

**INDIVIDUALS/
HEALTH
OVERVIEW &
SCRUTINY
COMMITTEE**

REPORT

12 APRIL 2011

Subject Heading:

Dementia Strategy Topic Group Report

CMT Lead:

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Policy context:

Findings of the Dementia Strategy Joint
Topic Group

SUMMARY

This report contains the findings and recommendations that have emerged after the Joint Topic Group scrutinised the subject selected by the both the Individuals and Health Overview and Scrutiny Committees in June and July 2010 respectively.

The financial, legal and HR implications are addressed within the topic group's report.

RECOMMENDATIONS

That Members:

1. Note the report of the Joint (Individuals and Health) Overview and Scrutiny Committee Topic Group (attached);
2. Decide whether to refer the recommendations of the Joint Topic Group to Cabinet, the North East London NHS Foundation Trust (NELFT) or other bodies as appropriate.

REPORT DETAIL**1.0 BACKGROUND**

- 1.1 At their meetings on 29 June 2010 and 8 July 2010, the Individuals Overview and Scrutiny Committee and Health Overview and Scrutiny Committee respectively agreed to establish a joint topic group to scrutinise the Dementia Strategy in Havering.
- 1.2 The following Members formed the topic group at its outset: Councillors Linda Trew (Chairman), June Alexander, Wendy Brice-Thompson, Linda Hawthorn, Lynden Thorpe and Fred Osborne.
- 1.3 The joint topic group met on four occasions and carried out two visits. One was to the Alzheimer's Society Dementia Café, and one to visit sessions run by Age Concern Havering.

2.0 SCOPE OF THE REVIEW

To consider the following areas as part of the National Dementia Strategy as it is applied in Havering but to focus on these five main issues and their impact on the local Havering population. The three main themes reflect those of the National Dementia Strategy.

Raising awareness and understanding

- To gather accurate information on the numbers of people affected by dementia in Havering.

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- To consider the role of informal carers in Havering and their views of local dementia services

Early Diagnosis

- To consider the role of the dementia care advisors and how this meets the needs of Havering residents

Living well with Dementia

- To investigate the range of dementia therapies available locally.
- To investigate the role of Admiral Nurses and the work they undertake in Havering.

3 FINDINGS**General overview****3.1 The Alzheimer Society, describe Dementia as:**

" An umbrella term. It describes the symptoms that occur when the brain is affected by certain diseases or conditions. There are many different types of dementia although some are far more common than others. They are often named according to the condition that has caused the dementia. Some of the more common types include, Alzheimer's Disease, Vascular Dementia, and Fronto-temporal dementia"

3.2 In Havering, the numbers of people over 65 years of age with dementia is expected to increase by 33% by 2025. Over the next 15 years the biggest impact overall for Havering will be in the change in the over 65s (23% growth compared to London 19.2%) and the over 85's (49% growth compared to London 38.1%).

3.3 The most recent records held indicate that, there are approximately 1015 patients registered with NHS Havering as having some form of Dementia. This represents only a third of the number that would be expected to have dementia in Havering, based on the prevalence data. This under diagnosis reflects the national picture. The number of dementia patients registered represents 0.4% of the entire registered GP population (a total of 250,662) giving a prevalence below the England national average of 1.1%. There is also a higher prevalence of dementia in women, partly due to a generally longer life expectancy for women than men.

3.4 NICE guidelines confirmed that the prevalence of dementia increases sharply with age. Throughout the UK there are approximately 700,000 cases of dementia and the prevalence of the condition is set to more than double in the next 30-50 years

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- 3.5 A significant burden of care can fall on the children of Dementia patients, particularly adults in the 50 plus age group. This may lead to an increase in mixed anxiety and depression and generalised anxiety for the 50 plus age group. The proportion of Havering residents who identified themselves as carers in the 2001 Census was 10.4% of the total population (highest in London), compared to 8.5% for London as a whole.
- 3.6 The Topic Group were informed that there was a multi-agency group that had been formed to take forward the three themes identified in the group's scope. These included London Borough of Havering, Age Concern Havering, North East London Foundation Trust (NELFT) including psychiatric representatives, the Alzheimer's Society, Health Commissioners, Public Health, BHRUT and the medicines management lead. This group also has carer's representatives. NHS Havering had commissioned services at Queen's Hospital to improve the quality of care for people with dementia. A project was also underway at Queen's Hospital to improve the focussed care of older people, including basic training for nurses in dementia issues.
- 3.7 The Topic Group were alerted to concerns regarding the implications for Community Mental Health Services, of the Coalition Government plans to transfer responsibility for Commissioning to GP Consortia. Evidence has been presented indicating the under representation of Dementia cases by GPs. Work would be needed with GPs and Practice Nurses about identifying signs and symptoms of Dementia.
- 3.8 Work was needed with GPs and practice nurses about identifying the signs and symptoms of dementia. Officers informed the group that the local memory service was under review to improve the service and its capacity to see a high volume of people with memory problems. It is likely that this will include working with GPs to improve care pathways and detection protocols. GPs did have different levels of experience with mental health generally. Research had shown that ten years ago GPs were more likely to use standard dementia tests but were less confident with how to manage the condition. It was important that GPs were able to refer dementia sufferers on for support at an earlier opportunity.

NELFT

- 3.9 The group met with Professor Orrell - an Old Age Psychiatrist as well as a professor at UCL. He also carried out a research role, with the main area being in dementia care for which he had developed a treatment technique – cognitive stimulation therapy. The group were provided with copies of the "Making a difference – An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia".

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- 3.10 Professor Orrell was also involved with developing the Camberwell Assessment of needs for the elderly; he chaired the National Accreditation Panel and also undertook clinical work, including home visits, in-patient work and a range of duties related to old age psychiatry.
- 3.11 The group also met with Dr Stephen O'Connor, who was also an Old Age Psychiatrist and an Associate Medical Director. He explained to the group that the Community Mental Health Team is comprised of a range of professionals, including Occupational Therapists and Admiral Nurses, who support carers of people with dementia with complex/ challenging behaviour. It was dependant on the needs of the client as to the type of carer they needed. The clients were assessed on the basis of their physical health and wellbeing to ensure that the correct support was in place. Carers were also provided by Social Services in partnership with NHS Havering, if the client lived in their own home.
- 3.12 The group noted that the main base for the Older People's Mental Health services was currently sited at Suttons House at St. Georges Hospital, and following the closure of Mascalls Park, the medical staff would be relocated to Church Road as an interim measure. Since they were however unable to run clinics from this site, suitable accommodation for the medical staff was being sought. A range of clinics are provided at the Petersfield centre, however NELFT are in discussions with a view to future provision for borough dementia services, since additional resources have been provided for the further development of dementia services by NHS Havering. (See recommendation 5.1)
- 3.13 The group were pleased to note that the transfer of wards from Mascalls Park to the new facility at Sunflowers Court at Goodmayes Hospital was proceeding on schedule.
- 3.14 The group noted that NELFT were working closely with London Borough of Havering, Human Resources to recruit to current Social Worker vacancies. (See Recommendation 5.2) NELFT had signed a Section 75 document which agreed that Older Peoples Social Care Staff will be recruited by NELFT. Social Workers in the Older Peoples Mental Health Team are not dedicated to working in dementia services and therefore NELFT were also in discussions with the Adult Social Care Reablement Team in regard to future collaborative working within Queens Hospital and the new liaison team being developed.
- 3.15 The group were concerned that Havering had not joined the Memory Network. The Memory Network is a network to share information with colleagues on the resources in shaping memory clinics. It also enables colleagues to learn from each other, share worries and difficulties and enable professionals to speak with a united voice. (see Recommendation 5.3)

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- 3.16 Officers stated that there was an excellent memory service in Havering with specialist staff and NHS Havering did have an early intervention and treatment theme as part of their dementia strategy. NELFT confirmed that it is their intention to become a member on completion of the development of their redesigned memory service.

Overview of Expenditure for services for people with dementia

- 3.17 Officers provided details on Local Authority and Primary Care Trust expenditure on services for people with dementia, which included:
- Funding for commissioned dementia specific services, i.e. Age Concern;
 - Estimates of funding for generic social care services that include provision for people with dementia, i.e. Reablement team dealing with dementia as well as other medical issues;
 - Estimates of funding for older person's mental health community and inpatient services that include provision for people with dementia, i.e. NELFT.
- 3.18 Officers explained that there were also a number of hidden costs included in primary care/ GPs and acute hospital care which included dementia, but were services provided on a generic basis and therefore broad assumptions based on population, prevalence and typical case mix were made to estimate dementia specific costs.
- 3.19 The group were informed that the estimated costs for 2010/11 were:
- £1,478,018 for all specialist dementia community activities, £636,625 for dementia related inpatient activities and £425,000 for Dementia Collaborative care hospital liaison team to develop an in-reach service for people with dementia and other mental health problems. Officers explained that these were block contract and therefore included different elements. These were estimated as 50% of clients with dementia.
- 3.20 Officers explained to the group that there was forecast expenditure for 2010/11 of £1,200,610 for the 30 dementia beds at Heatherbrook Nursing Home (Care UK) and for individual "spot" purchased placements of which, on average, this would be 65 at any one time with a budget of £1,747,793. The forecast expenditure for 2010/11 was £2,934,000 - an overspend of £1,186,207 compared with an outturn in 2009/10 of £2,204,000.
- 3.21 The group were informed that places within care homes are rated. These were dependant on the rating of the client as to whether the funding came from the NHS or Local Authority. The group were informed that there were a lot of voids in care homes, therefore there were more beds than people. They were further informed that there had been a 25% decrease in the take-

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up of care home beds, due to the Memory Centre and Dementia Service Advisors providing services which lead to less admissions to care homes or hospital and keep the services within the community.

- 3.22 Officers explained to the group that the growth of medical costs had risen between 2004/5 and 2008/9. Whilst the medication prescribed was not a cure, it did slow down and delay the progress of the symptoms. This medication can only be initiated and prescribed by a Psychiatrist following an assessment by a specialist first; however the GPs then have to monitor the progress.
- 3.23 The group felt that there needed to be more robust monitoring of financial and performance information so that this could aid future planning of the services available to people with dementia. This would link with the Joint Strategic Needs Assessment which describes the stages of the process, including stakeholder involvement, engaging with communities and recommendations on timing and linking with other strategic plans. (see Recommendation 5.6)

London Borough of Havering Services

- 3.24 Officers explained that the cost of services provided by the London Borough of Havering were difficult to give accurately, since people with dementia only made up a small part of the overall cost. The group were informed that the Council pay a higher rate of dementia care for approximately 122 service users in residential nursing homes. The total cost of this care is £3,124,000. For care in a residential home, the cost is £7,252,000 for approximately 270 service users.
- 3.25 The group were informed that there were approximately 89 users identified as having dementia who received homecare packages, the estimated total cost for these users was £1,190,000. There were approximately 39 users identified as having dementia who receive day opportunities; the estimated cost for these users was £154,000.
- 3.26 The reablement service is a short term intervention service to enable vulnerable adults to maintain their level of independence, usually following a major incident such as hospital admission or significant deterioration in health or home circumstances e.g. for a person with Dementia. On average 14% of the general population over the age of 65 will suffer from a level of dementia. On this basis, the estimated general cost of reablement services for those with dementia is approximately £322,000 per annum. Officers stated that there would be some clients of the reablement services who may go on to need additional support, however some may only need short intensive support just to overcome the significant event.
- 3.27 Other services that may be provided to those with dementia included respite, direct/self directed payments and occupational therapy, however at the time, it is not possible to estimate the costs specifically linked to

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dementia. Officers explained that the Resource Allocation Calculator is being developed to assess people's social care needs in order to allocate sums of money to achieve identified outcomes. The roll out of this system should provide more accurate information on specific client groups and service user needs.

- 3.28 Officers explained that previously places had been commissioned for providing day opportunities, however many of these took place in care homes, which are no longer in council possession. They could stimulate the market for other provisions, however service providers would have to be specialists to deal with the needs of the users, but there was no reason why this could not work on a "spot" purchase basis. (see Recommendation 5.4)
- 3.29 The group found that throughout the scrutiny review there was a lack of evidence of early diagnosis from GP's and that information available to the public to spot the signs in their relatives was also lacking. (see Recommendation 5.7) The group found that there was information leaflets and advice available; however there was an issue in the public accessing this information and knowing the symptoms. The group thought it would be useful if leaflets/ DVD's or a checklist of possible symptoms could be displayed in GP surgeries and libraries. (see Recommendation 5.8)

Age Concern

- 3.30 The group met with the Director of Development from Age Concern Havering. The group were informed that there were three clubs running for the Young Onset Dementia Group, these ran in different areas of the borough, however there was in excess of 120 people on the carers list and even though a new club had recently opened they were still not meeting the demand. The aim of these clubs is to provide respite for carers by facilitating clients with early onset dementia who are under the age of 65. The cost to Havering is £12,000, and this is a voluntary contribution and forms part of a grant. The group were informed that there is still a growing need for advice and assistance, given the growth of older people in Havering. As a result Age Concern Havering had doubled its capacity.
- 3.31 Age Concern has been commissioned by the PCT to run a Dementia Advisory service, building on the long standing early intervention dementia team. This has enabled them to double their existing capacity, recruit new advisors, and re-model the service based on the objectives of the national dementia strategy. This service will aim to allocate an advisor to everyone diagnosed with dementia. Working closely with the memory service, the advisers will ensure people with dementia and their carers have access to information and advice from the point of diagnosis onwards. The group discussed the proposed Government changes and who would be responsible for this in 2013. The group felt it should be a clear transition and that support of the GP Consortia and the Health and Wellbeing Board was vital. (see Recommendation 5.9)

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- 3.32 The group were informed that there were some areas of the borough where the need for services was greater. As a result there were over 40 people on the waiting list. The main problem was finding suitable premises to run sessions, as they would need to be secure, have comfortable seating, and a kitchen; however cost would be a big implication. (see Recommendation 5.5)
- 3.33 Age Concern Havering were currently recruiting in Havering to educate the GPs on early diagnosis and NELFT and Age Concern had been working well together on a number of projects over the last 3-4 years. The current project is where an experienced carer can assist a new carer and is called "Shield". Age Concern carry out CRB checks for all volunteers that are recruited. They also undertake full induction and dementia training before commencing any sessions with clients. They were currently registering for a pilot "sitting" service, this would be available daytime, evening and weekend but was literally a sitting service and would not provide any personal care.
- 3.34 The group were informed that Age Concern Havering was currently piloting "self-funding" clubs to see how these worked. At the moment there had been some uptake, however they found that clients were often reluctant to part with their money and felt that spending their allowance on a day opportunity was a waste of money. It was explained that a whole day peer support group, with the correct ratio of client/ staff would cost £45 per client per day.
- 3.35 The group carried out a visit to a number of sessions run by Age Concern Havering to see them in progress, and to speak with carers about their experiences. The group felt that these sessions were very worthwhile, and found that all the staff and volunteers who ran the sessions were very passionate and enthusiastic about the clubs and the service provided. The clients that were attending on the day of the visit were very relaxed and enjoyed the clubs. The staff informed the group that these are regular clients who take ownership of the clubs. The activities included were coffee clubs, lunch clubs, dancing, reminiscence and keep fit.

Alzheimer's Society

- 3.36 The group met with the Support Services Manager for Redbridge and Havering Alzheimer's Society. She informed the group that the Alzheimer's Society provide a more national level of information, through advertising on television and radio, campaign literature and also contributed to the Dementia Strategy Group. The group were informed that the local office had recently produced a dementia pack on how to get a referral in Havering; this had been developed jointly with Public Health as part of the National Dementia Strategy implementation group tasks.
- 3.37 She informed the group that there were a number of peer support and social inclusion groups for carers and people with dementia. These groups included a monthly social inclusion group with access to outings and social

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activities, a monthly lunch support group, held at Jackson's Café, a Saturday Social Support Group which was specifically for those families that worked during the week but were weekend carers to families and the Dementia Café, which was held on the last Friday of the month, supported by Admiral Nurses and was an information and social event for carers of, and people with a diagnosis of dementia. The total cost to Havering for all these projects was £43,000, and came from the Carers Grant.

- 3.38 The group were informed that there was also an online forum for carers and early diagnosed clients to discuss their thoughts and feelings. This forum was well used and was an electronic peer support network.
- 3.39 The group attended the Alzheimer's Café to see it in progress, and to speak with carers about their experiences. The group were informed that the café met on a monthly basis, with on average between 30 and 40 attendees, with this being a drop-in centre it was difficult to specify exact numbers and therefore hard to plan for numbers attending. The Alzheimer's Café also had speakers on specific subjects, which were relevant to both carers and clients.

4.0 CONCLUSIONS

- 4.1 As outlined above, the joint topic group have scrutinised in detail the impact of the National Dementia Strategy on the population of Havering.

5.0 RECOMMENDATIONS

- 5.1 That the relevant Cabinet Member liaises with NELFT with a view to future provision for borough dementia services.
- 5.2 That NELFT recruit Social Workers to fill the current vacancies and ensure that collaborative working with the Adult Social Care Reablement Team, on dementia services, is put in place.
- 5.3 That Havering join the Memory Network.
- 5.4 That the Commissioners continue to develop the local market to increase opportunities for day support for people with dementia and their carers.
- 5.5 That the Council work with Age Concern to find further premises which meet requirements to provide additional sessions.
- 5.6 That work is undertaken to develop more robust financial and performance information, linked to Joint Strategic Needs Assessment, to aid future planning of services.

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- 5.7 To encourage NELFT and Havering PCT to encourage early diagnosis of dementia by GPs, and provide training and public awareness of the signs of early dementia,
- 5.8 To encourage partnership working groups to assist in the provision of public information on signs of dementia in the form of leaflets, DVDs or checklists of symptoms.
- 5.9 To encourage the GP Consortia/Health and Wellbeing Board to continue the commissioning of the Dementia Advisory Service currently run by Age Concern.
- 5.10 That the Borough Director of NELFT develop an action plan from these recommendations and report back to the relevant Overview and Scrutiny Committees in 6 months regarding progress.

ACKNOWLEDGEMENTS

During the course of its review, the topic group were supported by, met and held discussions with the following people:

David Cooper – Head of Adult Social Care
Peter Keirle – Head of Mental Health Commissioning, NHS Havering
Fiona Weir – Operational Director, NELFT
Professor Martin Orrell – Old Age Psychiatrist, NELFT
Adrian Dorney – Assistant Operational Director, NELFT
Dr Stephen O'Connor – Associate Medical Director, NELFT
Carol Kathro – Alzheimer's Society
Dora Hill – Director of Development, Age Concern Havering

IMPLICATIONS AND RISKS**Financial implications and risks:**

The figures as provided within the body of this report are as submitted by Adults Services and are based on current (2010/11) costs. Havering's current cost implications are as at 3.24, 3.25 and 3.26.

As per recommendation 5.6 there is the need to project service user need and related financial implications to ensure consideration can be given to deployment of available resources on a timely basis.

There is a pooled budget Section 75 agreement in place between NELFT and the Council. Consideration may need to be given to the scope of this arrangement as a result of the Dementia Strategy in Havering.

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Ongoing changes within the Health Service, with regard to structures and GP Commissioning, may have resultant financial implications which will need to be considered as they arise.

Legal implications and risks:

No implications or risks identified

Human Resources implications and risks:

The recommendations in this report include reference to the need to ensure that the services to support delivery under the Dementia Strategy are appropriately resourced in terms of professional social care staff and that there is clear communication and effective collaboration between Adult Social Care and NELFT social care workers.

The action plan to support the requirements of the Dementia Strategy needs to be robust in terms of workforce planning and development in order to set in place the right staff with the right skills to implement the agreed areas of responsibilities and bring about expected outcomes for people with dementia in the Havering community.

BACKGROUND PAPERS

Notes of Dementia Strategy Joint Topic Group Meetings:

4 November 2010
16 December 2010
31 January 2011
14 March 2011