Classification: Official

Dementia Reviews and Care Coordination

The Pilot

Publication reference:

Contents

Background

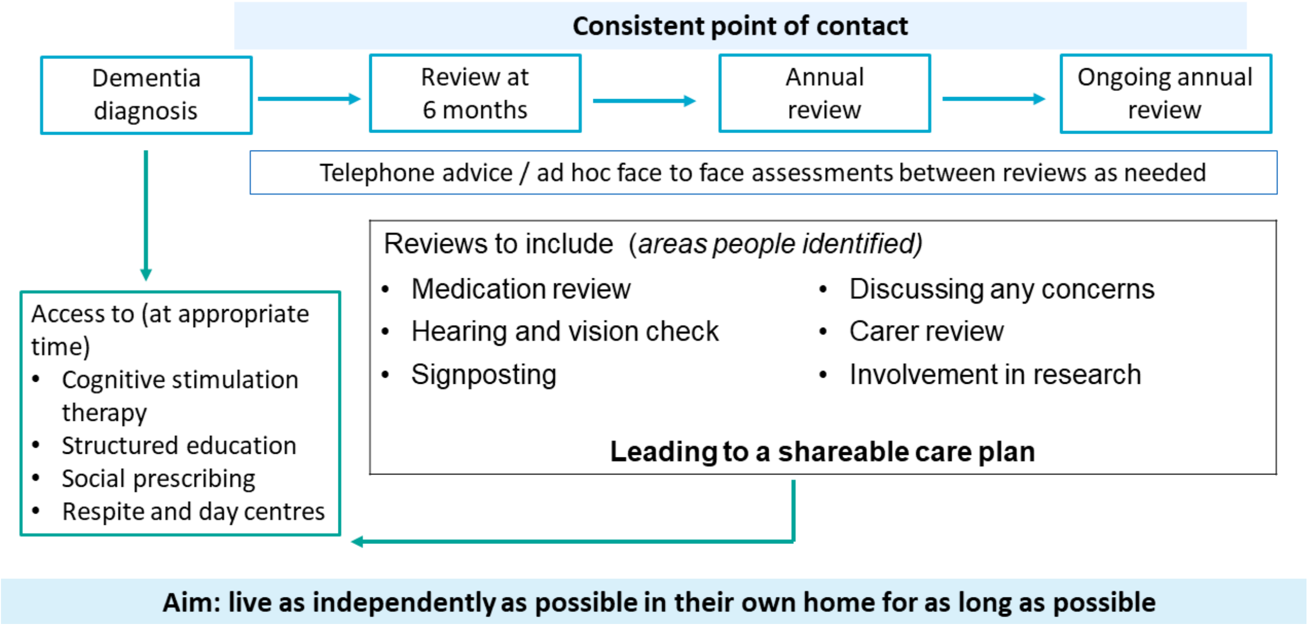
In London there are over 74,000 people living with dementia (NHS Digital, 2024); this number is expected to rise to 108,000 by 2030 (Wittenburg et al, 2019a). People typically live with dementia for 5-10 years following a diagnosis (Alzheimer’s Society, 2021), yet after receiving their diagnosis from a memory service most are discharged without specialist follow-up. The NHS Long Term Plan, London Health and Care Vision, and NICE guideline all recommend that people living with dementia receive ongoing support to live well (NHS, 2019; Healthy London Partnership, 2019; NICE, 2018).

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. This is aimed at providing integrated care systems (ICSs) with an opportunity to address gaps, inequalities and unwarranted variation that currently exist in dementia care. The project consisted of four phases:

1. Mapping post-diagnosis dementia care across London
2. Consulting people living with dementia, and their families, carers and healthcare professionals to identify unwarranted variation and best practice
3. Developing guidance for a best-practice dementia care framework
4. Running a pilot of the key elements of framework

The outcomes of phases one and two were published in April 2023 in the report ‘Living with Dementia in London 2023’. Based on the above work, a draft framework was developed by the LDCN.

Figure 1 - illustration of the draft framework



Summary of findings

An outline of findings from this pilot are as follows:

- 14 out of 15 reviews resulted in referrals or actions
- Referrals were made for physical and mental health and for social needs
- Medication changes, investigations, health advice and increased monitoring were initiated
- Patients lost to follow-up for outpatient care, were reconnected with appropriate services
- The needs of carers were addressed
- People felt listened to and supported and knew where to turn if they had future concerns
- Feedback collected from clinicians, patients and carers was positive

Pilot

What did we do?

A number of GP surgeries were approached to explore the possibility of hosting the pilot. The aim was to identify a minimum of two sites; however, despite interest, finding the capacity and space to participate was challenging. Western Road Medical Centre in Romford was able to host the pilot and agreed to use their existing staff, equipment and clinic rooms. The pilot took place from April to May 2023.

After consultation with the practice, it was agreed that the pilot reviews would be completed by a practice nurse and a pharmacist. Clinic rooms, waiting areas and the use of the Ardens dementia clinical template (https://www.ardens.org.uk/) were agreed. The Ardens template was ideal as it is already available on the electronic patient record management system (EMIS) and includes most of the details to be covered in the review.

A two-hour introductory training session was completed on 18 April 2023 for the GP surgery staff. This included a review of the Ardens dementia clinical template, discussion around conducting dementia reviews and more detailed planning for the pilot clinics.

Identifying patients

The dementia lead at the surgery agreed to identify five patients from each of the following categories:

- Six months post-dementia diagnosis
- Over one year post-dementia diagnosis

- Over three years post-dementia diagnosis
- Living in a care home (advanced dementia)

The aim was to review 12-20 patients overall.

A letter (appendix A) was provided for the surgery to send to patients to inform them of the review details. The GP surgery invited people by telephone, after which the letter was sent once an appointment was agreed. Patients were offered clinic appointments, home visits or care home visits.

Up to five patients were scheduled for clinic appointments per day.

Questionnaires

Patients and their family members were interviewed before and after the review. Quantitative and qualitative feedback was collected. Capacity to consent, General Data Protection Regulation (GDPR) and dementia-friendly interview processes were observed throughout the evaluation.

Conducting the reviews

It was estimated that a review would take approximately one hour to complete. At the end of each clinic day, a multidisciplinary meeting with a GP was scheduled to discuss key outcomes, actions and reflections generated from the reviews.

At the care home, it was requested that a care worker who knew the patients well attended the reviews. For home visits, a joint visit with a nurse specialist and occupational therapist was arranged, with an online multidisciplinary meeting to be arranged afterwards.

Review template

A template was used to guide the clinicians during the reviews. This was adapted from a combination of the Camden & Islington Memory Service review template, a comprehensive geriatric assessment and the Ardens template (https://www.ardens.org.uk/) within EMIS. The patient centred template covered:

- Physical health
- Medication review
- Mental health
- Activities of daily living
- Carer needs

See **Appendix B: Review** .

Physical health

Vital sign observations were recorded, and advice given and/or action taken when abnormalities were found. Weight was recorded for most of the participants to monitor general health, for medication review and to calculate fracture risk.

The Clinical Frailty Scale (CFS) is a 9-point scale for determining a person's level of frailty, and risk of hospitalisation, falls, conveyance, death and other adverse events (Rockwood, 2009). Frailty guides healthcare decisions and care plans. Frailty scores were calculated for all patients to identify those at increased risk for adverse events such as prolonged recovery from illness, hospital admission, delirium and falls (Bergman et al., 2007). Other areas were reviewed as appropriate such as medications, activities of daily living, fracture risk, blood tests, vision, hearing, weight loss, dental care, smoking and alcohol intake.

Medication review

The practice pharmacist completed a comprehensive medication review for each patient including opportunities for deprescribing and an updated risk/benefit analysis for each medication (Bužančić et al, 2022). As part of this, fracture risk was calculated using the Fracture Risk Assessment (FRAX) tool to identify those at risk and as a result either measure bone mass density (BMD) with a dual energy X-ray absorptiometry (DEXA) scan, discuss treatment options or provide lifestyle advice.

Mental state examination

A mental state examination was carried out including the following domains:

- Appearance and behaviour
- Speech, mood and affect
- Perception and thought
- Insight
- Neuropsychiatric symptoms

The patient and their carer were asked about recent changes in cognition. Cognitive screening instruments were not administered as all patients had an established dementia diagnosis. Cognitive screening is not required once the diagnosis has been made. This is a degenerative condition and cognitive testing may put undue stress on the patient. There is evidence supporting the long terms use of anticholinesterase inhibitors and Memantine and all patients should stay on the prescribed medication long term as long as they do not experience side effects. Some clinicians may choose to continue with cognitive testing if it does not cause the patient any distress and is requested by the carer.

Activities of daily living

In addition to the physical health review, there were a number of questions addressing activities of daily living (ADLs) including eating, drinking, continence, washing, sleeping, mobility, falls and ability to manage finances. Housing situations were explored and potential risks discussed.

Carer needs

The carer was asked how they were managing and whether any additional practical support was needed, e.g., a care package, respite, or emotional support. They were asked whether they had been referred for a carers assessment, which would enable them to obtain relevant entitlements or benefits.

Patient, carer and healthcare professional feedback

Pre- and post-review questionnaires were completed for patients and carers on site by the Care City team. Staff were also asked to complete an online reflection questionnaire (**Appendix C: Pre-review** , **Appendix E: Post-review** and **Appendix G: Questionnaire** for staff **questionnaire**).

Findings

Reviews completed

Appointments were offered to 24 patients of whom 15 were seen.

- Two patients did not attend (DNA):
    - One was subsequently seen at home
    - One patient had not received the appointment letter

- Eight patients declined reviews:
    - One cancelled on the day and did not want to reschedule
    - Main reason given was availability of carers

- Of the 15 patients who were seen, the location was as follows:
    - Nine clinic reviews (in GP practice)
    - Four care home reviews
    - Two home visits

All patients attending clinic had one or more carer with them. For those in care homes a care worker who knew them well attended. During one home visit a carer was able to attend and for the other the patient was seen alone.

Patient demographics

The demographics of the 15 patients reviewed were closely aligned to those of the local area.

- Gender – 47% male, 53% female
- Ethnicity – 82% White British, 6% Asian, 6% White Irish, 6% White Other
- Time since dementia diagnosis (taken from medical records)
    - 47% over three years
    - 20% one to three years
    - 33% under one year

Clinician completing the review

The bulk of the reviews were completed by the practice nurse, followed by a medication review with a pharmacist. Initially, patients had separate appointments with the nurse and the pharmacist. The reviews became quite lengthy and participant feedback on day one highlighted repetition and duplication. It was decided to conduct the nurse and pharmacist reviews together, which shortened appointment time significantly and eliminated duplication.

For care home patients, a care worker who knew the patients well contributed to the review. Carers were unable to attend but are regularly updated by care home staff. For home visits, a nurse specialist and occupational therapist from the pilot team conducted the reviews. An online multidisciplinary team (MDT) meeting was held the following day. Telephone medication reviews were completed by the pharmacist after the home visits were completed.

Referral for social prescribing would be valuable as many people were looking for opportunities to participate in social activities.

Our findings emphasise the importance of the review being undertaken by a clinician, particularly for complex cases. During the consultation phase, Londoners told us they preferred a qualified clinician to lead dementia reviews. A medication review completed by a pharmacist also leads to better outcomes (Bužančić et al., 2022).

Duration of review with the patient

The length of the reviews varied, mostly depending on the complexity of the situation. Reviews completed on the first day were longer due to separate nurse and pharmacist appointments; the duration reduced once the appointment was combined. The shortest review took 40 minutes and was in a care home; the longest took two hours due to complex circumstances. The mean review time was 80 minutes (the median was an hour). However, when the nurse and pharmacist appointments were combined, the mean duration was just over one hour.

Care home reviews took just over three hours to complete for the four residents. The home visit reviews each took 90 minutes to complete, plus time for telephone pharmacy reviews completed afterwards.

The aim was for the clinician to document on EMIS during the review; however, this was quite challenging due to the complexity of the reviews during which the clinicians wanted to give their full attention to the patient. As a result, documentation, referrals and other actions took an additional one to two hours to complete.

The post-review multidisciplinary meetings conducted with a GP took 60 to 90 minutes, depending on how many patients were discussed and their complexity.

Referrals

In total, 18 referrals for 13 patients were made to other services (some patients had more than one referral).

Physical health referrals (8) included: rheumatology, cardiology, oncology and speech and language therapy (SALT).

Mental health referrals (6) included: talking therapies and the memory service.

Social referrals (4) included: respite care, package of care and social activities.

One review did not generate any referrals or actions; this person was living in a care home.

Physical health review findings

Urinary Tract Infection (UTI)

One care home resident reviewed was fidgety, restless, disengaged and staff reported some aggression. It transpired that UTIs were common in this person and often associated with changes in behaviour. Staff were aware to start antibiotics. However, the recurrent nature of these behaviours was distressing for the patient, other residents and staff. After a discussion with the GP, it was agreed to start the patient on prophylactic low dose antibiotics to prevent UTIs. If successful, this will prevent future infections and hospitalisations and support the health and wellbeing of the patient, other residents and staff.

Blood results

Eight patients underwent a blood test, of whom 7 had at least one abnormal result:

- Five people had impaired kidney function
- Two people had elevated HbA1c requiring diabetes advice or medication changes,
- One person had elevated cholesterol requiring treatment with medication
- One person had a prolactin level outside the normal range due to a condition which had been previously diagnosed; specialist advice was sought
- Three people had folate deficiency
- One person had anaemia

Five patients did not have the recommended blood test during the pilot. This could be due to challenges in booking or attending a phlebotomy appointment.

Fracture risk

Some patients had fallen in the last year; the falls themselves had been addressed by the GP or other professionals prior to the review.

Fragility fractures are a common problem for people living with dementia and can impact on quality of life and baseline function (Van Balen et al., 2001). As a result of calculating the FRAX score, in five people a recommendation was made to start treatment. Lifestyle advice was recommended for four patients and in one person a bone density scan was recommended. One patient was on a bisphosphonate holiday, which was subsequently reviewed by the GP. Two people were over 90 and were flagged for a discussion about bone protection with the GP as this age group is automatically considered high risk (NICE, 2019). Unfortunately, in four patients FRAX score could not be calculated due to lack of recorded height/weight within ten years and no opportunity to complete this during the reviews.

Medication review

A comprehensive medication review was done for each patient by the pharmacist in consultation with the GP. Out of 15 reviews, ten resulted in a recommendation for changes in medication and three resulted in the GP seeking specialist advice. These actions were mainly generated by the blood test results. Most medication changes were related to prescribing of vitamin/mineral deficiency replacement, anti-diabetic medication, anti-hypertensives and cholesterol-lowering drugs.

Medication passports listing all medications and the health condition or symptom they are prescribed for were offered by the pharmacist and a number of people accepted (exact number unclear as some pharmacy reviews were completed after the pilot finished). Research shows that a medication passport is a useful tool for patients so they can be better informed about their care (Ali et al., 2023).

Clinical Frailty Scale (CFS)

Nine people were identified as having either mild (CFS=5), moderate (CFS=6) or severe frailty (CFS=7) and could have benefitted from referral for a comprehensive geriatric assessment (CGA); however, this service was not available in the community at the time of the pilot (Hopper, 2021). One person was vulnerable (CFS=4), two were managing well (CFS=3) and one person was well (CFS=2).

Mental health review findings

Most reviews uncovered low mood and poor mental health in both patients and carers. Where referrals to mental health services were discussed most patients and carers asked for time to think about it. Information on self-referral to counselling services for patients/and or carers was sent to six people. Three patients were referred to the memory service for review. One had declined a cholinesterase inhibitor when this was previously offered by the memory service and was keen to be referred back for further discussion. One had been prescribed medication to facilitate sleep. They were still experiencing disrupted sleep and early morning waking and wanted this medication to be reviewed by the memory service. One was for the carer to obtain advice on managing the patient’s behavioural and psychological symptoms (BPSD).

One patient reported visual hallucinations; however, these were not distressing to her and therefore antipsychotic medication was not recommended.

As described above, one of the care home reviews prevented an unnecessary referral to the Community Mental Health Team (CMHT) as recurrent UTIs were identified as the cause of behavioural change and this was managed with prophylactic antibiotics.

Other topics included in the review

Wishes for the future

When appropriate, patient wishes around advance care planning were explored. This was discussed in 11 of the reviews. This was a difficult conversation for some patients, families and healthcare staff. However, some patients and carers felt that it should be talked about more openly with healthcare professionals, particularly while a person living with dementia has capacity to share their wishes. Some people already had an advance care plan and many people had a Lasting Power of Attorney (LPA) or were in the process of doing this. Two people started the process for LPA as a result of the review. At least one person had a Universal Care Plan (UCP) created to share their wishes with all health and social care staff. It was also identified that training in advance care planning would be beneficial for staff.

Carer needs

Carer needs were also explored as part of the review. They were asked whether they were coping emotionally, mentally and physically, and all were signposted to local carers support organisations via text or as a leaflet, including information about respite care. Several carers spoke about the importance of having time alone with the healthcare professional and the need to address issues they were not comfortable talking about in front of their relative.

Research

Seven people were offered the opportunity to be involved in dementia research; three were interested and were referred to Join Dementia Research (JDR).

Intervention/Action	Number
Blood test abnormality found	8
Medication change	9
Referral for physical health	8
Referral for mental health	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. Interventions arising from the 15 reviews.

Patient, carer and healthcare professional feedback

A full description of questions and responses is provided in appendices C-H.

At the care home only one patient was able to engage with the questionnaire. For patients reviewed at home, Care City attempted to complete questionnaires by telephone.

Pre-review questionnaire responses (appendix D)

Approximately 30% of people reported having a review of their dementia with a medical professional within the previous six months. The remainder could not remember or reported it was five years ago or longer. The surgery that hosted the pilot aims to review their patients living with dementia yearly; however, due to pressures in primary care, this is not always possible. Even with this support from their GP, nearly half of respondents reported feeling unsatisfied with support in relation to dementia care.

When asked who they would contact for advice or support relating to their dementia, most people said that they would either go to their GP or the memory service; nearly a third were not sure. Patient and carer expectations of the review were explored; most people said they had little or no idea what to expect.

Post-review questionnaire responses (appendix F)

Using the Friends and Family Test, over 80% of people said they would recommend this review to friends and family if they had dementia. Everyone said the review was helpful. They appreciated having a holistic review completed by a healthcare professional, as they had time to talk about important issues that in some cases had been troubling them for years. They felt listened to. People also expressed the importance of local knowledge of organisations they could turn to for support with non-health issues.

Most people reported that attending a clinic appointment at the surgery was a positive experience. One family with multigenerational caring responsibilities felt a home visit would have been easier for them. Those who are housebound and/or without carers would also benefit from a home visit. People who had joint reviews with the nurse and pharmacist felt this was efficient and beneficial.

Patients and their carers were asked for feedback on how to improve the reviews. Key themes were as follows:

- Clear communication
- Efficient and organised meetings
- Support and information sharing
- Sensitive language use
- Addressing advance care planning
- Continuity of care and support
- Emotional support and engagement
- Better preparation of what to expect in the review included in an appointment letter
- Named contact person for dementia care

Staff questionnaire responses (appendix H)

Overall, the healthcare professionals conducting the reviews found it to be an intense yet positive experience, and was more rewarding than they had anticipated.

Care home reviews were completed in less time, as it was felt most needs were already being met by care home staff and regular GP reviews. However, medication reviews were felt to be useful.

The healthcare professionals felt that the reviews were beneficial for both patients and their carers, through facilitating early recognition of problems, and potentially avoiding negative outcomes. They appreciated having the time to listen to and support patients.

Discussion

Dementia is a progressive illness; life expectancy is 5 to 10 years after diagnosis (Alzheimer's Society, 2021). A lack of appropriate support increases the likelihood that these years will be experienced as a series of stressful adverse events such as falls, unnecessary hospital conveyances and admissions, and rapid cognitive and functional decline (Wheatley et al, 2021). Evidence shows that good quality post-diagnostic dementia care at an earlier stage may prevent some of these events, thereby maintaining quality of life, proactively preserving better health and providing cost savings to the NHS (Kelly & Innes, 2016; Michalowsky et al., 2019).

Out of 15 reviews performed in this pilot, only one did not generate any referrals or actions. For the others, referrals were made for physical and mental health and for social needs (table 1). Medication changes, investigations, health advice and increased monitoring were also initiated. During the pandemic, some patients had been lost to follow-up for outpatient care, including monitoring of life-threatening conditions such as cancer. The needs of carers were addressed. People felt listened to and supported and knew where to turn if they had future concerns.

Location

Most of the appointments were completed in the clinic environment at the local GP surgery. Feedback from these patients was positive; most preferred a clinic appointment. Some patients, especially those who have carers with multiple caring responsibilities, those without carers, and those who would find it cognitively and/or physically challenging to get to the surgery, preferred a home visit. This highlights the value in offering a flexible approach to appointment types to ensure an equitable service that can access everyone regardless of their circumstances.

Care home patients are best reviewed in their care home in the presence of someone who knows them well, such as a carer or care worker. These patients had fewer unmet needs but a medication review was especially useful.

Any necessary blood tests are best done at the time of the review to avoid patients having to navigate a phlebotomy booking system or make repeat visits. This can be facilitated by the reviews being co-located with a phlebotomy service or one of the team being able to take bloods.

Staffing

Dementia reviews should be comprehensive and holistic (Bamford et al., 2021). This is more likely to be achieved if at least one of the team conducting each review is a healthcare professional. Feedback from service users endorsed this.

A medication review with a pharmacist prompted a significant proportion of interventions and advice. A pharmacist has been shown to be an effective component of the community-based multidisciplinary team for people with dementia (Dann-Read et al., 2020).

Benefits

A holistic dementia review can have many positive benefits for a person living with dementia and their carers (Giebel, Morley & Komuravelli, 2021).

- Improved wellbeing and mental health of patient and carer
- Prevention of future illness and adverse events
- Dignified death, ensuring patient wishes are followed

The social aspect of the review addressed social isolation, low mood and depression. Research has shown that social isolation can have a negative impact on both mental and physical health (Leigh-Hunt et al., 2017; Shankar et al, 2011).

Carer burden and stress is a challenge in health and social care as it has a negative impact on both the care giver and receiver (Gilsenan et al., 2023). This can have serious consequences if the carer is unable to provide care due to ill health (Prince et al., 2014).

In 14 out of 15 reviews, interventions and actions were completed. Although there was no control group, we believe it likely these reviews prevented adverse events and encouraged improved health and wellbeing.

Regular monitoring of health risks and conditions e.g., by reviewing symptoms and vital signs, and blood tests where clinically appropriate, ensures any change is promptly addressed, potentially preventing adverse outcomes (Piercy et al., 2018). Falls and associated fractures can be prevented through appropriate risk mitigation. Antibiotic prophylaxis to address regular UTIs, and ensuring care home staff are trained to recognise the symptoms of a UTI, can reduce complications such as delirium or sepsis.

Cost effectiveness

A holistic dementia review, similar to the one in this pilot, leads to improved quality of life and decreased health and social care costs, in particular 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, 2019b). By keeping people happier, more independent, healthier and safer at home for longer, proactive care is likely to reduce these costs (Bleijenberg, 2017; Kelly & Innes, 2016). Costs of NHS services frequently used by living with dementia are itemised in appendix I.

Examples of existing lifetime post-diagnostic services in London are given in appendix J and estimated staff costs in appendix K.

Limitations

The population in which this pilot was performed is not representative of London as a whole, due to a low proportion of people from ethnic minority communities, and relatively low levels of deprivation. This might affect the appropriateness of the model in more diverse and/or deprived settings. The surgery in which the pilot was performed already takes a proactive approach to supporting people living with dementia; this might have reduced the amount of unmet need in our cohort. The sample size was small, inevitably given the time and resources available, so might not be representative. There was no control group, so the impact of the intervention is hard to assess compared to usual care. Follow-up was not performed, so the outcome of referrals and interventions could not be ascertained.

Conclusion

Our findings support the case for investment in a lifetime post-diagnostic service. Examples of existing lifetime post-diagnostic services in London are given in appendix J and estimated staff costs in appendix K. Service design, location and provider will vary. The priority is on the offer, which 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, 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/carer access to a named dementia keyworker between reviews
- Inclusion of vulnerable patients e.g., those affected by digital exclusion, 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

About

Care City

Care City is an innovation centre for healthy ageing and regeneration. Our mission is a happier, healthier older age for East Londoners. We pursue this mission by working as an innovation partner to East London's health and care system. We do research, innovation and development work of local benefit and national significance. Care City was commissioned by NHS England (London) Dementia Clinical Network and worked in partnership with UCLPartners on the research and development of this report.

About London Dementia Clinical Network

The NHS England (London) Dementia Clinical Network (LDCN) brings together clinicians, commissioners, people living with dementia and their carers to support improvements in dementia services, so that people living with dementia receive an effective and timely diagnosis and evidence-based treatment and care.

About UCLPartners

UCLPartners (UCLP) is one of 15 Academic Health Science Networks (AHSNs) across England and brings together people and organisations to transform the health and well-being of the population across parts of London, Hertfordshire, Bedfordshire and Essex.

Appendix A: Invitation letter

Dear XXXXX

Our records show that you have a diagnosis of dementia.

We are writing to you to offer you an enhanced dementia review at XXXX as part of a quality improvement project we are working on in partnership with the London Dementia Clinical Network.

This review will cover how you are currently managing and what will be helpful to support you. The review will last up to 1.5 hours and you are more than welcome to bring someone with you.

Please contact us on telephone number XXXXXXXX to book an appointment or if you have any questions. If you are unable to travel to the GP practice, we may be able to offer a home assessment where needed.

We look forward to meeting you.

Kind Regards

xxxxxx

Appendix B: Review template

Post-Diagnosis Dementia Assessment

Review to be completed with patient and someone who knows them well if possible.

Post Diagnosis Pilot Dementia Review			
Name:	**DOB:**	**Address:**	**NHS No:**
Diagnosis:			

Introduction
What matters to you
Vital Sign Observations
Blood pressure: Pulse: Oxygen Saturation:
Plan
1.
Mental State Examination
Appearance and Behaviour: **Speech:** **Mood:** **Perception:** **Thoughts:** **Insight:** **Neuropsychiatric Symptoms:** **Changes in Cognition (Carers observations):**
Level of Mental and Physical Functioning
Activities of Daily Living (ADL) (eating, drinking, continence, washing, sleeping, mobility, finances): **Mobility issues:** **Housing:** **Falls or fear of falling:**

Medication

Covid vaccine status:

Physical Health

Recent Physical Health Issues, Recent GP Visits, Hospital admissions, Outpatient Clinics:

Vision:
Hearing:
Teeth:
Weight loss:
Smoking and Alcohol consumption:
Bloods:

Wishes for the Future – ACP – LPA - UCP

Carers

How is carer coping and current stressors:

Safety and Wellbeing Risks

Research

Would the patient and/or carer be interested in participating in further research?

Clinical Frailty Scale

FRAILTY QUESTIONNAIRE

For each question, please select **all** of the options that apply to you.

Two weeks **BEFORE** your current illness...

Q1. Did you need help with any of the following personal care?

☐ Using the toilet ☐ Getting dressed ☐ Bathing/Showering ☐ Walking

**Stop here if you have selected any of the options above.*

Q2. Did you need help with any of the following activities?

☐ Going outside ☐ Handling Money ☐ Taking Medications

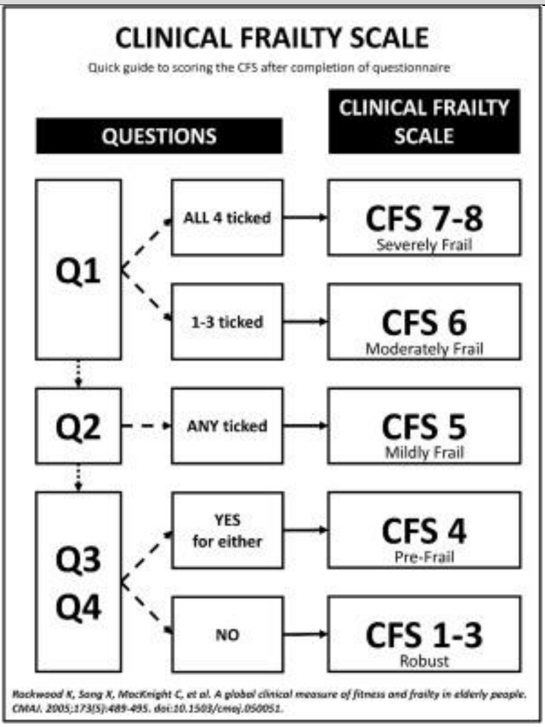
**Stop here if you have selected any of the options above.*

Q3. Did you feel constantly tired throughout the day?

☐ Yes ☐ No

Q4. Did you feel that you were walking slower than usual?

☐ Yes ☐ No



Rockwood K, Song X, MacKnight C, et al. A global clinical measure of fitness and frailty in elderly people. CMAJ. 2005;173(5):489-495. doi:10.1503/cmaj.050051.

Bone Health – Fracture Risk

FRAX Score (age at menopause, parents fracture hip, previous fracture):

Appendix C: Pre-review questionnaire

Do you mind me taking note of your views? (do you give consent to my gathering your experience view)

- Yes
- No

Who is completing this questionnaire?

- Person with dementia
- Carer
- Person with dementia and their carer together

How long ago did you receive a dementia diagnosis?

- Around 6 months ago
- Around a year ago
- Around three years ago
- Over five years ago

Can you recall the last time you had a review of dementia with a medical professional?

- Within the past month
- Within the past six months
- Within the last five years
- Longer than 5 years
- I can't recall

How well do you (as a family) feel supported with dementia care?

😁 Very satisfied

😃 Satisfied

😳 Unsure

😟 Unsatisfied

😖 Very unsatisfied

Who would you contact if you were worried or needed advice?

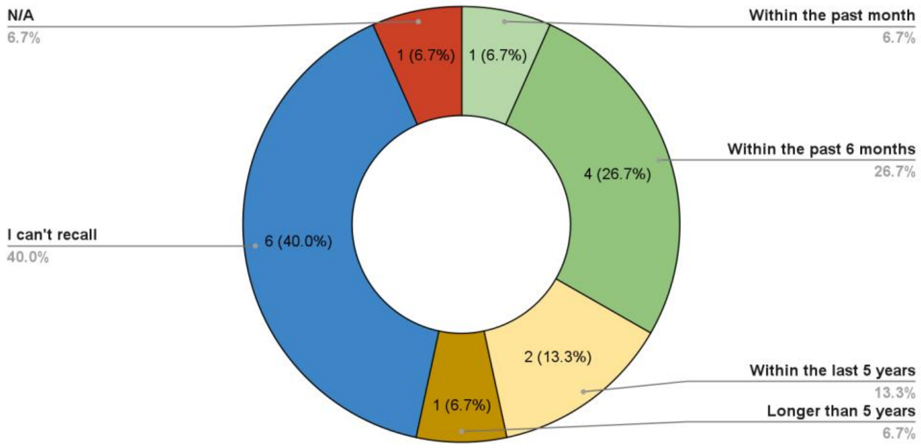
What are your expectations of this review?

Appendix D: Pre-review questionnaire answers

Can you recall the last time you had a review of dementia with a medical professional?

Six out of 15 people (40%) reviewed were unable to remember when they last had a review of dementia. The majority of these were care home residents. One person was not informed of their dementia diagnosis, and so this was labelled as 'Not Appropriate.' Four people had received a review within the past six months.

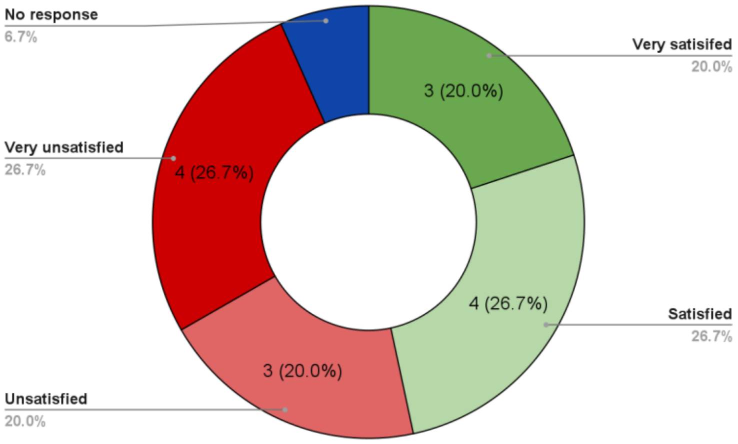
Figure 1 – Patient reporting of when previous dementia review occurred



How well do you (as a family) feel supported with dementia care?

Emoticons were used to aid communication. Around half were satisfied and half were unsatisfied with the dementia care received.

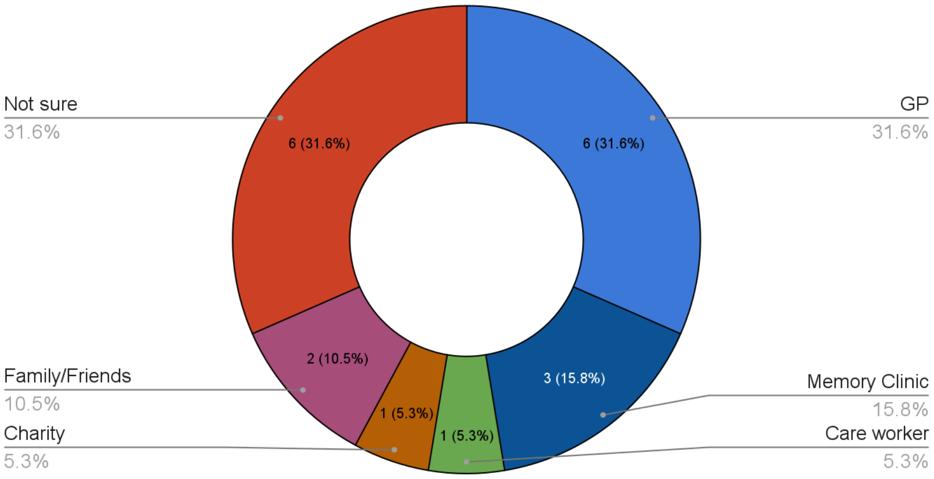
Figure 2 – Opinions on dementia care



Who would you contact if you were worried or needed advice?

Some gave more than one response. More than half of the responses (52.7%) stated they would access health or social care if they were worried or needed advice. Some said they would contact family or friends (10.5%). However, almost a third of people (31.6%) said they did not know where to go for advice.

Figure 3 - Who people would go to for advice



What are your expectations of this review?

Most people (53%) said they did not know what to expect during this review. Some commented that a detailed letter arriving prior to the appointment would have been helpful. Some (20%) felt the review was an opportunity to discuss the needs of the family.

Appendix E: Post-review questionnaire

How likely would you be to recommend a care plan review to your friends / family (if they had dementia)?

😄 Extremely Likely
😀 Likely
😐 Neither likely or unlikely
🙁 Unlikely
😠 Extremely Unlikely
😕 Unsure

Thinking about the question above - why do you feel this way?

How helpful was your care plan discussion?

🙂 Very helpful
😐 OK
🙁 Not helpful

Why was it helpful / unhelpful?

What was your experience of coming into the GP surgery?

🙂 Impressed
😐 OK
🙁 Not great

Where would you prefer to have future reviews?

- GP surgery
- Home visit

Did you feel listened to during your care plan review?

- Yes
- No
- Unsure

What could we have done differently?

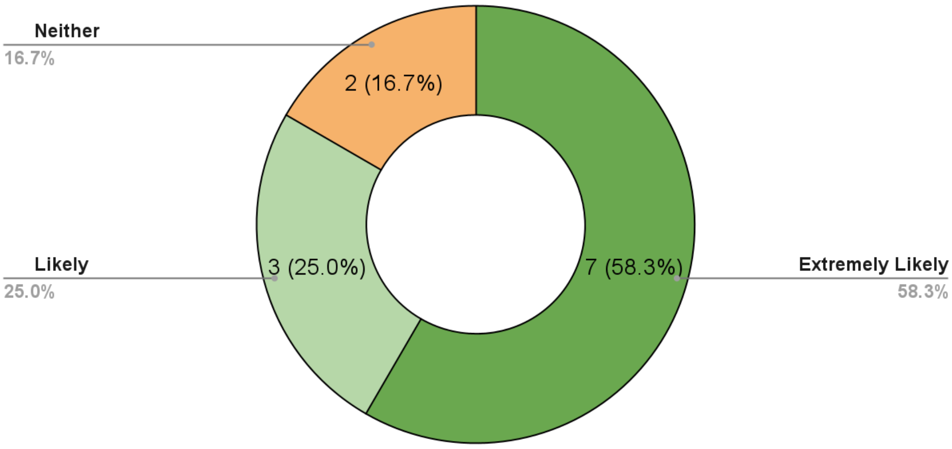
Appendix F: Responses to post-review questionnaire

The people reviewed had varying levels of communication, this meant that not all questions could be answered. In these cases, attempts to contact family members for further information were unsuccessful.

How likely would you be to recommend a care plan review to your friends / family (if they had dementia)?

A visual scale was used to aid communication. Most people said they would be ‘Likely’ or ‘Extremely likely’ to recommend this review to others they know who have dementia, 83% of people. No one said they would be ‘Unlikely’ or ‘Extremely unlikely’ to recommend this review.

Figure 1 - Likelihood of recommending the review to others



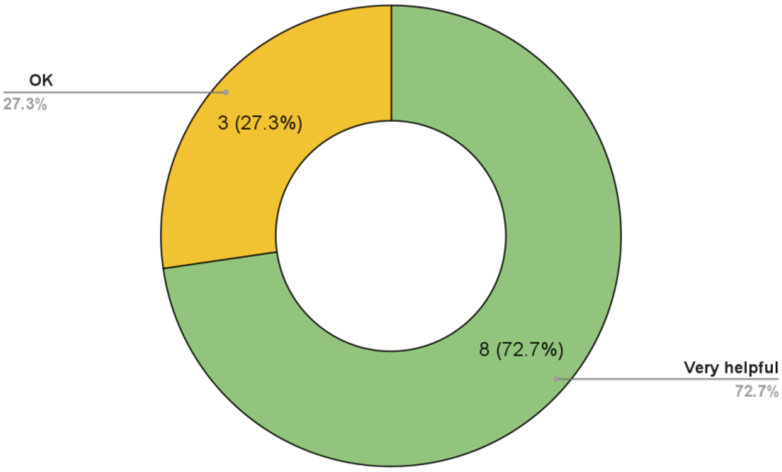
Thinking about the question above - why do you feel this way?

People appreciated the opportunity to raise concerns with a medical professional. Some felt reassured and felt that longstanding issues could be addressed due to the holistic nature of the review. People also appreciated the local knowledge of where to get support when non-health issues arise.

How helpful was your care plan discussion?

A visual scale was used to aid communication. Most people (73%) felt the care plan discussion was helpful. No one said the review was ‘unhelpful.’

Figure 2 - Opinions on whether the care plan discussion was helpful



Why was it helpful / unhelpful?

Some of those living with dementia did not identify with the term ‘dementia’ and said the reviews were ‘Ok.’ But even those people agreed it was a worthwhile endeavour. One person also noted that they found talking about dementia an emotional topic.

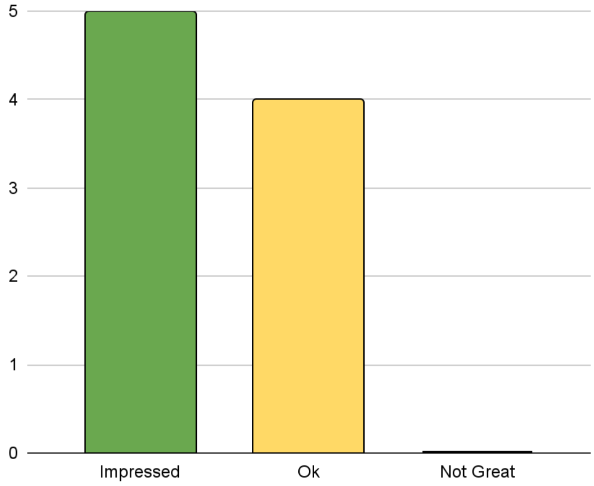
Most people reported the review was ‘very helpful.’ Many found the review provided them with information about available resources, such as support from the local authority and local clubs.

The individuals felt the healthcare professionals conducting the dementia review were good listeners with a calm and understanding demeanour. They were grateful that their needs were being considered. The carers specifically mentioned that the healthcare professionals helped them to feel understood and supported. They appreciated having someone to talk to and guiding them through their journey.

What was your experience of coming into the GP surgery?

Most were ‘Impressed’ or felt it was ‘OK’ attending the GP surgery for the review. When asked how this could be improved, some mentioned that a formal letter would have been appreciated.

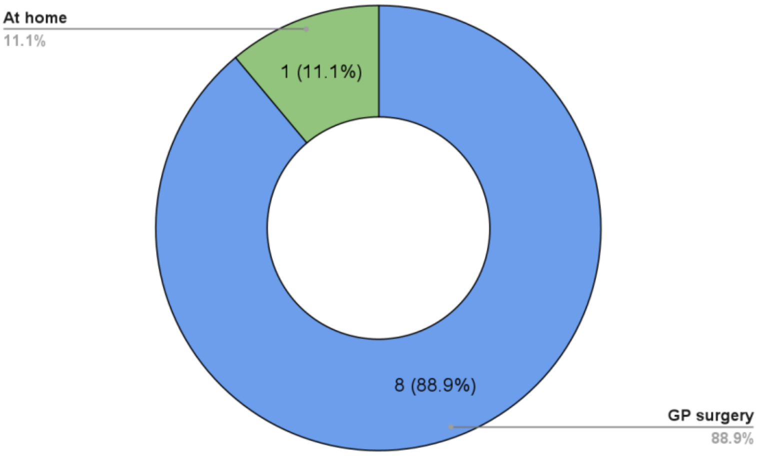
Figure 3 - People’s experience of coming into the GP surgery



Where would you prefer to have future reviews?

This question was asked to those who attended the pilot at the GP surgery. The others involved in the pilot had to be seen in their location. Most (88.9%) said they would prefer to have the review at the GP surgery. The results of this answer seemed to differ from the London-wide consultation, where the majority stated they would like to have the review in their own home.

Figure 4 - People’s preference for location of review



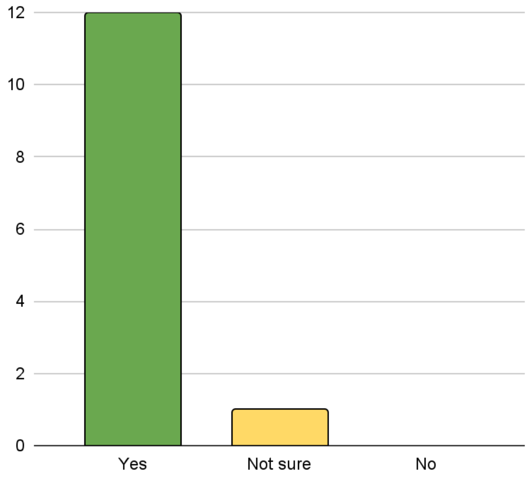
When asked why they would rather have the review at the GP surgery, people said they felt this meant their dementia was seen as a health condition. Others also mentioned that they liked to keep parts of their life separate, dementia did not define them, it was only one part of their life. Some felt having the review at home may blur those lines. One person felt that they wanted to have the review at the GP surgery as they wanted to minimise the stress on NHS services.

Some families who preferred to be reviewed at home, felt that the stresses of caring meant that they felt “too burnt out” to manage a trip to the GP surgery.

Did you feel listened to during your care plan review?

Most (92%) felt they were listened to during the review. Two people were unable to respond and one person was not sure.

Figure 5 – Did people feel listened to during the care plan?



What could we have done differently?

The key themes for improving a dementia review included clear communication, efficient and organised meetings, support and information sharing, sensitive language use, addressing advance care planning, continuity of care and support, emotional support and engagement.

Carers expressed the need for more information about the review process to help them prepare appropriate questions for medical professionals.

Participants emphasised the importance of having all relevant professionals present at the same time, to avoid duplication of questions and reduce time spent waiting. This approach was seen as beneficial and preferable.

It was noted that using appropriate and non-distressing language when discussing dementia is essential. The medical term used during the review caused distress for some, highlighting the importance of using more sensitive language. Consent to share information was mentioned as an important aspect, and it was suggested that medical professionals could communicate with carers prior to the review to better understand the person's needs. Participants mentioned the need to discuss advance care planning (ACP) while the person with dementia still has the capacity to participate.

Carers mentioned the lack of support and follow-up after being discharged from the memory clinic. They suggested having a designated contact person in the surgery to provide ongoing support and information. They also requested guidance on how to support the person living with dementia.

Participants reported a positive experience and appreciated the opportunity to speak with people during the review. They valued being listened to and praised the nurses for their care and attention. But felt that the environment of the GP surgery was not optimal, and creating a more homely and comfortable environment during the review was also recommended.

A carer expressed the wish for a cure for dementia, highlighting the ongoing need for research and medical advancements in this area. Seven of the 15 participants were directed to ‘Join Dementia Research.’ This is in line with NICE guidance (NG97). Those with communication difficulties or who found the term dementia distressing, were not directed to the research site.

Appendix G: Questionnaire for staff

- Can you tell us a little about your experience in completing these reviews? Positives, negatives, how did it feel completing these reviews?
- What were the main outcomes of the reviews?
- How do you think the reviews supported the patient and/or carer?
- Do you think there was anything not covered in the reviews that should have been?
- If the review had not happened, how and where do you think the patient and/or carer would have got help from?
- Any other thoughts, recommendations, suggestions?

Appendix H: Answers for questionnaires for staff

Can you tell us a little about your experience in completing these reviews? Positives, negatives, how did it feel completing these reviews?

The medical professionals who conducted the review had a positive overall experience and felt that the reviews were more rewarding than they had initially anticipated, benefiting both themselves and the patients/caregivers involved. The nurse who conducted the interviews found them to be intense but worthwhile.

The staff noted that nursing home residents were already well cared for, leading them to question their own necessity in the process at this location. Nevertheless, they recognised the importance of conducting an in-depth medication review at that time.

Visiting patients in their own homes was described as a lovely experience. Initially, the patients were unsure about the purpose of the visit, but after the review, they became more comfortable and happy that the medical professionals had come. Overall, the review was perceived as beneficial for both the patient's care and their overall well-being.

What were the main outcomes of the reviews?

Action plans were established during the multidisciplinary team (MDT) meetings, which proved to be beneficial. Medications were reviewed, dental and optician referrals were made, as well as requesting up-to-date blood tests. Patients were referred to local charities for additional support.

A lost to follow-up case was identified. The patient was supposed to see the breast clinic, but there was no clear plan regarding the duration of her medication. Another patient was referred back to the memory clinic to seek assistance with symptom management.

How do you think the reviews supported the patient and/or carer?

Staff highlighted the positive impact of involving both patients and their caregivers. The carer was able to discuss concerns and benefited from a follow-up appointment with a doctor, resulting in the initiation of antidepressant medication for the carer.

Medications were optimised through processes such as de-prescribing, providing medicines information and discussing side effects. It was felt that these discussions reassured the carers, allowing them to be open and honest about their experiences.

Additionally, clinicians felt the review of patients and carers emphasised early recognition of potential problems. The aim was to reassure carers that they were taking the right steps and offer advice on further actions, while also providing a space for patients to express the difficulties they were facing. Building a long-term relationship and trust with the same person or team through yearly interactions would further enhance these benefits.

Do you think there was anything not covered in the reviews that should have been?

No suggestions were made. However, one person noted that a patient with no carers may require a more in-depth review and may have additional unmet needs.

If the review had not happened, how and where do you think the patient and/or carer would have got help from?

Overall, it was felt that this review has helped prevent potential negative outcomes, such as fragmented or delayed help, waiting for scheduled reviews, not seeking help at all, and ongoing visits from healthcare professionals or mental health teams.

It was felt that the patients involved in the pilot would have eventually received assistance from a doctor or nurse, but it might have been provided in a disjointed or delayed manner. There was a possibility that some individuals might not have asked for help at all. Without this review, they might have continued to suffer without seeking appropriate assistance for their condition.

It was identified that the involvement of a mental health community response team may have been avoided due to the new review. This indicates that the individuals' needs were effectively addressed, reducing the requirement for additional specialised support.

Any other thoughts, recommendations, or suggestions?

Staff believe that implementing the dementia reviews on a national scale would be beneficial. However, there is some uncertainty regarding whether it should be implemented in primary care settings. Instead, they suggest that Dementia Centres, equipped with appropriate multidisciplinary teams and the ability to provide comprehensive support to both carers and patients, may be more suitable for conducting reviews.

Additionally, the professionals highlight the importance of longer appointment durations. They consider this an excellent feature, as it allows for more thorough assessments and discussions with patients.

Furthermore, the review emphasises the need for extra staffing and financial resources for leisure activities. The current lack of funding and staffing levels has led to a reduction in activities available, which negatively impacts the quality of life for patients.

Lastly, the review acknowledges the significance of home visits, stating that without this option, many of these patients would not have been seen at all.

Appendix I: Costs for common NHS treatments/services

Table 1. Cost estimations (per person) for common adverse events impacting people living with dementia (Jones et al., 2022; Walford, 2023). London adjustments when not available were calculated by comparing the market forces factor in trusts in England versus trusts in London, the difference between these is a 12% increase for London (NHS England, 2023).

Service/treatment	Cost (national average)	London adjustment
Ambulance services – see, treat and convey to ED	£367	£411
Non-elective inpatient stays (long stays) – average cost per episode	£4,974	£5571
Non-elective inpatient stays (short stays) – average cost per episode	£985	£1103
Patient costs following discharge from acute medical units	£2,431*	£2723
Cost of hospital and social care services in the last year of life (dementia)	£20,909**	£23,418
Package of care (per hour)	£25	£28
Residential home (per week)	£1,174	£1,476
Nursing home (per week)	£1,333	£1,619

*Includes average cost of hospital care, mental health care, social care and primary up to 3 months post discharge

**Higher cost than any other diagnostic group

Appendix J: Current lifetime post-diagnostic memory services in London

Place-based services in three London boroughs currently offer lifetime dementia support: City and Hackney, Camden and Islington.

City & Hackney

City and Hackney memory service offers lifetime post-diagnostic care to people living with dementia and their carers. This is delivered by dementia specialist nurses, navigators and social care practitioners with the support of a multidisciplinary team. The borough is broken into neighbourhoods; each navigator, nurse and social care practitioner are assigned two neighbourhoods and a caseload of patients who remain under their care for life, unless they move out of area. The team is consultant-led and includes clinical psychologists, psychiatrists, an occupational therapist, nurses, navigators, social workers, managers and team administrators.

Ideally the aim is for four contacts a year; two by telephone and two home visits. Patients and carers are also able to contact the service at any point for advice and/or a review, typically with a nurse or a navigator. Initial contact is a phone call and is done within three months of the referral date. The first home visit is offered six months after the referral date. Each member of staff should have approximately 150 people on their caseload, though this number has grown as demand increases.

The service is designed to be a step up and step down model. The navigators see most patients and refer to clinically-qualified colleagues where required. Assessments vary by staff member but can include the following:

- Dementia navigator: signpost, monitor risks, education, encourage engagement, carers support, also pre diagnosis support for complex patients prior to diagnosis
- Dementia nurse: medication efficacy, cognitive stimulation therapy (CST) groups, monitor deterioration, advance care planning, lasting power of attorney, palliative care, support carers
- Occupational therapist: functional assessment
- Psychologists: neuro assessments, cognitive stimulation therapy (CST) groups, high-intensity psychotherapy, carer intervention
- Social care senior practitioners: social care assessments
- Community Mental Health Team (CMHT): care coordination for complex patients with behavioural & psychological symptoms of dementia (BPSD)

The electronic patient record system used is Rio and access to other health records is via Health Information Exchange (HIE) where some hospital results, medications and some clinic letters can be viewed. Clinicians have access to and update the Urgent Care Plan (UCP) system as needed for advance care planning. Frailty scoring is completed by the nurses and patients can be referred to the Integrated Independence Team if further frailty assessment is needed. Outcomes are mostly measured by number of visits completed within the target timeframe.

Camden & Islington

Camden & Islington memory services support patients and carers from diagnosis to end of life, unless they leave the area or move to a care home.

Post-diagnostic care is provided using a step up and step down model in which frequency of contact is dependent on the level of need and risk but is a minimum of twice a year. Patients and carers can contact the team for advice and/or request a visit if needed. The dementia navigators/assistant practitioners hold the biggest caseload and see most patients but step patients up to clinically qualified colleagues depending where needed.

Rio is used as the electronic patient record system and access to other health records is via Health Information Exchange (HIE). Clinicians do not currently update the Urgent Care Plan (UCP); however, frailty scoring is completed by the nurses and there is a multidisciplinary frailty hub or community frailty service to which patients can be referred.

All people with a diagnosis of dementia in these two boroughs remain under the care of the memory service unless they are receiving treatment from the Community Mental Health Team, are entering permanent residential care or are at end of life.

Appendix K: Cost estimates for post-diagnostic dementia service

Table 1. The following table offers a generic guideline for potential employee costs for a post-diagnostic dementia service (Jones et al., 2022).

Post-diagnostic staff costs	Cost (national average)
Cost per hour band 7 (pharmacist, nurse, occupational therapist, physiotherapist)	£74
Total yearly cost for each full time band 7 *	£114,737
Cost per hour band 6 (pharmacist, nurse, occupational therapist, physiotherapist)	£63
Total yearly cost for each full time band 6*	£97,676
GP time for multidisciplinary meeting	£159 per hour

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

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