



City of Westminster

# Family & People Services Policy and Scrutiny Committee

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<b>Title:</b>	Dementia Overview
<b>Report of:</b>	Bernie Flaherty, Bi-Borough Exec. Dir. ASC & Public Health
<b>Cabinet Member Portfolio</b>	Family Services and Public Health
<b>Wards Involved:</b>	All
<b>Policy Context:</b>	City for All – Caring and Fairer City
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## 1. Executive Summary

- 1.1. This paper provides an overview of the issue of dementia in Westminster and the progress of the developing strategy to date. The Committee is invited to discuss this and make any further suggestions as to how the strategy can help prevent this disease and support those with dementia and their carers, friends and families to secure a timely diagnosis, to live well and to die well.
- 1.2. Feedback from the discussions will be used to inform the developing dementia strategy for the Royal Borough of Kensington & Chelsea (RBKC) and the City of Westminster. The Strategy will be developed in partnership with Central and West London CCGs.

## **2. Key Matters for the Committee's Consideration**

2.1. The committee is asked to consider and give feedback on

- Dementia health and care support, as well as the strategy's progress to date, in RBKC and Westminster, as set out in this paper
- How the strategy can prevent and support people living with dementia and their carers, families and friends with reference to the following questions:
  - What works well to prevent dementia and support people with dementia, their carers, friends and families in Westminster?
  - What are the challenges to preventing dementia, providing great services and to living well with dementia?
  - What local/national/international best practice in whole-systems dementia care and support are you aware of?
  - Are there any gaps in services that we should be aware of?

## **3. Background Information about Dementia**

3.1. 'Dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. A person with dementia may also experience changes in their mood or behaviour.

3.2. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia. Other common types of dementia are vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia.

3.3. Dementia is a progressive condition. As such, these changes are often small to start with, but they can become severe enough to affect daily life for someone with dementia. This progression will vary from person to person, and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary.

3.4. The specific [symptoms](#) that someone with dementia experiences will depend on the parts of the brain that are damaged, the disease that is causing the dementia and how far the disease has progressed. However, common symptoms can include

- day-to-day memory – e.g. difficulty recalling events that happened recently,
- concentrating, planning or organising – e.g. difficulties making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal),
- language – e.g. difficulties following a conversation or finding the right word
- Perception/visuospatial skills – e.g. problems judging distances and seeing objects in 3D
- orientation – e.g. losing track of the day or date or becoming confused about where they are.
- changes in mood – e.g. becoming frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad.

With some types of dementia, the person may hallucinate or strongly believe things that are not true (delusions).

- 3.5. The Alzheimer's Society report found that in 2013 the total cost of dementia in the UK was estimated to be £26.3 billion. Of this, approximately £4.3 billion consists of health care, and approximately £10.3 billion consists of social care. The remaining £11.6 billion accounts for estimated unpaid care contributions.
- 3.6. Dementia mainly affects people over the age of 65. The likelihood of developing dementia increases significantly with age. Dementia can affect younger people too; more than 42,000 people in the UK under 65 have dementia.
- 3.7. Risk factors for dementia include
- Ageing
  - Gender (higher prevalence amongst women)
  - Genetics
  - Cardiovascular factors (Type 2 Diabetes, high blood pressure/cholesterol levels and obesity)
  - Other medical conditions e.g. Parkinson's, MS, HIV
  - People with Down's syndrome and learning disabilities

In addition, the latest research suggests that other factors are also important. These include:

- hearing loss
  - untreated depression
  - loneliness or social isolation
  - a sedentary lifestyle
- 3.8. Although there is no certain way to prevent all types of dementia, there is good evidence that a healthy lifestyle can help reduce an individual's risk of developing dementia. It can also help prevent cardiovascular diseases, such as stroke and heart attacks, which are themselves risk factors for Alzheimer's disease and vascular dementia. Research indicates that by modifying the risk factors people are able control, our risk of dementia could be reduced by up to 30%.
- 3.9. In addition, emerging research that suggests cultural and arts-based activities can reduce the risk of dementia and/or slow down its decline.

#### **4. Strategic context**

##### National

- 4.1. In March 2012, the government launched a national challenge to fight dementia. This programme of action was set up to deliver sustained improvements in health and care, create dementia friendly communities, and boost dementia research.

- 4.2. The Prime Ministers' Challenge on Dementia 2020 (launched February 2015) sets out the UK Government's strategy for transforming dementia care within the UK. The Challenge aims to build on the previous programme of action, and, by 2020, see England become
- the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
  - the best place in the world to undertake research into dementia and other neurodegenerative diseases.
- 4.3. This will be achieved by
- Improving diagnosis, assessment and care for people living with dementia
  - Ensuring that all people living with dementia have equal access to diagnosis
  - Providing all NHS staff with training on dementia appropriate to their role
  - Ensuring that every person diagnosed with dementia receives meaningful care
- 4.4. The government acknowledged that this cannot be achieved alone and the vision is also a call to action for all to show understanding and compassion to those with the disease to transform dementia care, support and research.

### Regional

- 4.5. The Dementia Friendly London ambition sees Alzheimer's Society, the GLA, London Health Board and other partners working together to achieve the following by 2022:
- 2,000 dementia friendly organisations
  - 500,000 Dementia Friends
  - Every London borough working to becoming a dementia friendly community
  - Meaningful involvement of people affected by dementia

### Local

- 4.6. The 2020 Dementia Challenge is in line with the findings of the North West London Collaboration of CCGs' report *NWL Strategic Review of Dementia 2015*. Details of the report's findings are included later in this report.
- 4.7. The Westminster Joint Health and Wellbeing Strategy priorities include "reducing the risk factors for, and improving the management of, long-term conditions, such as dementia". Commitments include "[creating] the conditions for dementia friendly communities, where an understanding of dementia supports communities to value the contributions of people experiencing the condition and their carers.
- 4.8. Westminster's City for All vision outlines the Council's commitment to

- A Caring and Fairer City – where caring and supporting the most vulnerable within the community is, and will always remain, the Council’s most important priority.
- A Healthier and Greener City – the Council will work closely with partners including the NHS to encourage individuals and families to enjoy active and healthy lives, while we focus our resources on the support needed for the most vulnerable in our city.

The City for All vision also outlines plans to open a new 84-bed home to provide specialist care for people living with dementia as part of a wider dementia strategy to support those and their families living with this difficult illness.

4.9. The Bi-Borough ASC and Public Health six priorities are

- Personalisation
- Market shaping & development
- Quality Assurance
- Safeguarding
- Prevention
- Integration

## 5. Dementia in Westminster

5.1. According to GP data, 1,275 people in Westminster have a dementia diagnosis. As 48,798 people in London have a dementia diagnosis. As such, Westminster is home to 2.6% of the diagnosed population of London.

5.2. However, as not all cases of dementia are diagnosed, it is estimated that ca. 1,630<sup>1</sup> people in Westminster are living with dementia. Approximately 50% of the population with dementia are aged 85+.

5.3. In June 2019, Westminster’s dementia diagnosis rate is above the London average (Westminster: 78.2% vs the London average of 70.5%). The table below provides an overview of the number of current and estimated future people living with dementia in Westminster, broken down by those with and without a diagnosis.

	2017/18	2026	2051
Dementia 65+ potential	1,630	1,956	2,445
Dementia diagnosis	1275	1530	1912

<sup>1</sup> According to GP records on PHE Fingertips, the number of over 65 residents diagnosed with dementia is **1,275**. Further data from the same PHE Fingertips profile suggests that, compared to expected numbers of over 65’s with Dementia, numbers diagnosed represent 78.2% of the potential **1,630** residents aged over 65 years have dementia.

5.4. The table below provides an estimate of current and future numbers of Westminster residents with dementia, broken down by ethnicity. These estimates assume the national projected increase in BAME 65+ population is reflected in the Westminster population.

	<b>2017/18</b>	<b>2026</b>	<b>2051</b>
Number of cases BAME	83	158	499
Number of cases non-BAME	1,547	1,798	1,946
Dementia 65+ potential	<b>1,630</b>	<b>1,956</b>	<b>2,445</b>

5.3. Diagnostic, treatment and care service provision may need to expand proportionately to meet this increasing need, including the specific needs of the expanding BAME population. For example, dementia presentation/help seeking is later in certain BAME groups.

5.4. Based on Alzheimer's Society's severity estimates from [Dementia in the UK \(2014\)](#), the tables below outline the estimated severity of dementia of the confirmed 1,275 residents with a dementia diagnosis and the potential total 1,630 residents aged 65 years and over living with Dementia in Westminster:

<b>Severity of dementia</b>	<b>%</b>	<b>No. living with specified severity in Westminster</b>	<b>Severity of dementia</b>	<b>%</b>	<b>No. living with specified severity in Westminster</b>
Mild	55.40%	706	Mild	55.40%	903
Moderate	32.10%	409	Moderate	32.10%	523
Severe	12.50%	159	Severe	12.50%	204
TOTAL +65 with a dementia diagnosis	100%	1,275	TOTAL +65 living with dementia	100%	1,630

5.5. According to [Alzheimer's research \(2014\)](#), it is estimated that the typical cost (based on 2012/13 costings) of dementia care for one person with a dementia diagnosis is £32,242 per year. This figure includes health & social care, unpaid care and other costs for people with mild, moderate and severe dementia.

5.6. Based on this figure, the table below outlines the estimated current and future costs of caring for people with a dementia diagnosis in Westminster. According to these estimates, the cost of dementia could increase by £8,219,518 between 2017/18 and 2026 and £20,548,794 between 2017/18 and 2051.

<b>Year</b>	<b>2017/18</b>	<b>2026</b>	<b>2051</b>
Number of people with a dementia diagnosis in Westminster	1275	1530	1912

Cost of care per person, per annum	£41,097,588	£49,317,105	£61,646,382
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## 6. Initiatives to prevent the onset of dementia, support people with dementia and their carers, friends and families in Westminster

- As highlighted above, keeping physically and mentally active can help prevent dementia. Initiatives to encourage an activity and mental stimulation for older people includes a range of community provision. This is in addition to Older People's Day Services, and other offers. For example, if you're over 60, you may be entitled to free swimming and other discounts with the Active Westminster Card.

### 6.1 Westminster ASC commissions the following specialist dementia services:

- Westbourne Dementia Day Centre – London Care
- Pullen Day Centre – Thursday's Dementia Day – London Care
- Dementia Extra Care Housing Units @ Leonora - Octavia Housing
- Dementia Extra Care Housing Units @ Penfold - Notting Hill Genesis
- Carers Dementia Group – Carers Network

### 6.2 The quality of residential and nursing homes for those living with dementia is above average, with 75% receiving a good or outstanding rating from CQC, compared to 69% nationally and is similar to London rate of 71%.

### 6.3 A significant number of people with a dementia diagnosis have co-morbidities. Residents also want to be treated holistically. As such, a balance of universal services is needed to support a wide range of needs with staff that have the skills to support residents with a dementia diagnosis and their families. This is in addition to having specialist services in place where needed.

### 6.4 As such, these services are in addition to:

- Universal services that support people with dementia/cognitive impairments & physical impairments across the Bi-borough, includes befriending, 121 support, day centres, homecare, community equipment, general Extra Care Housing, residential and nursing homes.
- The input of the Council's social work teams and information and advice team
- The option of direct payments, when relevant and desired

### 6.5 The Voluntary and Community Sector also offers a number of activities for people living with dementia. This includes choirs, concerts, sporting reminiscence at Lord's Cricket Ground and InMind at the Royal Academy of arts.

## 7. Key Achievements and Upcoming Milestones

### Regional

- 7.1 RBKC and Westminster Officers are working with partners to meet the Mayor's Dementia-Friendly London challenge.
- 7.2 The Bi-Borough Exec. Dir. of Adult Social Care & Public Health is the London ADASS Dementia Lead and has been working on improving dementia care and support across the capital. Key elements of London ADASS's work programme include:
- Increasing the number of dementia friends across London
  - Enhancing the personalisation of care of those with dementia
- 7.3 The Mayor has committed the GLA and TfL to work towards becoming dementia friendly organisations and committed to partnership working with the Alzheimer's Society. A Pan-London working group has been set up to discuss Dementia Friendly London.
- 7.4 The London ADASS Dementia Lead and the Alzheimer's Society are working together to make London dementia-friendly and creating dementia-friendly communities. Highlights include:
- Recruiting people with dementia to sit on the Mayoral People's Panel
  - A Dementia Champion for the GLA has been appointed
  - TfL launched a new e-learning Dementia Friends package in December 2018
  - London ADASS's programme to improve dementia awareness and call to action for all Health and Wellbeing Boards and the Dementia Commissioners Network to become dementia friends
  - London ADASS is working with a specialist IT company to develop a video profiling the virtual characters with dementia, "Martha" and "Arthur". The animations aim to show how a personalised approach can empower and enable people with dementia to live as independently as possible. The characters were launched at the ADASS Dementia Summit in May 2019.

### Local

- 7.5 In partnership with NHS colleagues, officers are currently developing a holistic dementia strategy that aims to make RBKC and Westminster global leads for Dementia-Friendly Communities.
- 7.6 Since January, activities for developing the strategy have included:
- 1 large resident workshop in RBKC and many 1-2-1 or small group interviews with care home residents.
  - 60 residents consulted, of which 56 have dementia (30 in group settings and 26 individual interviews) and 4 carers



- 45 meetings with stakeholders, including Health & Social Care partners, and representatives from diverse disciplines, including public sector, arts and culture, and the VCS
  - 12 Resident Service visits e.g. Dementia Café, Care Home & Dementia Action Alliance visits
  - One Dementia Expert Panel with over 70 attendees and one Roundtable with Frontline Health and Social Care professionals
- 7.7 So that the strategy is truly co-developed by residents living with dementia, their carers, families and friends, additional workshops are taking place in June and July to inform and shape the strategy.
- 7.8 Officers will draft the strategy over the summer, before it is presented to the Health and Wellbeing Board for approval. Subject to the Health and Wellbeing Board's approval, the strategy will be launched in the autumn.
- 7.9 To support the strategy's aims, a programme of work is on-going across Westminster to ensure the Council is dementia friendly. These include all staff attending Dementia Friends sessions, a programme of activities during Dementia Action Week and exploring making Council-owned properties dementia-friendly.
- 7.10 The Health and Wellbeing Board and staff from a number of departments have already attended the Dementia Friends sessions (including all ASC staff). The sessions continue to be rolled out and Dementia Champion "train the trainer" sessions are being arranged to ensure that the programme is sustainable and can be carried out in-house.
- 7.11 During Dementia Action Week (20-24 May) a programme of activities took place to raise awareness of dementia and encourage action. This included scarves knitted by people living with dementia being placed on statues, as well as a series of comms activities promoting dementia awareness. Events aimed at residents living with dementia took place across the borough (many of which were free), including a trip to Kew Gardens, an exercise class and Dining4Dementia at Comptoir Libanais.
- 7.12 In terms of Council-owned buildings, officers are working with the City Hall Inclusivity programme to ensure dementia needs are considered. Significant work has also taken place to ensure Westminster's Housing stock is dementia-friendly; the repairs & maintenance and major works contracts include dementia-friendly specifications. Since April 2018, ca. 400 void properties have been refurbished to this standard.
- 7.13 Examples of best practice in other boroughs include Greenwich's development of a red and yellow dementia-friendly business sticker and an online dementia hub for residents. In addition, Havering has co-developed with service users a Multi-Agency Approach to Deliver Better Quality Services to People with Dementia

**If you have any queries about this Report or wish to inspect any of the Background Papers, please contact: Anne Pollock, Principal Policy Officer ([apollock@westminster.gov.uk](mailto:apollock@westminster.gov.uk); 020 7641 2757)**