group in a meaningful way.

While the ongoing public consultation process includes the NHS Change Portal, these digital platforms often present significant accessibility barriers for people living with dementia. For instance, their overly complex layouts, dense and unclear language, and limited accessibility features – such as lack of screen-reader compatibility, poor contrast settings, or absence of navigational aids – can make digital platforms highly inaccessible. As the symptoms of dementia worsen, there is a deterioration of cognitive processing, short-term memory, and written communication, which further exacerbates the ability of those with dementia to engage.

Recent insights from a survey of our supporter base highlights some of their experiences with the NHS Change Portal. Of 396 respondents who were prompted to engage with the consultation, 18% did not manage to complete their submission, 15% found the process either somewhat or very inaccessible, with 40% being unaware that there was an accessible version being offered. Less than half respondents found the consultation process either very accessible (21%) or somewhat

accessible (17%). Written feedback on their experience with the NHS Change Portal from respondents illustrates the difficulties encountered:

- *"Not really given sufficient guidance, needs to be more than a form-filling exercise."*
- *"A bit of a mix. Maybe some instructions on how to go about filling in the consultation. Being elderly makes it a little confusing."*
- *"I wouldn't have known about the consultation had it not been for the Alzheimer's Society."*
- *"Almost gave up, but I cared too much about giving my views."*
- *"It was difficult to populate the fields as you could only see a few words at a time of what you'd written."*

In-person consultation methods such as Workshops in a Box present their own set of challenges. The physical spaces where these events will be held may be difficult for people living with dementia to navigate, particularly if they lack dementia-friendly considerations such as clear signage and room layout, low-sensory environments with suitable lighting and acoustics, and step-free access. The chosen venues may lack facilities for continence needs, like accessible restrooms and spaces for breaks, or for mobility and balance issues, such as supportive seating and handrails for safety. Furthermore, these events could be without dementia-trained facilitators who have the skills and understanding needed to communicate effectively with people living with dementia

As the largest dementia charity in the UK, Alzheimer's Society has an extensive network of individuals living affected by dementia, many of whom engage regularly in support groups that we facilitate physically and virtually across the UK. We are uniquely positioned to support and lead meaningful participation in this consultation, and we have extensive experience in overcoming access barriers in creating dementia-friendly engagement strategies. Our extensive research, evidence base, and direct insight into the challenges faced by people living with dementia will make us a valuable partner in this process.

We urge the Health and Social Care Committee to press the Secretary of State for Health and Social Care for clarity over the mechanisms to engage this often under-represented patient group during the Oral Evidence Session scheduled for the 18th of December. It is vital that the Government ensures the voices of the 1 million with dementia and the countless others that are affected by this devastating disease are heard, and we encourage you to use the session to help clarify how this will be achieved.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Rachael Martin-Ball', written in a cursive style.

Rachael Martin-Ball | National Influencing Manager | Alzheimer's Society