

Backbench Business Debate on inequalities in dementia services

Debbie Abrahams MP will lead a backbench business debate on **inequalities in dementia services** on Thursday 16th May at 1.30pm in Westminster Hall.

For more information on this briefing, please contact Lewis Scott - Lewis.Scott@alzheimers.org.uk

1. Background

- In October 2023, the All-Party Parliamentary Group on Dementia published its [latest report on regional variation in dementia diagnosis rates in England](#).
- The dementia diagnosis rate in England is currently 64.8% (March 2024) - meaning that of those who are currently living with dementia, **more than a third do not have a formal diagnosis**.
- Diagnosis rates vary wildly between local authorities in England from Stoke-on-Trent at 90.5% to Swindon at 51.3% - **a difference of 39.2%**.
- A diagnosis of dementia is essential in accessing post-diagnosis care and support, also helps to facilitate future care planning, and gives people valuable time to plan their affairs and spend time with loved ones at the earlier stages of the disease.
- Getting a diagnosis can be daunting, but the sooner people receive one the sooner they can plan for the future and gain access to treatment, care, and support. 91% of people Alzheimer's Society surveyed (in 2022) said they benefitted from getting a dementia diagnosis.
- Public Health Scotland estimated the dementia diagnosis rate in Scotland at 64% in 2021.
- There were 13,625 people on the dementia register in Northern Ireland in March 2023. Wittenberg et al. (2019) estimates prevalence at 22,700. The indicative dementia diagnosis rate in Northern Ireland is therefore 60.0%.
- The Dementia Action Plan for Wales gave the diagnosis rate in Wales as 53% in 2018.

2. The Scale of Dementia

- Dementia is the leading cause of death in the UK.
- An estimated 900,000 people are currently living with dementia in the UK, and this will rise to 1.4 million by 2040.
- Dementia costs the UK £42bn per year, but this will balloon to £90bn by 2040, with more than 60% of the cost borne by people with dementia and their families.
- 1 in 3 people born today in the UK will develop dementia in their lifetime.
- A total of 53% of the UK know someone who has been diagnosed with the condition, with 49% of UK adults reporting that dementia is the health condition they fear getting in the future most.
- However, awareness of dementia is not reflective of the scale of prevalence, with polling suggesting that only 60% of UK adults realise that dementia is a cause of death.
- In the absence of treatment, people with dementia rely upon social care. However, the costs of social care can be catastrophic – an individual with dementia spends an average of around £100,000 on care.

3. Key Report Findings and Recommendations

- **The APPG on Dementia concluded that variation in dementia diagnosis rates is unwarranted.** Although rurality and deprivation can affect dementia diagnosis rates, the vast majority of variation is not explained by either factor.
- **At the Integrated Care System (ICS) level, variation was inconsistent.** Each ICS has good and bad aspects of its diagnosis pathway, and the Group are keen to emphasise that every part of the country has something to be proud of.
- **The Group strongly believes that the ingredients to achieve quality dementia diagnosis are present in pockets around England, and recommends that ICSs make targeted local plans to scale up best practice and bring it closer to people who need to access diagnostic services.**

The report provides a total of 8 recommendations across the core themes of dementia diagnosis, data, public health messaging and workforce. Collectively, the recommendations outline how dementia pathways can be strengthened to enable access to quality diagnosis services across all settings, communities and regions in England. A summary of each recommendation is included below:

Enabling dementia diagnoses

- Each ICS must develop a comprehensive dementia strategy to enable and support the implementation of the Group's recommendations,** commissioning services based on local need and reaching underserved communities.
- All dementia diagnoses must include an accurate subtype.** People deserve to know what is wrong with them, and accurate subtyping will allow better tailoring of care and treatments.

Data

- NHS England must continue to develop its methods for calculating dementia prevalence and dementia diagnosis rate** to enhance accountability and improve the quality of care for patients.
- A national Dementia Observatory should be created** to collate and publish existing data collected across the diagnostic system (i.e. nationally, at ICS and sub-ICS level). This should include the development of additional indicators to improve quality of, and access to, a dementia diagnosis.

Public Health and messaging

- Ensure that data from the Office for Health Improvement and Disparities (OHID) regarding the scale and spread of associations between deprivation, rurality and estimated dementia diagnosis rates is translated into action.** Specifically, this should include targeted public health messaging in regions and localities most in need of improving dementia diagnosis rates.
- A broader range of regional and local channels for communication must be utilised to reach those who may be lost to the system.** Making dementia more of a strategic priority for national and local systems will help to raise awareness of dementia and tackle the stigma of a diagnosis as part of a system-wide approach to increasing national diagnosis rates.

Workforce

- vii. **Government should ensure the primary care workforce is adequately planned and resourced** to enable capacity, including to engage in continuing professional development on the assessment and benefits of dementia diagnosis.
- viii. **Post-diagnostic dementia support services must be available more equitably across England and supported by a named professional to coordinate each individual's dementia journey.** This requires a workforce plan from the Government which is inclusive of allied health professionals and a broader range of non-clinical roles such as social prescribers and dementia advisors.

4. Alzheimer's Society's 'Left to Cope Alone' Report

Guidance states that people living with dementia should be offered a review with a healthcare professional at least once a year. **Annual dementia reviews are contained in the Quality and Outcomes Framework (QOF)**, a pay-for-performance scheme which aims to improve the quality of care patients receive from GPs.

Alzheimer's Society's [report on post-diagnostic support for dementia, entitled 'Left to Cope Alone'](#), sought the views and experiences of over 2000 people affected by dementia. **Just 25% of them said that they or their loved-one had had an annual dementia review** within the last twelve months, and **only 16% said that they had received enough support from local services** in the last twelve months.

Alzheimer's Society made a central recommendation that **every person diagnosed with dementia should have access to a dementia support worker** or similar service, automatically referred by memory services. Other recommendations included:

- Local health systems should undertake a multidisciplinary team approach to annual reviews and **stagger reviews throughout the year to improve quality and increase primary care capacity.**
- Achieve the Memory Services National Accreditation Programme standard, which states **everyone diagnosed with dementia should be offered a post-diagnostic meeting.** This should be offered at an interval after diagnosis that suits the individual's needs.
- Provide post-diagnostic information and education support **in relevant community languages other than English**, as well as in non-written resources, to reduce health disparities.

5. The Role of Integrated Care Systems in improving dementia diagnosis

- The King's Fund recently released [a report](#) on the potentially transformative role that Integrated Care Systems could play in improving dementia diagnosis and services across the country.
- High-quality dementia diagnosis and care involves many different parts of the health and social care system working together effectively. Integrated care systems (ICSs) were created to achieve this kind of whole-system approach.

- Early and accurate diagnosis means people living with dementia can access support that can help to improve their quality of life, and potentially treatments that can help with managing symptoms. Diagnosis also enables people and their families to plan ahead.
- Improvements in dementia diagnosis in the three case study sites involved in our research are the result of several years' work and are not attributable to the introduction of statutory ICSs in 2022. However, their broad emphasis on working together as a system over the past decade has helped to create positive conditions for improvement.
- Key enablers of improvement in the sites we examined included efforts to strengthen relationships between primary care, memory clinics and other services; public awareness-raising activities; and the introduction of new extended roles for GPs (for example, to improve diagnosis in care homes).
- ICSs can contribute to improved dementia diagnosis by:
 - ensuring all partner organisations have shared priorities and an agreed plan for delivering improvement
 - providing visible cross-system leadership and effective governance arrangements for overseeing the delivery of the plan
 - connecting people working in different parts of the system, building mutual understanding and reinforcing a culture of collaboration
 - sharing learning and spreading good practice
 - supporting action at scale across larger geographies
 - addressing inequalities by ensuring sufficient attention is paid to improving diagnosis rates in underserved communities.
- In the longer term, ICSs need to build the capabilities and processes required to support testing new approaches, learning, and scaling and spreading successful innovations. This will need support from the government, NHS England and other national bodies.