

Dementia

*A Joint Strategic Needs Assessment (JSNA) Report for
Hammersmith and Fulham Kensington and Chelsea Westminster*

Executive Summary

1 Executive Summary

1.1 Purpose of the JSNA

The purpose of this Joint Strategic Needs Assessment (JSNA) is to provide a comprehensive evidence base and information about the **local population** to inform **commissioning intentions** for Hammersmith and Fulham, Kensington and Chelsea, and Westminster, that takes account of national and local policy, the North West London strategic approach to dementia and guidance.

Specifically the report aims to:

- Draw together the strategic drivers from central and local government
- Describe the local picture of need and model future trajectories to enable forward planning
- Set out the current pathways and services for people with dementia and their carers including diagnosis, treatment and post –diagnostic support
- Identify and understand the gaps in service provision for local residents and their carers
- Review guidance and evidence to inform best practice locally
- Make recommendations to inform commissioning across the three boroughs and meet likely future needs.

Information has been collected from a variety of sources including audit, relevant policy and research as well as local data provided by stakeholders, providers, service users and carers. This evidence has been analysed to identify gaps and solutions and forms the basis of the recommendations outlined in the next chapter.

Throughout this document people with dementia have been referred to as patients, service users, clients or customers. These terms have been employed in different sections depending on the context and relationships.

It is also worth noting that this JSNA overlaps with other JSNA reports that have already been published or are currently in development, such as the End of Life Care JSNA. For further information on other JSNAs please visit <http://www.jsna.info>

The full version of this report is available at <http://www.jsna.info/document/dementia>

1.2 Key themes of the JSNA

In the current health and social care climate there is much emphasis on sustainability through better community care, living as well as possible with dementia, keeping people out of hospital and reducing length of hospital stays. This focus is particularly salient when applied to the needs of people with dementia. In the course of writing the report, several priority themes have been highlighted. These are described in the table below.

Table 1: Themes of Dementia JSNA

1. Numbers of people locally who have dementia will increase over the next few decades (around 55% in next 15 years), primarily due to a greater number of older people (aged 80+)	We need adequate resource to deal with this challenge and we need to provide services more efficiently and sustainably
2. Dementia diagnosis rates have been rising in each of the three boroughs	This has to be followed by an equal input into post-diagnostic care to ensure people are living well with dementia
3. Most of the cost of supporting those with dementia falls on unpaid carers and adult social care . With more care provided at home, pressure on carers may increase	We need to support, advise and empower carers to fulfil this enhanced role without a detriment to their own quality of life
4. Whilst it is important to maintain independence for longer, there needs to be appropriate escalation of care when needed	There may be a need for increased training for paid and unpaid carers residential care staff, and other appropriate professionals
5. Dementia services are provided by a range of agencies - acute and primary care, mental health services, social care and third sector	Better cohesion and collaboration is needed via well-coordinated information, advice, advocacy and outreach services
6. People with dementia do not always receive fair access to services which support their mental and physical health needs	People with dementia need to receive parity of access across mental and physical health services

1.3 Recommendations

The report draws together population analysis, policy, research and clinician and user views to inform an analysis of gaps and opportunities, and to evidence our recommendations for commissioning intentions. These recommendations are arranged according to the following priority areas:

- Memory Service Care
- Community Care
- Residential Care
- General Medical Care
- Whole Systems Care
- Patients and Carer’s Rights

A summary of how each recommendation has been developed from this analysis can be found in the full report (insert link) in Appendix A: RAG rating of local assets.

Table 2: Recommendations

	Gap/Opportunity	Recommendation(s)
Memory Service Care	<p><i>A. Memory service care varies between provider: in some cases the patient may not have access to timely diagnostic or adequate community support.</i></p> <p><i>B. Peer support is now being commissioned as part of Living Well service in Westminster and Kensington and Chelsea; however there appears to be a lack of resource in Hammersmith and Fulham.</i></p>	<p>1. Develop a single point of access to diagnostic assessment and ensure all patients across all three Boroughs have equitable access</p> <p>2. Introduce a peer support programme across three boroughs taking into account evaluation findings of Kensington and Chelsea/Westminster programme</p>
	<p><i>C. Diagnosis rates still do not meet estimated prevalence and can be further improved</i></p> <p><i>D. Training is needed for GPs, staff in care and support roles and families to recognise the signs and symptoms of dementia and know what to do next</i></p>	<p>3. Improve screening and diagnosis in care home and Extra Care residents</p> <p>4. Consider training to increase referral from or support diagnosis in primary care, in line with NWL strategy</p> <p>5. Audit completion of diagnostic assessment for those first identified in hospital and address accordingly</p> <p>6. Establish a good standard of training to achieve a level of expertise across all partner agencies including social care, residential care, extra care, clinicians, GPs</p>

	Gap/Opportunity	Recommendation(s)
Community Care	<p><i>E. It is not clearly understood whether voluntary sector resources and support available to carers is adequate to need, distributed equitably and accessible to all. There is variation between boroughs in the extent of such services available</i></p>	<p>7. Ensure adequate provision, through 3rd sector and health and social care services, of activities and support around living well with dementia and managing distressing behaviours</p> <p>8. Provide adequate infrastructure and training for care staff.</p> <p>9. Ensure people are supported to access the care appropriate to them through the use of personal budgets</p> <p>10. Ensure that there are sufficient Dementia Advisers to coordinate access to services.</p>
	<p><i>F. There appears to be insufficient community support for people with dementia and their carers to learn to manage distressing signs of dementia, e.g. through purposeful activity.</i></p>	
	<p><i>G. There are Dementia Advisers and Dementia Guides but there appears to be insufficient resources to meet need. There is a lack of dementia advice/care coordination to support timely access to advice. Resources are needed across 3 boroughs to ensure care staff have support to recognise and signpost people for diagnosis and to provide the right interventions and level of support.</i></p>	
	<p><i>H. There is insufficient support for work of the Dementia Action Alliances across the three boroughs (can eventually join up across 3 boroughs and the Pan-London Alliance)</i></p>	<p>11. Ensure adequate resource to support the work of the Dementia Action Alliance and other opportunities to raise public awareness of dementia across the three boroughs</p>

	Gap/Opportunity	Recommendation(s)
Residential Care	<i>I. The provision of care home beds locally (particularly dementia specific beds) tends to be lower than many other areas, meaning a significant proportion of residents are placed out of borough, in some cases away from family and friends.</i>	12. Address supply of local care home beds in future local authority and CCG commissioning intentions, including those specifically for dementia care.
	<i>J. Little is known about the quality of dementia care in care homes locally</i>	13. Address findings from Care Quality Commission (CQC) national report on dementia care in care homes; audit to provide assurance of quality of care in care homes. 14. Ensure there are opportunities for coordinated training and support for care homes to enable recognition of patients with dementia and to improve confidence in care for complex needs and difficult behaviours. 15. Ensure either all staff in intermediate care have appropriate training for looking after people with dementia or a specialist service is provided.
General Medical Care	<i>K. Little is known about adequate use of antipsychotics – an audit is due to take place in Chelsea and Westminster Hospital.</i>	16. Audit and address accordingly use of antipsychotics in hospitals and community prescriptions
	<i>L. A need has been speculated for increased liaison psychiatry provision in Hammersmith and Fulham, dementia specialist nursing in the community and in hospital, and care navigators. M. Opportunities for reducing escalation of problems and care need have been identified through early targeted hospital care.</i>	17. Ensure adequate monitoring, assessment and provision of care for other physical and mental health needs for people with dementia. 18. Ensure timely identification and targeted care of those with dementia in hospital 19. Provide dementia friendly environment within hospitals 20. Ensure adequate provision of liaison psychiatry and dementia nurses, consider expanding remit

	Gap/Opportunity	Recommendation(s)
Whole Systems Care	<i>N. There are few easy channels of communication between different providers of dementia care</i>	<p>21. All patients, carers and clinicians should have consistent and comprehensive information with clear signposting of care pathways</p> <p>22. The current fragmentation in care provision would be addressed through centralised coordination and improved communication/collaboration between services</p>
	<i>O. Numbers of people with dementia are likely to increase by 55% in the next 15 years, all relevant providers and services must be equipped with adequate resource to meet this need.</i>	<p>23. Ensure adequate training and support across all services for staff and carers looking after people with dementia</p> <p>24. Current practice and resources must be scaled to meet increasing need or consider adapting models of care with innovation across health and social care to reduce the scale of care required. Ensure that any changes to services are evidence based.</p> <p>25. Explore joint working with police and other community safety partners to support appropriate and effective use of assistive technology/telecare for patients with dementia.</p>
	<i>P. The Dementia Strategy in Kensington and Chelsea will end in 2016. The Westminster and Hammersmith and Fulham strategies have both expired. The North West London Mental Health Programme Board has recently produced a dementia strategy for diagnosis and treatment support</i>	<p>26. There should be a joint health and social care dementia programme board for the three boroughs to facilitate implementation of the North West London dementia strategy in alignment with findings and recommendations from this JSNA.</p> <p>27. Local services are active stakeholders with wider initiatives to ensure strategy is sensitive to local needs</p>
	<i>Q. Housing, environment and planning strategies do not specifically mention dementia or carers of people with dementia</i>	<p>28. The increasing numbers and needs of people with dementia and their carers are taken into account in wider local authority and health strategies, especially housing and</p>

	Gap/Opportunity	Recommendation(s)
		environment
Patient and Carer's Rights	<p>R. Lack of sufficient resource to support with end of life care across the three boroughs.</p> <p>S. Lack of defined carer support pathway.</p> <p>T. Support is needed for advocating peoples' best interests and awareness of the Mental Capacity Act 2005</p> <p>U. There is little supporting infrastructure available to provide help to self-funders to "micro-commission" care as mandated by the Care Act 2014.</p> <p>V.</p>	<p>29. Ensure that there is a clear end of life care pathway for people with dementia with appropriate advanced care planning and powers of attorney and clinicians are responsive to these wishes.</p> <p>30. Provide a clear and comprehensive pathway, including respite care, for carers with equality of access across three boroughs, taking into account the unique needs of carers of people with dementia.</p> <p>31. Patients and carers should be aware of advance directives and power of attorney and how to initiate them.</p> <p>32. Ensure there is adequate infrastructure to support self-funders to access care</p>

1.4 About dementia

Dementia is a condition that affects about 800,000 people in the UK¹. Dementia is an umbrella term that is used to describe a group of progressive symptoms such as memory loss, changes in personality, and difficulties in day-to-day living. There are several different causes of dementia, the most common being Alzheimer's (62% of cases) and vascular dementia (17% of cases).

Dementia has a significant impact on an individual's health and quality of life. It can result in a range of health and social problems which can be challenging for the person with dementia, their carers, and health and social care professionals.

People with dementia are likely to have significant physical and mental comorbidities, such as depression, hypertension and diabetes. Average life expectancy ranges from 6.5 years for those diagnosed between the ages of 60-69; to 1.8 years for those diagnosed at age 90 and older.

The main risk factor for dementia is growing older and ageing. While the evidence base on the prevention of dementia is not yet fully developed (and will be informed by a number of current studies), research has indicated that most success lies with modifying cardiovascular risk factors.

'Looking after someone with dementia is the most difficult job in the world' Local Carer, 2014/15 Survey of Adult Carers

¹ Alzheimer's Society <http://www.alzheimers.org.uk/statistics>

Carers play a vital role in supporting people with dementia. Unpaid care contributes more in financial terms than contributions from any other agency (45% of the total, with social care providing 40%). Carers are often old themselves, more likely to be women, and are likely to be providing a substantial number of hours of support.

Carers for people with dementia often experience poorer physical and mental health, social isolation, fewer opportunities to employment or education, or having time to themselves or with friends. For young carers, it can often mean life chances are severely limited.

At any one time, a quarter of acute hospital beds are in use by people with dementia (Royal College of Psychiatrists, 2013). The recent introduction of dementia CQUIN payments (Commissioning for Quality and Innovation) has led to increased provision of dementia specialist nursing and better identification of dementia.

Nationally, 1/3rd of people identified as having dementia are resident in a care home², and local audits have identified at least two thirds of older people newly admitted to care homes had dementia. Care home provision is therefore an important factor in dementia.

The average costs of caring for people with dementia in England are approximately £37k per year for people in residential care and £29k per year for people in the community. For the most complex cases, annual costs of c. £70k have been reported³.

If the national figures are apportioned locally using the number aged 75+, then the estimated total cost of dementia care in the three boroughs is expected to be £161 million of which £70 million is for unpaid care.

Table 3: Estimated local cost of dementia care in the three Boroughs

Cost Type	Amount (£)
Unpaid Care	70,000,000
Social Care	64,000,000
Healthcare	25,000,000
Other Costs	700,000
Total	161,000,000

² Alzheimer’s Society Statistics <http://www.alzheimers.org.uk/statistics>

³ London Dementia Needs Assessment 2011, NHS London

1.5 Dementia in our population

Current estimates of the number of people with dementia in the local population are approximately 1200 in Hammersmith and Fulham (LBHF); 1500 in Kensington and Chelsea (RBKC) and 1800 in Westminster (WCC). About half of these people are aged 85+. The total across the three boroughs is estimated to rise from 4,500 in 2015 to 7,000 in 2030 for those aged 65+, if the current prevalence rates in the population remain the same. Prevalence rates do fluctuate and recent estimates may indicate a reduction in prevalence due to an improvement in general health in recent years.

Current published diagnosis rates – the numbers known by GPs to have dementia - are 63% of the estimated prevalence rates in Hammersmith and Fulham Clinical Commissioning Group (LBHF), 65% in West London CCG (RBKC plus Queens Park and Paddington) and 65% in Central London CCG (WCC minus QPP,) based on old prevalence rates⁴. This compares to 60% across London. There are unpublished results that are included in section **Error! Reference source not found.**

'A significant proportion of people [with] dementia don't want to know, they won't bring it up of their own accord'

Local Clinician, 2014

Through the aging of the population alone, we can estimate a 55% increase in the number of people across the three boroughs with dementia over the next 15 years: 50% for Hammersmith & Fulham; 70% for Kensington & Chelsea; and 45% for Westminster. Diagnostic, treatment and care service provision may need to expand proportionately to meet this increasing need.

Across the three Boroughs there are approximately 39,000 residents who identify themselves as providing unpaid care. According to the Survey of Adult Carers in 2014/15 in the three boroughs, around a quarter of carers responding to the survey in WCC and RBKC care for someone with dementia, rising to a third in LBHF. Of the survey responders, over 50% were providing more than 50 hours a week of unpaid care, with many living with the person they care for. Around 50% had been caring for the person for 5 years or more

'My mother is unaware she has dementia and is very depressed and anxious and depends entirely on me. She refuses to pay for a carer insisting that I am there and care for her. She is scared of being left alone and I am afraid of leaving her for any length of time'

Local Carer.
2014/15 Survey of Adult Carers

⁴ Prevalence rates are discussed in more detail in the full report in section 3.5

1.6 Dementia services and asset mapping

Basic pathways of care involve diagnosis in a Memory Service; either led by mental health or by general medical services. Patients are referred to this service via their GP, although some will be identified through hospital admission or adult social care. The voluntary sector is also often well placed to notice early signs of dementia in their service users. On-going care is provided initially by the Memory Service then via GP, social care and the voluntary sector.

Memory Services are shared between RBKC and WCC. A Living Well service for on-going care is also being developed jointly between RBKC and WCC. LBHF has Memory Services provided by West London Mental Health NHS Trust and Imperial College Healthcare NHS Trust. A detailed map of service provision has been created and is available in Chapter 5.

‘Having the same referral strategy across whole trust is important’

Local Clinician, 2014

Local authority Adult Social Care departments are responsible for supporting people with dementia to live safely and independently within their own homes, and local community, for as long as possible. Staff will assess an individual’s social care needs and work with that person to devise and coordinate a tailored, person centred support plan detailing what the person wishes to achieve, what is needed to make this possible and who will provide it. Core services provided are home care, memory cafés, and day services.

People who need adult social care services will be allocated a personal budget which can be used to fund a range of support including information and advice, home adaptations, assistive technology, rehabilitation or reablement, or moves to extra care sheltered housing or residential care where necessary. Adult Social Care also commission services to support carers, such as respite care, to prevent carers from developing their own needs for care and support.

Published rates of care home bed provision have identified a national rate of 114.1 beds per 1,000 aged 75+. Provision across the three boroughs is less than half of this at 45.5 per 1000; 59.3 in LBHF, 46.6 in RBKC and 35.7 in WCC (the lowest in England). Surrounding boroughs also have lower provision of beds than the national average. A local audit of those identified as having dementia indicates 60% are placed outside of their original borough of residence.

There is a strong local emphasis on caring for people at home for longer and delaying entry to care homes when that person can be supported in the community. It is important to ensure that patients are receiving adequate support whether at home or via residential care regardless of capacity and availability of care, and that external placement where possible do not go against the wishes of patients.

'Voluntary services are huge and play a massive role'

Local Clinician, 2014

The voluntary sector plays a key role for people living with dementia in the community, including providing day services, activities and befriending schemes.

Our needs assessment has collated feedback from local clinicians and service users. Through this we have identified several areas for improvement regarding quality, supply and cohesion of services. These are addressed in the gaps and recommendations.

1.7 Views of people with dementia and their carers

Research shows that a large proportion of people with dementia feel unsupported, do not feel part of their community, often experience anxiety or depression, and do not feel society is geared to deal with dementia (Alzheimer's Society, 2012). While a survey undertaken by the Alzheimer's Society (Alzheimer's Society, 2013) suggests that progress is being made, with almost two-thirds (61%) of respondents reporting that they were living well with the condition, the report also found that quality of life is still varied for a significant number of people with dementia. Environment, presence of depression, social isolation and loneliness are key drivers for quality of life for people with dementia.

Patient and carer's choices over type of support and care they receive may be influenced by cultural background, beliefs and their relationship and communication with professionals. Some may find it difficult to engage with advance care planning.

This is reflected locally where users and carers have identified that they particularly value respite care, practical (financial and legal) advice, memory cafes and day centres. Areas for improvement include staff training, access to and cohesion of services, consistency of support and personal control when choosing services

*'...(x) is great; she organises a book clubs... reads books out loud,
...royal academy workshop discusses paintings - once a month'*

Service User

1.8 Review of evidence and models of care

Management of dementia centres around medication for symptoms of cognitive impairment and distressing behaviour, and care that includes stable staffing, calm environments and appropriate stimulation (NICE, 2006). The Prime Minister's Challenge has prioritized research into finding a cure for dementia or solutions to delay the progress of symptoms, and sharing best practice for service delivery.

There is increasing emphasis on the creation of 'dementia friendly communities' and dementia friendly environments, supported by the Dementia Action Alliance and Prime Minister's Challenge⁵.

Technologies such as remote tracking, alarms and telecare may aid in diagnosis of dementia and management of problems such as wandering, however need to be supported by surrounding infrastructure.

'Caring communities are difficult in an urban inner city'

Local Clinician, 2014

The Blackfriars Consensus⁶ recognises the overlap between risk factors for vascular disease and dementia, and the potential for effective approaches to prevent non-communicable diseases, such as cardiovascular disease, to be effective in the prevention of dementia.

Key routes to reducing the risk of dementia are:

- modifying cardiovascular risk
- maintaining mental stimulation
- social engagement
- physical activity
- treating depression.

Three large research studies are currently taking place in Europe and the results will inform the case for preventive intervention. NICE is currently developing guidelines referring to midlife prevention of dementia.

New models of care may enable provision of better quality and more streamlined, cost effective services. The North West London dementia strategy highlights a primary-care based diagnostic approach. Scotland's national Dementia Strategy outlines the '8 Pillars' model with care centred around a 'dementia practice coordinator'. Watford's Dual Frailty ward and Delirium Recovery Programme may reduce incidence of escalation to residential care.

⁵ Prime Minister's challenge on dementia 2020 <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020> (accessed 1 July 2015)

⁶ Public Health England/UK Health Forum. *Blackfriars Consensus* http://nhfshare.heartforum.org.uk/RMAssets/Dementia/Blackfriars%20consensus%20%20_V19b.pdf

1.9 Conclusion

The North West London Strategic approach to dementia was finalized in the course of writing this report. The strategy includes a co-produced 'exemplar framework,' outlining the ideal client and carer-centred dementia service. A high level clinical pathway and service specification has also been produced to accompany this with an outcomes framework set against achieving the 'I statements' for both people with dementia and their carers based upon the national quality outcomes framework.

This JSNA provides a comprehensive evidence base and information about the local population to inform the development of commissioning intentions and support the strategic approach taken across North West London.

It provides an opportunity to understand the whole landscape and customer journey for people with dementia and their families and carers, and to highlight areas for improvement.