

## Westminster Health & Wellbeing Board

## RBKC Health & Wellbeing Board

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<b>Title:</b>	<b>Dementia Overview</b>
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### 1. Executive Summary

- 1.1 This paper aims to provide an overview of the issue of dementia in the two Boroughs, and to encourage a discussion on what actions the Health and Wellbeing Boards, and their constituent organisations, can take to collectively prevent this disease, as well as supporting 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.

### 2. Key Matters for the Board

- 2.1 The RBKC and Westminster Health and Wellbeing Boards are asked to
  - Consider dementia health and care support in RBKC and Westminster, as set out in this paper
  - Discuss and share feedback using the following guiding questions:
    - What is your experience of supporting people with dementia and their carers, friends and families in your organisations or service areas?
    - Do you know of any local success stories for supporting dementia?

- What global/national/international best practice in whole-systems dementia care and support are you aware of? Can any of these initiatives be implemented in RBKC and Westminster?
- Have you any particular areas or groups of concerns about dementia locally?
- Share an organisational commitment that will support a whole-systems approach to dementia. Examples of commitments could include
  - Rolling out dementia friends training to staff in your organisation
  - Committing to providing a dementia-friendly environment e.g. through clear signposting in buildings.
  - Introducing dementia-related requirements in contract specifications

### 3. Background Information about Dementia

- 3.1 The word '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 for something,
  - visuospatial skills – e.g. problems judging distances and seeing objects in three dimensions,
  - 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 (one in 14 people in the UK in this age group have dementia), and the likelihood of developing dementia increases significantly with age. Dementia can also affect younger people too. There are more than 42,000 people in the UK under 65 with dementia.

3.7. Risk factors for dementia include

- Ageing
- Gender (higher prevalence amongst women)
- Ethnicity (BAME people are more likely than white Europeans to develop dementia)
- Genetics
- Cardiovascular factors (Type 2 Diabetes, high blood pressure/cholesterol levels and obesity)
- Other medical conditions e.g. Parkinson's, Multiple sclerosis, 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. Currently there is no certain way to prevent all types of dementia as researchers are still investigating how the disease develops. However, 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%.

## 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.

4.5 The Care Act 2014 created a new legislative framework for adult social care, and also gives carers a legal right to assessment and support. NICE has produced guidance, quality standards and advice for the health and social care system to drive improvements in quality.

### Regional

4.6 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

4.7 As part of this London dementia challenge, Alzheimer's Society held its first annual Dementia Friendly London Summit at the GLA in May 2018, as part of Dementia Action Week. Over one hundred delegates from across industries gathered at City Hall to share their plans to bring the Mayor of London's vision of a dementia-friendly capital to life. Key speakers included representatives from ADASS, the NHS, the Met Police, TfL, and London & Thames Valley CBI.

### Local

4.8 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.

4.9 The RBKC Joint Health and Wellbeing Strategy priorities include “Good mental health for all”, with a specific commitment to “[encouraging] awareness and [improving] the quality of local services and support for people living with dementia and their carers.

4.10 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.

4.11 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.

4.12 The Bi-Borough ASC and Public Health six priorities are

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

## **5. Dementia in RBKC and Westminster**

5.1 Current estimates of the number of people living with dementia in the local population are ca. 1,500 in RBKC and 1,800 in Westminster. Approximately 50% of the population with dementia are aged 85+. (JSNA)

5.2 Through population projections, the number of people living with dementia is estimated to rise by 70% for Kensington & Chelsea; and by 45% for Westminster by 2030. Although the rates are not increasing as much predicted in the 2015 JSNA, they are still rising. Diagnostic, treatment and care service provision may need to expand proportionately to meet this increasing need.

5.3 In March 2015 WL CCG had a diagnosis rate compared with expected prevalence of 73%, and CL CCG 72%. This compared with 66% in London and 65% nationally.

## **6. Initiatives to support people with dementia and their carers, friends and families in RBKC and Westminster**

6.1 Appendix A provides an overview of some of the current commissioned services available for those at risk of developing dementia, those living with dementia and those who care for them. Please note that not all are dementia-targeted services and some are general services that support people with dementia and their carers, friends and families.

6.2 These services are in addition to:

- The input of the Council's social work teams and information and advice team;
- The option of direct payments, when relevant and desired

## **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 Bernie Flaherty, Bi-Borough Director of Adult Social Care and Public Health, is the London ADASS Dementia Lead and has been working on improving dementia care and support across the capital. Key elements of the London ADASS 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. The group's successes will be presented at the Dementia Summit in May 2019, following on from the May 2018 Dementia Summit.

7.4 On 18 December 2018, the London Health Board received a progress update from the Alzheimer's Society and the ADASS dementia lead on making London dementia-friendly and creating dementia-friendly communities. Highlights include:

- Recruitment of people with dementia to sit on the Mayoral People's Panel is on-going
- The Mayor has appointed a Dementia Champion for the GLA
- TfL launched a new e-learning Dementia Friends package in December 2018, fronted by CEO Mike Brown
- 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

7.5 London ADASS also presented the London Health Board with an update on their work to enable championing a personalised approach. This includes

- Working with a specialist IT company to develop a video profiling the virtual character, "Martha's", dementia case. Martha is an animation of a 64-year old woman in the early stages of dementia. The animation aims to show how a personalised approach can empower and enable Martha to live as independently as possible.

- Exploring developing a second virtual male character – Arthur; and
- Launching both Martha and Arthur at GLA’s digital event on the 13 February 2019 and presenting them at the ADASS Dementia Summit in May 2019.

## Local

7.6 The table on at Appendix B outlines some recent achievements in progressing dementia care in RBKC and Westminster, as well as upcoming milestones for the New Year.

**If you have any queries about this Report or wish to inspect any of the Background Papers please contact:**

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## **APPENDICES:**

Appendix A – Overview of Some Current Dementia Care Services in RBKC and Westminster

Appendix B – Overview of Some Recent Achievements and Upcoming Milestones in Dementia Services in RBKC and Westminster

**Appendix A – Overview of Some Current Dementia Care Services in RBKC and Westminster commissioned by the local authorities\***

Preventing Well	Availability
<p><b>Raising public awareness and understanding of dementia in the wider community.</b></p>	<p><u>RBKC and WCC</u></p> <ul style="list-style-type: none"> <li>Community Champions (All Community Champions projects work with older people to support physical activity, healthy eating, wellbeing etc. Although not a targeted dementia service, some projects have Dementia Friends-trained Champions)</li> <li>Communications Channels (e.g. information shared via People First, Westminster Plus etc.)</li> <li>Dementia Friends Staff training in RBKC and Westminster</li> </ul>
<p><b>NHS Health Checks</b></p>	<p><u>RBKC and WCC</u></p> <p>Dementia is included in as part of the NHS Health Check for people aged 65-74 years.</p>
<p><b>Reducing the risk of people developing dementia - ASC Commissioned Prevention Services</b></p>	<p><u>RBKC and WCC</u></p> <p>Public Health commissions a range of healthy lifestyle services that will contribute to lowering the risk of vascular dementia, including smoking cessation service, the cardio-vascular disease prevention programme and the alcohol service</p> <p>ASC commissions a range of preventative services that support in targeting the key modifiable risk factors for dementia in older adults; social isolation, lack of physical activity, depression</p> <p><u>RBKC</u></p> <ul style="list-style-type: none"> <li>Open Age - Second Half Resource Centre; New Horizons Resource Centre; Meet, Eat and Learn; Health Lungs; and Phone Club</li> <li>SPID –Older People Supper Club</li> <li>Octavia – Befriending</li> <li>Age UK –Exercise at Home; Exercise for the Mind; Health Promotion, Community Engagement and Shopping</li> <li>K&amp;C Forum - Health Talks Support</li> <li>Pepperpot – Day and Drop in Centre</li> <li>Everyone Active – Exercise for those with long term conditions</li> </ul> <p><u>WCC</u></p> <ul style="list-style-type: none"> <li>Open Age -Osteoblast Bone Health; Churchill Hub; Westbourne Hub; and Queens Park and Harrow Road Hub</li> <li>Bishop Creighton House - Falls Prevention &amp; Keep Active</li> <li>Notting Hill Genesis - Penfold Hub</li> <li>Octavia - Leonora Hub and Outreach</li> </ul>
Diagnosing Well	
<p><b>Information and Advice</b></p> <ul style="list-style-type: none"> <li>These generic services are often the first point of contact for stakeholders to receive further info or to be signposted to more specialist services, as necessary</li> </ul>	<p><u>RBKC</u></p> <ul style="list-style-type: none"> <li>Age UK - Information and Advice</li> <li>CAB – Information and Advice</li> <li>MIND - Peer Support</li> <li>Action Disability Kensington and Chelsea</li> </ul> <p><u>WCC</u></p> <ul style="list-style-type: none"> <li>Westminster Advice Services Project</li> </ul>
<p><b>Diagnosis</b></p>	<p><u>RBKC and WCC</u></p> <p>The Memory Service - Westbourne Park is joint funded by the Local Authority and the NHS. It comprises of a team of health and social care professionals with expertise in working with people with memory difficulties and dementia. They also have close links with the Admiral Nursing Service.</p>
Supporting Well	
<p><b>Targeted Carers Services</b></p>	<p><u>RBKC</u></p> <ul style="list-style-type: none"> <li>Carers Network - Hub</li> <li>Age UK - Carers Alliance</li> <li>Open Age – Time for Me</li> <li>Midaye – BME Support for Carers</li> <li>K&amp;C Mental Health Carers Association</li> <li>Everyone Active – Carers</li> <li>CAB – Advice &amp; Information</li> </ul> <p><u>WCC</u></p> <ul style="list-style-type: none"> <li>Carers Network – Hub</li> <li>CAB – Advice and Information</li> </ul>
<p><b>Targeted Dementia Services</b></p>	<p><u>RBKC</u></p> <ul style="list-style-type: none"> <li>Age UK – Dementia Advisor; Dementia Outreach; Dementia volunteer co-ordinator; and Dementia Café</li> <li>Octavia – Reed Dementia Day Centre</li> <li>RBKC – Chamberlain House Day Centre</li> </ul> <p><u>WCC</u></p> <ul style="list-style-type: none"> <li>Westbourne Park Dementia Day Centre; and Pullen Day Centre Dementia and Physical Disabilities</li> </ul>



Living Well	
<b>Dementia Friendly Communities</b>	<ul style="list-style-type: none"> <li>There are a number of community institutions e.g. museums that run dedicated sessions for attendees with specialist needs and Faith organisations that offer support through various methods.</li> </ul>
<b>Accommodation-Based Services</b>	<b>RBKC</b> <ul style="list-style-type: none"> <li>Octavia - Burgess Field Extra Care Home (ECH); James Hill House ECH; Miranda House and High Level ECH Dedicated Dementia Service</li> </ul>
	<b>WCC</b> <ul style="list-style-type: none"> <li>Octavia – Leonora House has a dedicated dementia wing within the scheme.</li> <li>Notting Hill Genesis – Penfold has a dedicated dementia wing within the scheme.</li> </ul>
<b>Residential &amp; Nursing Care Services</b> <ul style="list-style-type: none"> <li>Resident’s needs resulting from illnesses such as dementia may mean that they are best met by residential and nursing care services.</li> <li>Residential and nursing care services focus on improving physical and mental health, providing improved social activity and mental and physical stimulation.</li> </ul>	<b>RBKC</b> <ul style="list-style-type: none"> <li>Care UK – Ellesmere Housing Nursing/Residential</li> <li>Gold Care Homes – Alan Morkill House Residential</li> <li>Sanctuary Care – Princess Louise Kensington Continuing Health Care Nursing</li> </ul>
	<b>WCC</b> <ul style="list-style-type: none"> <li>Sanctuary Care – Westmead Residential; Carlton Dene Residential; Athlone House Continuing Health Care Nursing; Butterworth Specialist Nursing Care; and Garside House Continuing Health Care Nursing</li> </ul>
<b>Dying Well</b>	
<p>Most residents with a dementia diagnosis (and their families) wish to receive palliative care their own home.</p> <p>The services that support residents and help them live well also provide palliative care.</p>	<b>RBKC</b> Advice & Support Services <ul style="list-style-type: none"> <li>Age UK – Information &amp; Advice on advance care planning</li> <li>Age UK Dementia Advisor – supports re advance care planning</li> </ul> Extra Care Housing Services <ul style="list-style-type: none"> <li>Octavia – Extra Care Housing supports residents to remain in their own home as long as they wish and is viable including end of life plans.</li> </ul> Residential and Nursing Care <ul style="list-style-type: none"> <li>Providers work with residents to develop end of life plans to help residents die as they wish. Some residents are very reluctant to engage in this activity.</li> <li>A number of providers are signed up to and accredited with the Gold Standard Framework, an end of life programme to ensure residents received good quality, person-centred care</li> </ul>
	<b>WCC</b> Westminster residents are able to use their personal budget to support end of life care. Services can then be tailored to meet their individual needs or circumstances.
	<b>More widely</b> <ul style="list-style-type: none"> <li>Where appropriate, a range of services will encourage residents to engage in advance and end of life planning.</li> </ul>

\* NB this table details all services provided from 31 March 2019

**Appendix B – Overview of Some Recent Achievements and Upcoming Milestones in Dementia Services in RBKC and Westminster**

Area of Work	Key Achievements	Upcoming Milestones
Dementia Strategy	<ul style="list-style-type: none"> <li>• Plan and DoT approved by Members</li> <li>• Engagement plan signed off by senior officers</li> </ul>	<ul style="list-style-type: none"> <li>• Engagement events signed off by Members</li> <li>• Officer-level engagement with frontline health &amp; social care officers and LAG</li> <li>• Planning for Dementia Group meeting/Expert Panel</li> </ul>
Training & Awareness Raising	<ul style="list-style-type: none"> <li>• RBKC Cabinet and ELT, and RBKC and WCC HWBB trained as Dementia Friends</li> <li>• All Community Champions projects undertook a mental health awareness campaign from May to July supported by the CCGs and linked with Mental Health Awareness Week.</li> <li>• KCTMO committed in principal to training frontline staff as Dementia Friends</li> </ul>	<ul style="list-style-type: none"> <li>• Rollout of Dementia Friends Training across the workforce</li> <li>• Community Champions committed to prioritising dementia in the next financial year and having a programme for upskilling champions in place in the New Year.</li> </ul>
Service Commissioning – Well Pathway	<ul style="list-style-type: none"> <li>• Dementia Friends included in new service specifications and encouraged with existing providers;</li> <li>• Provider-led workshops on social isolation (key modifiable risk factor for dementia in Older People);</li> </ul>	<ul style="list-style-type: none"> <li>• Commence tender exercise for Extra Care Houses – staff dementia and dementia friends training and a built environment check list will be included.</li> <li>• New contracts issued and services specs for the 56 services being renewed.</li> <li>• Dementia friends and built environment check lists will be included in the new contracts and service specs.</li> </ul>
Dementia Friendly Community Initiatives	<ul style="list-style-type: none"> <li>• Healthy Workplace Charter Businesses now encouraged to become Dementia Friendly too.</li> <li>• Built environment dementia checklist rolled out among building based services               <ul style="list-style-type: none"> <li>○ Dementia Friendly Environment checklists carried out for the new Westminster City Hall and in all Westminster Libraries</li> <li>○ Libraries Health Information Officer trained as Dementia Champion trainer.</li> <li>○ Maida Vale Library hosting user group sessions for clients of the memory service and their carers</li> </ul> </li> <li>• Dementia Action Alliances</li> </ul>	<ul style="list-style-type: none"> <li>• Libraries meeting with Resonate Arts and the Westminster Memory Service to explore devising and loaning memory boxes to community organisations for members to host memory cafes.</li> <li>• Dementia friends information sessions planned for library staff and customers</li> </ul>