

Lord Hunt of Kings Heath will ask a question on **the number of people with Huntington's disease displaying mental health symptoms and being denied access to mental health services** on the grounds it is an organic brain disorder at the start of business on **12th June 2023**.

For more information, please contact National Influencing Officer, Lewis Scott at lewis.scott@alzheimers.org.uk

1. Suggested interventions

- “My Lords, Alzheimer's Society reports that 61% of people affected by dementia want mental health support that they are not receiving, and that 57% of those who are referred to mental health support wait up to 12 months. What steps are the Government taking to ensure that all people with dementia are able to access mental health services that they need in a timely manner?”
- “My Lords, in 2018, just over 2,000 of the more than 1 million referrals to NHS Improving Access to Psychological Therapies (now NHS Talking Therapies) were for people with dementia. However, there are more than 900,000 living with the condition – more than 30% of whom will experience anxiety or depression during the course of their illness. How will the Government ensure that people with dementia are actually being referred into mental health services in the first place?”
- “My Lords, Huntington's disease is just one of more than 200 conditions which cause dementia. Will the Minister assure me that efforts will be made to improve access to mental health services for people with all types of dementia, and particularly also to their carers who are often forgotten when we are talking about treatment pathways?”

2. Background information

- Huntington's disease is an inherited genetic condition that causes dementia, which normally begins when a person is in their 30s or 40s. Symptoms include severe depression, apathy, irritability, and obsessive-compulsive behaviours. At later stages, people with Huntington's will experience memory and motor problems.¹
- There are over 200 conditions which cause dementia – the most common types include Alzheimer's disease, vascular dementia, and dementia with Lewy bodies.²
- Dementia shares symptoms with many mental health conditions such as anxiety and depression, and people with dementia can benefit from mental health services such as talking therapies.³

3. Alzheimer's Society's *Left to Cope Alone* report

Alzheimer's Society published a report on post-diagnostic support for dementia in June 2022, entitled [Left to Cope Alone](#). More than 2,000 people affected by dementia contributed their experiences to the report and its central recommendation was that **every person with dementia should have a named dementia support worker, or similar service**. The report found that:

¹ <https://www.alzheimers.org.uk/about-dementia/types-dementia/huntingtons-disease>.

² <https://www.dementiauk.org/about-dementia/types-of-dementia>.

³ <https://www.mentalhealth.org.uk/explore-mental-health/a-z-topics/dementia>.



- 61% of respondents said that they needed, but weren't receiving, support for their mental health or that of their loved ones.
- 57% of people affected by dementia who had been signposted to mental health services reported having to wait up to 12 months to access support.
- Of the more than 1 million referrals to mental health services in 2018, just 2,277 (0.2%) were for people with dementia.⁴ This is substantially lower than would be expected given the prevalence in the general population.
- Research has shown that the structure of some mental health services, and the demands it places on staff, means they are not flexible enough to meet the needs of people with dementia, with cost-effectiveness and patient care priorities often in opposition.⁵
- These pressures mean that some services may reject referrals of people living with dementia. Additionally, the lack of dementia expertise in primary care may mean people with dementia are less likely to be referred to these services.

⁴ ADAPT Lab. (2022). The MODIFY Project. Available: <https://www.adaptlab.net/modify>.

⁵ Baker, S. et al. (2021). Barriers and facilitators to providing CBT for people living with dementia: Perceptions of psychological therapists. *Clinical Psychology and Psychotherapy*.