



Dementia Services Scrutiny

Lead Member Foreword

“Mother had an accident. She suffered short term memory loss and became aggressive. The GP did not recognise her symptoms and the Practice Nurse arranged referral for dementia”.



This was a typical story from a carer told to the Health and Adult Services Select Committee at the start of its in-depth scrutiny on dementia services in Barking and Dagenham. We found a fragmented service and worrying lack of knowledge amongst health professionals about the referral pathway and the help available to patients and carers. Although we saw some excellent practice, for instance at Kallar Lodge Care Home, the GP we interviewed did not know about all the services available there and how to refer patients.

The Select Committee was impressed by the dedication and quality of the carers, staff and volunteers interviewed as part of the evidence gathering. The Select Committee valued their honesty in highlighting the pitfalls of the existing arrangements and suggestions to improve the well-being of dementia sufferers and their carers.

However, there is a lack of strategic oversight of local dementia services and no coherent plan to develop services in the future or address gaps in provision. The Select Committee did not feel dementia had been given sufficient priority by local commissioners.

We hope that the recommendations set out in this report will help improve dementia services for local people and lead to a more confident, better informed and trained health work-force.

Councillor Evelyn Carpenter

Lead Member, Health and Adult Services Select Committee

1 Introduction

The Health and Adult Services Select Committee (HASSC) was first established on 15 July 2009 building on the work of the Health Scrutiny Panel under the leadership of Councillor Mrs Marie West.

The membership of the Health and Adult Services Select Committee is comprised of nine Councillors:

- Councillor Evelyn Carpenter (Lead Member)
- Councillor Mrs Dee Hunt (Deputy Lead Member)
- Councillor John Denyer
- Councillor Mohammed Fani
- Councillor Mrs Kay Flint
- Councillor Nirmal Gill
- Councillor Terry Justice
- Councillor Mrs Christine Knight
- Councillor Mrs Marie West

The HASSC Scrutiny Champion was Bill Murphy, Corporate Director of Resources, and the Lead Service Officer for the Dementia Services scrutiny was Bruce Morris, Head of Adult Care Services. The Senior Scrutiny Officer supporting the scrutiny was Pat Brown assisted by Glen Oldfield, Overview and Scrutiny Officer.

In addition to its statutory work to scrutinise local health services, the HASSC agreed to undertake an in-depth scrutiny of dementia services in Barking and Dagenham after considering a range of options. The theme for the scrutiny was particularly timely because the National Dementia Strategy had recently been published. This is the Government's five year plan for improving health and social care services in England for everyone with dementia and their carers.

1.1 Structure of Report

This report is intended to be a brief summary of the evidence considered by the Health and Adult Services Select Committee with the main recommendations arising. The full set of minutes of the Health and Adult Services Select Committee is available for perusal and this report sets out in the appendices lists of those consulted, site visits made and the range of documents considered by the HASSC.

The report covers:

- Terms of Reference
- Methods of Scrutiny
- What is Dementia?
- Prevention
- Identification

- Early intervention and treatment
- Living well with dementia
- Care in hospital
- End-of-life care

The report's recommendations flow from the evidence considered by the Select Committee.

1.2 Terms of Reference

The terms of reference for the in-depth scrutiny on dementia services in the Borough were agreed at the first meeting of the HASSC. These were:

- to review the services in the borough with the aim of improving overall delivery, addressing gaps in services and areas where services are weak in comparison to the quality of other services
- when accessing general and secondary health services, to investigate whether patients with mental health problems are identified and whether the connection is made between them and the required treatment
- to involve the community in the scrutiny process, provide them with opportunities to give evidence and inform the review
- to ensure that any evidence collected is used appropriately
- to listen to concerns and suggestions from local people, especially service users and carers that have had experience of dementia services
- to investigate whether services have equal access and equal outcomes across the borough
- to collaborate with partner organisations to identify opportunities where partner working could benefit the service user's experience
- to review best practice nationally and in other local authorities, including London Borough of Barking and Dagenham's statistical neighbours
- to consider any related equalities and diversity implications, and to encourage members of the public to engage with this important issue and,
- to produce a final report with findings and recommendations for future policy and/or practice.

1.3 Method of Scrutiny

The methods of scrutiny and types of evidence considered by the HASSC comprised:

- presentations by Council officers and senior managers from health services about local dementia services during HASSC meetings

- presentations by the Department of Health London Region Dementia Lead, and managers from the independent and voluntary sectors at HASSC meetings
- site visits to meet users of dementia services and see the places where people suffering from dementia were treated and/or cared for in the Borough
- a site visit to a service outside the Borough (in Croydon) to see an example of good practice elsewhere in London
- site visits to service providers such as the London Ambulance Service and the Alzheimer's Society in Havering and Redbridge
- research of a wide range of documents and background material

A list of background papers, including reports and presentations, used for consideration is set out in Appendix 1. A list of all those who gave evidence to the HASSC either at Select Committee formal meetings or at site meetings is set out in Appendix 2. A list of terms and common abbreviations is set out in Appendix 5.

The HASSC agreed questions in advance to ask all those who gave evidence (see Appendix 3 for examples of questions to carers, the voluntary sector and health professionals). Questions were emailed to interviewees in advance of meetings.

To help ensure accuracy, and to identify the key issues:

- full confidential interview notes and notes of presentations were prepared
- draft interview notes were distributed to interviewees for amendment
- there was the opportunity to glean evidence on the same issue from a variety of sources.

The scrutiny began at the first HASSC meeting on 15 July 2009 and the final site visit for evidence gathering took place on 4 December 2009.

1.4 What is Dementia?

The Alzheimer's Society has useful fact sheets about dementia on <http://www.alzheimers.org.uk/factsheet/400>

The Department of Health's National Dementia Strategy says that dementia is an illness caused when parts of someone's brain stop working properly. While the causes are not yet fully understood, most people with the symptoms of dementia have Alzheimer's disease (a degenerative condition) with a significant number showing signs following a stroke or series of strokes. There is no cure for dementia which gets more common with age. Once a person has dementia they will get worse over time until the end of their life. However, people with dementia can often have a good quality of life for a number of years.

People with dementia have problems with:

- thinking clearly
- remembering
- communicating

- doing day-to-day activities such as cooking or getting dressed.

People with dementia can be:

- depressed
- subject to mood swings and aggression
- prone to wandering or getting lost

The National Dementia Strategy states that if dementia is diagnosed early enough, there are interventions that can be put in place to help people overcome problems and to improve their quality of life.

Dementia is very common and can affect anyone whatever their gender, ethnic group or age. People with learning disabilities are at particular risk.

Dementia makes the lives of people who have it, and the lives of their families and carers, very difficult. This is exacerbated when family carers are often old and frail themselves. The strain of caring for someone with dementia can cause physical or mental health problems in the carer.

1.5 Prevalence of Dementia

At least 560,000 people in England have dementia and because of an ageing population, the number of cases nationally is predicted to rise by over 30% over the next 15 years. However, this level of increase is not expected in Barking and Dagenham because of the younger age profile of our community in the longer term. In fact, the number of people with dementia aged over 65 years in Barking and Dagenham is projected to decrease by two percent between 2009 and 2021.

Nationally, approximately one in five people over the age of 80 are predicted to suffer from dementia. In addition, it is likely that there will be an increase in the younger age group possibly associated with long term heavy drinking and drug use.

As stated in the Dementia Standards Self Assessment submitted by the partnership between NHS Barking and Dagenham, London Borough of Barking and Dagenham and North East London Foundation Trust in consultation with Carers of Barking and Dagenham and recognised in the Joint Strategic Needs Assessment, just 379 cases of dementia are reported on the Quality and Outcomes Framework Dementia Registers by Barking and Dagenham GPs, compared to the 1,702 expected cases. While this may be due to problems with data, these findings suggest serious inequity in access to diagnosis between GP practices and merits further investigation.

2 Findings and Recommendations

2.1 Prevention

Although there had been a recent article in 'The News' about spotting the signs of dementia, there was little evidence of local health campaigns promoting healthy life-styles linked to helping prevent the onset of dementia, particularly early onset dementia amongst younger people.

However, prevention is a longer term strategy. Changing lifestyles and behaviours for people aged 40+ is intended to promote living more healthy lives in old age some 30 year later.

Recommendation 1:

The Health and Adult Services Select Committee recommends that, in order to help prevent the early onset of dementia, NHS Barking and Dagenham organise local health promotion campaigns to raise public and professional awareness about life-style changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks.

2.2 Identification

Identifying dementia was a major problem for both carers and health service professionals. There was a basic lack of information about what dementia is and how to spot the signs. Carers, North East London Foundation Trust, NHS Barking and Dagenham, GPs, Local Authority services and the voluntary sector all agreed that more information was needed to help improve public awareness leading to self identification. A cultural shift was needed to de-stigmatise the condition.

Nationally, it is estimated that about 66% of people with dementia are not diagnosed. This maybe due to sufferers and carers being reluctant to come forward because of the associated stigma. The Government will be running a national awareness campaign in the spring 2010, to help overcome issues around stigma and the need for early diagnosis.

Recommendation 2:

The Health and Adult Services Select Committee recommends that local Health Services, together with the Local Authority and Voluntary Sector, mount an awareness raising campaign about dementia to build on the Government's national campaign and to begin the process of reducing the stigma attached to dementia.

The Select Committee was unable to gather easily a comprehensive picture of the services available to people suffering from dementia and their carers. There was also evidence that health professionals themselves were not aware of local services.

Carers spoke about the length of time to get a diagnosis from their GP and sometimes the diagnosis had been as a result of the intervention of a nurse, not the GP. The GP interviewed confirmed the serious level of ignorance amongst his peers

about the condition and said, for example, that he himself did not know about the services of Kallar Lodge Care Home and the referral pathway. He spoke about the need for training.

Recommendation 3:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham, the Local Authority and other health providers, improve awareness of dementia and memory services available to health care professionals, particularly GPs, and the voluntary sector through a planned workforce development programme and a clear referral pathway.

2.4 Early Intervention and Treatment

It was a struggle for most carers interviewed to get an early diagnosis of dementia for their loved one. Early intervention and treatment can delay the onset of more serious symptoms and significantly improve the quality of life for the dementia sufferer and their carers.

Dementia is a degenerative disease and may affect younger people with strokes, alcohol problems, drug addiction and HIV. People are living longer and, therefore, there will be an increase in the number of dementia patients amongst older people too.

The care pathway for dementia patients, however, is complex and difficult to navigate with access to quality services more difficult for some. In practice, the Select Committee found that people had different types of service and different quality of support depending on who they saw when they first began to recognise they were having problems. In fact, there is no integrated care pathway linking the various statutory and voluntary services available, only (sometimes) separate pathways to individual services, such as the Local Authority's Specialist Dementia Homecare Team.

Recommendation 4:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham, together with its health care partners including the North East London Foundation Trust, Barking, Havering and Redbridge University Hospitals NHS Trust, and the Local Authority, prepare a joint strategic plan and undertake joint commissioning to develop an integrated care pathway for GPs, dementia patients and carers, which is clear and provides one point of contact. It is important that the plan is based on accurate estimates of the number of dementia sufferers in Barking and Dagenham and that sufficient facilities are put in place to meet the expected increase in demand.

The Select Committee was impressed by the London Borough of Croydon memory service which has doubled the number of dementia assessments and helped overcome the stigma attached to referral for dementia. It is an integrated service that offers a comprehensive assessment and diagnosis and enables a high patient throughput. Assessments are carried out with both the patient and carer at their

home and a plan is discussed at a multi-disciplinary team meeting to help maintain the patient's independence and quality of life.

North East London Foundation Trust runs a new Memory Service at Morland Road, which is similar to the Croydon provision, except that the Local Authority care services and the voluntary sector are not integrated within this service.

Recommendation 5:

The Health and Adult Services Select Committee recommends that the Local Authority, together with its health partners, review the delivery of services and consider providing a single point of contact for dementia patients and their carers. The Select Committee recommend a more holistic, efficient and improved service by integrating relevant adult care services and voluntary sector services with the Memory Service at Morland Road. When implemented, information about this new one point of contact should be included in a publicity campaign for potential users, GPs and health care professionals.

Outreach work with the Black and Minority Ethnic Community voluntary sector and other hard to reach groups in Croydon was necessary to increase the number of referrals from different groups in the community.

Recommendation 6:

The Health and Adult Services Select Committee recommends that as part of the action plan to improve dementia services, NHS Barking and Dagenham and the Local Authority should undertake an Equality Impact Assessment to consider the needs of the whole community and review the delivery of dementia services to the Black and Minority Ethnic Community and hard to reach groups possibly through outreach in partnership with the voluntary sector.

The Select Committee was impressed by the dedication and quality of the staff interviewed as part of the evidence gathering for the in-depth scrutiny set out in Appendix 2. The Select Committee valued their honesty in highlighting the pitfalls of the existing arrangements and suggestions for improvements in the early intervention and treatment of dementia. These suggestions included: improved information to carers about treatment and drugs for dementia; giving medication; dealing with challenging behaviour, which can be aggressive; and preventing other conditions such as urine infections.

Recommendation 7:

The Health and Adult Services Select Committee recommends that that Local Authority, health care professionals and the voluntary sector assist carers to keep their loved ones at home for as long as possible through improved information and training regarding treatment and drugs for dementia; techniques in administering medication; dealing with challenging behaviour; and preventing medical conditions such as urine infections.

The Government in its National Dementia Strategy suggests giving everyone with dementia their own dementia advisor to be a constant and continuing link on their journey through their illness and to help them access resources and services.

Carers spoke highly of the Admiral Nurses, a small team, who partly perform this function at the moment. There is a pilot of five local areas looking at the role of dementia advisor identified in the National Dementia Strategy to develop a model that would work across the National Health Service and voluntary services.

Recommendation 8:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham and the North East London Foundation Trust assess the need for, and the number of, dementia advisors to be linked to individual dementia patients and their carers for the duration of the illness to assist in accessing resources and services.

2.5 Living Well with Dementia

Living well with dementia has to be a top priority for health partners in Barking and Dagenham. The Healthcare for London Dementia services guide outlines:

- the importance of regular reviews for dementia patients
- carer and family interventions for improving patient care such as strategies for communication and managing challenging behaviour
- strategies to support carer well-being including support and counselling, peer group networks, respite and reliable information
- different psychological, social and creative interventions as well as money management to improve patients' well-being
- reviewing physical care including eating, continence, co-morbidities such as diabetes or high blood pressure
- environmental interventions such as adjustments to housing, technology, such as Telecare¹, provision of home care, and ensuring a safe environment.

Throughout the scrutiny, the Select Committee heard evidence that backed up the above scenario and some specific issues raised are set out in the recommendations.

Carers, for example, said that dementia sufferers often became incontinent and it was very difficult to get any assistance. The incontinence pads provided through the health service were too small and many carers purchased the bigger pads at their own expense. NHS Barking and Dagenham confirmed the need to re-tender this service and that they were aware of carers' comments.

Recommendation 9:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham take into account the specific needs of people with dementia when re-tendering the service to supply incontinence pads for dementia patients, ensuring that they provide the right size and quantity.

¹ Telecare is a service that enables people, especially older and vulnerable people, to live independently in their own home.

- 1.1. There are twenty five home care agencies serving Barking and Dagenham. The quality of care in the home was variable and there were some complaints about staff arriving late, or too early to put patients to bed. There is not enough provision at week-ends. The Health and Adult Services Select Committee considers that all home care services should be delivered to a minimum standard in line with the Local Authority provision. The introduction of the Personalisation Programme will give users more choice and control over their support.

Recommendation 10:

The Health and Adult Services Select Committee recommends that the Local Authority review the specification for home care services to dementia patients to ensure consistent and high quality care across both private and Local Authority services, and for services to be available at week-ends.

Respite care was crucial to enable often elderly carers undertake everyday tasks or take a short break for a family event, like a wedding. There was a lack of information about respite care amongst some carers and health care professionals, including GPs.

Recommendation 11:

The Health and Adult Services Select Committee recommends that the Local Authority review arrangements for communicating the availability of respite care with dementia patients, carers, GPs and other health care professionals to ensure equitable access to these facilities across the Borough and by different ethnic groups.

2.5.1 Social Activities

The Select Committee saw examples of social activities and creative art therapies in the community and in care homes. Kallar Lodge Care Home, for instance, works with patients and their families to produce a Life Story book of photographs, letters and cards to bring back good memories. A carer criticised provision at one of the day centres where his wife had been offered activities inappropriate for her condition and whose staff, he said, were not dementia trained.

The Select Committee visited the Alzheimer's Society in Havering. Representatives informed Members of the Memory Café which offers a social outlet for patients and their carers.

Some social, occupational and creative activities are offered in patients' own homes. The Local Authority's Specialist Dementia Home Care Team focus on personal services to clients, which includes the encouragement of historical skills, such as knitting. Familiar music relating to when clients were younger is also used by the team, with some staff carrying their own CDs. The team also gives ongoing support to families, offering advice and guidance.

Recommendation 12:

The Health and Adult Services Select Committee recommends that the Local Authority and health partners review the social, occupational and creative art therapies on offer across the Borough in different settings for dementia patients and to work towards services and resources that are fit for purpose, accessible to meet changing needs and are staffed by appropriately trained staff and volunteers representative of Barking and Dagenham's diverse population. This review will need to take account of the impact of the personalisation of care services.

2.5.2 Transport

Transport to hospital or to social activities was another area explored in depth by the Select Committee.

- Three carers had tried Dial-A-Ride, but it was difficult to get a bus at the time required.
- One carer was unhappy with the transport provided because his wife had to stay on the bus too long and this made her confused and agitated. He felt that sufferers should be given the option to go when convenient and not have to be ready to go so early in the morning.
- Transport staff develop a relationship with regular travellers and the patient is less agitated if a known escort is travelling with them. If the booking could be through their GP, where the patient's full records are held, it would mean all appropriate information would be available to the transport carrier.
- Public transport links are poor to Cherry Orchard Nursing Home - there is a long walk from the bus and train stops. There was a request for a bus service down Goresbrook Road some time ago, but this did not materialise. Many of the visitors to this Nursing Home are elderly spouses, family members and friends.

Recommendation 13:

The Health and Adult Services Select Committee recommends that transport needs of patients and their carers be assessed when reviewing patient and carer plans and tenders for non-emergency transport for dementia patients be regularly reviewed to ensure that they address the changing needs of patients and their carers.

Recommendation 14:

The Health and Adult Services Select Committee recommends that Transport for London be approached about a bus service along Goresbrook Road to improve public transport links to Cherry Orchard Nursing Home.

The London Ambulance Service raised issues that they faced when having to attend in an emergency.

- Frequent callers to the Emergency Services were raised as a problem, especially in care homes. When a resident has a fall there is a readiness to dial 999 before assessing whether the person is hurt.
- Poor information flow between agencies. Again mainly in care homes, when a member of their staff is made available to escort or deal with London Ambulance Services staff, it is often the most junior member or agency staff who often do not know the patient, including their medication or medical condition.

However, the London Ambulance Service were pleased with the improving communication with GPs and nursing teams and they were encouraged with the alternative arrangements being put in place, such as Barking and Dagenham's Unique Care, to avoid unnecessary emergency call outs.

2.5.3 Resuscitation

The London Ambulance Service asked that wishes regarding resuscitation and medical intervention be recorded and easily available to ambulance staff and emergency medical staff. Sometimes GPs are not always informed of the patient's wishes. If these records are not available, ambulance staff have no alternative but to commence resuscitation. This may not be in the best interest of the patient and cause unnecessary stress for the family and the ambulance crew.

Recommendation 15:

The Health and Adult Services Select Committee recommends that health agencies and the Local Authority ensure that all service providers, including GPs, have an easily accessible patient pack/file available for ambulance and hospital staff setting out the resuscitation and medical intervention wishes of the patient and their families. The Select Committee recognises that sharing of this information must be in line with data protection requirements.

2.6 Care in Hospital

Sometimes dementia patients have co-morbidity (a physical illness) and have to enter hospital. The hospital may not always know if a patient has dementia. It can be difficult for other patients and visitors if a person with dementia has behavioural problems. For instance, the patient may be noisy, aggressive, and unco-operative with health care professionals. They can wander and disrupt the treatment of other patients. The overall confused state deteriorates after dark when there is less nursing staff around. They will often require specialist nursing delivered by those with Elderly Mentally Infirm (EMI) training if they are to be managed on a general ward.

Measures to mitigate problems while the dementia patient is in hospital while in hospital include:

- avoiding excessive sedation
- placing the patient's bed near the toilet and not near the doors of ward
- ensuring the patient's bed is a well illuminated at night

- reality orientation - such as providing the patient with a clock with day, date and location
- involving relatives to reassure the patient

The Barking Havering Redbridge University Hospitals NHS Trust has established a Champion Matron for older people at King George's and Queen's hospitals to ensure older people are treated with dignity.

Barking Havering Redbridge University Hospitals NHS Trust stated that more specialist dementia training was needed and all wards should have a designated dementia trained nurse. Additional staff are required to help patients who are less co-operative in taking food and medication and to help combat urine infections and to make sure patients can reach food and drink – all of which would aid recovery. Barking Havering Redbridge University Hospitals NHS Trust has introduced a scheme where patients, who require assistance with feeding, have their food served on a different coloured tray so that staff can easily identify them.

Recommendation 16:

The Health and Adult Services Select Committee recommends that Barking, Havering and Redbridge University Hospitals NHS Trust review dementia training for all staff in its hospitals and assess whether all wards should have a designated dementia trained nurse and additional staffing, such as health care assistants, to help patients who are less co-operative in taking food and medication and to assist those with mobility problems, which may help prevent falls and infections.

Black and Minority Ethnic Community dementia patients may suffer if English is a second language, translators are not available and tests not carried out as a result.

Recommendation 17:

The Health and Adult Services Select Committee recommends that Barking, Havering and Redbridge University Hospitals NHS Trust review their arrangements for the provision of translators to help identify the needs of dementia patients whose first language is not English.

Barking, Havering and Redbridge University Hospitals NHS Trust safeguarding adults' policy does not specifically address dementia.

Recommendation 18:

The Health and Adult Services Select Committee recommends that Barking, Havering and Redbridge University Hospitals NHS Trust address the needs of dementia sufferers and carers in its safeguarding adults' policy.

It is recognised across London that some boroughs are offering very good services and practices.

Redbridge dementia patients with a mix of problems, who attend King George's or Queen's Hospitals because of a physical condition, have access to a joint clinic with physicians and psychiatrists. Also, Community Psychiatry Liaison Nurses work with physicians and psychiatrists for Redbridge patients.

Recommendation 19:

The Health and Adult Services Select Committee recommends that, in line with suggestions from Barking, Havering and Redbridge University Hospitals NHS Trust, as part of a local action plan, NHS Barking and Dagenham develop proposals for improved liaison between specialist services which should include:

- a monthly joint clinic with psychiatrists to be established so patient referrals can be dealt with efficiently and smoothly
- NHS Barking and Dagenham and North East London Foundation Trust develop dementia link nurses to work with medical teams at King George's and Queen's Hospitals to improve patient care and
- the voluntary sector be involved in this service.

North East London Foundation Trust stated that there is a need for improved liaison with Queen's Hospital. This year NHS Barking and Dagenham has invested in a small Older Persons' Liaison Team of staff (two people) that will be based at Queen's Hospital to monitor patient outcomes. The Liaison Team will deal with patients across all the age range. North East London Foundation Trust is aware that there is a problem with delayed transfers of care of dementia patients. A patient with dementia is not discharged home as quickly as they should be. The Liaison Team will be working predominately on older persons' wards at Queen's Hospital. They will carry out initial screening, give a speedy assessment, recommend what next steps should be taken and people will be discharged with an appointment to ongoing services as required.

Recommendation 20:

The Health and Adult Services Select Committee recommends that the Local Authority, North East London Foundation Trust, Barking, Havering and Redbridge University Hospitals NHS Trust, NHS Barking and Dagenham review and improve arrangements for the transfer of dementia patients from hospital to ensure that they are speedily back in the comfort of their own homes in familiar surroundings.

2.7 End of Life Care

Dementia is a terminal illness. The Select Committee did not specifically investigate end of life care for dementia patients. The Health and Adult Services Select Committee suggests that the Healthcare for London dementia services guidelines, which set out the issues to be addressed in end of life care, be included in any future strategy and/or commissioning. These include:

- following guidance in the Department of Health's end of life care strategy involving carers and the family
- exercising the Mental Capacity Act. (The GP interviewed requested training in this area)
- ensuring faith and cultural preferences are taken into account if the patient cannot communicate their choice

- identifying whether the person with dementia already has a plan and acting on that plan
- where possible, patients with dementia should not be moved from their usual place of residence in their last days.

Recommendation 21:

The Health and Adult Services Select Committee recommends that the Local Authority, North East London Foundation Trust, Barking, Havering and Redbridge University Hospitals Trust and NHS Barking and Dagenham, as part of their joint strategic plan for dementia services, set out their plans for end of life care and ensure health care professionals, including GPs, have appropriate training in relevant legislation, for example, the Mental Capacity Act.

3 Conclusion

“My mother, who is in her nineties, had a fall at home and was taken by ambulance to King George Hospital, on a Friday, Although it transpired that she had not broken any bones and was only badly bruised, she remained in hospital overnight for observation. A nurse at the hospital noticed that my mother was having some memory problems and she arranged for her to be assessed. The following day, Saturday, the on-duty social worker arranged a home visit with my mother to ascertain what adaptations would be required to enable my mother to stay at home with additional support. On the Monday, my mother was transferred to Gray’s Court for rehabilitation before she returned home. My mother is now at home with additional support from the Local Authority and is doing well.”

This was a recent experience of a local resident and shows what can be achieved when health professionals are aware of the symptoms of dementia and how the services can work well together for the benefit of sufferers and their carers.

However, this is not the experience of all patients and many slip through the net and are never diagnosed, because the memory problems and unusual behaviour is put down to ‘getting old’.

The vision of the Personalisation Programme, which has been introduced in Barking and Dagenham, is that by 2011 a personalised system of care offers the highest standards of professional expertise, care and dignity. Personalisation means that every person who is eligible to receive Adult Social Support, whether provided by statutory services or funded by the service user, could be using personal budgets to access health and social care. Users will have more choice and control over the shape of their support in all care settings. At the heart of the Personalisation Programme is the concept of better advice and information available to all residents and professionals.

Nationally it is estimated that within the next five years around 1.5 million people could be using personal budgets to access health and social care.

The Select Committee feels that this will give residents choice and assist in improving the type and quality of services that are available.

The Select Committee’s priorities for immediate action are:

- (a) local health services and the Local Authority to run a local campaign alongside the national campaign to remove the stigma of suffering from dementia
- (b) training for GPs, health professionals, local authority staff and the voluntary sector to be rolled out
- (c) provision of suitable incontinence pads
- (d) ensure there is a comprehensive booklet setting out a clear referral path and what services are available to the dementia sufferer and the carer. This information should also be made available on websites.

The following priorities are for action six months:-

- (a) to build on the excellent home service provided by the Local Authority
- (b) provide mandatory training for GPs and hospital staff
- (c) to establish integrated services across the Local Authority, the Health Service and voluntary organisations.

Background Papers

Author	Title	Date
Alzheimer's Society	Fact Sheets	2010
Commission for Social Care Inspection	Inspection Report: Cherry Orchard Nursing Home	2007
Department of Health	What are the Mental Capacity Act 2005 Deprivation of Liberty Safeguards	2008
Department of Health	National Dementia Strategy	2009
Department of Health	Living Well with Dementia – National Dementia Strategy – Accessible Summary	2009
Healthcare for London	Dementia Services Guide	2009
London Borough of Barking and Dagenham	HASSC Agendas and Minutes	2009/10
Pat Brown, Senior Scrutiny Officer	Site Visit Notes (confidential)	2009/10
Tribal Group	Barking and Dagenham Joint Strategic Needs Assessment	2009
Tunstall Health UK Limited	Dementia Care: solutions for independent living	2009

Presentations

Author	Title	Date
Adult Care Services	Living Well with Dementia	15/7/2009
DABD (UK)	Provision of Non-Emergency Patient Transport	2/12/2009
Lesley Carter Department of Health	The National Dementia Strategy and London Implementation Plan	4/11/2009
London Ambulance Service	Dementia	3/12/2009
North East London Foundation Trust	Local Barking and Dagenham Dementia Services	15/7/2009
Safeguarding	Safeguarding Adults with Dementia	2/12/2009

Reports

Author	Title	Date
Barking, Havering and Redbridge University Hospitals NHS Trust	Overview of Hospital services, policies and issues relating to dementia patients	23/9/2009
Carers of Barking and Dagenham	Overview of Services for Dementia Sufferers and their Carers	4/11/2009
Commission for Social Care Inspection	Cherry Orchard Nursing Home	2007
NHS Barking and Dagenham	Implementation of the National Dementia Strategy	23/9/2009
Personalisation Programme Director	The Personalisation Programme	2/12/2009

List of Contributors and Site Visits

The following people submitted reports or presented evidence at formal Select Committee Meetings:

- Pat Brown Senior Scrutiny Officer
- Bruce Morris Head of Adult Care Services
- Jacquie Mowbray Interim Joint Director Mental Health
- John Goulston Chief Executive, Barking, Havering and Redbridge University Hospitals NHS Trust
- Dr. N. Ahmed Consultant Physician
- Stephen Langford Chief Executive of NHS Barking & Dagenham
- Bernard Hannah Head of Mental Health Commissioning
- Lorraine Goldberg Chief Executive, Carers of Barking and Dagenham
- Sue Bernie Manager, Memory Lane Dementia Services
- Lesley Carter London Region Dementia Lead Social Care and Partnerships, Department of Health
- Dawn Cock Transport Development Manager, DABD (UK)
- Helen Oliver Group Manager, Safeguarding Adults
- Nick Kingham Programme Director, Personalisation

Site Visits

The following site visits were undertaken by Members during the course of the review:

- Barking and Dagenham Carers 15, Althorne Way, Dagenham – 7 August 2009
- Dementia Patient and Carer Dagenham – 7 August 2009
- Kallar Lodge Care Home 75, Gregory Road, Chadwell Heath – 29 September 2009
- Specialist Home Care Team London Borough of Barking and Dagenham – 13 October 2009
- Alzheimer's Society Havering Branch Junction Road, Romford, RM1 3QT – 20 October 2009
- Heavers Resource Centre London Borough of Croydon – 3 November 2009
- Croydon Memory Service

- Cherry Orchard Nursing Home Dagenham Avenue,
Dagenham – 17 November 2009
- GP Representative Dagenham – 19 November 2009
 (Specialist in Dementia)
- Age Concern Health Clinic, Porters
Avenue, Dagenham – 23 November 2009
- London Ambulance Service Fielden House, London
Bridge – 3 December 2009
- Memory Services Morland Road,
Dagenham – 4 December 2009

EXAMPLES OF QUESTIONS DURING EVIDENCE GATHERING**Question to Carers**

1. How long had you been concerned before you sought help? How long ago was this? Were you encouraged to seek help early?
2. Roughly, how many times did you visit your GP before your loved one received the diagnosis of suffering from dementia or Alzheimer's disease?
3. How well did the GP or other health professionals explain what was happening to you and your loved one? What options for treatment were you offered?
4. Were your needs as a carer assessed? How was this done and how were your needs met? Has this improved recently?
5. What are your views on the respite care offered to you?
6. What services are offered in the home to help you as the carer, or to help the person with dementia remain independent in their own home?

Questions to Voluntary Sector

1. What different types of roles do your volunteers and staff perform to support the branch? Are any volunteers specifically recruited to help carers of people with dementia?
2. How accessible is the Memory Lane Café? The opening hours are good, but can all who want to attend, go along to this or do they need to book? How many does it cater for at each session? Where is it based?
3. Black and Ethnic Minority Project – how many carers of people with dementia are supported from BME groups?
4. Do you provide transport for service users?
5. What is your relationship with the Local Authority and Primary Care Trust? Do you work with other local voluntary organisations?

Questions to Health Professionals

1. What memory services do you provide? Do you use the most up to date practices to stimulate your patients? How do you involve carers, friends, and relatives in activities?

2. The Select Committee would like your comments on the recent BBC reports on (a) the Glasgow Memory Clinic carrying out trials of a new drug dimebon and (b) the needless use of anti-psychotic drugs in dementia care, which is claimed to contribute to the death of many patients.
3. Are there particular difficulties in getting patients with dementia comply with treatment and dealing with their nutrition needs? What are you doing about this?
4. What are you doing to improve public awareness of dementia and any research findings to delay or stabilise the condition, such as the Mediterranean diet, drinking tea, or the importance of exercise?

List of Recommendations

The following recommendations are set out here as a list, for ease of reference.

Recommendation 1:

The Health and Adult Services Select Committee recommends that, in order to help prevent the early onset of dementia, NHS Barking and Dagenham organise local health promotion campaigns to raise public and professional awareness about life-style changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks.

Recommendation 2:

The Health and Adult Services Select Committee recommends that local Health Services, together with the Local Authority and Voluntary Sector, mount an awareness raising campaign about dementia to build on the Government's national campaign and to begin the process of reducing the stigma attached to dementia.

Recommendation 3:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham, the Local Authority and other health providers, improve awareness of dementia and memory services available to health care professionals, particularly GPs, and the voluntary sector through a planned work-force development programme and a clear referral pathway.

Recommendation 4:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham, together with its health care partners including the North East London Foundation Trust, Barking, Havering and Redbridge University Hospitals NHS Trust, and the Local Authority, prepare a joint strategic plan and undertake joint commissioning to develop an integrated care pathway for GPs, dementia patients and carers, which is clear and provides one point of contact. It is important that the plan is based on accurate estimates of the number of dementia sufferers in Barking and Dagenham and that sufficient facilities are put in place to meet the expected increase in demand.

Recommendation 5:

The Health and Adult Services Select Committee recommends that the Local Authority, together with its health partners, review the delivery of services and consider providing a single point of contact for dementia patients and their carers. The Select Committee recommend a more holistic, efficient and improved service by integrating relevant adult care services and voluntary sector services with the Memory Service at Morland Road. When implemented, information about this new one point of contact should be included in a publicity campaign for potential users, GPs and health care professionals.

Recommendation 6:

The Health and Adult Services Select Committee recommends that as part of the action plan to improve dementia services, NHS Barking and Dagenham and the Local Authority should undertake an Equality Impact Assessment to consider the needs of the whole community and review the delivery of dementia services to the Black and Minority Ethnic Community and hard to reach groups possibly through outreach in partnership with the voluntary sector.

Recommendation 7:

The Health and Adult Services Select Committee recommends that that Local Authority, health care professionals and the voluntary sector assist carers to keep their loved ones at home for as long as possible through improved information and training regarding treatment and drugs for dementia; techniques in administering medication; dealing with challenging behaviour; and preventing medical conditions such as urine infections.

Recommendation 8:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham and the North East London Foundation Trust assess the need for, and the number of, dementia advisors to be linked to individual dementia patients and their carers for the duration of the illness to assist in accessing resources and services.

Recommendation 9:

The Health and Adult Services Select Committee recommends that NHS Barking and Dagenham take into account the specific needs of people with dementia when re-tendering the service to supply incontinence pads for dementia patients, ensuring that they provide the right size and quantity.

Recommendation 10:

The Health and Adult Services Select Committee recommends that the Local Authority review the specification for home care services to dementia patients to ensure consistent and high quality care across both private and Local Authority services, and for services to be available at week-ends.

Recommendation 11:

The Health and Adult Services Select Committee recommends that the Local Authority review arrangements for communicating the availability of respite care with dementia patients, carers, GPs and other health care professionals to ensure equitable access to these facilities across the Borough and by different ethnic groups.

Recommendation 12:

The Health and Adult Services Select Committee recommends that the Local Authority and health partners review the social, occupational and creative art therapies on offer across the Borough in different settings for dementia patients and to work towards services and resources that are fit for purpose, accessible to meet changing needs and are staffed by appropriately trained staff and volunteers representative of Barking and Dagenham's diverse population. This review will need to take account of the impact of the personalisation of care services.

Recommendation 13:

The Health and Adult Services Select Committee recommends that transport needs of patients and their carers be assessed when reviewing patient and carer plans and tenders for non-emergency transport for dementia patients be regularly reviewed to ensure that they address the changing needs of patients and their carers.

Recommendation 14:

The Health and Adult Services Select Committee recommends that Transport for London be approached about a bus service along Goresbrook Road to improve public transport links to Cherry Orchard Nursing Home.

Recommendation 15:

The Health and Adult Services Select Committee recommends that health agencies and the Local Authority ensure that all service providers, including GPs, have an easily accessible patient pack/file available for ambulance and hospital staff setting out the resuscitation and medical intervention wishes of the patient and their families. The Select Committee recognises that sharing of this information must be in line with data protection requirements.

Recommendation 16:

The Health and Adult Services Select Committee recommends that Barking, Havering and Redbridge University Hospitals NHS Trust review dementia training for all staff in its hospitals and assess whether all wards should have a designated dementia trained nurse and additional staffing, such as health care assistants, to help patients who are less co-operative in taking food and medication and to assist those with mobility problems, which may help prevent falls and infections.

Recommendation 17:

The Health and Adult Services Select Committee recommends that Barking, Havering and Redbridge University Hospitals NHS Trust review their arrangements for the provision of translators to help identify the needs of dementia patients whose first language is not English.

Recommendation 18:

The Health and Adult Services Select Committee recommends that Barking, Havering and Redbridge University Hospitals NHS Trust address the needs of dementia sufferers and carers in its safeguarding adults' policy.

Recommendation 19:

The Health and Adult Services Select Committee recommends that, in line with suggestions from Barking, Havering and Redbridge University Hospitals NHS Trust, as part of a local action plan, NHS Barking and Dagenham develop proposals for improved liaison between specialist services which should include:

- a monthly joint clinic with psychiatrists to be established so patient referrals can be dealt with efficiently and smoothly
- NHS Barking and Dagenham and North East London Foundation Trust develop dementia link nurses to work with medical teams at King George's and Queen's Hospitals to improve patient care and
- the voluntary sector be involved in this service.

Recommendation 20:

The Health and Adult Services Select Committee recommends that the Local Authority, North East London Foundation Trust, Barking, Havering and Redbridge University Hospitals NHS Trust, NHS Barking and Dagenham review and improve arrangements for the transfer of dementia patients from hospital to ensure that they are speedily back in the comfort of their own homes in familiar surroundings.

Recommendation 21:

The Health and Adult Services Select Committee recommends that the Local Authority, North East London Foundation Trust, Barking, Havering and Redbridge University Hospitals Trust and NHS Barking and Dagenham, as part of their joint strategic plan for dementia services, set out their plans for end of life care and ensure health care professionals, including GPs, have appropriate training in relevant legislation, for example, the Mental Capacity Act.

Useful Terms and Abbreviations

This list (including extracts from the National Dementia Strategy Summary) tells you the meanings of some of the terms and abbreviations used in supporting documents.

Terms:

Alzheimer's Disease	The most common illness that causes dementia
Carers	Family, friends or paid carers who look after people with dementia
Clinicians	Medical professionals such as doctors, nurses and therapists.
Consultant	The most senior type of doctor who is a specialist in a particular area of medicine.
Dementia	Loss of mental ability severe enough to interfere with normal activities of daily living. It is a group of symptoms caused by the gradual death of brain cells.
	A person who advises people with dementia and their carers where to go for help
Diagnosis	Deciding what is wrong with a person's health
Ethnic Group	Also referred to as BME (see abbreviations below)
Foundation Trust	NHS foundation trusts are part of the NHS and subject to NHS standards, performance ratings and systems of inspection. Foundation trusts are different from other NHS trusts because they are independent legal bodies.
General Hospitals	Hospitals that provide a range of services, rather than specialising in one sort of disease
Intermediate Care	Help for people who are not quite ill enough to be in hospital, but not quite well enough to manage on their own at home
National Dementia Strategy	The Government's 5-year plan for improving health and social care services in England for everyone with dementia and their carers
Social care	When someone is cared for in the community
Specialist Assessment	A health check done by a dementia specialist
Stigma	The idea that something (in this case dementia) is shameful

Telecare

Special equipment that helps people receive care from far away, for example by telephone

Abbreviations:

BHRT

Barking, Havering and Redbridge University Hospitals NHS Trust

BME

Black and Minority Ethnic Community

EMI

Elderly Mentally Infirm

GP

General Practitioner

HASSC

Health and Adult Services Select Committee

LAS

London Ambulance Service

NHS

National Health Service

NHSBD

NHS Barking and Dagenham (also referred to as the Primary Care Trust or PCT)

NELFT

North East London Foundation Trust

LA

Local Authority (Barking and Dagenham)

PCT

NHS Barking and Dagenham

Primary Care Trust

NHS Barking and Dagenham

Select Committee

See HASSC