

**Debate Pack**

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# Inequalities in dementia services

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# 1 Background

## 1.1 What is dementia?

Dementia is not a single disease; it is a general term used to describe the deterioration of cognitive functioning.<sup>1</sup> Symptoms differ depending on the type of dementia<sup>2</sup> and can also vary in severity, progressing through multiple stages. They include difficulties with thinking, problem-solving, remembering and making decisions, to the extent that daily activities can become challenging. Some people with dementia may also find it hard to control their emotions and aspects of their personality may change. It can be a life-limiting condition but how long someone with dementia will live for depends on many factors.<sup>3</sup>

Alzheimer's disease is the most common type of dementia, accounting for between 60% and 70% of all dementia cases.<sup>4</sup>

In England it is estimated that around 676,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated at 850,000.<sup>5</sup>

In England, around 540,000 people care for an individual with dementia. Around half of this number are employed and it's thought that some 66,000 people have cut their working hours to care for a family member, whilst around 50,000 people have left work altogether.<sup>6</sup>

NHS England note that the estimated economic cost associated with the disease is £23 billion a year, which is predicted to triple by 2040.<sup>7</sup>

There have been numerous Government strategies and NHS commitments to improve dementia diagnosis and services, as well as to increase support for research. The 2019 NHS Long Term Plan committed to offering better support for people with dementia through more support in the community and greater personalised care. Dementia is also expected to be one of the areas covered by the Government's forthcoming Major Conditions Strategy.

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<sup>1</sup> US NIH National Institute on Aging, [What is Dementia? Symptoms, Types, and Diagnosis](#), National Institute on Aging, December 2022

<sup>2</sup> For further information see Alzheimer's Research UK, [Types of dementia](#)

<sup>3</sup> Alzheimer's Society, [How to know when a person with dementia is nearing the end of their life](#)

<sup>4</sup> Alzheimer's Research UK, [Subtypes of dementia - Dementia Statistics Hub](#), accessed 20 December 2023

<sup>5</sup> [NHS England, Dementia](#)

<sup>6</sup> See above.

<sup>7</sup> See above.

The Alzheimer's Society's Dementia Action Week runs from 13 – 19 May 2024. This year it is focussing on dementia diagnosis and calling on the Government and the NHS to prioritise dementia in policy and decision making.<sup>8</sup>

## 1.2 Dementia policy

### Forthcoming Major Conditions Strategy

In January 2023, the Government announced it will publish a Major Conditions Strategy that will cover six conditions, including dementia.<sup>9</sup> The strategy will be published instead of a separate strategy for dementia, which had been expected in 2022.<sup>10</sup> The Government has said all previous research will be used to inform the plan and it remains committed to accelerating diagnosis and developing the latest treatments.<sup>11</sup>

In August 2023, the Department of Health and Social Care published the [Major conditions strategy: case for change and our strategic framework](#). The framework commits to recovering the 'national ambition' for dementia. The ambition, first announced in 2013, is for at least two-thirds (66.7%) of people with dementia to have a formal diagnosis.<sup>12</sup>

The framework says the national ambition was not achieved for the first time in four years in March 2020, and that this reflects the impact the pandemic had on memory assessment services and GP referrals into those services. The framework also says there is significant variation across England, in terms of access to accurate and timely diagnosis. The commitment to recovering the diagnosis rate is included in the [NHS England 2024/25 priorities and operational planning guidance](#). The NHS England planning guidance notes a target to increase the dementia diagnosis rate to 66.7% by March 2025.

The Major conditions strategy strategic framework also notes the Office for Health Improvement and Disparities (OHID) will support the investigation of the variation in rates across the country.<sup>13</sup>

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<sup>8</sup> The Alzheimer's Society, [Dementia Action Week](#)

<sup>9</sup> HCWS514 [on [Government Action on Major Conditions and Diseases](#)], 24 January 2023

<sup>10</sup> HCWS514 [on [Government Action on Major Conditions and Diseases](#)], 24 January 2023

<sup>11</sup> Department of Health and Social Care blog post, [Major Conditions Strategy: What you need to know](#), 17 May 2023

<sup>12</sup> Department of Health and Social Care press release, [Dementia diagnosis to be overhauled](#), 15 May 2013

<sup>13</sup> Department of Health and Social Care, [Major conditions strategy: case for change and our strategic framework](#), August 2023

## 1.3

## Data on dementia diagnosis rates in England

NHS England publishes monthly data on the [number of people diagnosed with dementia](#). This is available at GP practice level, and at local authority and Integrated Care Board (ICB) level.

In England, around 482,000 people of all ages had a recorded dementia diagnosis in March 2024. Most people with a diagnosis were aged 65 and over (97%).<sup>14</sup>

Nationally, it's estimated that the diagnosis rate was 64.8% in March 2024, which is below the Government's target of 66.7%.<sup>15</sup> The diagnosis rate represents the percentage of people aged 65 and over who are estimated to be living with dementia and who have received a diagnosis.

Diagnosis rates vary considerably across local authorities, from a high of 90.5% in Stoke-on-Trent to a low of 45.5% in the South Hams.<sup>16</sup>

In November 2023 NHS England stated that dementia diagnosis rates were at the highest they had been for three years. NHS chief executive Amanda Pritchard said she was "...determined that by next year, we will reach our ambition of diagnosing two thirds of people with dementia so that they don't have to go through it alone."<sup>17</sup>

On 31 January 2024, NHS England published a paper providing an overview of the national dementia programme and specifically updates on progress on work to improve rates of dementia diagnosis.<sup>18</sup>

## 1.4

## Understanding inequalities in dementia

Dementia charities and a number of other organisations have highlighted inequalities in dementia services, with key factors including local service provision, gender and ethnicity<sup>19</sup>, and variation in diagnosis rates. The [Care Quality Commission](#) has stressed the particular importance of appropriate adaptations to services where people living with dementia have a protected characteristic or have experienced deprivation.

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<sup>14</sup> NHS Digital, [Primary Care Dementia Data, March 2024](#), Summary datafile, Table 1

<sup>15</sup> See above.

<sup>16</sup> NHS Digital, [Primary Care Dementia Data, March 2024](#), Summary datafile, Table 4

<sup>17</sup> [NHS England, NHS dementia diagnosis rates at three-year high](#), 15 November 2023

<sup>18</sup> [NHS England, Dementia programme and preparation for new Alzheimer's disease modifying treatments](#), 31 January 2024

<sup>19</sup> [Inequalities in dementia - Dementia Statistics Hub](#)

Alzheimer's Research UK have highlighted some of the most significant inequalities in dementia risk, incidence, diagnosis and management, including:

- **Sex and Gender:** Women are more likely to develop dementia than men, and they are more likely to become a carer for someone with dementia.
- **Socioeconomic status:** People in lower socioeconomic groups in the UK are exposed to a higher risk of developing dementia, and may face additional barriers such as limited access to healthcare services.
- **Ethnicity:** People from Black, Asian and minority ethnic communities living in the UK may be at a higher risk of developing dementia due to increased exposure to dementia risk factors.
- **Down's Syndrome:** People with Down's Syndrome are at a higher risk of developing dementia.

The Alzheimer's Society has also highlighted research showing that [people from Black, Asian and minority ethnic communities often face delays in diagnosis and barriers](#) accessing services, and Alzheimer's Research UK have reported on the [impact of dementia on women](#).

The [All-Party Parliamentary Group on Dementia](#), co-chaired by Debbie Abrahams and Baroness Browning, has published a report showing significant regional variations in dementia diagnosis rates across England.

In April 2024, the King's Fund published a briefing on the role of ICSs in improving dementia diagnosis, highlighting how they can improve rates in "underserved communities". They also note that reducing health inequalities is one of the core purposes of ICSs, and they should support partner organisations to identify communities (defined by geography or other characteristics) where the dementia diagnosis rate is lower than expected and to improve the accessibility of services to these groups. The King's Fund also note this engagement work is often best led at borough rather than ICS level, but ICS support can help local work have greater impact.<sup>20</sup>

NHS England's January 2024 update on the national dementia programme referred to the known inequalities within dementia diagnosis and set out steps it was taking to address these. In particular, NHS England has commissioned the Office for Health Improvement and Disparities (OHID) to develop a resource to support investigation of the underlying variation in dementia diagnosis rates, including the assessment of underlying population characteristics such as rurality, ethnicity, and age. The aim of this work is to

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<sup>20</sup> The King's Fund, [The Role Of Integrated Care Systems In Improving Dementia Diagnosis | The King's Fund \(18 April 2024\)](#)

provide context for variation and enable targeted investigation and provision of support at a local level to enhance diagnosis rates.<sup>21</sup>

The update also said NHS England had released a number of resources during Dementia Action Week 2023, “to help narrow the health inequalities gap for people living with dementia from an ethnic minority background.”<sup>22</sup>

## CQC literature review (December 2023)

In March 2023 the Care Quality Commission (CQC) asked RSM UK Consulting LLP (RSM), with Queen Mary University and the University of Birmingham Library Services, to look at information about inequalities in dementia care. In December 2023 the CQC published the resulting review of research, looking at this issue in care homes with people in different equality groups (as defined under the Equality Act 2010) or living in poorer areas.<sup>23</sup>

Conclusions from the literature were that, where people living with dementia had a protected characteristic or experienced deprivation, nursing and residential services need to be aware of a number of intersecting considerations.

Previous negative experiences of stereotyping or discrimination from health and care services may be re-lived, particularly as a person’s dementia progresses, which can result in anxiety, mistrust and poor engagement. Beyond interactions with health and care services, seldom heard populations are more likely to have faced trauma in their life which can also be retriggered by day-to-day activities when living with dementia. As a person’s dementia progresses, they may experience a loss of cognitive function. For individuals with equality considerations, this may bring up additional challenges such as confusion about their gender identity, fear of hiding their sexual orientation, losing English language skills (where it may not be their first language) or using non-verbal behaviour that is specific to their culture, community or previously learned coping strategies. Understanding the specific nuances of an individual’s behaviour and what non-verbal expressions means to that person can help staff and providers to support people’s needs.<sup>24</sup>

An overarching finding from this CQC commissioned research was that good quality care should be individualised. It noted that providing a person-centred care approach required health and care staff “to have early and regular conversations with the people who access the service as well as their family and those closest to them.” The CQC review also noted a scarcity in published literature that investigates what good dementia care looks like in residential and nursing settings for those with protected characteristics or living in deprived areas.<sup>25</sup>

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<sup>21</sup> [NHS England, Dementia programme and preparation for new Alzheimer’s disease modifying treatments](#), 31 January 2024

<sup>22</sup> See above.

<sup>23</sup> CQC, [Rapid literature review: Inequalities in dementia \(December 2023\)](#)

<sup>24</sup> See above.

<sup>25</sup> See above.

The Alzheimer's Society and the Dementia APPG have also called for further research exploring the experiences of different communities in diagnosis, access to dementia care and treatments.<sup>26</sup>

## **Dementia APPG report, Raising the Barriers (October 2023)**

In October 2023 the All-Party Parliamentary Group (APPG) on Dementia published [Raising the Barriers: An action plan to tackle regional variations in dementia diagnosis in England](#) (PDF). The report found that there is significant variation in how quickly and accurately people are being diagnosed with dementia based on where they live in the country. The APPG highlighted there is a difference of over twenty percentage points in the dementia diagnosis rates between the highest and lowest performing ICSs in England as at September 2023 (73.5% in South Yorkshire ICS, and 53.4% in Herefordshire and Worcestershire ICS).<sup>27</sup>

The APPG found that although associations between demographics and estimated dementia diagnosis rates are reasonably strong, although data indicates that only around 20% to 27% of the variation in rates can be explained by the level of deprivation or rurality.<sup>28</sup>

The APPG reported a number of factors that might explain variations in the ability of patients to obtain a diagnosis, including variations in access to GP appointments and memory assessments, the availability of scanners and difficulties travelling to appointments.<sup>29</sup>

The APPG report called on the Government to “significantly increase” scanning capacity and workforce and for ICBs to introduce strategic local plans to increase access to diagnostic services.<sup>30</sup>

The APPG on Dementia recommended:

1. Each ICS must develop a comprehensive dementia strategy
2. All dementia diagnoses must include an accurate subtype
3. NHS England must continue to review and develop its methods for calculating dementia prevalence and diagnosis rates
4. A national Dementia Observatory should be created to collate and publish existing data collected across system levels

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<sup>26</sup> See for example, APPG on Dementia, [Raising the Barriers: An action plan to tackle regional variations in dementia diagnosis in England](#) (PDF), October 2023

<sup>27</sup> See above.

<sup>28</sup> See above.

<sup>29</sup> See above.

<sup>30</sup> See above.

5. Government intelligence about variation in dementia diagnosis rates must be translated into action
6. A broader range of regional and local communication channels must be used to reach those who may be lost to the system
7. Government should ensure the primary care workforce is adequately planned and resourced to enable dementia diagnosis
8. High-quality post-diagnostic support services for dementia must be available more equitably across England<sup>31</sup>

## 1.5

### Alzheimer's Research UK report, Towards Brain Health Equity (October 2023)

In October 2023 Alzheimer's Research UK published a report, [Towards Brain Health Equity: how can governments tackle inequalities in dementia risk?](#), highlighting research showing vulnerable groups face increased dementia risk. It referred to research in England and Wales that shows socioeconomic deprivation is linked to increased dementia mortality, younger age at death from dementia, and poorer access to specialist diagnostics. It also noted that Black and South Asian people living in the UK are more likely to be diagnosed at a younger age and die earlier from dementia, and dementia rates are over 20% higher among Black adults compared to the UK average.<sup>32</sup>

To prevent ill health, tackle health inequalities, and improve brain health, the report calls for a cross-government strategy, and sets out specific actions that should be taken to:

1. Reduce air pollution
2. Lower smoking rates
3. Promote healthy eating
4. Tackle high blood pressure
5. Identify and treat hearing loss<sup>33</sup>

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<sup>31</sup> APPG on Dementia, [Raising the Barriers: An action plan to tackle regional variations in dementia diagnosis in England](#) (PDF), October 2023

<sup>32</sup> Alzheimer's Research UK, [Brain Health Equity: how can governments tackle inequalities in dementia risk?](#), October 2023

<sup>33</sup> See above.



## 2

# Parliamentary material

## 2.1

# Parliamentary questions

### **Dementia: Diagnosis**

**9 May 2024 | UIN 24065**

**Asked by: Justin Madders**

To ask the Secretary of State for Health and Social Care, what steps her Department is taking to help increase the rate of diagnosis for people who develop symptoms of dementia before the age of 65.

**Answering member: Helen Whately | Department: Department of Health and Social Care**

As part of the spending review settlement in 2021/22, £17 million was allocated to the National Health Service to address dementia waiting lists, and to increase the number of diagnoses, which had been adversely impacted by the pandemic. NHS England will share learning on the impact of this funding and examples of good practice with dementia clinical networks, by the end of Summer 2024.

However, the dementia diagnosis rate is not calculated for patients aged under 65 years old. This is because the numbers of patients known to have dementia in the sample population age groups comprising the zero to 64 years old age range, is not large enough for reliable estimates to be made.

The Primary Care Dementia Data publication does include a monthly count of the number of patients aged 65 years old and under who do have a dementia diagnosis on their patient record, which is expressed as a raw count, and as a percentage of registered patients aged zero to 64 years old.

### **Dementia: Health Services**

**8 May 2024 | UIN 24067**

**Asked by: Justin Madders**

To ask the Secretary of State for Health and Social Care, if she will make an assessment of the adequacy of levels of age-appropriate support offered by Integrated Care Boards for people with young onset dementia.

**Answering member: Helen Whately | Department: Department of Health and Social Care**

NHS England is committed to delivering high quality care and support for every person with dementia at every age, and central to this is the provision of personalised care.

The Dementia Well Pathway includes diagnosing well, living well, supporting well, and dying well, and highlights that services need to be integrated, commissioned, monitored, and aligned with the National Institute for Health and Care Excellence's standards for each component of the pathway. It makes it clear that the needs, wishes, and preferences of each individual, including those with young onset dementia, should be taken into account when planning and providing their care.

**Dementia and Parkinson's Disease: Health Services and Social Services**  
**23 April 2024 | UIN 20658**

**Asked by: Peter Dowd**

To ask the Secretary of State for Health and Social Care, what steps she is taking to ensure that health and social care professionals are trained in Parkinson's-related dementia care.

**Answering member: Helen Whately | Department: Department of Health and Social Care**

The standard of training for health care professionals is the responsibility of the health care independent statutory regulatory bodies. They set the outcome standards expected at undergraduate level and approve courses and Higher Education Institutions to write and teach the curricula content that enables their students to meet the regulators outcome standards.

Whilst not all curricula may necessarily highlight a specific condition, they all nevertheless emphasize the skills and approaches a health care practitioner must develop in order to ensure accurate and timely diagnoses and treatment plans for their patients, including for dementia.

Individual employers across health and social care are responsible for ensuring their staff are trained and competent to carry out their role, and for investing in the future of their staff by providing continuing professional development (CPD) funding. The required training needs are set out in the Dementia Training Standards Framework, which is available at the following link:

<https://www.skillsforhealth.org.uk/info-hub/dementia-2015-updated-2018/>

The framework was commissioned and funded by the Department, and developed in collaboration with the sector. It sets out the essential knowledge, skills, and expected learning outcomes applicable across the health and care spectrum.

It is applicable to health and social care staff who work with people living with dementia, staff providing direct care and support, and those who provide leadership in transforming care, including social care managers and leaders.

To supplement local National Health Service employer investment for CPD, the NHS Long Term Workforce Plan, published on 30 June 2023, sets out NHS

England's commitment to continue national CPD funding for nurses, midwives, and allied health professionals. There are a variety of resources available on the NHS England e-learning for health platform, designed to enhance the training and education of the health and social care workforce. This includes a programme on dementia care, and modules in Parkinson's disease in geriatric medicine.

**[NHS: Dementia Commission Report](#)**

**22 February 2024 | 836 cc703-6**

**Asked by: Baroness Wheeler**

To ask His Majesty's Government what actions they are taking in response to the NHS Innovation and Life Sciences Commission's Dementia Commission: 2023 Report.

**Answered by: Lord Markham**

We welcome the Dementia Commission: 2023 Report and are taking steps to address each of the recommendations. The Government remain committed to improving dementia diagnosis rates and providing high-quality care and support following a diagnosis. The Government have committed to double funding for dementia research to £160 million per year by the end of 2024-25. We welcome all research that will help us to improve how we diagnose and care for people with living with dementia.

**[Dementia: Screening](#)**

**22 January 2024 | UIN 9518**

**Asked by: Debbie Abrahams**

To ask the Secretary of State for Health and Social Care, how many and what proportion of patients waited more than 15 weeks for an initial dementia assessment in 2023; what is the average waiting time for an initial dementia assessment; and what steps she is taking to improve those waiting times.

**Answering member: Helen Whately | Department: Department of Health and Social Care**

The information requested is not held centrally. To improve waiting times, we have set an expectation that everyone who needs an appointment at a general practice should get one within two weeks, with the most urgent patients being seen on the same day.

The Dementia Care Pathway: Full implementation guidance, commissioned by NHS England, outlines the dementia care pathway and associated benchmarks to support improvements in the delivery and quality of care and support, for people living with dementia and their families and carers. The guide showcases good-practice examples of services that have successfully reduced their waiting times. More information is available at the following link:

<https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf>

## 2.2

## Debates

### Dementia Care in Hospital

6 March 2024 | House of Commons | 746 cc993-942

### New Dementia Treatments

11 January 2024 | Westminster Hall | 743 cc183-198WH

### Dementia

18 January 2024 | House of Lords | 835 cc98-112GC

To ask His Majesty's Government how they plan to create a parity of esteem between health and social care to address dementia.

## 3

# Press material and journal articles

The following is a selection of news and media articles relevant to this debate.

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[Lower socioeconomic status 'triples risk of early-onset dementia'](#)

The Guardian

29 November 2023

[Inequality leaving 115,000 dementia cases 'undiagnosed' in England](#)

The Guardian

23 October 2023

[Dementia risk factors pose more danger for ethnic minorities, finds study](#)

The Guardian

11 October 2023

[Uneven playing field: new board game highlights inequalities in dementia care](#)

University of Liverpool

29 September 2023

[New NHS training launched as dementia rates increase among Asian and Black people](#)

The Independent

21 May 2023

[A 3-UK-nation survey on dementia and the cost of living crisis: contributions of gender and ethnicity on struggling to pay for social care](#)

Aging & Mental Health

7 April 2023

[Dementia care advice for transgender patients drawn up](#)

BBC News

12 March 2018

## 4

## Further reading

[Dementia Commission: 2023 Report](#) (PDF)

NHS Innovation and Life Sciences Commission

November 2023

[Raising the Barriers: An action plan to tackle regional variations in dementia diagnosis in England](#) (PDF)

APPG on Dementia

October 2023

[Brain Health Equity: how can governments tackle Inequalities in dementia risk?](#)

Alzheimer's Research UK

October 2023

[South Asian communities affected by dementia deserve better support](#)

Alzheimer's Society

14 July 2023

[People living with dementia face a critical situation as cost-of-living crisis intensifies](#)

London School of Economics

3 May 2023

[Inequalities in dementia](#)

Alzheimer's Research UK

28 April 2023

[The Impact of Dementia on Women](#)

Alzheimer's Research UK

May 2022

[Improving dementia and Alzheimer's support in Black communities](#)

Alzheimer's Society

30 September 2020

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