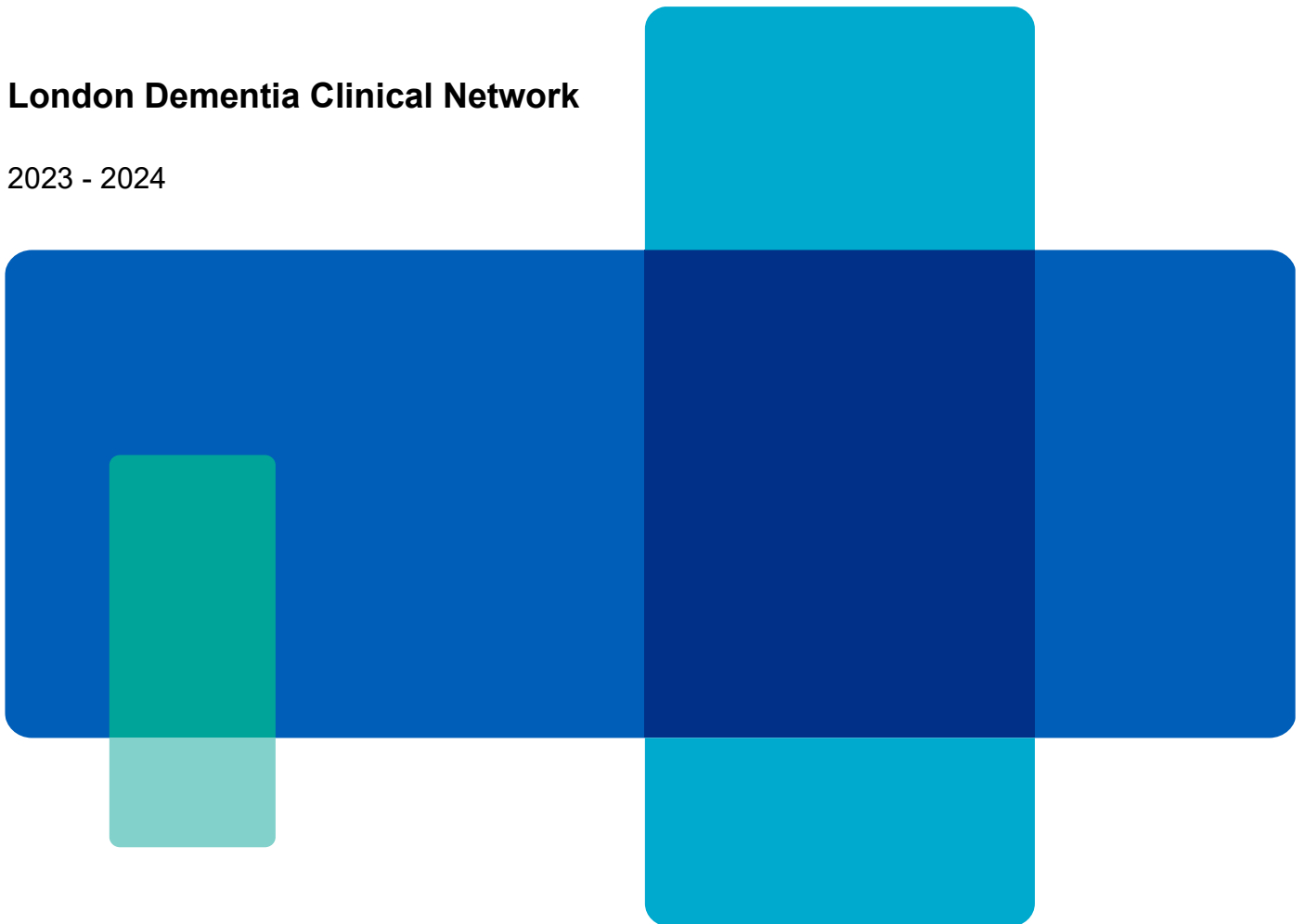


Dementia Reviews & Care Coordination Framework

London Dementia Clinical Network

2023 - 2024



Executive Summary:

In London there are over 74,000 people living with dementia; this number is expected to rise to 108,000 by 2030. Most people receive their diagnosis from a memory service and are then discharged without ongoing follow-up in secondary care.

The London Dementia Clinical Network (LDCN) received funding from the Office for Health Improvement and Disparities (OHID) to develop a commissioning framework for post-diagnostic care for people living with dementia.

The work was carried out in four phases:

1. Mapping of post-diagnosis dementia care across London
2. Interviews, surveys and focus groups with people living with dementia, family, carers and healthcare professionals to identify unwarranted variation and best practice
3. Development of a best practice dementia care framework
4. Pilot of the framework in a GP practice

Conclusions

The engagement work with people living with dementia and those important to them highlighted the lack of advice and support available following a diagnosis of dementia. Using their feedback, a framework was developed which included a suggested structure for a clinical review for the person and examples of the type of support that they would like to receive as part of their ongoing care. The framework was piloted in a primary care setting. The pilot demonstrated the high level of unmet need among people with dementia and their carers which had not previously been identified. This resulted in numerous referrals and signposting to services for the benefit of patients and their carers.

Background:

Dementia is one of the 10 priority areas in the [London Vision 2019](#) which commits to Londoners receiving a timely accurate diagnosis and ongoing support and being able to live well in their community.

There are estimated to be over 74,000 people in London living with dementia of whom about 50,000 have a recorded diagnosis ([NHS Digital, 2024](#)). The number of people in London living with dementia is predicted to increase by over 40% between 2019 and 2030.

London has a uniquely diverse demographic. 14% of people diagnosed with dementia in London are from an ethnic minority group (note: ethnicity was not stated in 23% of records). According to [2021 Census data](#) (Greater London Authority, 2023), 4.8% of Londoners identify as LGBTQ+ and 0.9 per cent of Londoners state that their gender identity is different from their sex assigned at birth. Just over half of all London households are deprived in at least one census (education, employment, health, housing) [Census 2021 - Household Deprivation](#). London is the UK region with the highest proportion of households deprived in all four dimensions (0.4%).

Life expectancy following a dementia diagnosis is typically 5-10 years. How services support people to live with this progressive long-term condition varies significantly. In London, memory services are predominantly funded only to diagnose dementia and provide initial

post-diagnostic support, typically for 3-6 months following diagnosis. Ongoing support is provided in various ways in different boroughs e.g., voluntary sector dementia advisors, dementia navigators linked to a memory service, community-based dementia nurses or practitioners. These services vary significantly, with no best practice model or consistent approach to commissioning.

People living with dementia should be offered a yearly review in primary care as part of the [Quality Outcome Framework 2023/24](#). However, data show that only 62.4% of people on primary care dementia registers in London have an annual review, and the quality of these is not currently monitored [Office for Health Improvement & Disparities: Fingertips](#)

The London Dementia Clinical Network was awarded funding by OHID to develop a framework for post-diagnostic support. The project was undertaken in collaboration with CareCity and UCL Partners.

What do people living with dementia and their carers want?

Insights were gained from people living with dementia, carers and healthcare professionals. Flyers were sent in the 11 languages most commonly spoken in London, to dementia organisations, groups and services. Information was also posted on social media and local radio. This resulted in feedback from 125 people through workshops, interviews and surveys.

Londoners living with dementia told us that they felt 'lost' after discharge from memory service follow-up, and they didn't know who the main point of contact for dementia-related issues was or how to contact them when things changed.

People living with dementia and their carers told us they wanted:

- A consistent offer and continuity of care in order to live as independently as possible in their own home.
- A review 6 months after diagnosis and then an ongoing annual review, with access to support between reviews as needed.
- Medication reviews, hearing and vision checks with signposting to appropriate follow up, opportunities to discuss carer concerns and advance care planning.
- Where appropriate counselling, involvement in research, respite care, day centres and training to manage dementia.

The report on the engagement work can be accessed online: [Care City Living with Dementia in London 2023](#)

A draft framework was designed that would meet these needs. The framework includes ongoing health-based reviews at least on an annual basis. The proposed reviews comprise assessment of physical and mental health, including sensory deficits, medication review, opportunities for carers to express needs and concerns and advance care planning. Ideally, the review should be conducted by a healthcare professional. This framework was presented in a workshop and refined.

NICE guidance

Our recommendations are aligned with the [Dementia NICE Guidance \(NG97\)](#). This recommends that people with dementia should have a single named professional who as part of their role should develop and review the person's care and support plan. Having a single named practitioner to coordinate the care of people with dementia is one of the [NICE quality statements](#). NICE recommends that commissioners *ensure there is local agreement on the assignment of a single named practitioner and clarity for the role and responsibilities of this person*.

Piloting the framework

The framework was piloted in a general practice in Havering. 15 people living with dementia, at various stages of the condition, received a review. The review process followed a template that was designed to meet the needs identified by patient and carers during the consultation. In summary, only one out of 15 reviews did not generate any actions to improve the patient or carer's physical or mental health or their social provision (table 1). This demonstrates the high level of unmet need among people with dementia and their carers.

Intervention/Action	Number
Blood test abnormality found	8
Medication change	9
Referral for unmet physical health needs	8
Referral for unmet mental health needs	6
Referral to social care	4
Advance Care Plan discussion	11
UCP created	1
Bone health intervention (advice, treat or measure BMD)	11
Referral to Join Dementia Research	3

Table 1. Number of interventions arising from the 15 reviews.

Feedback was positive. Out of 13 patients able to complete the Friends and Family Test, 7 were extremely likely and 3 likely to recommend a care plan review to family or friends. Comments about the process were extremely positive in that patients felt listened to and understood and grateful for onward referrals and support.

The full report on the pilot is in Paper 2

Workshop discussion of the framework

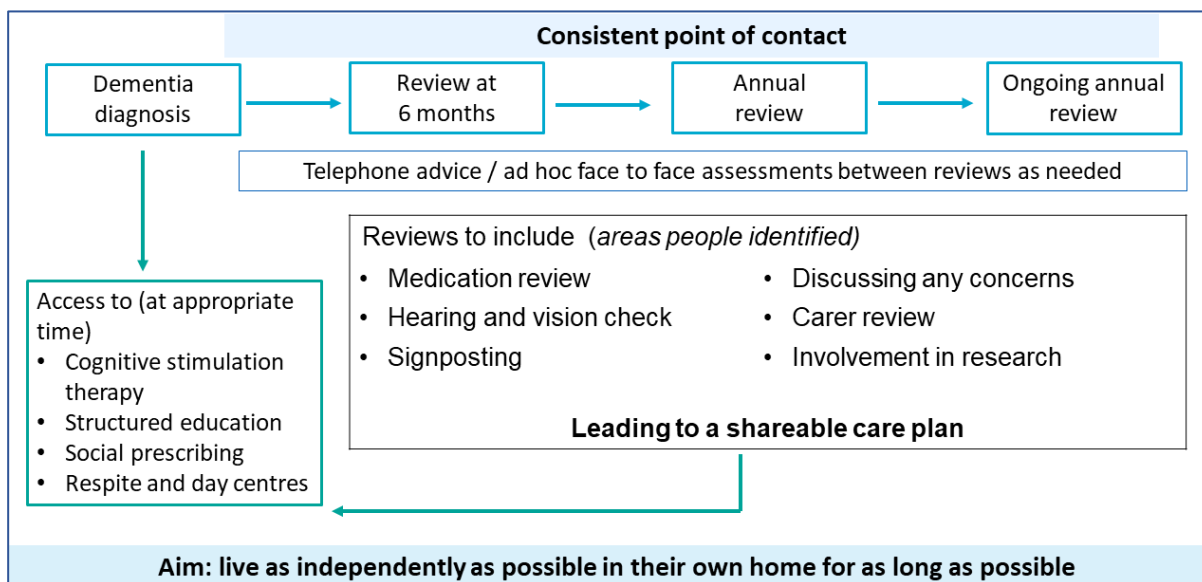
The findings of the project and next steps were discussed at a workshop on 29th June 2023 . Experts by experience, clinicians and project staff were invited alongside colleagues from ICBs.

Suggested next steps included:

- Use of the UCP linked to a pan-London ambition to increase the number of care plans (and therefore number of reviews)
- Use of additional roles in Primary Care Network (PCN) teams such as pharmacists to complete annual reviews for people with dementia
- Integrated joint working e.g., combining NHS and voluntary sector resources to ensure health reviews and signposting are delivered
- Demonstrating cost savings of enhanced reviews as anticipated that people would be staying at home and living independently for longer and there would be a reduced risk of crisis presentation
- Use of risk stratification to grade the intensity of support offered

The framework

The framework was updated following the pilot and discussions with focus groups consisting of people living with dementia and those important to them.



The central component of the framework is a named keyworker who provides clinical dementia reviews and a consistent point of contact. Other aspects of post-diagnostic support are included.

The framework outlines the principles of post-diagnostic support. It is purposefully not prescriptive e.g., the professional background of the keyworker and where the reviews are completed, to allow for flexibility around local population needs and service provision.

It is designed to align with other frameworks such as the [Enhanced Health in Care Homes Framework \(NHS England, 2023a\)](#) and the [Quality and outcomes framework guidance 2023-24](#). This should reduce administrative burden for professionals and carers, whilst building on existing good practice.

Dementia reviews

People living with dementia should be offered a meaningful review with their keyworker 6 months after diagnosis, and then annually.

These reviews have been designed to be undertaken by any competent healthcare professional with an interest and knowledge of dementia and may work best using a multidisciplinary approach e.g., a combination of an allied health professional, pharmacist, social worker, dementia advisor or nurse. However, it is recommended that these reviews are undertaken by NHS staff, so that the patient's electronic health record is available and to ensure health and care aspects of the review are completed and unmet needs identified.

Signposting and wider non-health related support are also key aspects of the review process; this may be completed by voluntary sector personnel such as dementia advisors or support workers.

The review should include the core aspects of the [dementia good care planning guide \(NHS England, 2020\)](#):

- Diagnosis – review understanding
- Effective support for carers and details of current social situation
- Structured Medication Review
- Evaluation of risk
- New symptoms enquiry
- Treatment and support
- Individuality – supporting to live well
- Advance care planning

Where appropriate, the review should also encompass the other principles and domains of a [Comprehensive Geriatric Assessment \(CGA\)](#).

People living with dementia specifically asked for enquiry about hearing and vision to be included in reviews. Research participation was also highlighted; people with dementia and carers can be signposted to local research or sign up to [Join Dementia Research \(National Institute for Health and Care Research, 2023\)](#).

The outcome of the review should be a [personalised care plan](#) that is shareable with the patient, their carer (if appropriate) and other appropriate professionals involved in their care. It is recommended that the [London Universal Care Planning \(UCP\)](#) system is used (due to launch in 2024) (Universal Care Plan, 2024). The UCP is an NHS service that will enable every Londoner to have their care and support wishes digitally shared with healthcare professionals across the capital. The London Dementia Clinical Network has worked with clinicians across London to develop and design the UCP in a way that is personalised and meets the needs of people with dementia.

Much of the information that will be included in the UCP is a core part of the Quality and Outcomes framework. Data extracted from reviews using the UCP could be used to anticipate future care needs at both individual and population level.

Support between reviews:

People living with dementia and their carers should have a named clinical keyworker to contact for advice and guidance between reviews. This might prompt additional reviews as required.

Other key aspects of post-diagnostic support

Dementia reviews and care co-ordination should sit alongside a wider package of evidence-based post-diagnostic support. Depending on service users' needs and preferences, this could include cognitive stimulation therapy, carer psychosocial education, peer support and access to social support such as day centres and respite.

Workforce, contractual and funding considerations

The positioning of the personnel conducting the dementia reviews and acting as a "point of contact" can be determined locally. Options include staff in primary care or situated within neighbourhood or community health teams or supervised by the local memory service. Health needs will be best addressed if the person conducting the reviews is a qualified healthcare professional, as in the pilot.

The appropriate size of the caseload assigned to each member of the team will evolve over time. Based on guidance for neurology specialist nurses, a caseload of approximately 250 patients per staff member is recommended. Considering the current number of people in London with a known dementia diagnosis, this would require a pan-London workforce of 200 WTEs.

Research shows that a holistic dementia review, similar to the model proposed here, leads to improved quality of life and decreased health and social care costs. In particular, evidence shows lower hospitalisation rates and delayed admission to a care home or other supported living environment (Eichler et al., 2014; Thyrian et al., 2017; Michalowsky, 2019). This is even more cost effective for people living alone, who comprise nearly one third of people with dementia (De Medeiros, Berlinger & Girling, 2022; Wattmo, Londos & Minthon, 2014; Miranda-Castillo et al., 2010).

The average yearly health and social care cost in the UK for someone living with mild dementia is £24,400, moderate dementia £27,450 and severe dementia £46,050 (Wittenberg, 2019). By using a proactive care approach [NHS England: proactive care and support](#), to keep people happier, more independent, healthier and safer at home for longer, these expenditures might be reduced (Bleijenberg, 2017; Kelly & Innes, 2016).

Table 2 lists projected employee costs for a post-diagnostic dementia service (Jones et al., 2022), adjusted for London (NHS England, 2023c).

Post Diagnostic Staff Costs	Cost (adjusted for London)	Staff requirements	Yearly Cost
Total yearly cost for each full time band 7*	£128,505	1 (team leader)	£128,505
Total yearly cost for each full time band 6*	£109,397	5	£546,985
GP time for multidisciplinary meeting	£178 per hour x 4 hours per week = £712 per week	52 weeks	£37,040

YEARLY TOTAL £712,523

Table 2. Projected workforce costs for a post-diagnostic dementia service in a medium sized borough with approximately 1500 dementia patients, a team of five band 6 clinicians led by a band 7 clinician. This also includes four hours a week of GP support.

*Includes salary/wages, salary oncosts, qualifications, overheads, capital overheads

Summary

People living with dementia and those important to them have consistently highlighted the lack of support after diagnosis. This project reinforced this. There was a clear request for annual reviews, and a named contact for advice and support for the person living with dementia and their carer between reviews.

The pilot study of enhanced reviews in a primary healthcare setting demonstrated that people living with dementia have significant unmet physical and mental health and social care needs. The reviews should, therefore, be led by appropriately trained healthcare staff. The need for signposting was also identified; this could be undertaken by a dementia navigator or advisor.

This framework has a number of potential positive outcomes:

- A named contact for advice and support throughout the dementia journey resulting in reduced patient and carer stress
- Earlier detection of emergent health and care issues to prevent crises, including Emergency Department conveyance and unplanned admission to hospital
- Improved health and wellbeing for people with dementia and their carers

Our vision is that everyone living with dementia can access a good quality annual review by a healthcare professional, and has a consistent point of contact to support them and those important to them to live as well as possible.

Recommendations

Our findings support the case for investment in a lifetime post-diagnostic service. The offer should include:

- Initial review six months post-diagnosis
- Yearly multidisciplinary holistic dementia reviews completed by a healthcare professional
- As a minimum, reviews to include: discussing concerns about physical and mental health, medication review, carer review, hearing and vision check, signposting and offer information about research
- A Universal Care Plan (UCP) for all people living with dementia to share wishes and preferences with other healthcare professionals across London
- Patient/carers access to a named dementia keyworker between reviews
- Inclusion of vulnerable patients e.g., those affected by digital exclusion, language barriers, sensory impairment, living alone, lack of informal carers, learning disabilities, mental illness, severe frailty, insecure or unstable housing, safeguarding concerns, substance addiction
- Reviews supported by someone who knows the person well (with consent and where appropriate)
- Provision of information about cognitive stimulation therapy, structured education, social prescribing, respite and day centres

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