

Report of the Dementia Working Group

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Chairman's Foreword

This Working Group was set up to review the provision of dementia services in the Borough. I was appointed to chair the Group which would investigate the issues and report back to the parent Committee, the External Services Scrutiny Committee.

We started the review with a Dementia Stakeholder Event which was attended by 140 individuals, the majority of whom were carers of people with dementia. The comments and suggestions gathered at the Event identified a number of key areas of concern to carers. These issues were the main focus for our Working Group.

It is clear that only a small percentage of people with dementia have actually been formally diagnosed and are receiving the support that they need. Whilst some of those that remain undiagnosed are already in the care system, there is a large number that are being cared for by their spouse or other family members, many of whom are managing without any support at all. The work undertaken by all carers should be applauded as they are enabling the people they care for to remain in familiar surroundings and improving their quality of life.

We are very grateful to the many witnesses and Council officers who came to our meetings to provide us with the information needed to make our recommendations and we particularly thank:

Natalie Fox, CNWL; Dr Lawrence Woo, Woodland Centre, CNWL; Keith Bullen, NHS Hillingdon; Joan Veysey, NHS Hillingdon; Dr Ellis Friedman, NHS Hillingdon/LBH; Jules Jones, Admiral Nurses; Linda Matthews, Alzheimer's Society; Joyce Moon, Age UK Hillingdon; Stephanie Collins, Age UK Hillingdon; Jill Patel, Hillingdon MIND; Penny Chubb, Parkfield Nursing Home; Andrew Campbell, Woodlands; Dr Patricia Hurton, Hillingdon CCG; Derval Russell, The Hillingdon Hospitals NHS Foundation Trust; Lorna Kelly, The Hillingdon Hospitals NHS Foundation Trust; Claire Thomas, Hillingdon Carers; Paul Feven, LBH; Gary Collier, LBH; Belinda Norris, LBH; Brian Barry, LBH; Hari Pillai, LBH; Sandra Lake, LBH; Angela Woolley, LBH; and Nikki O'Halloran and Nav Johal, Democratic Services, LBH.

A very special 'thank you' goes to all of those people that have been involved in the different stages of this review. These people very kindly gave up their time to talk to us about their personal experiences of dementia - both the positives and the negatives, from personal and professional perspectives - and how this impacted them. All these people have clarified the importance of this review and shown the need for the recommendations that we have made.

During the course of our review, it has become clear that the number of people with dementia is increasing and is not going to go away. As such, the status quo is not an option.

Cllr Peter Kemp



Summary of Conclusions

As part of the Dementia Working Group's review, Members have reached the following key conclusions:

- a. Unpaid carers are hugely important in maximising the time that people living with dementia can remain independent in the community and should be recognised as such. Work is also being undertaken by Council officers to increase flexibility for carers in the support options available to them through the extension of personalisation in the form of Personal Budgets to carers. It should be noted that the NHS will also be providing support to carers of people with dementia who meet eligibility criteria for Continuing Healthcare.
- b. It is important to hold regular reviews of people with dementia on anti-psychotic medication to prevent avoidable loss of functionality and independence. Furthermore, it is important that regular, multi-agency reviews of the needs of people with dementia are undertaken. The Working Group believes that the voluntary sector has an important role in providing post-review support.
- c. There is already significant work being undertaken by partners across the Council, NHS and voluntary sector to review the models of care to ensure that people with dementia receive support in the community and get the right help from the right person at the right time, including:
 - development of extra care as a viable alternative to institutional care for people with dementia;
 - development of specialist resource centres for people with dementia that will also provide short break opportunities for carers of older people with more complex needs, the details of which will be set out in the Older People's Commissioning Plan to be considered by Cabinet in the autumn;
 - specialist dementia services with voluntary sector organisations such as the Alzheimer's Society and the WRVS to prevent admission (and readmission) into hospital and care homes;
 - development of bed and non-bed based intermediate care services for people with dementia; and
 - inclusion of psychiatric support within the Rapid Response Service to enable it provide crisis intervention to prevent avoidable hospital admissions.
- d. As well as there being a need to provide of a programme of training for community health and social care staff, GPs and staff within care homes, the Committee is pleased to note that the NHS will be encouraging the development specialisms within general practice. The training available to GP practices through the GP National Programme will be important in ensuring that GPs' skills are kept up to date with regard to dementia.
- e. It is intended that a particular focus of provision for Council provided services for older people will be on people with dementia in the greatest need. This is in accordance with the Adult Social Care Personalisation and Commissioning Plan 2011 - 2015 approved by Cabinet on 26 January 2012 and reflects the projected increase in the numbers of people with dementia. Support for people with a variety of eligible needs will be provided in partnership with the private and voluntary sectors, e.g. accessing day activities in care

homes, through Personal Budgets. The level of Personal Budgets will reflect the need for contingency plans to cover emergency situations.

- f. Cabinet's decision in January 2012 to provide initial funding of £50k to the WRVS in 2012/13 is greatly welcomed. This funding will help to train and grow the number of volunteers to provide a dementia monitoring and befriending service.

Summary of Recommendations

Cabinet is requested to give its backing to the following recommendations from the Working Group in order for them to be wholeheartedly taken forward:

Recommendation 1

To ensure timely assessment, diagnosis and treatment of dementia, Cabinet requests that NHS Hillingdon and the Local Clinical Commissioning Group be asked to explore the expansion of memory clinic services in Hillingdon and that this be done on a multi-disciplinary, multi-agency basis, reporting back to the Health and Wellbeing Board.

Recommendation 2

That Cabinet gives its full support for the development of a single point of access through the Council's on-line information portal (which will be provided in partnership with the West London Alliance) to ensure that people with dementia and their carers/families can access timely information, advice and sign-posting to the memory clinic and other appropriate services to aid early diagnosis.

Recommendation 3

That Cabinet endorses the Working Group's enthusiastic support for the wider distribution as well as online publication of the dementia information booklet (the 'red book') to GPs, other professionals and voluntary organisations and, in particular, to people with dementia and their carers. As such, Cabinet agrees that officers work with NHS partners to encourage them to identify funding streams to enable this wider distribution.

Recommendation 4

That Cabinet takes into consideration the increasing pressure on those voluntary sector organisations that deliver services to people with dementia when developing its budget proposals for 2013/2014 onwards.

Recommendation 5

That Cabinet agrees that the information gathered from the Dementia Stakeholder Event held on 12 January 2012 and throughout this review be used to form the foundation of Hillingdon's Dementia Strategy.

Recommendation 6

That Cabinet endorses the provision of a programme of effective basic training and continuous professional and vocational development in relation to dementia for community health and social care staff, GPs and staff within care homes to be developed jointly by the Council and NHS Hillingdon.

Introduction

1. This report presents the findings of the Dementia Working Group which was established by the External Services Scrutiny Committee to review and recommend improvements and formalisation of the Council's arrangement for addressing the issue of dementia in the Borough.
2. Dementia is used to describe a number of different symptoms, defined by Healthcare for London as including changes in memory, reasoning and communication skills, with a gradual loss of ability to carry out daily activities. These symptoms are caused by changes to the brain due to physical diseases such as Alzheimer's Disease. It should be noted that around two thirds of individuals diagnosed with dementia have Alzheimer's; the majority of the remainder have vascular dementia.
3. Given the cross-cutting nature of the review, the Working Group comprised Members of the External Services Scrutiny Committee and the Social Services, Health and Housing Policy Overview Committee.

Reason for the Review

4. Although individuals with learning disabilities that have dementia are more likely to have developed dementia at a much younger age, this review will focus on older people. It will look at what the Council and other organisations are currently doing to diagnose dementia and what support is available to these individuals and their carers. Consideration should also be given to possible improvements to joint working across the different sectors.
5. There are estimated to be 600,000 people in England with dementia and the numbers are expected to double in the next 30 years. Approximately one third of those with dementia have been formally diagnosed – therefore, two thirds of people with dementia remain undiagnosed and untreated. The estimated costs of dementia are expected to increase from £15.9 billion in 2009 (of which around £8.2 billion are direct health and social care costs) to £34.8 billion by 2026 – this is an increase of approximately 119%.
6. This increase in the number of cases of dementia will put increasing pressure on carers and the voluntary sector, as well as having significant financial implications for the Council and the health services.

Aim of the Review

7. The review sought to answer a series of questions including:
 - i. Are residents' expectations and concerns about dementia care and diagnosis reflected in the Council's services?
 - ii. How well developed are local strategies and partnerships with regard to dementia?

- iii. How are instances of dementia currently identified and dealt with in the Borough and is there any additional scope for this to be improved and standardised?
- iv. How have other areas/councils successfully dealt with the issue of dementia care?
- v. What training is available to staff to properly detect and assess dementia cases?
- vi. How can education and training in relation to dementia for health and social care professionals, care home staff, dementia patients and their carers be improved?
- vii. What progress, if any, is being made with the development of a Dementia Gateway?
- viii. How could the use of anti-psychotic drugs, telecare/health/medicine, coordination of care between health and social care ensure a higher quality of care/life for individuals with dementia? What other support would be advantageous to individuals with dementia and their carers?
- ix. How can dementia-related hospital admissions and unscheduled care costs (on the health side) and care home admissions (on the Local Authority side) be reduced? What impact would this have on individuals with dementia and their carers?
- x. How good are local awareness, early identification and diagnosis?
- xi. What information and advice is available locally? What treatment and support services are available?
- xii. How good is care for people with dementia in hospital? How are people with dementia supported in living at home? What is the quality of life for people with dementia in care homes?
- xiii. How are people with dementia involved in their communities and civil society?
- xiv. What support is available for the carers of people with dementia? Is this support sufficient/how could this be improved?

The aim of the review was to review and recommend improvements and formalisation of the Council's arrangements for addressing the issue of dementia in the Borough.

Terms of Reference

- 8. The Working Group's Terms of Reference were agreed as follows:

- To consider existing internal and external arrangements in the Borough with regard to dementia care and diagnosis and any improvements that could be made;
- To review whether dementia care and diagnosis arrangements are timely, effective and cost efficient;
- To review the guidance and support that is currently available from the NHS and the Council to those with dementia and their carers;
- To seek out the views on this subject from residents and partner organisations, including the voluntary sector, using a variety of existing and contemporary consultation mechanisms;
- To examine best practice elsewhere through case studies, policy ideas, witness sessions and visits; and
- After due consideration of the above, to bring forward cost conscious, innovative and practical recommendations to the Cabinet in relation to dementia care and diagnosis arrangements in the Borough.

Methodology

9. There were a number of methods used to collect evidence for this review:
 - a series of four witness sessions were held in January and February 2012;
 - research was undertaken through relevant literature and websites; and
 - a dementia stakeholder event was held on 12 January 2012.
10. In the latter part of 2011, the Centre for Public Scrutiny (CfPS) made a national offer of two days free expert advisor support for 10 local authorities for scrutiny reviews in relation to Ageing Well. Hillingdon made a successful bid for this support, which was subsequently increased to 3 days. It was agreed by the External Services Scrutiny Committee that the support would be used to facilitate a stakeholder event which would take place prior to the start of the review. The information gathered at this event has been used as part of the review. Approximately 140 people attended the event which involved carers, individuals with dementia and representatives from a range of organisations. Those present at the event received presentations from Linda Sanders, the Council's Director of Social Care, Health and Housing, and Laura Murphy, a facilitator from CfPS, to set out the national and local situation with regard to dementia.
11. In addition to this work, the Working Group attended two site visits: one to the Woodland Centre and the other to the Templeton Café in Hayes. These visits gave Members the opportunity to speak to individuals with dementia and their carers about their experiences.
12. This report presents the findings from these meetings and the Stakeholder Event. It sets out the background to how the review was undertaken and presents the Working Group's findings from the witness sessions. The recommendations contained within this report address the main issues that arose in the discussions.
13. The Working Group is incredibly grateful to those people who gave up their time to attend the meetings and advise Members on the key issues. In addition to those people who attended the meetings, the Working Group is also grateful to those people that spent time discussing their personal experience of dementia with Members.

14. The Working Group set out to establish what services and information were needed and valued by individuals with dementia and their families/carers and gained this information from the Stakeholder Event. The witness sessions were then used to speak to the voluntary, public and private sector service providers to establish what services were currently available for people with dementia and their families/carers.
15. The Working Group looked at:
 - a) improvements that could be made to the awareness and understanding of dementia for members of the public and professionals;
 - b) early diagnosis of dementia; and
 - c) the breadth, quality and availability of information and services for people with dementia and their families/carers.
16. It became clear that the earlier a person receives a diagnosis for their dementia, the more that can be done to help them to live fulfilling lives. However, this also meant that the right information, support and advice had to be in place and easily accessible.

Evidence & Findings

BACKGROUND

17. It should be noted that dementia is primarily a condition faced by older people. The ageing population in Hillingdon indicates that this is going to be a major cause of need in the future. Projections suggest that the number of older people in Hillingdon is likely to increase by over 8% to 37,000 in the next 5 years.
18. Furthermore, there are currently approximately 4,700 residents in Hillingdon that are aged 85 or over, which equates to 13.6% of the over 65 population. Two thirds of the anticipated increase in dementia cases in the next five years will be attributed to this over 85s group (which is expected to grow by 11% during this period).
19. People with learning disabilities are more susceptible to dementias as they get older. Projections suggest that the number of people with learning disabilities living into old age is increasing and it is predicted that there will be an increase in Hillingdon of 7.6% between 2010 and 2015.
20. As the older population in Hillingdon grows, so does the number of people living with long-term conditions:
 - 4,093 people are living with the impact of stroke – approximately 250 new incidences annually;
 - 57,119 people are living with high blood pressure; and
 - It is expected that the number of dementia patients will increase by 9% to 2,710 people in the next five years, and 16% by 2020.
21. This will mean that there will be a growth in the demand for care services in the Borough. In 2010/11, 3,375 older people accessed care services, including 2,076 Home Care Packages. During the course of that year, £36m was spent on older people's care services (£22m on residential/nursing care). It is anticipated that the expenditure on people with dementia will increase to £7m by the end of 2011/12.
22. Despite the increasing number of people with dementia and the huge impact it has on them, on their families and on health and social care services and budgets, as a society, we may not be doing as well as we could to support people with dementia and those who care for them. It is suggested that coordinated services such as rapid response, intermediate care, rehab/re-ablement, supported housing, Admiral Nurses and other carer support services could reduce dementia-related hospital admissions and unscheduled care costs on the health side and care home admissions on the Local Authority side. As well as reducing costs, it is anticipated that early intervention, diagnosis and support could improve the quality of life for the individuals and their carers.
23. Changes currently proposed in the Health and Social Care Bill are likely to result in 80% of NHS commissioning budget transferring to Local Clinical Commissioning Groups. Given that dementia is expected to have such a significantly increased impact on Social Services and NHS budgets, it is essential that all partners work together and that GPs

are involved in the production of joint strategic needs assessments (JSNAs) and health and wellbeing strategies.

Resources available

24. The Working Group believes that it is important to remember that the Council's resources (and those of other public and voluntary sector bodies) are limited and that any action taken to address issues in relation to dementia should not raise residents' expectations too high.
25. As well as commissioning dementia services from Admiral Nurses, Alzheimer's Society, Enara and Hillingdon Carers, Cabinet has recently provided financial support for the provision of additional dementia services by WRVS. However, these resources are limited. As such, any work undertaken as a result of this review would have to be fulfilled within the current budgetary constraints and subsumed within the workloads of existing officers.
26. There is no new money available in Hillingdon to fund the local dementia strategy and any improvements in pathways and services to improve outcomes for people living with dementia and their carers will have to be funded by existing resources being utilised differently.

CURRENT WORK

Dementia Gateway

27. The London Borough of Hillingdon is currently developing a Dementia Gateway. This Gateway would be a set of resources created to support people with dementia, their carers and staff working in dementia services. The Gateway would provide practical tips, tools and activities in relation to dementia. It would also enable individuals with suspected cognitive impairment to be assessed and a diagnosis undertaken at an early stage of the condition. If an individual is diagnosed as having dementia, the service would then review the person within appropriate time scales. In addition the service would signpost people to services which would support them in preventing their mental health deteriorating for as long as possible. As well as improving the individual's quality of life, preventing this deterioration would reduce the financial impact on the health and social care sector.

National Work

28. The 'Living well with dementia - a National Dementia Strategy' was published in February 2009. It set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.
29. In addition to this Strategy, scrutiny reviews have been undertaken by various Local Authorities including Lincolnshire County Council, Middlesbrough Council, Brighton & Hove City Council and Warwickshire County Council.

Council

30. Although the exact figure is unknown, there is a significant number of people who are undiagnosed. It is anticipated that there will be a vast increase in the number of dementia patients as the years progressed which means that there is an increasing need for a formal assessment process for dementia.
31. The Council has contact with a large number of clients with dementia and the social care team attempts to prioritise them. There is a need for a balanced range of cost effective services – which is difficult to achieve as there are already delays for those that require the service. The economic environment has deteriorated since the dementia model was described so this resource allocation needs to be looked at again. It is likely that, if the current service provision remains in situ, the issues faced by both the service users and the service providers will increase.
32. It is thought that roughly two thirds of dementia patients have Alzheimer's and that the majority of the remaining third have vascular dementia, for which there is no treatment at all. Around 70% of those patients with dementia that were admitted to hospital do not go home, but instead are placed in institutional care.
33. An integrated dementia plan is required in social care. The Council is seeking to support people more in the community and in their own homes in order to prolong their independence. However, this work is hindered in that a lot of resources are locked into institutional care.
34. Mental stimulation is a key factor for improving the care for dementia patients - these patients also benefit from physical activity.
35. The Council funds a number of voluntary organisations to provide services and is looking at the provision of a specialised dementia service. Advice and information is already being provided by a number of organisations in the voluntary sector. Although the Council currently provides a respite at home service for carers of those people with dementia, the Council is looking to re-model the existing service.
36. Services are already under pressure and there is a large number of people that are not using the service as they have not been diagnosed with dementia. It should be noted that the effect of dementia on life expectancy is very modest and the financial burden is more on social care rather than on medical care. As such, it is thought better to concentrate on those known to the system rather than trying to find those that are not known as this would be a very difficult task and there are not enough resources to meet the un-met need.
37. There is an increasing older population in Hillingdon with approximately 34,000 residents aged over 65. Although the census information due for publication in September 2012 will provide a more accurate current figure, a dramatic increase in this group is expected over the next 10 years.
38. 3,375 older people accessed care services in Hillingdon in 2010/11 – this figure includes 2,076 Home Care Packages. Of the £36m spent on Older People's Care Services in 2010/11, £22m was spent on residential/nursing care and £6.2m was spent on people

with dementia. In 2011/12, there was a total of 4,114 older people receiving a care service:

- of the 2,531 older people receiving domiciliary care, 156 had been diagnosed with dementia.
- of the 290 older people attending day services, 97 had been diagnosed with dementia.
- of the 575 permanent placements, 163 were in dementia residential homes and 86 were in dementia nursing homes.

39. The projected spend on Older People's Care Services in 2011/12 is £30m – this is £6m lower than the previous year and is thought to be achievable, in part, as a result of improvements in the support available for people with complex care needs in their own homes. The projected spend on people with dementia in 2011/12 is estimated to be over £7m (which is an increase on the previous year).
40. The Council's Older People's Service (OPS) is involved in a range of work including risk assessments, mental capacity assessments and best interest assessments. OPS also works in partnership with a range of individuals and services including: Safeguarding Adults Service; Community Health Team/Woodland Centre; carers; acute health providers; OPS Provider Services; Housing; private and voluntary care agencies; and organisations representing carers and service users. Some of this work enables the provision of services to support carers.
41. With regard to the support provided for carers, carer assessments are undertaken by OPS and, where applicable, referrals are then made to additional services such as Admiral Nurses. Carers are also signposted to voluntary organisations offering services that are suitable to the individual's needs. Further consideration needs to be given to focussing more on the prevention of crises.
42. Practical support offered by OPS after the assessment process includes:
- Telecareline – bed sensors and mobile response (this was the subject of a previous Police Overview Committee review)
 - Occupational therapy interventions – specialist seating, home adaptations, etc
 - Extra care sheltered housing
43. The Council has three day centres: Grassy Meadow, Poplar Farm and Asha. Grassy Meadow is not a specialist dementia day centre as it is also used by the frail elderly and younger people with sensory and/or physical disabilities. Poplar Farm is a specialist centre for dementia. Further detail in relation to capacity and attendance is as follows:

Day Centre	Capacity (on a week day)	Capacity (on a Saturday)	Total No. Of Service Users (each week)	Total No. Of Service Users With Dementia (each week)	Total No. Of Service Users With Other Cognitive Impairments (each week)
Grassy Meadow	60	0	139	44	26
Poplar Farm	12	12	42	42	0
Asha	40	40	109	11	21

44. There are 259 service users supported by the mobile response service (MRS) which operates 24 hours a day, seven days a week and is available to individuals that do not have responders or relatives that can be contacted (these individuals have to have a key safe fitted outside their homes to enable access). The service is provided in conjunction with Telecareline so that, where necessary, a member of the Telecareline team will visit the property with a member of the MRS team.
45. With regard to staff training, training workshops are held in the day centres (two have been held at Grassy Meadow in the last three months). Other training is provided for staff in relation to dementia awareness and challenging behaviour. Westminster Training & Development has also been commissioned to deliver training in relation to quality drivers, the provision of a centred approach to care, communication and interaction.
46. Other work currently being undertaken includes the development of an Older People's Commissioning Plan. The Older People's Personalised Service (OPPS) will be focussing on providing day services to those with the highest needs and those with diagnosed dementia.
47. There is concern about the provision of services for individuals with undiagnosed dementia, although there will be a number of these individuals that are already in the care system. Furthermore, it is acknowledged that there will be a number that remain undiagnosed and are self-managing their condition.
48. The provision of support for carers is essential as the carers save the Council and the NHS a lot of money. The Council needs to understand the concerns of the carers to ensure that their needs are met. With regard to social care support, there are eligibility criteria which need to be met. Although the OPS facilitate the process of obtaining social care support, the situation can be more complicated, for instance, where the person has a dual diagnosis, e.g., where an individual has been diagnosed with dementia and Parkinson's disease. It is acknowledged that more needs to be done to establish where there are individuals with dementia that are living alone so that adequate support can be provided.

Council – Inspection Team

49. The Council's Care Services Inspectors undertake inspections in relation to domiciliary care to ensure that the services that have been commissioned by a user are actually being delivered. The inspector's findings are then included in a report that includes any recommendations for improvement.
50. The inspections undertaken in nursing homes and residential homes involved observing staff interacting with the service users to ensure that they are providing the care as detailed in each resident's care plan. Any issues are included in an action plan with timescales attributed to each action. Progress on these actions will then be checked at a later date and support provided where necessary. This work with the homes provides an objective perspective and helps to deliver improvements to the quality of life for their residents.

51. The inspectors attend relatives meetings, provider forums and carers' monthly supervision meetings and liaised with the Council's Safeguarding Team and the Care Quality Commission (CQC).
52. Currently, two inspections of each home are completed every year – one of these will be announced and the other is unannounced. Regular inspections, which are all unannounced and are undertaken at various times of the day and night (e.g., 5am and weekends), are also undertaken with regard to domiciliary care.
53. Many other local authorities do not have an inspection team. A number of West London councils are looking at the possibility of paying Hillingdon to provide an inspection service for them. If agreed, it is likely that an additional post will be created in the team.

Woodland Centre – Memory Clinic (CNWL)

54. A shared strategy has been developed across the Borough and a lot of work has been carried out over the last 2 years to examine issues across the Borough and look at what dementia services are needed. CNWL is aware of what the model for dementia care needs to look like in the future but there are issues to consider around resourcing the model and the work around the partnership to enable resourcing.
55. The Borough has a limited memory service for residents; this has been echoed in the feedback received from the Dementia Stakeholder event on Thursday 12 January 2012. There are long waiting lists for patients; whilst an initial assessment can be carried out quickly, the follow-up appointments can take some time and the waiting list is getting bigger.
56. The service provided by the Memory Clinic is mainly around medication but also offers advice. The Woodland Centre does not have the resources to deal with the number of patients coming though so the waiting lists are growing. In the last 3 years, the number of patients has increased, particularly in the last year. The services provided to dementia patients at the Centre include diagnosis, explanation and containment of people's anxiety. The immediate needs of the condition are often not met.
57. It should be noted that the number of people with dementia in the Borough is around 2,400 and the Memory Clinic has seen around 411 people in the last year. The remaining 2,000 or so patients are likely to be seen elsewhere in the health system (e.g., GP surgeries) and will not necessarily require a psychiatrist but could need care-based assistance. The onward process for dementia patients can be very slow, e.g., the process after hospital discharge and referral to social services.
58. A Clinic patient will be seen initially, have a follow-up appointment 4-6 months later and then have yearly reviews. If there are other issues or the patient becomes progressive, then they will go back to the community team. There is very little space for patients to re-schedule missed or cancelled appointments as the diaries are very full. It is estimated that around two thirds of people with dementia remain undiagnosed so work needs to be undertaken to resolve this and to look at resourcing the service effectively to meet this need.
59. As people are getting older and living longer, and as peoples' awareness is increasing, the demand for the memory service is also increasing. This also means that people are

becoming more demanding in what they want and expect from the health service. There has also been an increase in demand for more support.

60. Dementia training is provided for CNWL staff and there are bids for training which members of the public have access to – this is a tier-based process for training that is carried out in partnership with other organisations, e.g., Dementia UK. Training courses are being co-produced with carers and there are two Admiral Nurses locally who run regular training sessions and raise awareness across the Borough. However, there is no respite care routinely available for the individuals with dementia so that their carers can attend the training provided by the Admiral Nurses. Carers currently need to make alternative arrangements or take the individual with dementia with them to the training course. Carers are made aware of training that is available to them through advertising, voluntary sector, leaflets, etc.
61. Medication currently available can slow down the process for those with dementia, or appears to slow down the signs. In reality, it is rare for a patient to show any signs of improvement and the medication does not cure patients as it does not address the underlying brain deterioration of dementia sufferers. New treatments are being tested but will not be available in the immediate future.
62. As the main benefit of medication is that it helps to slow down the process, it therefore can delay the point at which patients need more personal care and are taken into care homes. This has an enormous economic benefit if the length of time that a patient spends in institutionalised care is reduced. If there are no foreseeable improvements to the quality of life of a patient, medication should not be prescribed. The prescribing of medication also needs to be balanced with the patient's needs and those of the carer.
63. Medication can have negative side effects and it often sedates patients. There are limits to how helpful medication can be as it can affect movement and increase the risk of falls and accidents. There has also been recent press coverage regarding the increase in the chance of having a stroke when taking a certain medication for dementia (Risperdal).
64. NHS Hillingdon currently commissions a memory assessment service in the Borough – although it is a differing model from that highlighted in the National Dementia Strategy. The Department for Health will be releasing a framework for commissioning services for the memory service which will show what the service should look like.

Recommendation 1

To ensure timely assessment, diagnosis and treatment of dementia, Cabinet requests that NHS Hillingdon and the Local Clinical Commissioning Group be asked to explore the expansion of memory clinic services in Hillingdon and that this be done on a multi-disciplinary, multi-agency basis, reporting back to the Health and Wellbeing Board.

NHS Hillingdon

65. Although there has been a shift to up-streaming care and early diagnosis, there is still an over-reliance on institutional care. Joint working is already underway between CNWL, the Council and NHS Hillingdon to develop a model of care for dementia which

would take account of the demographic impact of a rising demand. Over the last 6 months, NHS Hillingdon has been looking at how to shift resources to meet the demand.

66. A lot of work has been undertaken in other boroughs with regard to the effect that admission into hospital or other medical care has on individuals with dementia. It should be noted that there is no bed based intermediate care service available in the Borough for people with dementia – this is a big gap in the service.
67. Work has been done around local strategy and partnership and NHS Hillingdon is looking at shifting away from dependency and into community care – GPs are a key group to take things forward. As such, training for GPs and providing support for them to recognise symptoms of dementia is important. Work is underway across London to commission training for the GPs.
68. Four key groups of people have been identified for training: GPs, hospital staff, community staff and care home staff. Any training provision will need to be targeted around these key groups. There is strong board leadership at NHS Hillingdon which is very engaged on the issues around dementia care. A Dementia Strategy, which has sign up from GPs, has been developed but consideration will need to be given to how savings can be made in order that it can be spent differently.
69. NHS Hillingdon is committed to review those patients on anti-psychotic medication. 30% of these patients have already been reviewed and it is anticipated that 60-70% of these patients will be reviewed by April 2012.
70. There is a possibility that a third sector group could be involved in the delivery of a memory assessment service. There could also be a key role for the voluntary sector once people are diagnosed with dementia, e.g., a dementia advisor role, follow-on support, case management and sign-posting.

Admiral Nurses

71. The charity Dementia UK was established around 20 years ago by the Levy family who personally experienced dementia. Joseph Levy, 'Admiral Joe' had vascular dementia and although his family were in the fortunate position where they could financially afford care for him, they felt that the support offered was very limited. The family struggled to find appropriate support so developed the charity Dementia UK; with research and carer involvement, the family also set up Admiral Nurses.
72. Dementia UK promotes and develops Admiral Nurses in the UK. Dementia UK Training provides high quality training by professionals working with older people, carers and people with dementia. There are currently 75 Admiral Nurses in the UK, two of which are located in Hillingdon.
73. Some time ago, John Suchet appeared on breakfast television to speak about his experiences of dementia and the importance of Admiral Nurses in supporting him. Following the broadcast, there was a lot of press coverage of the service provided by Admiral Nurses which resulted in a general increase in demand. Referrals to the Admiral Nurse service in Hillingdon during that year doubled and, as a result, the way the service works has since changed.

74. The Admiral Nurses in Hillingdon are employed by CNWL and are part funded by the London Borough of Hillingdon. They are based within Social Services at the Civic Centre – this is the only Admiral Nurses service that is based in Social Services and it works well.
75. The journey of dementia can be described as a ‘mystery tour’ as people don’t understand or appreciate the issues that they will face because of the uncertainties of the condition. Patterns do not exist and what happens to one person will not necessarily happen to another. The journey is not linear and there can be some particularly difficult times.
76. Admiral Nurses in Hillingdon use an open referral service: 80% of referrals come directly from the carers themselves; the remaining 20% are from professionals, social services, etc. An answer phone and email service is also used and this is always very busy.
77. The levels of support offered by Admiral Nurses vary. Originally the philosophy for Admiral Nurses was to support from pre-diagnoses to after death or when the person with dementia enters full time care. However, constraints have meant that carers ‘dip in and out’ of intensive support, and use other support that is available. The carers’ information programme is a seven week programme for carers to give them intensive support, guidance and information. Carers’ information days are also provided as a condensed version of the carers’ information to provide training for carers that can’t attend the 7 week programme to get support.
78. The Templeton Café gives carers an opportunity to socialise with their peers and access to an Admiral Nurse on a monthly basis. A carer clinic also enables carers to come into the Civic Centre and see the Admiral Nurses - rather than being open on particular days/times, carers can make arrangements to visit when it is suitable for them. Carers are encouraged to consider important legal aspects and advanced decision making, which includes preparing wills.
79. The Admiral Nurse service offers support, education and expertise to a variety of organisations and departments. Considerable education support is given to the Social Services department and Admiral Nurses work closely with the Duty Team and Safeguarding Adults.
80. More Admiral Nurses are needed to:
- work with primary care;
 - develop post diagnostic support groups for people with dementia and their carers to enable them to plan for the future; and
 - work more closely with palliative care.
81. Carers often miss out on respite care and find it difficult to secure. They appreciate the day centres as this gives them a break in their own homes and they are nervous that access to day centres is going to be withdrawn in the future.
82. Admiral Nurses received approximately 200 referrals in the last year but also provided support for many more that were on their books from previous years. It seems that people find out about the Admiral Nurse services through Dementia UK and CNWL websites and through information at the Woodland Centre and hospitals.

83. Admiral Nurses are currently working with Hillingdon Carers, CNWL, etc, to produce literature for carers and dementia sufferers. The Working Group believes that the service offered by Admiral Nurses could be highlighted in Hillingdon People and on the Council's website to raise the profile of the organisation.

Alzheimer's Society

84. The Alzheimer's Society has been established for about 30 years and started as a charity for carers. A support group was been set up locally and the Society grew from there. The Society has a day centre for young onset dementia patients which provides support for carers and cares for people with dementia of working age.
85. The day centre in Joel Street, Northwood Hills, is a unique cross-borough resource which is not particularly well used by Hillingdon residents. This day centre has some funding issues, although it does receive some funding from the Council.
86. The Alzheimer's Society has a telephone helpline which is available Monday to Friday, 9am to 5pm. Over the last 12 months, the Society has received 441 calls for support – which averages at about 36 per month. A national helpline is also available and it has been suggested that, if consideration is given to having a 24 hour helpline, it will need to be provided on a national basis.
87. In the Borough, there is a Saturday day support centre and two dementia cafés:
- Northwood Hills at the United Reform Church which is open on Tuesday mornings. This café had 1,374 visits last year, an average of 114 per month.
 - Hayes & Harlington Community Association which is open on Friday mornings. This café had 1,148 visits last year, an average of 94 per month.
88. The cafes do not have a funding stream in Hillingdon and the support group receive no funding. The majority of the cost of the cafés is for staffing rather than for the hire of the venues. These cafés are used as a source of information.
89. A monthly Sunday social function group has also been set up and has an average of around 20 people attending. These groups were set up as Sundays can be very lonely for people and often the social life of carers can dwindle to nothing.
90. Dementia Support Workers work with people with individuals with dementia, relatives, friends and carers to improve understanding of dementia. The service provides a personalised information and support service to people with dementia, their carers and families separately from statutory provision. Support Workers, over the past 12 months, started with a case load of 137 and received a total of 177 new referrals. 140 of those were referrals from families of those with dementia, 17 from Hillingdon Hospital, 9 from Social Services, 6 from GP's and 5 from Hillingdon Carers. There had also been 19 referrals for help with getting a diagnosis. The service is important for keeping dementia sufferers in the community and out of hospitals.
91. An analysis of the support work shows that, over 12 months, most people require advice, information and support to gain access to services: Respite Care, Day Care, Sitting Services and Home Care.

92. There is a current National campaign around early diagnosis. As part of this campaign a leaflet entitled 'Worried about your memory?' has been produced and has proven to be the most popular leaflet that the Service has produced. In the past, the Alzheimer's Society sent CDs to GPs about the benefits of early diagnosis, e.g., reducing costs, helping with support and preventing costly interventions later on with the illness. It is thought that awareness raising will help with early diagnosis and that early diagnosis will then open doors to the support services that are available.
93. A study undertaken by the Alzheimer's Society, in partnership with Tesco and Alzheimer's Society Scotland, provided projections and diagnosis rates for dementia – Hillingdon was rated 157th worst out of 169 with regard to diagnosis, measured at the current rate. The study estimated that 2,149 people would be undiagnosed with dementia in Hillingdon by 2021 if the current trend continued.
94. The Alzheimer's Society has some concerns that personal budgets might reduce the options available to service users as well as the resultant quality of care and services that are provided. However, this is still work in progress and the standard of care offered will be looked at closely by officers to ensure that the Council fulfilled its duty of care to residents.
95. There are concerns about GP care, how to get someone with suspected dementia to the doctor, and residents' perception of how good the doctor is and what action they will take. There are still some GPs who will tell patients that 'it is your age' rather than providing them with information in relation to referrals, waiting lists, etc.

Age UK Hillingdon

96. Although Age UK does not specifically target dementia sufferers, about 10% of the individuals dealt with by the organisation are thought to have dementia/memory problems (the majority of clients are 80-90 years old). As such, consideration is being given, subject to funding, to developing specific services for people with dementia which could include more transport availability to take individuals to day centres, singing for the brain and life stories.
97. The 'Willing Hands' service had originally been established by Age UK to provide a cleaning service (not for profit at £20 per hour) but the organisation is now getting enquiries about the provision of a sitting service. Although Hillingdon Carers provide a sitting service, Age UK Hillingdon has been advised by service users that there is a waiting list for the service.
98. Age UK has concerns that care packages for people with dementia are currently inadequate. For example, there appears to be a lack of available respite care and some carers find themselves desperate for a break. It is often difficult for carers to get a week to themselves as there are few respite beds available.
99. Age UK provides a befriending service where volunteers visit people in their own homes – the Council provides funding for this service. These volunteers will then take the person for walks, go to the hairdresser, etc. They also encourage their clients to drink to ensure that they do not dehydrate. There are currently 167 people using the service – 25 of these have dementia and 30 have memory problems.

100. The Active Ageing Group set up by Age UK in Ruislip Manor has 36 clients - 17% of which have dementia. The organisation also holds a Friday Fun-Day Group where around 20% of the users have dementia.
101. Although Age UK does not provide a respite service, the organisation is aware that there is a lack of respite service for carers. It is clear that there is a risk that carers will burn out and become ill if they are not adequately supported. This could result in care being needed for the carers of those with dementia as well as care being needed for the person with dementia.
102. As life expectancy increases, there is an increase in demand for services and action needs to be taken to manage this.

Private Nursing Homes

103. Parkfield Nursing Home cares for 44 individuals, 34 of whom have dementia (although only three of them have been formally diagnosed). Individuals tend to move into the home in the later stages of dementia.
104. Over the last four years there had been approximately 60 residents at Parkfield with dementia. The experience of access to services for these individuals had not been very good. It is thought that a single point of access would be hugely advantageous to those with dementia and their carers.
105. There are times when family members felt that they are unable to look after an individual with dementia, e.g., if a child has been abused by their parent, they should not automatically be expected to look after them later in life. In these circumstances, consideration needs to be given to what support can be provided.
106. It is important that a person with dementia is not ignored. Too often, the relatives are asked about an individual's preferences, likes and dislikes when they should be asking the person themselves. It is important that individuals with dementia are spoken to as equals.
107. Woodlands is a nursing home specifically for individuals with dementia which provides a homely, caring and safe environment for its residents. It is thought that there are a number of issues around emergency care, respite care and funding that need to be investigated.
108. The needs of each person with dementia need to be looked at in isolation to ensure that the services they receive are what is best for them. This might mean that they are placed in a private nursing home. Relatives often worry about someone going into a care home, particularly when the home doesn't meet the needs of that person and they then need to be moved. Adequate interventions need to be in place in these situations.
109. In the past, there has been little choice for individuals in crisis and there has been an excessive and unnecessary use of institutionalised care. Research into extra care housing with 24 hour care and support on site shows that this form of housing is capable of delivering better outcomes and similar or lower costs for people who would normally move into residential care homes. In the future, there will be a range of

options available which will include sheltered housing, extra care housing, residential provision and nursing homes.

Hillingdon Carers

110. Hillingdon Carers support around 4,000 adults and 400 children that are carers - this is around 13% of all carers in the Borough and 1 in 8 households in Hillingdon Borough has carers of some kind. The organisation provides a range of services and has a contract with Hillingdon Council to provide this. It should be noted that one size does not fit all.
111. Hillingdon Carers offer a range of services including a newspaper posted to carers, a carers handbook, access to a named support worker and a specialist support worker, appointments to consider carers situation and needs, referrals to partner organisations, access to training, access to its Wellbeing Service and access to one-to-one intensive support if this is required. The organisation also offers one of the largest young carers' services in West London. Quite a lot of people do not realise the impact that dementia has on children and that most of the young carers that go to Hillingdon Carers for support and advice are primary carers.
112. Over 50% of referrals to Hillingdon Carers in last year were for carers looking after people with dementia. This figure has significantly increased year on year with around 20% of the organisation's current case load being in relation to those with dementia.
113. Hillingdon Carers provides a generic service for any carers, regardless of the need. The service is not specialised for dementia patients. The organisation works closely with the Alzheimer's Society, which provides specialist information on dementia.
114. Hillingdon Carers issues cards at locations across the whole Borough for front line services (e.g., GP surgeries and Hillingdon Hospital). These cards include contact details for the Alzheimer's Society and Hillingdon Carers. It is important to locate services close enough to carers to ensure ease of access.
115. As a result of constraints, the service provided by Hillingdon Carers has changed focus in last year. Previously, the focus was on carers that needed a break but, due to the lack of services available, this focus has had to change. The service has had to think of ways to give carers something meaningful and at the same time be able to bring the individual with dementia with them - examples of such services include the Carers Café.
116. There are six Carers Café's across the Borough which are run in conjunction with the Alzheimer's Society. The purpose of these cafés is to provide a place for carers to go that is close to where they live and where they can take the person they are caring for with them. The cafés offer support, somewhere for people to socialise, provide information and include bite sized training sessions. Staff and volunteers are present at the cafés.
117. The cafés fulfil a need and are more specifically targeted at an older age group. As such, Hillingdon Carers is looking at providing different ways to support younger people that need the service. It should be noted that carers with highest care burden are often the ones that are not getting the kind of service that is necessary for them. Unless a

really robust break service is provided, carers can often find it difficult to leave the house to do things that others take for granted, e.g., the weekly shopping.

118. There is a lot of confusion around the information that is available and people often ask Hillingdon Carers about the services that are available to support them and the person that they care for. There is also confusion about the eligibility criteria for services and how the criteria could be met. Hillingdon Carers have contact with a lot of people that are confused by the information and services that are provided, including the service providers themselves.
119. Although there are carers that meet the criteria for a break, there are often issues about the flexibility of the service to ensure that carers get a break at the right time and for the right amount of time. Quite a lot of carers are middle-aged and were unaware of the break provision.
120. Carers, especially younger adult carers, often feel that they are not told by the Council that the person they care for can be taken into institutionalised care (rather than being cared for in their homes) when they want a break but do not want to go away. This means that carers believe that they can't have a break in their own homes. There has been a general reduction in the number of breaks for people having care relief in their homes. There has also been a reduction in short breaks and in availability and there are long waiting lists for respite care placements. This results in carers who want a small break being unable to have one, even for a few hours, as the services are not able to provide this break.
121. Consideration needs to be given to carers' needs and how providing care for someone on a 24/7 basis affects carers. As Hillingdon Carers has contact with a number of carers that are at crisis point, it provides a counselling service for them.
122. Dementia is a terminal illness so carers for individuals with dementia have a lot of needs. Even though dementia is a terminal illness, it is not seen in the same way as diseases such as cancer (which can be terminal) and the range of care and services offered in support of the illness is more limited.

Clinical Commissioning Group

123. The Hillingdon Clinical Commissioning Group (CCG) has been set up in shadow form and has appointed Dr Tricia Hurton as its GP Dementia Lead. Dr Hurton has the lead role on the CCG for dementia in the Borough and, as a GP, has a lot of personal involvement with patients with dementia.
124. The issues around dementia care are often in relation to clinical care and social care. Patients with dementia often need a lot of social care at short notice and, as it is not planned, this is often not available. As such, patients will often go into hospital as there was nowhere else for them to go.
125. There is an issue with the capacity of the memory service in that, whilst initial appointments for diagnosis are scheduled quickly, follow up appointments take longer to programme in. This meant that the ongoing support and treatment was not necessarily being provided at the right time.

126. GPs often see patients with dementia for other conditions they have. Furthermore, an important aspect of general practice is to prevent vascular dementia. However, there is still an issue with regard to the variability and under diagnosis of dementia in general practices. This then has implications as patients with dementia are not necessarily being identified and signposted to secondary care and follow up.
127. The CCG has set up a scheme to collect information for certain chronic dementia cases. In Hillingdon, about 780 patients were diagnosed with dementia by the end of March 2011 – this suggests that there has been an under diagnosis. A comparison study undertaken would now be undertaken.
128. About 80% of those patients diagnosed by GPs with dementia have a care plan or care review within 12 months. The quality of this care review is unknown so it is difficult to know the quality of care that is being received by patients.
129. There is currently no standard compulsory dementia training for GPs – this is a particular issue for young GPs and care home staff. In fact, although it is thought that there is generally not enough training with regard to dementia, national general and online dementia training is available and there are plans to try and improve the provision of training to GPs and nurses. Briefing papers were also regularly sent to GPs on a national basis but, given the volume of paperwork that they have to deal with, it is unclear how many of them read and digest the information contained therein.
130. A lot of work is needed in primary care with regard to dementia with regard to training, signposting and diagnosis. Hillingdon CCG is trying to get all general practices to undertake anti-psychotic drug training and further work needs to be undertaken to establish how much individuals know about dementia to begin with so that there is a base to start from. Although there is a lot of value in learning 'on the job', it would also be useful for more experienced practitioners to provide dementia training.
131. Work has been undertaken nationally over the last 18 months/2 years in relation to early diagnosis tests. GPs have been asked to ask patients some very basic questions which effectively identify individuals with a high probability of having dementia. The CCG is looking at the changes needed in general practice to ensure that all patients receive the same quality of care and service at all surgeries. This could be achieved through general practices working more closely together to share services and specialisms / expertise – this would mean that there would be no expectation for all GPs to have a specialist knowledge of dementia, but that that every practice would have a specialist.

The Hillingdon Hospitals NHS Foundation Trust (THH)

132. Staff at Hillingdon Hospital come across patients who have dementia on a daily basis and that, as such, a need has been identified for a high level of training. Investigations have been undertaken with regard to the provision of training and it should be noted that 18 members of staff have taken part in a training course designed by Sterling University which is specifically for dementia – these staff have become dementia champions. The 18 champions are now able to deal with all aspects of dementia and are cascading the training that they have received to their colleagues. These champions are deemed to be the local hospital experts and also take part in a dementia group.
133. In addition to the dementia champions disseminating information to their colleagues, every new member of THH staff is given dementia training within two days of starting in their new post. So far, 500 members of staff have been trained across all levels. An e-

learning module is also being introduced as mandatory training for all junior doctors. Although THH is proud of the progress made with regard dementia training, it needs to ensure that those that have received training now deliver what they have learnt.

134. A 4-point assessment tool is being used in A & E at Hillingdon Hospital, which is quicker and therefore a more suitable tool to use to look for signs for dementia in patients. Paperwork is also being re-designed to incorporated assessment tools.
135. The Butterfly Scheme was originally set up by a carer of a patient with dementia after their admission to hospital. This carer identified that staff needed to be more aware of dementia and the Scheme enabled patients in hospital with dementia to be identified with a discreet butterfly symbol. Although under consideration, the Butterfly Scheme has not yet been launched at THH.
136. THH is currently working with carers to produce a 'This is me' portfolio for dementia patients. The portfolio will include things such as: what the patient likes to be called, what they like to eat, their dislikes, etc. The hospital has had very good feedback from patients about the portfolios so this is something that will continue to be produced.
137. 'Life books' are also used by occupational therapists, in the longer term wards and by a lot of nursing homes. The books, which are a record of the person's life and include photos, remain with the patient to help anyone working with that individual to improve their patient experience.
138. Different colour name bands are issued to patients that are unable to discuss their care themselves – this discreetly highlights those individuals with dementia. Some of these patients are unable to tell staff that they are in pain and this sometimes resulted in challenging behaviour – as such, staff need to look for signs of pain. Clear signage placed at eye level (1.2m from the floor) is also useful, e.g., having a picture of a toilet on the door of the toilet and THH has introduced calendar clocks which include the time, day of week and date to give patients a perspective of time.
139. As moving individuals with dementia can be stressful, THH makes every effort to ensure that patients are not moved around the hospital too much. This can be particularly disorientating after a patients has familiarised themselves with their environment. Consideration has also been given to important little things such as coloured glasses and using the most appropriate method of communication with patients.
140. A short term pilot programme is currently underway at Hillingdon Hospital to look at putting in a mental health liaison team. This service provision is for all mental health care and will bring together physical care and mental health. The pilot will be evaluated in March 2012 with view to subsequently rolling it out.
141. A further piece of work is also underway to improve the pathway of care out of hospital. NHS Hillingdon is looking at what happens in a crisis as well as what happens when the patient is then well enough to leave hospital. Access and timely care is stressed as being important.

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FUTURE WORK

142. The following dementia priorities have been set by the Council and the NHS for the Borough:
- to increase awareness and understanding of dementia
 - to develop early diagnosis and intervention
 - to ensure a higher quality of care/living well with dementia
 - to reduce dementia-related hospital admissions and avoidable care costs
 - to support residents in the community
 - to facilitate future planning, i.e., finances/decisions

Information

143. It is important that very clear information is provided for individuals with dementia and their carers with regard to what services are available and what the criteria is for accessing these services. As there is currently a lot of misinformation and confusion, there is a need for a central point of contact and clearly signposted services.
144. There are concerns that the information in relation to the support/funding that is available to individuals with dementia and their carers/families is confusing and difficult to find. Consideration needs to be given to making this information more transparent and clearer signposting should be provided to reduce the number of crises that arise. An information board is being developed as part of the work being undertaken by the West London Alliance. The facility is called “Care Place” and will provide an access point for service users. The Council is currently working with the libraries and it is anticipated that the facility will go live in the next 2-3 months. Future possible developments to the functionality of “Care Place” could include the ability for carers to upload reviews.
145. Central & North West London NHS Foundation Trust (CNWL) publishes a detailed booklet containing information about the different types of dementia and the support services that are available locally. As this booklet is being given out at the point of diagnosis, there are many people with dementia that remain undiagnosed so Members are keen to ensure that these booklets are made available to GPs and other primary care providers. The Working Group is really keen to ensure that this booklet is widely available in both hard copy format and electronically. Ideally, as the first point of contact, GPs need to be able to pass on the booklets to those that they believe have dementia before they are formally diagnosed. As the booklet is not currently available electronically, it is suggested that work be undertaken to ensure that it is made available on the Internet – thus widening its availability.
146. The Council is looking at developing a Life Book for individuals with dementia. It is anticipated that these documents will provide a map of the person’s life from childhood through to the present day. This will then be useful for reminiscence, will identify the likes and dislikes of an individual and will provide useful information for any staff in contact with the individual.

Recommendation 2

That Cabinet gives its full support for the development of a single point of access through the Council's on-line information portal (which will be provided in partnership with the West London Alliance) to ensure that people with dementia and their carers/families can access timely information, advice and sign-posting to the memory clinic and other appropriate services to aid early diagnosis.

Recommendation 3

That Cabinet endorses the Working Group's enthusiastic support for the wider distribution as well as online publication of the dementia information booklet (the 'red book') to GPs, other professionals and voluntary organisations and, in particular, to people with dementia and their carers. As such, Cabinet agrees that officers work with NHS partners to encourage them to identify funding streams to enable this wider distribution.

Respite and Housing Provision

147. Consideration is being given to the number/types of units available for sheltered and extra care housing and what the need will be by 2020. This work is being undertaken as part of the Corporate review of land and property assets and will involve new build and remodelling work – it is important that developments include the right mix of extra care provision. Projections for the new build will include dementia provisions. For example, consideration will be given to the provision of two bedroom accommodation for couples where the condition has progressed so far that the individual with dementia does not recognise their spouse.
148. Holidays for carers are vital and it has been suggested that a mechanism be put in place to enable carers to have a break. This could mean that they are able to go on holiday but would also enable them to visit the doctor or go to bed for a few days when they are ill to allow them to recover.
149. When in crisis in the community, a person's situation can change dramatically. Consideration needs to be given to how the Council can work more effectively with partners (including GPs) to raise awareness and provide timely responses to these situations. Often, individuals will present at A & E when they feel that there are no other options available to them, e.g., respite care provision. As such, more work needs to be completed in relation to crisis care. If patients are admitted to hospital, they could be an in-patient for some time as it is often difficult for hospitals to find patients a suitable alternative.
150. Carers cannot currently book respite care a long time in advance. As such, it is suggested that the Council consider placing advance respite bookings for a small number of people so that those carers that want respite can book it in advance – conversely, there will be some carers that are very flexible about when they have a break. This booking system would potentially enable those that wanted to have a holiday with their family to do so.

151. Officers are currently looking at more flexible support options for carers through an extension of Personal Budgets and the provision of brokerage support, including within the voluntary sector, which would help to address some of the issues referred to above. Making a life changing decision about where a person should be cared for is not appropriate at the time of discharge from hospital. Further work needs to be undertaken to improve this process. As part of this, consideration will need to be given to ensuring that there are appropriate safe places for vulnerable people.

Resources

152. Resourcing is something that needs to be looked at and worked out between the service providers - there needs to be a shift in resources as funding is tight. CNWL is already working with the health commissioners and other partners on how to work better with what they have.
153. In order to meet the demand for dementia services, there will need to be a change in the way that money is spent. There is a need for more community based care, support for carers, training for carers, staffing at care homes, person-centred activities and therapies that help dementia patients. The unit spend on housing in Hillingdon is highest in relation to dementia care so work needs to be undertaken to plan how to use the money available more effectively in the community.
154. The input that carers have with regard to existing care provision needs to be recognised and improvements are needed in this area. It is recognised that carers are saving the Borough a lot of money with the care they provide for family members without (or with limited) support. Although some carers don't necessarily have the skills they need to provide care at home, they do try - these instances need to be identified and support needs to be provided where required.
155. With regard to commissioning, the key themes are integration and cost and how these are spread across different areas. It is clear that work needs to be undertaken to look at how funds can be better used, how dementia patients can be diagnosed earlier and how NHS Hillingdon can work with Social Services to provide independent care at home for patients.
156. It is anticipated that the Hillingdon's Dementia Strategy will be published in the autumn of 2012.

Recommendation 4

That Cabinet takes into consideration the increasing pressure on those voluntary sector organisations that deliver services to people with dementia when developing its budget proposals for 2013/2014 onwards.

Recommendation 5

That Cabinet agrees that the information gathered from the Dementia Stakeholder Event held on 12 January 2012 and throughout this review be used to form the foundation of Hillingdon's Dementia Strategy.

Training

157. The feedback about services provided by GPs is varied with some being more receptive than others. Admiral Nurses have been involved in GP training but it appears that the majority of those GPs that sign up for the training are the ones that are already aware of the signs of dementia and the support that is available to the patients and their carers. It is difficult to engage some GPs into taking up training so additional effort needs to be made to establish the training needs for GPs and primary care workers.
158. The Council has secured funding from the PCT to train staff that come into contact with dementia patients. Officers will be working with the PCT to establish the training needs of GPs, social workers, care homes, etc, and then making arrangements to meet these needs. The Council's Learning & Development team currently provide access to training packages but further awareness training is needed for staff, including those that visit residents in their homes. This could be done through e-learning where appropriate.

Recommendation 6

That Cabinet endorses the provision of a programme of effective basic training and continuous professional and vocational development in relation to dementia for community health and social care staff, GPs and staff within care homes to be developed jointly by the Council and NHS Hillingdon.

Carer Support

159. The eligibility criteria for different support services provided by Council is currently available in one place but will need to be reviewed once new legislation (arising from the Adult Social Care White Paper due to be published in the spring of 2012) has been ratified.
160. The provision of support for carers is important - the alternative is that a carer could go into crisis and the statutory authority will then have to care for them as well as the person that the carers cares for. In the long term, providing support for carers is a cheaper and more effective solution. It is noted that carers save the authority a lot of money as they provide care through the night, which is often the most expensive time to provide care. As such, it makes financial sense to support carers, within an assessment framework, to ensure that those people with more complex needs receive breaks and are not waiting for services. The burden on these carers is significant and service providers need to ensure that they meet their needs as closely as possible.
161. Services are commissioned by the Council from Admiral Nurses, Alzheimer's Society, Enara and Hillingdon Carers. It is anticipated that additional dementia services will be provided in the future by WRVS – this will include targeted signposting and the provision of support for individuals being admitted to, or being discharged from, hospital. Improvements in service provision are needed and could be achieved through better partnership working. It has been suggested that private providers will be part of the solution to cope with the increasing demands on services.

162. It is anticipated that the support provided by Hillingdon Carers will move towards the older carers as the number of people with dementia increases. This increasing demand will also mean that the organisation will have to target its resources and potentially reduce the amount of support directly provided to concentrate more on lower cost services, e.g., cafés.

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Closing word

163. It is clear that the implementation of the recommendations contained within this report will not be something that can be completed overnight. The approach to implementing change is likely to be slow to ensure that we get it right first time and to manage the expectations of those affected by dementia.
164. Given the continuing increase in the number of people with dementia, it is clear that doing nothing is not an option and supporting people to remain in their homes is a clear way forward. This will mean that carers will need more support than they currently receive.
165. On 26 March 2012, the Prime Minister pledged that the Government's dementia research budget would be doubled to £66m by 2015. Mr Cameron is keen to see improvements in diagnosis and awareness of the condition and is encouraging the creation of 20 "dementia friendly communities" where individuals, businesses and the state work together to support people with dementia.
166. It should be noted that, as part of these plans, the Department of Health will be running a public awareness campaign in the autumn. Hospitals will also be given financial incentives to carry out checks on patients to see if they have the condition. It is hoped that the steps that are being taken will enable Britain to become a "world leader in dementia research and care".

Comments of the External Services Scrutiny Committee

167. The External Services Scrutiny Committee established this Working Group to examine the services currently provided in the Borough for individuals with dementia and their carers and families. We, the Committee, have considered the Working Group's findings outlined in this report and are delighted to present these to Cabinet and the Council's partners. The report clearly outlines the scale of the situation in Hillingdon and, given the anticipated increase in the number of people being diagnosed with dementia, the areas of growing need that need to be addressed. We fully endorse the recommendations.



Appendix 1: Glossary & Further Reading

Glossary

CCG	Clinical Commissioning Group
CfPS	Centre for Public Scrutiny
CNWL	Central and North West London NHS Foundation Trust
CQC	Care Quality Commission
GP	General Practitioner
JSNA	Joint Strategic Needs Assessment
LBH	London Borough of Hillingdon
MRS	Mobile Response Service
NHS	National Health Service
OPPS	Older People's Personalised Service
OPS	Older People's Service
OSC	Overview and Scrutiny Committee
PCT	Primary Care Trust
THH	The Hillingdon Hospitals NHS Foundation Trust

Further reading

- Hillingdon Joint Strategic Needs Assessment 2009-2014; <http://www.hillingdon.gov.uk/index.jsp?articleid=21833>; 2010 Refresh
- Dementia in Middlesbrough Final Report; **Middlesbrough Council**; August 2009
- Review of Dementia Care for Older People in Warwickshire; Report of the Adult & Community Services Overview and Scrutiny Committee, **Warwickshire County Council**; October 2007
- Scrutiny Select Committee on Dementia; Report of the Adult Social Care & Housing Overview and Scrutiny Panel, **Brighton & Hove City Council**; September 2010
- Services for Older People with Dementia; Adults' Services Select Committee Task Force, **West Sussex County Council**; April 2007
- Dementia Services in Buckinghamshire – Everyone's Responsibility; Public Health Overview and Scrutiny Committee, **Buckinghamshire County Council**; 8 June 2011
- They Killed My Dad; **Daily Mirror**; 27 February 2012
- Fiona: My Story; **Daily Mirror**; 28 February 2012
- "Guide to services for people in later life", "Welcome to Age UK Hillingdon", "Handyperson Service", "Nailcutting Service", "Home from Hospital Service", "Helping Hand Service", "Tidy Gardens Service"; **Age UK Hillingdon**
- Con artists are 'targeting dementia sufferers'; **BBC News** – www.bbc.co.uk/news/business-16167995; 14 December 2011
- Dementia: PM promises push to tackle 'national crisis'; **BBC News** – <http://www.bbc.co.uk/news/health-17507678>; 26 March 2012
- Dementia patients being cheated; **London Evening Standard**; 14 December 2011
- <http://www.hillingdoncarers.org.uk>
- <http://www.mind.org.uk/about>
- <http://dementiaaction.org.uk/>
- <http://www.dementiauk.org/>
- <http://www.ageuk.org.uk/hillingdon/>
- http://www.cnwl.nhs.uk/Hillingdon_Admiral_Nurse.html

Appendix 2:



HILLINGDON
LONDON



Review of internal and external services for Dementia Care in Hillingdon

Summary of stakeholder event held on the 12 January 2012

Introduction

Hillingdon Council External Services Scrutiny Committee in partnership with Hillingdon NHS and the Centre for Public Scrutiny hosted a stakeholder event to contribute to a review of internal and external services for dementia care in the London Borough of Hillingdon (LBH). The event was held on the 12 January 2012 at the LBH and was attended by 140 stakeholders, including over 90 residents (mostly carers of people with dementia), members, staff (across health and social services) and partners with strong links to dementia such as the Hillingdon Alzheimer Society and Age UK, and the Mayor of Hillingdon.

The event was primarily for us to gather resident feedback to enable us to review Dementia Services in Hillingdon in line with customer experience. The event focused on the following key themes:

1. Diagnosis and Medication
2. Early Intervention and Support
3. Crisis Situations and Emergency Help

The role of the external scrutiny function within the LBH

Two of the primary roles of the External Services Scrutiny Committee are to scrutinise local NHS organisations (in line with the health powers conferred by the Health and Social Care Act 2001) as well as examine the work of non-Council agencies whose actions affect residents of the Borough.

The Committee is charged with identifying areas of concern to the community within its remit and instigating an appropriate review process. In this instance, the Committee has chosen to undertake a review of the provision of dementia services in the Borough.

The role of the Centre for Public Scrutiny (CFPS)

The Centre for Public Scrutiny (CfPS) supports and promotes scrutiny and accountability throughout the public sector family. Hillingdon was one of 28 areas who bid for support from the CfPS under the national Ageing Well Programme launched by the Government in July 2010 and sponsored by the Department for Work and Pensions. The objective of the scheme was to aid

Local Authorities in identifying solutions that overview and scrutiny could bring to the challenges of the ageing society. The support built on the CfPS/LGID publications 'A good place to grow older?' and '10 questions to ask if you are scrutinising local preparation for an ageing society': (<http://www.cfps.org.uk/what-we-do/ageing-well-programme/>).

Hillingdon wished to use the available support to arrange a stakeholder conference, the information from which would set the scene for a forthcoming review of dementia services. This fitted with the Ageing Well programme of actively involving older people in the assessment, design and delivery of services. The Expert Adviser worked alongside Hillingdon Council in setting up and facilitating the event.

Summary from Centre for Public Scrutiny (CFPS)

Scrutiny reviews of services can often focus on strategy and physical aspects of delivery without truly understanding the needs of the individual. The comments expressed here illustrate the real benefit of engaging with users and carers at an early stage. Key points have been raised about communicating what the user actually wants, so that the service is personalised, rather than assuming the needs are known.

This goes to the heart of health commissioning for dementia care and the role that hospitals play regarding A&E and in-patient care. It has also highlighted the unmet need of carers' responsibilities when they are at crisis. With the health care reforms scrutiny has a vital role to play in ensuring that issues such as these are recognised and action taken.

The inter-relationship between user and carer amply demonstrates the importance of the Ageing well agenda. It is not just about providing services for the already elderly but preparing for old age. Addressing the issues raised here will benefit not only those who are already elderly but those who will reach retirement. Both groups should therefore be considered under the ageing well agenda. The event also illustrates how ageing well crosses organisational and service boundaries and that it is a theme that should permeate every aspect of an organisation's operations.

So many of these issues transcend the Borough's boundaries and have a common source (and probably a common solution). As I have been taking the ageing well agenda through other authorities, they also recognise that dementia care is an issue that needs tackling. It may be advantageous to consider running joint scrutiny investigations into various aspects of dementia care so that one Borough can focus on one aspect this, whilst another Borough addresses a second. Both resources and recommendations could then be shared across Boroughs.

Feedback from the event

Initial feedback from the event showed that 100% of the people that attended were 'satisfied' that event was worthwhile and they felt their views were heard. Over 80% of these said they were 'very satisfied'. Over a third of people who attended the event said they would like to continue to be involved in the development and improvement of local services. The majority of residents who commented valued the information given by speakers, the opportunity to listen to the experiences of other carers and to talk about their experiences as a carer for a person with dementia.

1. Key issues: Diagnosis and Medication

The following issues about diagnosis and medication were highlighted by carers who attended the event:

1. Listen to carers as their experience and knowledge of the cared for person could be valuable in the diagnosis process. If carers feel listened to and their opinions valued it will improve relationships with health professionals. Developing positive relationships in this way will increase trust and make the carer feel more supported.
2. Train Health care professionals on dementia including the different types of dementia and how to communicate appropriately with patients and carers.
3. Review memory tests with a view to improving:
 - Consistency of tests
 - Length of time of tests
 - Reviews
 - Availability of tests for people of a certain age
4. Consider issues that relate to waiting times and appropriate referrals:
 - Increase access to specialists if the health care professional dealing with the case does not have the right training and experience of dementia
 - Improve referral processes so that services can refer directly to one another and avoid going back to GPs to start the process again
 - Improve waiting times for appointments
 - Review progress of patients more frequently
5. Improve access to and quality of information and advice. Carers have different experiences of this; some health care professionals are signposting people to local services and support groups early on in the process. However, many carers say that they were not signposted early on in the process and if they have not been made aware of services, it is taking carers a long time to access support. Many carers at the event still didn't know about local support organisations such as the Alzheimer's society, Hillingdon Carers and Age UK despite caring for family members for a considerable length of time.
6. Promote information about access to services and advice. Ensure that social and health care professionals have access to up to date relevant information. GPs are often the first point of contact and they need to have the right information to give to people at the point of diagnosis so that people can access local services and information.
7. Give information packs at the point of diagnosis. These should include information about:
 - The various dementia conditions
 - Stages of dementia
 - Medication
 - Local services and support groups
 - Financial issues (power of attorney etc)
 - Benefits
 - Housing options
 - General information for disabilities (e.g. blue badge scheme, TeleCareLine, Reablement, accessing social services, local health centres)
8. Improve our understanding of unmet need. What are we doing to meet the need of vulnerable, isolated people living in Hillingdon with dementia without support?
9. Increase accuracy of diagnosis of dementia as many carers feel that the condition is not diagnosed accurately and that there is a considerable amount of time that elapses before an accurate diagnosis is given. Misdiagnosis can lead to inappropriate treatment, hospital stays and medication as well as increased stress and anxiety for carers and patients
10. Publicise in easy read format the medication available for dementia conditions, including the benefits and possible side effects. Have open forums where carers can share their experiences of medication. Include in information packs

2. Key issues: Early Intervention and Support

The following issues about early intervention and support were highlighted by carers who attended the event:

11. Standardise the way carers are signposted to support and information. From comments made at the event there is a lack of consistency in the way carers are signposted to support and information. Often it depends on who the carer spoke to, to whether they received appropriate signposting to relevant services.
12. Ensure all carers are given information about the local voluntary and community services such as services run by the Alzheimer's Society, Hillingdon Carers, the Red Cross and Age UK. These are highly recommended by carers as valuable services that enable them to get information, advice and support as well as giving them the opportunity to meet and share experiences with other carers and access activities that give them a break from their caring responsibilities.
13. Promote Admiral Nurses as these are highly valued by carers who have had a service from them.
14. Promote training provided by Woodlands and Hillingdon carers as these are valued by carers. Several carers mentioned the value of moving and handling courses.
15. Provide services that help people to remain at home as independently as possible. Reducing the need for hospital stays and the need for residential care home settings.
16. Increase public awareness of dementia with the following aims:
 - Reducing stigma
 - Enabling people to recognise early onset
 - Taking responsibility, such as being good neighbour, raising the alarm if a person is concerned about a vulnerable person in their local community
 - Getting people talking
 - Highlighting local services and support networks
17. Develop training about the different stages of dementia for carers so that they know what to expect and what they need to put in place to enable them to cope.
18. Host and promote events/activities (such as this event) to enable carers to get together to talk to each other and to learn about changes to local service provision and national issues that relate to the condition
19. Increase the information available on respite to include, how carers can access respite, what is the eligibility and any entitlements and also what respite options there are.
20. Review the local voluntary and community support services available to ensure they adequately meet the needs of carers in Hillingdon.

The requests raised here are common reflections across services i.e. a seamless transition between agencies, consistency, security of knowing that the information you have been given is accurate. It also illustrates the level of expert knowledge within the community as a whole. Scrutiny frequently looks for failures in service provision. Here is an ideal opportunity to utilise the appreciative enquiry approach to build on those community assets already identified through this event.

3. Key issues: Crisis Situations and Emergency Help

21. Review hospital dementia policy/procedures relating to hospital stays for people with dementia including:
 - What needs to be in place to safeguard patients with dementia
 - Assistance and support to eat and drink

- Personal care and toileting
 - What to do if a patient goes missing
 - Checks so that patients with dementia do not discharge themselves
 - Dementia training for all staff
 - Putting care in place before being discharged from hospital
 - The importance of listening to carers
22. Better training for staff in hospital to ensure dementia patients receive the right care and support
23. Review and publish information about what to do in a crisis situation, for example (include in the information pack):
- When the main carer is unable to provide care due to illness or a hospital stay
 - Who to contact if a person with dementia is missing
 - What to do if the cared for person becomes aggressive
 - Emergency numbers, covering 24 hour periods for different situations
24. Consider the possibility of a team of specialists who could react quickly to the needs of a person with dementia. To avoid the need to visit accident and emergency and/or hospital stays
25. Develop forward plans for patients and their carers that cover what will happen in the event that the main carer dies or becomes unable to provide care due to old age and/or ill health
26. Provide information on what will happen in the event that main carer dies or becomes unable to provide care due to old age and/or ill health, including:
What the process would be
- Housing options
 - Care options
 - Emergency respite
 - How points 2 and 3 would be financed and organised
 - Contact details

Appendix 1

Literal comments recorded at the event

1. Diagnosis and Medication

Diagnosis: Listening and respecting the views and experience of carers

- The group felt that when their cared for person developed dementia (and it took them a long time for them to realise what was happening) that GP's and other professional people did not listen to what they had to say and did not give enough weight to their experience and opinions.
- Use carers views to assist in assessment process
- Recognised that carers and families should be listened to at this early stage as they understand and are aware of the patient's condition
- A cared for person was admitted to the Woodlands Centre after being diagnosed with depression. The client received 3 batches of Electroconvulsive therapy (36 sessions in all). During this time (a 2 year period) the family became increasingly unhappy with the diagnosis and raised the issue with doctors, they felt that their concerns were not taken seriously. After 18 months of treatment the family asked for a scan and offered to pay. Eventually another doctor was brought in to investigate the condition and diagnosed dementia. The family want

to stress that the staff at Woodside were amazing but unfortunately they were treating the wrong condition.

- At what stage do professionals decide that a person has dementia?
- 4 years ago a wife approached her GP because she was concerned her husband was suffering from dementia. The GP said your husband has depression. She tried to convince the doctor that due to her experience of being with her husband (they are 80+ years old) that she was sure that he was not depressed and that in fact he had a form of dementia. The doctor could not be convinced and he prescribed anti depressants. After discussions with the wider family, the wife felt she couldn't give the prescribed drugs. They challenged the doctor again and eventually the husband spoke to two consultants at his home for 3 hours. They agreed that he had a problem of the brain and he was given an MRI scan and was diagnosed with dementia. No medication was given but he was told to increase exercise and his change diet.
- The carers first instance of visiting a GP with her 80 year old husband with unrelated query was dismissed as symptoms of old age.
- The GP said the symptoms were due to old age and didn't take it seriously, this situation is now improving.
- It seems there is a great reluctance to accept the partners view and as a consequence time is wasted trying to prove this view, instead of offering medication. I believe, in a large percentage of cases, the partners view is likely to be more accurate than the professional view.
- Some GP surgeries dismiss people and say "you are just getting older", this demonstrates the importance of training.
- Carers need to be listened to, understood and trusted.
- Carers are not always involved in the process of diagnosis and treatment.
- Having someone in the GP service to talk and listen to the family
- Observations from relatives, neighbours need to be taken into account.

Diagnosis: Training

- GPs should be more aware of signs for dementia – it took some persuading for my father in law's doctor to see there was anything wrong with him. He eventually had to go into a home but not before he had many falls after being found wandering the streets. We have found that not all staff are trained to understand dementia and still treat patients like naughty children in both the homes he eventually went into and especially in the hospital during his many visits.
- Hold study days for GPs, nurses and professionals about dementia.
- Look at which healthcare professionals need training, including GPs.
- Attitudes to older people need to improve e.g. in nurse training/care staff development.
- Doctor stated that patient was not as bad as other patients; more training required for Doctors in how to communicate with patients and carers.
- There is a huge variation of what a GP will pick up during diagnosis; more training will help GPs have a consistent approach.
- Doctors, health and social care professionals need training on different types of dementia to help with diagnosis.
- General hospital staff should have further training when dealing with Dementia patients.
- Staff need more training and awareness of infections such as urinary tract infections and the impact this has on patients with dementia.
- Getting an accurate diagnosis with depends on the GP you have, this is not how it should be and giving GPs updated training is very important as a way improving the situation.
- Hospital staff need additional and improved training when for diagnosis of dementia.

- GPs require training on the issue of diagnosis of dementia.
- GPs need more information and training

Diagnosis: Dementia Tests

- It might be worth doctors having an early diagnosis test.
- Dementia tests are very limited at the GP surgeries.
- Dementia tests at GPs to be looked at.
- The test sheets issued to, or used by GP's, are totally inadequate.
- Someone came to the house which was a positive experience and carried out tests and asked questions. We received letters with confirmation.
- We went to Mill House and had tests, there was no follow up.
- This happened in the London Borough of Ealing: A carer was told by a doctor that "you can't be 100% sure if a person has Alzheimer's until they are dead" doctor said at this time tests can confirm the disease.
- We require a national dementia test.
- Memory tests can be disorientating and increase anxiety of the person with dementia.
- Memory test too long – 1½ hours too long.
- Memory tests can be oppressive and make patients angry and anxious.
- Carry out yearly memory tests for dementia patients.
- Tests to be made more generally available at 60 years old.
- More frequent health check up and related to age
- People aged 80+ should be called in for annual check that include dementia

Diagnosis: Waiting times and referrals

- Appointment slots are sometimes only on a yearly basis (Woodlands).
- The consultant thought her husband had Parkinson's disease, but could not refer her had to go back to the GP for another referral. Services need to be linked up within and across health and social care.
- GP had no real knowledge of dementia, he said yes you have dementia but patient was not referred to a specialist unit or offered any medication, counselling or support.
- GP experience was good, referred to go the Woodlands Centre which was also a good experience. The only problem is getting there by taxi, Dr came to the house which was very helpful.
- The GP did not have the specialty to diagnose dementia and he should have made a referral to a specialist unit if he was unsure.
- Lengthy delays for appointments - where do you go when awaiting for help?
- It was a long time to wait to see a specialist.
- Carer said that the cared for person was waiting at home for an assessment from the GP and psychiatrist, once they arrived they said to the client "you have to come to hospital to be assessed, if you don't come we will take you by force". She was taken to the hospital and stayed there 3 weeks, she didn't have any clothes. The result of the assessment was that she might have Alzheimer's.
- Kings College did not want to step on Hillingdon's toes but didn't get MRI appointment for 8 months (appointment at 7 months was cancelled).
- Getting an appointment can be a long process after visiting the GP.
- Lack of access to early diagnosis, time between appointments and assessment too long.
- Length between follow up appointments too long, limited information provided between appointments
- It was a slow experience.

- It took 4 years to diagnose, had to wait 6 months before a scan and had to pay for it.
- Carer rang Social Services and asked to be referred for her husband's diagnosed dementia. Someone came from the council, agreed the problem but said couldn't do anything immediately, but was referred to Woodlands.
- There was a long period to wait for the review with the Specialist – 9 month interval between appointments.
- Distance between checks to be reduced.
- Getting seen on time at any hospital or doctor's appointment helps with the patient or carer

Diagnosis: Access to information and support during early diagnosis

- Carer's father-in-law was admitted to hospital for a stroke and following scans was diagnosed with vascular dementia. From then on the carer was left to her own devices with no further support, information or advice offered.
- Hillingdon carers and support groups provided guidance and information.
- Second GP investigated and Consultant gave details of several organisations who worked in the community.
- People need more instructions and information on dementia and diagnosis.
- Information on the symptoms on early diagnosis needs to be available.
- People living alone – who will help them/signpost them to the voluntary sector?
- There is a lack of support for carers.
- It is difficult to know what help is out there because it's not advertised.
- What are the community resources?
- Information should be there when you need it e.g. caring for family member and didn't know about support available/day centre etc; it took me 2 years to find out.
- In political ward surgeries, Councillors signpost to local services and people are totally unaware of the services.
- Prevention is better than cure, isolation can make you depressed etc. Need support to know what help and support is available.
- Isolation is a key factor. How do we encourage people to get support? Who knows about them, are they registered with a GP?
- There should be more support/ services available for families and carers at this early stage.
- Information for the public about dementia and symptoms to have sufficient knowledge to lead to a referral.
- People are not promptly signposted to relevant services after diagnosis.
- It is not easy to access information about care support and advice.
- Different GPs having different views, there is a big issue about information from different doctors, as a carer it is difficult to know who is right as you get different messages.

Accepting the diagnosis

- Husband is refusing diagnosis as he suffers from alcoholism.
- Some dementia sufferers won't accept they have a problem and carers have to pick up the pieces.
- Patients are fearful of being told they will their lives.
- The person doesn't want to/can't admit/see what is happening to them.
- Once diagnosed the family didn't want to tell the patient that they were suffering from dementia but the doctor said that they had a duty to tell her.
- Lack of understanding about dementia combined with a fear of talking about issues and feeling embarrassed about talking of forgetting things.

Clarity in diagnosis

- Carers recognise symptoms of dementia first.
- There were some assumptions about signs of ageing but the onset was not diagnosed.
- There is an assumption that older people have dementia because they may have forgotten something.
- Lots of people present with symptoms (confusion etc) and they need a timely diagnosis.
- What is the difference between dementia, Alzheimer's and Parkinson's as the symptoms can be similar and difficult for carers to understand?
- The carer was told the patient was too young for dementia. GP put a question mark against the diagnosis.
- The diagnosis was by chance at the GP surgery, Well done to the GP for recognising this and referring to the Memory Clinic
- Only 1 in 3 dementia diagnoses happening correctly so 2 out of 3 people are not being diagnosed.
- It is equally obvious to me that if I hadn't been aware of and made an approach to, the Alzheimer's office in Northwood Hills I would probably still be waiting for a diagnosis.
- One person went to India to get a quicker diagnosis
- The diagnosis can sometimes be rushed and come to the wrong conclusion
- Patchy diagnosis, not too confident about experience of diagnosis
- Need to get the right diagnosis, and if people aren't diagnosed then it won't inform the commissioning process
- Encourage individuals to go to GP but they are dismissive mixed stories around Non diagnosis has affected ongoing care

Dementia diagnosis other

- Doctor knows patient so knew behaviour was out of character, that's why having a relationship (GP – patient) is important.
- Problems for people living on their own, who can identify dementia signs and put care and support in place?
- The disease gets worse and people don't know what to expect in order to manage these changes.
- A client lost the use of English language through dementia.
- My involvement has been in supporting my parents, who lived in Ickenham; while my mother had Alzheimer's for the last 5 years and was cared for by my father (in his 80's). Observing and helping them I saw first hand how much work is involved in looking after someone with Alzheimer's. This is the case even if the carer is in full health but becomes especially difficult when the health of the carer is declining too.
My father died of a heart failure in October 2011 and I cannot help but feel that this was brought on partly from the exhaustion of caring for my mother with Alzheimer's.
- Family members were recognising different behaviours, including moving items around the house and the person was able to 'cover up' the symptoms at early onset. The behaviour included not only moving items around the house but clearing out and getting rid of items
- Husband calls wife a liar when she tries to explain to doctors about his condition.
- Professionals/neighbours etc all need to raise the alarm if they haven't seen someone for a while.
- Woodlands centre highly qualified although they have limited resources.
- Experience of being put on tablets for depression as dementia was mis-diagnosed.
- We had to pay for brain scans before any diagnosis was given.
- There is a lack of empathy from (medical) staff.

Medication

- Dementia patients are prone to urinary tract infections. How can this be addressed?
- We received advice on medication through the hospital and it was good advice.
- Departments should have study days about medication.
- We did not experience any issues with medication it was all adequately explained.
- Dr from Woodlands was very helpful.
- In care homes they like to keep dementia patients in a docile state and this is achieved with medication
- We were directed to a course by occupational health delivered by 'Admiral Nurses'. Admiral Nurses are excellent.
- Admiral Nurses have been brilliant but they struggle to provide courses with very limited resources and we need to build on this.
- There is a presumption that carers already know that there are Admiral Nurse courses at held in the Middlesex Suite.
- Patient prescribed Aricept, there were no side effects and the condition improved at start but can only stay on them for 2 years. What happens next?
- Patient prescribed Sodium Valporate some years ago and had a bad experience.
- You need to take Aricept early to slow down the process.
- More advice and information needs to be available about medication.
- One carer was told that Medication does not work for advanced dementia
- The carer is not happy with anti psychotic drugs given to wife as he believes they are reducing her life span. The family reduce the amounts of drugs based on a daily observation of her behaviour that day.
- Husband won't take medication for other problems e.g. high blood pressure. He refuses to let wife speak to doctors. He is in denial. He hides his drinking.
- Husband used to flush away his medication. Care workers now ensure he takes it.
- Not offered medication - unspecified diagnosis - cannot be certain.
- Professionals are not listening to carers' concerns about side effects of medication, in one case medication led to a mini-stroke.
- Husband, who is blind, was prescribed medication that made him very ill, he was immediately not 'with it', unable to respond and despite a number of alternative drugs, nothing seems to have any effect other than to experience a 'drugged' effect. He is now on reduced strength, which the dementia unit claims is totally ineffective, but he cannot function on a higher dosage. Carer is hoping that they will soon be doing trials of other drugs without such severe side effects, particularly given the major sensory disability of the patient.
- Doctor from Woodlands recommended medications for Carer's father in law. The family saw a Panorama programme about using drugs for dementia and how it can shorten the life of the patient. Although the patient is disturbed throughout the night, shouting all night and day, the family made a decision not to pursue with the use of drugs. Patient's situation deteriorated further, from mild through now to severe, and screams all night long. The original dosage led the patient to remain asleep for 3 whole days which worried the family. He is now on ¼ of the dosage to gain some respite through the night, but the family are not comfortable with these drugs although the dose has been reduced with the agreement of the medical staff.
- Worried that when first memory medication ceases what about the ramifications of what will happen then, they know that the patient will deteriorate and are concerned about what to expect and the extent of this when the medications stop working.
- Concerned that due to the cessation of medication it may require the person to go into a care home.

- The medication made the patient sick, depressed and emotional and they didn't want to take it.
- The Pharmacy gave advice on medication not the GP.
- There was not much improvement from the medication.
- As I am not registered with the same practice it was initially difficult to arrange a home visit by my mother's GP on the grounds that I felt she was in need of a diagnosis to access medication to alleviate her terrible anxiety and mood swings.
- I decided that I should talk to my GP about my wife and my suspicions that she was showing signs of dementia. This resulted in my GP testing my wife using a memory test chart. After this was completed my GP told me that my suspicions were unfounded. Some 10 or 12 months later, I requested my GP to repeat the tests and once again using her magic chart she reaffirmed her previous finding. I questioned my GP on the results and she told me that if she sent my wife to Woodland centre, they would laugh at her being sent there. Some two months later I discovered an Alzheimer's office in Northward Hills which I visited and they arranged for a home check to be made by a qualified interviewer who confirmed my suspicions. They wrote a report and sent copies to myself and my GP. Woodlands Centre sent yet another assessor to my home this resulted in an appointment at Woodlands Centre approximately two years after expressing my original concerns. The treatment at the centre consisted of yet another assessment interview. Some time after I heard, on the BBC news, of a drug being accepted by a committee for use by the NHS, for dementia, so I went to my GP to request a supply of this drug and was told that this could only be prescribed by the Woodlands Centre, who I contacted, which meant yet another assessment interview. I still think the name of the drug on the BBC broadcast was REMINYL, but nobody seems to have heard of it. A new drug was supplied at that time called Aricept or DONEPEZIL HYDROCHLORIDE. This caused stomach problems which it was hoped would subdue once the body got used to it. This failed to happen and when I had to wash three pairs of trousers in one morning, all occurring in the toilet, i.e. not incontinence, I stopped my wife taking the pills and informed the doctor at the Woodlands Centre of my action and the reason for it. I believe there are some drugs for protecting the stomach lining for so conditions such as lansoprazole and derivatives but nothing was suggested. Another appointment has been made for the 24th Jan... I'm hoping it not just another assessment test but I believe whatever is suggested will fail. My wife's condition has worsened considerably, which I believe is largely due to the massive delays in diagnosis and lack of quick and adequate treatment.
- My mother was prescribed Aricept. The timing of the original prescription was just before my parents were to go on caravan holiday abroad. My father who was caring for my mother decided to start giving my mother the Aricept while they were away on holiday without any support. My mother had some strong initial reactions to the drug which caused some quite alarming and potentially dangerous situations for them (near collapse and psychotic episodes while away in a foreign country without any help to hand). The decision to go ahead with starting the drug while on holiday and away from any support was his but I'm not sure that the risks of doing so were emphasised enough. In retrospect it would have been really helpful if the period of the first 2 weeks when starting on Aricept would have been much more closely supervised with medical advice to hand.
- My other comment is that one of the major side effects of the Aricept was to make my mother doubly incontinent. This put a huge burden on my father (in his 80's) in caring for my mother over the next 5 years. Given that there are very few options in the treatment of Alzheimer's its debateable what could be done differently once the choice is taken to follow a drug treatment with Aricept (maybe there were other drug options that could have been explored?). I just wanted to highlight the issue for consideration by those with more knowledge in the area (and offering advice to others) as the incontinence side effect of Aricept had a very detrimental impact on their quality of life.

- If prescribed drug treatment presents additional problems there seems to be no experience of this among the specialist professions and consequentially no instant telephone advice to overcome the problem.
- Positive that medication is not being used in the same way as previously and there is more opportunity to investigate the reasons behind the behaviour.
- Once you get the diagnosis medication and information, the service is good
- Power of Attorney to be done as soon as possible when diagnosed
- Issuing of medication is sometime dependent on cost to GP, example given of a hospital threatening to take medication away as it was “not doing any good” and costly.
- The responsibility of seeing if the medication works is left to the carers to decide, not always want to make these judgements
- Use of anti psychotic drugs/medication in nursing homes – side effects can be as bad as the illness and needs more medication to counteract the side effects. Patients need monitoring/follow up after diagnosis
- Information should be available about side effects for professionals going into the area of dementia care – what to expect, what to look out for – bullet points for staff.
- People with quite sever dementia may be reluctant to take medication
- There should be medication management for people in the latter stages.
- Medication can do more harm than good, sometimes given by GPs to get rid of them
- Issue about ensuring the correct medication is given
- Concern that some personality changes can be side effects of medication.
- Woodlands was a good experience, I got the correct medication, however the medication was not successful.
- Dosage for medications need to be managed
- Medication – anti psychotic drug – had to research the side effects on own was not told by GP, more advice needed.
- Lack of information, need to look at the care being given before medication is given
- Drugs slow down process – don’t want it – prolong agony. New drug should halt disease and may restore/regress.
- Someone with memory loss living on their own may forget to take their medication.

What would improve diagnosis process?

- Each GP practice has a dementia specialist
- “Catch it early, treat it fast” as the slogan for cancer.
- Recognise symptoms early so it can be dealt with
- Timing needs to be improved
- Speedier process would be better
- The referral process needs to be improved
- GPs should be more prepared to look at signs of dementia when diagnosing other ailments
- Improved and quicker assessment
- Greater alertness of presenting symptoms e.g. memory loss or confusion or disorientation.
- Reducing stigma – staff, patients and the community
- Carry out questionnaires – brief 4 or 5 questions at first visit would help
- To build into all people’s yearly assessments at GPs a very short simple memory test
- Memory clinics
- Receive timely information
- It would be good to receive community occupational health information
- There is a lack of understanding of what benefits you can access e.g. Carers allowance
- More information and support especially around benefits, blue badge etc

- To receive an information pack when diagnosed
- We are not on-line, we have no PC so need alternative methods to get information
- More information on the long term positive outlook for patients
- Information
- Checklist – you've become a 'carer'
- More information for core professionals (GPs, nurses etc)
- The GP is the first point of contact – should be able to provide all of the information the person needs, confidence, treatment etc. Doctor should stay in touch throughout the process
- We used to have a Hillingdon handbook for people with dementia (red book) – it was handed out when diagnosis was made and was very useful. Is it still in print?
- News sheet from the council at the GP surgery – to advise people what they are entitled to – council need to do this to help
- Voluntary sector support e.g. for cancer you know to go to MacMillan, do people know who to turn to for dementia support for carers?
- Information given out on strokes and heart attacks.
- A point of contact – who to go to
- Information not given at time of diagnosis
- It all starts with the GP they need to direct you to advice
- Offer help and assistance once diagnosed and following periodic review
- More publicity on dementia
- Dementia needs to be talked about more
- Profile raising
- Need public campaign to look out for signs for dementia.
- Treatment/Education – get it out in the open
- Events such as this are very valuable. The table generally agreed they're important and we need more.
- We should educate police etc about behaviour – it can be different/unusual but it might not be dangerous (linked to stigma)
- Increased awareness of dementia with health staff
- Education – what is the difference between and dementia
- Routine referral for confirmed diagnosis to specialist services.
- Services should talk to each other GPs talk to Consultants, both to talk to the Council etc.
- Communication skills of health staff with older people
- Routine CT/MRI scanning regardless of age
- Regular testing/screening
- Blood test for dementia?
- GP surgery to have nurses/CPN who have the time and who could go out and pinpoint; using their experience knowledge and skills to signpost onto psychiatrist.
- More support from Woodlands Centre
- More frequent consultation with specialist.
- One stop clinics
- Specialist clinics
- The importance of dignity and compassion in giving the diagnosis and in giving information
- Additional coping support for carers- often left on their own after original diagnosis
- Ways of recording behaviour to show doctor symptoms. Not always evident during appointments.
- Carers are a vital element – as country is focussed on less money, carers care is vital.

- Future planning – making decisions e.g. money, power of attorney etc, people need information about what to do when things happen or change in the future
- GPs having sufficient time to explore the issue with their patients
- Being able to see the same doctor, establishing a relationship with the GP
- Clear diagnosis – possibly not by GP maybe other specialist
- People living on their own – importance of care and support staff being able to recognise symptoms
- More inter-links
- Learn from diabetes care
- Facilities
- Expertise/Experience

2. Early intervention and support

Finding out about Services and information for Carers

- What are dementia services? - Not aware of what this means
- Had information from Woodland.
- Social workers very good they listen to you.
- You can find all the information that you need about dementia on the internet and by doing research. You have to have the skills experience and motivation to do this. This is hard when you are a carer and are just getting through the day
- Events like today help people as good networking opportunities.
- Council staff gave contact details of support services – right through to renewal of blue badge.
- The council was very supportive.
- No information or support from the Woodland Centre – they never said anything about benefits available.
- Church was very helpful – the community
- Told information from a hospital admission
- Patient diagnosed with dementia who has been offered no other support would like to know more about the illness, what is likely to happen to him.
- It took 2 months to process any financial support
- Not knowing where to go to
- Need someone to talk to – but don't know where to go
- We don't have any specialist dementia services – need to have right services with the right people in them
- Best to find out yourself online
- Wanted someone to tell more about what would happen rather than receive a booklet that is a year out of date.
- Can GPs print out a list of support services for families
- At the point of GP appointment – if any indication of memory loss or dementia a 'pop up' onto computer screen as an 'aide memo ire' to signpost the patient to support services

Experience of Support and Service Providers

- Templeton Café was good at providing information and helping to understand the stages of Alzheimer's
- Templeton Café are a really good community support group

- Templeton Centre (Joel Street, Northwood) - The most important thing that the Templeton Centre provided was the opportunity for my parents to meet once a week with other carers in a similar situation. The process of losing a partner to Alzheimer's and becoming their carer is a difficult emotionally as well as practically. My father found it very supportive just being able to meet with other people who were experiencing the same things and to know that he was not so alone. As well, it provided a forum to learn from each other what services were available, how to handle situations and to be more prepared for future.
- Templeton café, very good
- Hillingdon Carers are my lifeline. The Carers cafes that have been formed are as helpful as some of the best advice I've had has come from other Carers. More opportunity for this type of interaction is vital.
- Found out about Hillingdon Carers through Woodlands and got an information booklet, benefits and pads
- Do not know about Admiral Nurse Team or how to contact them or what they do
- Age concern, very good, daily centres held but daughter felt that she had to organise everything as she couldn't trust social services
- Eastbury Road Day Centre - and Poplar Farm day centres were a fantastic help to my father while caring for my mother. Out of all the services this was the one he found most helpful. My father was full time carer in his 80's for my mother. He knew that his wife was being well looked after while at the day centres and the activities put on provided experiences for her that he could not provide. The time she was away at the Day Centre was a real relief for him as the stage my mothers Alzheimer's was at required him to be with her all the time. On those days where it was provided it enabled him to have some time during the day to catch up with all the jobs that needed doing and also, at times, to get some rest.

Improving the service: What is provided at the Day Centres is really excellent. The main problem is shortage of places and their availability in the borough.

It would enable more people to get this help if there were more places available in the borough. There seems to be a long waiting list to get access to places at the day centres. Indeed, after the closure of the facility at Eastbury Road, there are now even fewer locations and places. It would have been a great help for my parents to have had more days at the day centre and for them to have been organised more quickly rather than a long wait (3 to 6 months) to be given additional days. They started on one day a week and then increased to 2 after a year or so and then eventually to 3 days a week. 3 days a week seemed to be the maximum while other boroughs (e.g. Watford) provided up to 5 days and my father, as carer, would have found it very helpful to have had more days. I expect that there are many other people who would really benefit from this support but are unable to do so because of the lack of places.

If I was to make only one suggestion in this review it would be to find an additional location and staff to provide more places for Day Care. (It appeared that there were not enough places in the borough even before the loss of the 20 places at the Eastbury Road Day Centre)

One other small improvement would be to make the days 1 hour longer. While at the Eastbury Road Day Centre my mother was picked up at about 9.30 to 10am and dropped off at about 4pm and this worked well. After the move to Poplar Farm, however, she would be dropped off at about 3pm which meant that the afternoon was too short for my father to do anything substantial in it. It would be much better for him if the Day Care service had continued to about 5pm giving a full afternoon to the carer to be able to attend to other things.

- Have had experience of Homecare - help with getting up and showering, Respite Care at a residential Care home (to give recovery time for the carer) and Alzheimer's Society

- Support groups available for carers run by the Red Cross
- Not all homes take dementia patients – makes it difficult to find a home.
- Some services when you call up are not experienced and don't necessarily give the correct advice e.g. social services
- Social services – some bad feedback so services offered
- Services in Hillingdon are good – but you have to find them yourself
- Day care – some people may want this. The carers need the day care as respite. Good experiences of day care.
- I do not think the services available now are much help
- These are the dementia services we have heard about or use:
Hillingdon Carers, Admiral nurses, Templeton Café, Alzheimer's Society, Bell Farm lunch club – Donna offered excellent support, PALS
- The only groups I have had any contact with are Alzheimer's Society & Hillingdon Carers who have given me assistance. I have no experience of the other organisations referred to in this paragraph. I would greatly value someone to talk to, experienced enough to advise with Alzheimer's and the combination problems of Alzheimer's/Diabetes/Arthritis, especially if this was available, for emergencies, on a daily basis.
- Felt as if left 'high and dry' with no support
- Access to personal care is not timely from Social care, health and housing
- Assessments for personal care from SCH&H needs to be timely
- Once you start receiving dementia services they are excellent
- Admiral nurses are very good
- Admiral service needs to be promoted more
- Use of Voluntary groups very good, give support and clear information
- Best support for carers is from the Voluntary sector
- Hillingdon is a good borough for services-
- Sign posting is OK, Libraries a good source of information
- Rapid Response has been used, good
- After initial assessment, left to carers to find out their own information, lack of IT skills for some people means it is difficult to access all the information provided on line.
- Funding: should be prioritised jointly with health services / support to carers. Need to work closely with health – economies of scale – reconfiguring what we've got
- Keeping people at home, preventing them going into hospital or residential care
- Support in the community for people with an early diagnosis
- Carers need confidence to maintain their family member at home – instead of feeling they need to go into hospital
- Resources/respite for carers to give them a break is so important
- Nurses could only take in critical cases, not all.
- Social services organised home care package for 30 minutes day. Carer used this time to make private calls on the house phone.
- Wife was previously allocated 4 hours a week sit-in service, this has been reduced to 4 despite her husband's health deteriorating. The couple are in their eighties. Carer is already unable to cope with her husband's dementia. He has a day at Asha Day Centre but would like 2. She is waiting to hear from a social care assessment to see if she can get some help with personal care for her husband.

Changing perception and removing stigma

- Have not experienced stigma at this stage for some.
- Stigma attached to dementia.

- What has been good is the media coverage from public figures – (leaders of nations and people in the media publicising – authors etc like Terry Pratchett)
- Sharing how dementia has affected people
- Set up in the local community stalls for drop in information in public places
- Do not think there is a stigma.
- Husband refusing to accept illness.
- There is more awareness now about the condition – there is not as much stigma as in the past.
- Take a holistic approach to people with dementia (conflicting performance frameworks do not help)
- Changing mindsets to working with people who have dementia – seeing the person with dementia as a person
- Dementia is not talked about enough
- We can change perceptions by talking about it more
- The subject is widely discussed
- Group not aware of any stigma
- General public to be more aware of the signs of dementia would help to remove the stigma
- Education events on dementia will help alleviate stigma
- Additional information/ publicity
- Promote more positive outcomes, different levels of Dementia
- Improve general awareness, this is a national problem that needs to be improved
- Raising awareness – being more open
- Society doesn't general accept behaviour – an example of extra care resident being stopped by police and returned to extra care scheme because he looked confused (but he was just walking to the bus stop and was quite ok)
- Campaign needed to change public perceptions
- Carers fairs and conferences help to raise awareness
- Should get reassurance from GPs - patients should not feel stigmatised
- Perceptions around building nursing homes etc. people don't want to live next door – need to change the perception
- Councillors go to Riverside Centre to talk to people – they can share knowledge afterwards when they go on to visit other residents at tenant and resident meetings etc.
- Public health advertising – similar to cancer/stroke campaigns
- Very difficult
- The stigma is very difficult
- Because you can not see it – people who do not know who has it
- Need to talk about it more – rather than hiding, inform people more
- Local level – council run events need to ask the carers if they need support for caring while they can attend events such as these.
- Stigma families do not want to share i.e. with others
- Need to be afraid to tell people as this can improve support worker
- Support worker to help/advice
- Case stories of individuals and meetings with carers and patients with dementia
- Dementia community group
- Better publicity
- Always tell people when we meet them that my wife has dementia
- Education – a lot of residents and older people even don't know what it is
- Teach locally and nationally
- National campaign needed

- Joined up thinking
- Did not know a lot about dementia before today
- Heard from others what experience was
- People think it's just forgetfulness – becomes a joke
- Cultural differences – some cultures don't understand there is such a condition (e.g. Indian – ALLEGEDLY)
- People need to ask questions
- Improve awareness through publicity
- National campaigns
- Covered in schools to raise awareness
- Awareness in health and social care that some older people 'hide' problems as they are afraid that they will lose their house if they have to pay for services
- Joined up thinking
- Notices in public – amenable

Support and Training for Carers

- Woodlands run training every evening. Not chosen to go. But needed a sitter for husband to attend. Not easy to get.
- Carer went to Hillingdon Carers for training on moving and handling for her family member. However she could not remember how to do it when she go home – and she feels it would be better to have someone come to the home so that you can see how to do it in your own personal situation – she said that the training had a trained person the other side, so they always took the lead, so could not implement what she learned.
- Employing agency staff does not ensure that they know how to handle the patient – insufficiently trained agency staff do not know how to use the sling to move patient – and only learned how to do it when attending Hillingdon Centre for Independent Living.
- Carer's information day at Admiral Nursing very positive
- You can get training through Hillingdon Carers through LBH – was signposted but Carer able to go to Civic on own volition
- Admiral Nurses course - learnt what to expect etc - appreciated the support from everyone else e.g. other carers.
- What happens when the carer needs to go out and the person with dementia refuses?
- Training in practical aspects of caring e.g. moving and handling needs to be improved
- Support is out there but more awareness needed on services available
- Need training to support some with dementia what to expect, how to deal with it etc
- Woodlands have a 6 week programme for carers - difficult to access as limited places
- Support from Admiral nurses
- Not enough support for carers
- Further resources required for training
- Additional crisis intervention
- Single point of contact
- Quicker initial assessment
- More information about future patient outcomes
- More consultation with families
- More support for carers after a bereavement, as all their support is taken away, unable to continue to access clubs i.e. Cafes due to funding
- Support for care home providers – psychiatric input? – how is medication reviewed?
- Right training for dementia care
- Training staff – would cost less to invest in training than put people in residential care.

- Staff – low or no cost – working with mental health teams – Woodlands etc making best use of skilled staff in mental health teams to support interventions in a community or care home setting
- Closer liaison between ward staff and nursing home – time to ask questions during transition, how did you manage that particular behaviour? etc
- Admiral nurses provide specialist training – understanding conditions, complex behaviour, etc How widespread is this?
- Reconfiguring services to cater for increasing demand for dementia care – reablement etc.
- Yes – through the Alzheimer’s society and NHS
- 6 week course
- Help while the course was being undertaken
- Nurses – help with training
- Alzheimer’s society have support group
- Booklets – given by Hillingdon carers
- Learnt a lot by going online and researching by myself
- Only from carer – none from LA/NHS
- Crossroad services – for Carer
- Self funders difficulty around knowing carers and choosing the right one
- Support from care agency – sitting service and early morning care
- Reduced and paying for private carer
- Moving and handling training
- Support from admiral nurses
- Support often comes from friends and family
- 4 hrs per week
- Templeton Centre – paid for social things/activities for a day.
- Most support is from day centres – without this patient would have gone home.
- Carers group available in Hillingdon Hospital foyer once a week.
- Respite care provided for 2 weeks.
- No training available at present
- How do Carers access support?
- Where do carers go to get this information (about training)?
- No training offered.
- No training – only what she found out herself
- I have not been offered any training
- I have not received any training at all to prepare me.
- Feel as don’t know what to expect next

What would improve dementia services/ what further support required?

Information and training

- We need information about handrail and adaptations for home e.g. bath/bed hoist
- Knowing what is available and where to go to get information
- Better information for self funders
- Need to know about what is available
- GP should have information packs
- Need to know who to contact for worries
- The information in GP surgeries is not enough
- Need people to explain to you what happens
- Need to tackle the lack of information

- Need a helpline advertised
- Get information early on – it is vital
- It's not knowing what the next stage is – not knowing what to expect. This is huge for carers. It would improve the stresses of caring if you know what comes next.
- More knowledge for carers on dementia and how to support people with carers
- Carer's information day is very useful.
- Knowing points of contact
- Where do you get a blue badge?
- Need more Dementia information days as held in January 2011
- Information about what services available and how to access
- A central point to go to for information
- Better information/advice around the condition what to expect
- Event like this for end of life review
- Event like this for staff who work with people with dementia – information about background and review of dementia
- Training in understanding the condition and what to expect
- A small thing that I feel would be helpful would be some form of counselling or training that helps carers not only provide for the person they are caring for but also care for themselves. Also having someone assigned that the carer at home can get to know personally as a contact point into the whole range of services to act as their personal advocate and advisor would be a great help in interfacing with the services available.
- Need help with falls - causing carer injuries when lifting
- The council to have a list of all residents who are over 65 – send out an information pack of who to contact if you are worried
- Knowledge, knowing what's available early on
- Need to have and understand the importance of having information and advice e.g. re opportunities for socialisation.
- Potential for long-term care and financial implications from this needs to be looked at i.e. Access to sound financial advice
- Additional support for carers in a crisis situation, there is no where to go for quick information in a crisis so patients end up in hospital/A& E
- More knowledge up front about options and issues.
- Telephone helpline and support groups.
- Limited understanding – need education
- Support isn't well publicised – needs to be advised at point of diagnosis.
- Pack of information from Hillingdon Carers.
- More training from Admiral Nurses specifically on dementia training

Transport

- Transport is an issue. Dial a ride refuse to walk the people to the door, this was 5 and over years ago and sometimes the clients wander off.
- Need help with transport as cared for persons mobility can deteriorate with dementia as coordination gets increasingly difficult
- Lack of transport – need transport to help within the borough
- Day care is also important – services should be expanded, and transport services to back up day care
- Transport – would not take carer in transport.
- Transport to day care

- Alzheimer's Concern in LB of Ealing was really good with help and support, functions to enable carers to go out and transport to get carers and cared for to and from functions.

Respite

- Help with funding and respite – on what resources are available
- Respite - carers should be able to stay at home. Sufferer should go somewhere else. Not vice versa (see as cost reduction).
- Carer has tried to book respite care services. However, the details and mechanics of this have never been explained and she has waiting for 3 months to have the date confirmed (next week). She is not sure of what if any entitlement she might have to caring for a husband who is blind and who also has dementia. Carer also claims that she 'hears' that name tabs have to be put on every item of clothing, including pants – and wants to know where you get them from, etc and if this is true.
- People work – therefore respite is vital
- When a carer falls ill and needs emergency respite care
- Confirmation of respite care is a problem. One carer arranges for care in their own home as father in law cannot be moved out to residential. Although a lot of notice is given with regard to dates, flights etc confirmation is often not received until after she returns from the trip – and therefore she arranges her own care prior to leaving and applies for a retrospective account to be settled by direct payment so that she can pay the agency involved.
- There is undue stress on Carers to know when respite dates/and/or payment is going through to arrange privately.
- More respite time - carer's own health is deteriorating - more post-hospital admission help
- Respite is full - Hillingdon Carers would like more and it is evident that some carers are not aware of it.
- Respite - needs to be regular and frequent.
- Carers do not have time have time for training - need respite in order to attend.
- No chance of a life without respite.
- Even social/leisure time is a break as always looking out for the sufferer.
- Restricts movements - "No time for myself".
- Respite – no one to call or rely on
- Respite care is important so the carers can have time off
- More respite for users
- More access to short breaks
- Emergency respite
- Respite and support
- Respite when they give it may not be suitable time/day
- Respite for women who work and would be carers.

Voluntary and Professional staff and Centres providing specialist care

- Better and more care services within the community
- More physiotherapy services and exercise programmes/other programmes that will support the person with dementia to be more active
- More intermediate care/rehab that are available for people with dementia
- More opportunities for mental stimulation
- Community to have a sitting service by a group of volunteers
- Outreach nursing provision for district nursing
- Designated social worker/allocated needs to be on point of contact

- We need culturally/ethnically sensitive person to contact – so I can talk in my own language and they understand the needs of my household
- Need an Alzheimer's Services for Hillingdon or on the council web site
- Provide nursing support along the lines of MacMillan nurses/Marie Curie nurses
- Expansion of Admiral Services and commitment to funding for Admiral services
- A regular visit from the social services etc to come and visit
- Training for social care staff – making decisions about support needs, intervention, medication especially physical health staff – may not be aware of needs of dementia patients
- Specialist dementia team/staff
- Needs somewhere where we can go to talk to similar people who have Alzheimer's
- We urgently need rehab for people with dementia in Hillingdon. It currently doesn't exist and we have generic services but need specialist services - both bed based and community, psychiatric/psychologist – to reduce hospital admissions
- Need people with skills to assess otherwise interventions won't be long standing (revolving door cases – need to reduce/prevent this)
- Consistency of care workers providing short breaks or domiciliary care
- More day centre availability – worried about closures
- Locate day care in residential setting rather than hospital. Respite could then be in familiar surroundings.
- More contact e.g. like district nurses did with post-natal
- Volunteers
- Volunteers – Ash retired nursing – keep expertise on board and fresh. Had to go volunteer herself – no one asked. DASH.
- Need to identify those suitable for volunteering.
- 24hr support – immediate
- 24 hour support – Immediate support
- Care homes nearby homes – closer
- Network group for carers of patients that go to day centres would be good.

Other support services

- More support for carers/feeling responsible for exercise programmes/activities
- Support for carers needs to be improved.
- Provide care support for people who are physically able but have limited cognitive ability
- More support in personal care e.g. washing sheets/clothes etc
- More support on personal care and personal hygiene
- Extra care for self funders
- Review assessment of carer needs
- In care homes – take in things from home so it feels like home
- GPMS technology – especially those living on their own
- If support was offered to those that want to live at home it would give them that option

Comments

- Media coverage is good
- As a carer feeling penalised for being a carers – sometimes this is financial.
- Find it difficult to get help when there is denial - carer having to cope in absence of support - self help - support through Hillingdon Carers café
- For hospital stays, discharge planning should start at admission stage.
- Need to reduce hospital/residential care admissions and/or reduce length of stay
- More individual care packages (moving away from breakfast at 12 and bed at 6)

- Dementia services needs to be advertised more
- There are lots of untapped resources – people don't have confidence or knowledge to use them
- TeleCareLine is good but cannot replace human element. People may struggle with technology
- Mobile response team attached to TeleCareLine is such a positive thing
- People may be going into care homes too early – need to tackle this
- Examples of people moving into sheltered/extra care from residential may have been in residential for a year and find it hard to adjust afterwards – totally different way of life. Talking, socialising, own equipment choices, positive, but still need to adapt
- Support for carers who are working/would like to go back to work – difficult to manage time
- Free fitting service – this is a risk if you do not know the person, need to have the same person each time.
- Crossroads very expensive
- Expensive to pay for the basic services, e.g. time out of the house to go shopping
- Need stability in the people you are dealing with
- Alzheimer's Society are good – 10 minute chat every so often
- Can't take things in isolation. Decisions can't be made in isolation as impact patients and carers.
- Carers can have mental breakdown
- Worry and stress – carers – needs to be considered
- Telecare – only free to over 85s
- Telecare free to all
- More proactive about publicising services.
- Concern how some people may be able to afford support as changes become more common

3. Crisis/Emergency Help

Experiences of crisis

- GPs are not the best person to speak to about a crisis – you have to make an appointment – it is not 'now' but in a few days time.
- Hospital staff were told about patient's dementia but unsure if consciously took this into account or not.
- Exhaustion of coping with the situation
- Not knowing where to go and who to turn to
- Hillingdon Hospital now have an 'assessment centre' – separated off and shorter waiting times
- When carer falls ill
- Husband didn't want to go to hospital - discharged he - tries to return home by bus - last time she arrived he had disappeared.
- Mother (92 yrs) was admitted - Communication problems (non-English speaker) - diet problems (no Indian vegetarian food) - carer brought in food for her to eat - staff took her toilet bell away from her as she was ringing too often (continence problems).
- Carers worry more when they are in hospital.
- Presumption that families are helping but carers are alone.
- When husband was in hospital - "There were no problems. I did everything myself."
- Hospital stays complicate carers' lives.

- When person went missing the relevant services needed to communicate with each other - Hospitals should have sent the information to the police and also the GPs watch would have helped in this situation
- Hip fracture – could have been prevented if there was the right diagnosis and respite home was aware of situation
- Better communication from health professionals
- 2 ambulances did not provide good services, they would not pick up the patient
- Bad experience in Hillingdon hospital
- Good experience of ambulance service – good carers
- Mother, Wales – hospital for 4 days – received a letter from hospital saying that carer had given permission to let patient go. This was not the case, received an office apology
- Lack of support – can lead to hospital admissions need consistent sup port.
- Patient in a lot of pain admitted to hospital – when he came out he had lost all of his confidence – he was a different person – it was caused from impacted faeces so carer would have known this. Patient taken to hospital and police called because they couldn't cope with challenging behaviour.
- Problems managing personal care (feeding/continence) leading to a hospital admission. Did not seek intervention and concerned their property will have to be sold
- Patient admitted to hospital – family could not find staff to talk to for updates (admitted for 7 days). When they wanted to discharge the patient, family had three nurse updates in one hour.
- Staff seem to forget they need food and water – no use leaving water on the side, they need to give it to them to drink e.g. in care homes
- Does best to help carers – Bora's care champion
- "Hope I die after the person I'm caring for". Don't want them to be left alone
- Added strain for carers when they are ill.
- If dementia patient going in for another condition, nurses need to understand how dementia affects the patient.
- Should be at school in national curriculum – part of life studies. What happens when you get older – when your grandparents/parent get older

What is a crisis or emergency or what causes it? Examples

- Admission to hospital through a fall is a crisis
- A crisis is wandering off – it causes a lot of anxiety and stress for the carer
- Attending A & E through having an accident
- Confusion about situations
- Not recognising people, family or places
- A carers stress – being unable to cope and bringing loved ones to A & E where they state they cannot cope any more
- Sudden onset of UTIs etc
- Crisis is more about if something happens to the Carer, more than the patient
- We went to A& E following a fall – there were no x rays carried out only an ECG and tests. No overnight stay required.
- The issues, dangers and stress associated with wandering and getting lost
- Attending hospitals and the issues with safety that this has, like wandering, not eating and/or drinking because patients with dementia are not being adequately supervised or watched.
- A client discharged herself from hospital after convincing a doctor that she was perfectly well and in good health. She later got lost and was confused miles away from the hospital and

her home. This meant involving the police to find her, lost keys, collecting and returning the client and the stress and anxiety for client and the carers.

- Husband has dementia and he gets very angry, he can get violent sometimes. Had to call the police on 3 occasions. The police have always been helpful but this is not a good use of their time. The police do not like attending to this type of call as they know it is not really their job. Person was told at a support group that if their husband becomes violent then they need to stay calm and be polite.
- Carer themselves becomes unwell – this is then a crisis
- A person leaving the gas on constantly
- Difficult behaviour that can escalate to violence
- People need to admit/be aware that there is an emergency situation
- Changing a light bulb when there is no one there to do this – can be a crisis for someone
- Where the carer can no longer care for their relative and that is when you need to look at residential care
- If you have a crisis during Christmas, where do you go? Need an emergency contact.
- Some people with dementia can retain physical mobility and strength – someone becomes unwell and attacks a loved one or day centre staff. No clear pathway of who then needs to act. If social services get involved then we put other residents at risk if we put them into a care home.
- Lady, who is acutely unwell, refuses to allow carers to care for her, even refusing continence pads. No joint team to manage this person – leads to pressure sore, malnourished, PCT may say pathway is through the GP, but what will the GP do?
- Messages between police, ambulance service and hospital is not filtered through like someone goes missing – communications need to be improved.
- There is no Emergency contact number for patient issues
- There is no Emergency contact number for carers in a crisis situation- example of using A&E in one situation
- Not aware of where to go when a situation changes unexpectedly
- Issue of who to contact “out of hours”
- Issue of sharing information between different trusts, i.e. MH, VS, PCT
- Length of time it can take A/E and or Hospital ward to gain patient information is between 24 hrs and 5 days
- If a patient is admitted to hospital without a carer, can take a while for hospital staff to identify patient needs
- People are going to A&E at times of crisis– this is not the right place for diagnosis – but people are ending up there because of a crisis situation as there are no alternatives
- Do carers know what to do in an emergency? What are they currently doing? What should they be doing? Reflections if something has gone wrong?
- Discharged person from hospital, but no support in place.
- What happens in an emergency? Hospitals are changing? Once someone has been admitted they need time to make decisions.
- Fractures, casualties
- Carer not being well, not being able to attend
- Break down in carer relationship
- Someone needs to pick up immediately that this is a carer and someone at home needs care

Actions to take when having a crisis or needing emergency help

- Call 999

- Have family and friends who can help
- Would be helpful to have some information of who to contact
- Use TeleCareLine, Rapid Response etc – needs to be developed more to assist with people to allow them to stay at home
- In an emergency our neighbour has a key
- I do not know where to go or what to do in an emergency or crisis (several contributions to this point)
- I need a list of emergency numbers for different situations
- Need access to the GIS monitor for people who wander. This gadget needs to be offered to people who wander.
- I need more information about what to do in an emergency
- So far my mother has not needed any crisis or emergency help and I'm really not sure what I would or should do if I was unable to cope. Admission to A&E would I feel be terrifying for a dementia sufferer. I would like to think that there is a helpline in such a situation to fast track onto a specialist dementia care service.
- I do not understand about crisis situations. I not know of any action other than 999 if I have a crisis or need emergency help due to my wife's Alzheimer's condition
- Call NHS direct - when wife has falls - paramedic
- Carry carer's card - with phone numbers of people to contact
- Message in a bottle (Rotary Club scheme)
- Message in a bottle (Green Cross)
- Emergency replacement carer's plan – where is this publicised?
- Age UK Handy person scheme
- Neighbour and family support (less so)
- No central point of contact
- Too long to have access to a social worker
- There should be a strategy to managing caring for these people – an integrated team
- Support needs to be very quick – can't wait if GP is at surgery
- Joint team – integrate resources for a quick response
- Regular review – carers may not see changes as can be gradual
- Plan for crisis situations
- Who needs to act? (team will work together because its in best interest of person, but a joint team would be better)
- Hotline to joint team to avoid A & E admissions
- Links to personalisation – building in contingency planning, Hillingdon Carers doing some work around this. Carers' assessments – looking at planning if something goes wrong.
- Call ambulance
- Family would take over
- Phone emergency number as advised by Hillingdon – need to inform people of this number – remind people of the number
- Ring social services – time delay waiting for the social worker to contact
- Don't know what to do in a real emergency, other than calling A & E. People do not know what to do in a real crisis
- Neighbours good support
- People do not know what to do if a patient 'falls' at home, need help lifting patients. Carers risk damage to them
- TeleCareLine – need to know the contact and telephone number
- Identifying potential crisis and possible responses
- "Message in a bottle" sticker somewhere obvious, front door and fridge. Info re: medication

- “SOS” bracelets – cost and keeping info updated
- Can be distressing for visitors etc to see how they can be treated
- Is it possible for a GP to diagnose?
- Lack of sleep for carers
- Telecare – has been helpful
- Crisis is often about what will happen to patient if something happens to carer.
- A&E is often the only place to go but not necessarily the best way.
- A&E attendance, often as last resort because no help from elsewhere
- Carers’ health and wellbeing gradually deteriorates and then can not support
- Local health centre
- NHS direct/111
- Friends/Neighbours (circles of support)
- Admiral Nurses (limited access)
- The Admiral Nurses do not return calls. We have 2 nurses but one has been on maternity leave and there doesn’t appear to be a replacement. Why can’t you recruit more Admiral Nurses as they are the specialists?
- Telecare – Neighbour helped with care for patient when carer suffered anaphylactic shock.
- Difficulty is when carer has an emergency rather than patient – what would happen to patient? Would council step in?
- Make provisions with own resources e.g. family, friends, and neighbours – have to be prepared.
- Patient taken into have dental work under general anaesthetic – signed consent form and took out SEVEN teeth – only went in for one
- Council – social care
- Outreach services – voluntary sector
- Carers have expressed concern that no organisation will take responsibility in a crisis
- How do families who have a full-time job support a parent with dementia in crisis situations?
- What happens to that need care when their carers pass away or can’t look after them? Worried about this.
- Hillingdon Carers have a card: “I’m a carer” and includes contact numbers
- Hillingdon Carers: Produce simple plan to keep at home – includes medicines, care needs etc
- Would call social services. Get pushed pillar to post and then forget them and deal with it. Needs someone in social services who has a good knowledge of dementia

Hospital stays for dementia patients

- For one family the needs of the patient were not met. The medical condition was treated very well but not the dementia issues which caused a great deal of stress for the carer who felt the only time her husband was cared for appropriately was when she was there – very worrying.
- This is a training issue – nurses should know and be sensitive to people with dementia needs.
- Those who enter care homes to ensure they have regular check ups to ensure not ‘dumped’ and left.
- Importance of dignity and privacy
- Time spent with an individual can be more valuable than providing medication
- Dementia patients’ needs are not met in general hospitals
- Staff in the hospital need to know when someone has dementia – this includes the catering staff as well

- Nursing staff need to tell catering staff when someone has dementia – as they may not be able to pick the right food etc
- Dementia needs profile raising between different sectors of staff within the hospital
- Nursing staff need to be better trained in dementia issues
- It would be helpful if people with dementia were in the same wards at the hospital
- Low staffing levels
- Lack of staff trained in Dementia care
- Need to treat the patient as an individual
- Staff need to engage and listen more to carers and families
- Information needs to be passed between staff, Dementia sometimes written on hospital notes but not made aware to all staff.
- Hospital procedures need to be discussed with carers /families e.g. Ward/Bed moves can be distressing for patients, example of a patient being moved at night when told by carer this would be a problem, move still went ahead causing distress to patient.
- “Butterfly scheme” being introduced at Hillingdon hospital identifying patients that need additional care.
- Best interest meetings should be held – professionals and families meet to discuss. This was started for people who did not have their affairs in order, no power of attorney etc.
- Promote the need to write a will/arrange power of attorney so it is in place if/when needed – series of articles about forward planning, - legal to be involved.
- Care service – UTI – this was left untreated and led to further infections/problem – patient care in hospital
- Respite – referred to A & E – difficulty getting information on the ambulance – took 7 hours had to undertake the caring in the hospital – poor caring at the hospital
- Poor treatment in the hospital, dementia patients should not be put in general wards with other patients. Wrote a letter of complaint to hospital – no response. A & E staff are not trained for this (Hillingdon hospital)
- Accommodate patients in the Woodlands centre – have Woodlands got all the relevant equipment?
- Woodlands cannot accept as patients
- Need to ensure there is a consistent service
- Word care non existent –nurses didn’t understand dementia or know how to deal with the patient
- Difficulties around feeding patients and assisting patients to choose from menus
- Disability not taken in to consideration
- Understanding of patient needs
- Depression being in hospital
- Sent sheet of information about illness of patient with them when they went into hospital so that this was readily available – this helped.
- Patients often restless so wander.
- No wards just for dementia patients as they have different medical needs (e.g. cancer, broken bones etc).
- No – needs are not met
- Misdiagnosis or no diagnosis of other conditions
- Relatives expect to carry out personal care (feeding/changing)
- Hospital acquired infections
- People with dementia are invisible to some staff
- Extensive trolley waits leading to other health issues e.g. pressure sores
- How can things improve if cuts to nursing staff?

- Nursing cover at night is poor
- What happens when carer get too old and is struggling to look after someone.
- Immediate, emergency respite care
- From care homes have been sent after fall to A&E – have been left there. Should be someone from care home travelling with them.
- Car park – in hospital is far from department in hospital they need to be in.
- Always a pharmacist on shift in hospital
- Does not think there is a smooth process when admitted to A&E.
- Big question – have to try to explain to triage nurse with person standing next to them – explaining their condition with them there to a triage nurse can be difficult
- Problems when dementia patient is in general hospital – nurse doesn't understand dementia patient (specialist department is fine)
- Behaviour – carer can be in fear – this can lead to crisis situation
- Carer can be unable to care anymore and reach a crisis situation - they can't go on – invention
- Council need support carers more – give a crisis pathway need support for carers
- Delays – need to know what to do 'right now'
- Lack of response by the local authorities – leads to crisis
- (Seizure) wife becomes unresponsive; call 999, has happened 5 times, first went to the hospital has since learned how to deal with the situation

What help needed in a crisis?

- To know if someone has trouble passing urine for example – to get medical help?
- How can we avoid a crisis?
- Early intervention is crucial
- What would help would be a buddy system – someone with some medical knowledge or qualified through their own experience who you can ask general questions of – for instance if you ask about a particular subject, they might advise taking to the GP or they might suggest coming round to put your mind at rest.
- Is there an alternative to NHS Direct – such as a helpline? Someone to talk to.
- Support for carers
- Emergency respite plan/service is vital to support carers
- Day services – carers peace of mind and respite
- Care homes – variable quality (staffing/training/knowledge)
- Decision taken in isolation – impact carers/sufferers of dementia

What would improve Crisis situations for people with dementia?

- Helping Alzheimer's carers to plan ahead for what to do in the eventuality of a crisis.
For a long time my father did not have a plan for what would happen if he became ill and unable to care for my mother. It would have been helpful to have had given some thought and to have a plan for what actions to take in this eventuality. In the end, when the need did arise, I (their son) was able to move in for a couple of weeks to care for them but that was only because I was available as I was not working at the time. There were also times when I was away abroad and I don't know what would have happened if he had become ill while I was away? So, in conclusion, I feel that it would be helpful if support was given by someone to coach the carer at home to make sure they have a plan for such eventualities.
- Emergency TeleCareLine support - In the last year he did have a TeleCareLine installed. There was an emergency situation where my father collapsed at home and he did use it but he was surprised to hear that the only options were for them to phone a neighbour or phone

for an ambulance. He turned down the option of the ambulance because he couldn't see how his wife would get looked after if he went to hospital. What he really wanted and expected was for someone to visit and check him over. At the time he was not aware that the ambulance could come and attend to him without necessarily going to hospital (and the person on the TeleCareLine didn't explain that to him either). So my suggestion for the TeleCareLine service is to add the ability for someone to visit the house of the person in distress and to educate subscribers ahead of time that if they need it the ambulance can be called but doesn't have to take them to hospital.

- In the days that followed I was in contact with Social Services Emergency support to arrange for respite care for my mother so that my father could recover his own health. In the end they did find a care home that turned out to be excellent (Seymour House, Rickmansworth) but the process of interaction with the service is quite stressful. The front-line staff are not able to take decisions themselves (or get a quick answer after referral) but instead then have to prepare a submission to a meeting which allocates resources before a decision is made (I get the impression these decision meetings only take place twice a week and are very dependent on particular staff being in the office). This means a considerable delay and a period of stress for the "client" not knowing whether the needed help will be provided or not. In their communications the front-line staff have to be very cautious not to promise anything which adds to the feeling of uncertainty for the "client" and gives the impression that "it's all about saving money". At the time I was able to help intermediate with these communications but if my father had been on his own this would have been very stressful and not helpful to his own health as he had a heart condition. One suggestion would be to find a way to either empower the front-line staff to be able to take these decisions or to have a mechanism of decision support that is faster.
- I'd also like to raise the issue that my father did not give enough time to caring for himself on an ongoing basis (there are many examples including: he stopped washing himself for more than a month saying that there was not time; he didn't go to the doctor to get health issues checked because of the difficulties getting there and looking after his wife at the same time). With all of his focus on caring for my mother he neglected aspects of his self care. My suggestion for this would be for more coaching in this area – perhaps a periodic visit where this and other issues above are discussed. It's so easy to put these things off in the difficult day to day situation of caring for someone with Alzheimer's.

Appendix 3: Hillingdon Care Homes

Dementia Housing Needs Info

There are currently 2,552 people with dementia living in Hillingdon. According to population projections, this will increase by 9% to 2,710 people in the next five years, and 16% by 2020.

The majority of these individuals can be supported to live at home in the community, as long as they are diagnosed early and receive timely care and support (e.g., medication, telecare, intermediate care, home care, respite, day care, information and advice). A proportion of people will require more intensive care and support than can be provided at home due to a variety of reasons (e.g. challenging behaviour, wandering, 24hr monitoring, break down in the caring relationship). There were 135 new dementia residential placements in 2010/11; this is projected to decrease in 2011/12 with 97 new placements into dementia residential.

Research has shown that approximately 60% of placements can be avoided with the availability of suitable extra care housing for people with dementia. Extra Care Housing provides 24 hr care and support to residents as and when required and is a flexible model of meeting the changing needs of people. It is projected that 58 units of extra care are required specifically for people with dementia. Future demand for additional schemes developed specifically for people with dementia will be reduced by the extension of telecare and intermediate care services, as these services will enable people to stay in their own homes for much longer or remove the need to move at all.

Summary of requested Dementia information

Number of carers receiving support	649	Below figures combined
Information & Advice: (2011/12 estimate based on figures to end Feb 2012)	204	Alzheimers Society
Day Service	4	Alzheimers Society
Drop-in Cafes: (Average attendance - 2011/12 based on figures to end Feb 2012)	112	Alzheimers Society
Generic: (2011/12 estimate based on figures to 6/3/10)	253	Hillingdon Carers
Respite at Home: (2011/12 estimate based on figures to end Jan 2012)	76	Enara

Projections of housing need for people with dementia	58
The Commissioning Team project that 58 units of Extra Care are required specifically for people with dementia.	

Numbers of people in residential and nursing provision outside of the borough (including those with dementia)	159
There are 159 older residents (including those with dementia) in residential and nursing placements outside borough boundaries	

Number of care homes in the borough:	26
There are 26 care homes for older people in LBH.	

Number of specialist dementia homes in the borough:	20
The majority of homes in Hillingdon accept people with dementia. 20 care homes specialise in dementia care.	

Number of both of the above in which LBH has placements	26
Hillingdon Council has placements in all of the care homes for older people operating in Hillingdon; i.e. in 20 homes that provide dementia care and in 6 homes that do not provide dementia	

Number of home care agencies operating in the borough:	16
There are 16 homecare agencies operating in the borough. The Council does not use all of them. The Council is also using a small number of agencies operating outside borough boundaries.	

Support for carers of people with dementia

Data for Members 08/03/12

	Service type	Carers Supported 2010/11	Carers Supported 2011/12	
Alzheimer's Society	Information & Advice	195	204	2011/12 estimate based on figures to end Feb 2012
	Day Service	4	4	
	Drop-in Cafes	70	112	Average attendance - 2011/12 based on figures to end Feb 2012
Hillingdon Carers	Generic	251	253	2011/12 estimate based on figures to 6/3/10
Enara	Respite at Home - dementia	80	76	2011/12 estimate based on figures to end Jan 2012
Notes:	These figures show the total number of carers supported, not the number of contacts			
	Please note that there will be double-counting in these figures, as cross-referral between generic and specialist services is encouraged to ensure carers have access to services relevant to their need			
	2011/12 figures are extrapolated from part year figures, as shown above Alzheimer's Society figures do not include ad hoc requests for support via telephone			

Service Name	Type of care	Address 1	Address 2	Town	County	Post Code	Tel Number
Aronmore Residential Care Home	Res/Res Dem	64/66 Hallowell Rd		Northwood	Middx	HA6 1DS	01923 825940
Ashwood Care Centre	Nur/Res/Res Dem	1a Derwent Drive		Hayes	Middx	UB4 8DU	020 8573 1313
Aston House Care Home	Nur/Nur Dem	Angel Lane		Hayes	Middx	UB3 2QX	020 8569 1499
Blenheim Care Centre	Nur/Nur Dem/Res/Res Dem/YPD	Ickenham Road		Ruislip	Middx	HA4 7DP	01895 622167
Brackenbridge House	Re/Res Dem	Victoria Road		South Ruislip	Middx	HA4 0JH	020 8422 3630
Cedar House Nursing Home	Nur/Nur Dem	39 High Street		Harefield	Middx	UB9 6EB	01895 820700
Clare House	Nursing/Dementia	Harefield Road		Uxbridge	Middx	UB8 1PP	01895 272766
Coppermill Care Centre	Res/Res Dem	Summer House Lane		Harefield	Middx	UB9 6TG	01895 820130
Denville Hall	Nur/Nur Dem/Res/Res Dem	62 Ducks Hill Road		Northwood	Middx	HA6 2SB	01923 825843
Franklin House	Nur/Rehab	The Green		West Drayton	Middx	UB7 7PW	01895 452480
Frithwood Nursing Home	Nur/Nur Dem	21 Frithwood Avenue		Northwood	Middx	HA6 3LY	01923 820955
The Harefield Nursing Home	Nur/Nur Dem	Hill End Road		Harefield	Middx	UB9 6UX	01895 825750
Hayes Cottage Nursing Home	Nur	Grange Road		Hayes	Middx	UB3 2RR	020 8573 2052
James House	Res	2 Sandy Lodge Way		Northwood	Middx	HA6 2AJ	01923 823122
Kingsley Court Care Home	Nur/Nur Dem/Res Dem	855 Uxbridge Road		Hayes	Middx	UB4 8HZ	020 8561 6681
Marian House	Res/Res Dem/Nur/Nur Dem	100 Kingston Lane		Uxbridge	Middx	UB8 3PW	01895 253299
Parkfield House Nursing Home	Nur/Nur Dem	Charville Lane West		Hillingdon	Middx	UB10 0BY	01895 811199
Ruislip Nursing Home	Nur/Nur Dem	173 West End Road		Ruislip	Middx	HA4 6LB	01895 676442
Sweetcroft Residential Care Home	Res/Res Dem	53 Sweetcroft Lane		Hillingdon	Middx	UB10 9LE	01895 230009
St Vincents Nursing Home	Nur/Nur Dem	Wiltshire Lane	Eastcote	Pinner	Middx	HA5 2NB	020 8872 4900 / 90

Service Name	Type of care	Address 1	Address 2	Town	County	Post Code	Tel Number
The Boyne Residential Care Home	Res/Res Dem	38 Park Way	Ruislip Manor	Ruislip	Middx	HA4 8NU	01895 621732
The Burroughs	Res/Res Dem	Mill Road		West Drayton	Middx	UB7 7EQ	01895 435610
The Fairways	Res/Res Dem	64 Ickenham Road		Ruislip	Middx	HA4 7DQ	01895 675885
The Poplars	Res/Res Dem	15 Ickenham Road		Ruislip	Middx	HA4 7BZ	01895 635284
Whitby Dene	Res/Res Dem	316 Whitby Road	Eastcote	Ruislip	Middx	HA4 9EE	020 8868 3712
Woodlands	Res/Res Dem	84-84A Long Lane		Ickenham	Middx	UB10 8SX	01895 634830 07968 078616

Total homes

26

Home	Home Capacity	Residential Dem Beds	Nursing Dem Beds	LBH Clients in Total	LBH Dem Clients
Aronmore Residential	27	8	0	11	5
Ashwood Care Centre	70	35	12	49	20
Blenheim Care Centre	64	12	10	41	16
The Boyne	25	25	0	7	6
Brackenbridge House	36	0	0	1	0
The Burroughs	75	35	0	56	30
Coppermill Care Centre	52	44	0	14	5
The Fairways	27	0	0	4	0
James House	12	0	0	2	0
Kingsley Court	85	25	30	41	32
Poplars	27	27	0	1	0
Sweetcroft Residential Home	20	20	0	5	1
Whitby Dene	60	30	0	41	25
Woodlands	18	17	0	8	3
Aston House	48	0	40	22	16
Cedar House	42	0	42	11	3
Clare House	40	0	0	7	0
Denville Hall	40	0	15	4	0
Franklin House	66	0	0	34	0
Frithwood Nursing Home	20	0	0	4	1
Harefield Nursing Centre	40	0	20	11	2
Hayes Cottage	51	0	0	21	0
Marian House	25	0	5	7	1
Parkfield House	44	0	44	18	11
Ruislip Nursing Home	24	0	24	3	1
St Vincents Nursing Home	60	0	5	8	0
Totals	1098	278	247	431	178

Domiciliary Care Agencies with offices in London Borough of Hillingdon

1	Accurocre
2	Adolphus Care
3	Allied Healthcare
4	Aquaflo
5	Cross Roads
6	Elite Total Care Services
7	Hayes Staff
8	Home Instead Senior Care
9	Northwood Nursing & Care Services Ltd (Dom Care)
10	Plan Care
11	R&S Medical & Allied Services Ltd
12	Reablement Team (LBH)
13	Signet Healthcare Ltd
14	Specialist Care
15	Tageero
16	Trinity Noir