

**APPENDIX A**

**Health and Adult Social Services Standing  
Scrutiny Panel 2014/15**

**A Review of Dementia Services in Ealing**

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**HEALTH AND ADULT SOCIAL SERVICES STANDING SCRUTINY PANEL  
2014-15**

**A REVIEW OF DEMENTIA SERVICES IN EALING**



Cllr Theresa Byrne  
(Panel Chair)

**CHAIR'S FOREWORD**

As our main project across the year, the Health and Adult Social Services Scrutiny Panel examined Dementia Services in Ealing. Dementia is widely seen as the biggest health and social care issue facing society today. Dementia mainly affects people over the age of 65 with the likelihood of being affected rising with age. It not only impacts on those individuals who are diagnosed with the condition but also on their families and local communities.

This report brings together various elements, including users and services, and aims to highlight the issues around dementia; a growing concern for residents as well as the Council. Ensuring an early diagnosis and providing high quality services, choice, influence, and control for those affected is key to living well with dementia.

The panel heard some moving and sensitive information from carers about their experiences of looking after loved ones with dementia and I would like to thank them for sharing this with us. I would also like to thank all the external organisations, our health partners, officers, and the panel members for their valuable input to this review.

I hope that the recommendations in this report will help raise awareness of dementia, encourage early diagnosis and support the provision of high quality treatment and care.

**Councillor Theresa Byrne  
Chair  
Health and Adults Social Services Scrutiny Panel**

## **1. INTRODUCTION**

Dementia is caused when the brain is damaged by diseases or a series of strokes. It is characterised by deterioration in the mental functions of an individual including memory, language, orientation and judgement. Symptoms vary and initially can be minor but for someone with dementia they often become severe enough to affect daily life.

Many different diseases can result in dementia. The most common types of dementia are:

- Alzheimer's disease
- Vascular dementia
- Mixed dementia
- Dementia with Lewy bodies
- Frontotemporal dementia (including Pick's disease)

Further information about the types of dementia can be found at Appendix 1.

In 2012 the Health and Adult Social Services Scrutiny Panel received a report on the development of Ealing's Joint Dementia Strategy 2013-16 which highlighted the fact that compared to neighbouring authorities more people with dementia in Ealing were admitted to hospital and those that were admitted stayed in hospital for longer.

Ensuring an early diagnosis and providing high quality services, choice, influence and control for those affected is key to living well with dementia. Therefore a year after its introduction the Health and Adult Social Services Scrutiny Panel wanted to follow up on the implementation on the Joint Dementia Strategy. The key question for this review was:

What is happening in Ealing to improve the diagnosis of dementia and the information, support, and services provided to those with dementia and their carers?

## **2. NATIONAL OVERVIEW**

Nationally there are around 800,000 people diagnosed with dementia and this is expected to rise to 1 million by 2021 with a cost of £23bn a year to the NHS, local authorities and families. Dementia is now one of the top five underlying causes of death and one in three people who die after the age of 65 have dementia.

There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it is estimated that 66,000 people have already cut their working hours to make time for caring, while 50,000 people have left work altogether.

People with dementia are sometimes in hospital for conditions for which, were it not for the presence of dementia, they would not need to be admitted. An estimated 25 per cent of hospital beds are occupied by people with dementia. People admitted to hospital who also have dementia stay in hospital for longer, are more likely to be

readmitted and more likely to die than patients without dementia who are admitted for the same reason.

Approximately 69 per cent of care home residents are currently estimated to have dementia. People with dementia living in a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration and pressure sores) than similar people without dementia.

In 2012 a YouGov poll showed that 61% of UK adults are worried about either themselves or someone they know developing dementia in later life. A 2011 poll found that 39% of respondent's perceived people with dementia had a fairly bad quality of life in the UK, while 19% thought they had a very bad quality of life in the UK. Only 7% thought that people with dementia had either a very good or a fairly good quality of life. This is a challenge both nationally and locally.

Living Well with Dementia – A National Dementia Strategy was launched in 2009. For the first time this provided a framework for care by raising awareness, encouraging early diagnosis and providing high quality treatment and care.

The Prime Minister's Challenge on Dementia (Extracts - Appendix 2), a challenge to the whole of society as well as government, was launched in March 2012. The Dementia Challenge work programme superseded the national strategy and focuses on three key areas:

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

In February 2015 the Prime Minister launched the next phase of his challenge on dementia, which set out what the government wants to see in place by 2020 and provided an update on progress so far.

### **3. LOCAL OVERVIEW**

The number of Ealing residents with late-onset dementia (over the age of 65) is currently estimated to be 2,630. This equates to 6.8% of the total population aged 65 and over. Due to the ageing population of Ealing, this number is projected to rise significantly in the next 25 years to 5,321 by 2038 (8.4% of the total population over the age of 65).

According to estimates generated from national prevalence data there are an additional 73 people with working-age dementia in Ealing. However data from local memory services suggests the true number is considerably higher.

57.2% of people estimated to have late-onset dementia in Ealing have a recorded diagnosis. This diagnosis rate has increased in recent years and is higher than the national average diagnosis rate, but remains lower than the local target diagnosis rate of 67% to be achieved by the end of 2014/15.

It is estimated that around 40% of people with dementia who live in their own homes, live alone, without a carer who lives with them. These individuals may be particularly isolated and vulnerable.

In 2012/13 there were 1781 admissions to general hospital for Ealing residents recorded as having a diagnosis of dementia. The cost of these hospital admissions was more than £5 million.

The mean length of stay for people with dementia admitted to general hospital was 13.0 days. 18.4% of admissions were for 21 days or longer compared to only 7% for England as a whole.

Public Health officers have undertaken a specific piece of work on dementia needs analysis which now forms part of the overall Joint Strategic Needs Assessment (JSNA). Ealing's Joint Dementia Strategy 2013 -16 and an action plan (attached as Appendix 3) was developed as a result of recommendations contained in the Joint Strategic Needs Assessment.

A multi-agency Dementia Programme Board, with members from Adult's Services, Ealing CCG, West London Mental Health Trust, Healthwatch, and London North West Healthcare NHS Trust, was set up in 2012 to oversee the delivery of the six key priorities contained in the action plan. These were:

- Improving diagnosis rates for people with dementia.
- Improving support for people with dementia and their carers in the community to prevent crises and hospital admissions
- Improving care for people with dementia in the general hospital.
- Improving residential and nursing home care for people with dementia.
- Developing a dementia friendly community.
- Dementia and learning difficulties

Ealing's Better Care Fund proposals make specific reference to the refreshed JSNA in relation to the recommendations for Dementia and Older People and Mental Health and aims to support priority four of Ealing's Health & Wellbeing Strategy 2012 -16: Older People and Healthy Aging.

Ealing Council's Corporate Plan 2014 – 2018 sets out how the council will contribute to improving the health, wellbeing and independence of the borough. Priority three highlights the importance of healthy lifestyles, independent living and access to good quality healthcare enabling residents with physical and mental health issues to be as independent as possible. One of the key promises is to make Ealing a “dementia-friendly” borough.

#### **4. LOCAL SPECIALIST DEMENTIA SERVICES**

Ealing has some highly valued specialist services for people with dementia including:

- West London Mental Health Trust's Cognitive Impairment and Dementia service (memory assessment services) – an outpatient service which provides a diagnostic assessment and ongoing review for people with dementia.

- Dementia Concern, a local independent charity, which provides information and support services for people with dementia and their carers. This includes assessment, advice & information, monitoring and support, advocacy, day care, short breaks for carers, dementia cafes, and carers' information evenings.
- Alzheimer's Society which in Ealing provides a dementia support worker, a monthly memory café, and the Carer Information and Support Programme
- Ealing Hospital's Psychiatric Liaison Team – people with diagnosed or suspected dementia or cognitive impairment have access to consultant led assessment and treatment when they are admitted to the hospital or Accident and Emergency for symptoms caused by dementia or by unrelated medical problems.
- Specialist dementia day centre provision

## 5. STRUCTURE OF REVIEW

The Health and Adults Social Services Panel undertook a short review as part of its normal work programme. As a part of this the Panel has received information on:

- Types of Dementia and treatments;
- Ealing population growth and estimates for prevalence of dementia;
- Overview of health and social care provision;
- Extracts from the Prime Minister's Challenge on Dementia; and
- Ealing Dementia Programme Board Strategy and Action Plan
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The Panel has met with the:

- Executive Director, Dementia Concern and with carers;
- Alzheimer's Society Ealing;
- Consultant Psychologist and the Clinical Lead for Dementia, West London Mental Health Trust;
- Clinical Lead Dementia, Ealing CCG; and the
- Head of Integrated Commissioning and the Joint Commissioning Manager for Older People Services, Ealing Council/Ealing CCG.

Panel members have visited:

- Sycamore Lodge and Elm Lodge, day centres that provide care for people with dementia
- Dementia Café at Michael Flanders Day Centre
- Reading Dementia Action Alliance

## 6. FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

### 6.1 Prevention

Research has identified many risk factors associated with dementia. It's impossible to eliminate every single one; after all we can't avoid age, which is the most significant. However, there are things that could affect the risk of developing dementia that we may be able to change

It is not usually possible to say for sure why an individual has developed dementia. It is known that high blood pressure, lack of physical exercise and smoking – all of which lead to narrowing of the arteries – increase the risk of developing Alzheimer's disease and vascular dementia. There is evidence that a healthy lifestyle, especially in mid-life, can help reduce the risk of dementia. Regular physical exercise, maintaining a healthy weight, not smoking, and drinking only in moderation are all linked to a reduced risk of dementia.

It is important that conditions such as diabetes, heart problems, high blood pressure and high cholesterol are all kept under control. Getting depression treated early is also important. A balanced diet may help to reduce risk. A balanced diet is one which is low in saturated fat, does not have too much salt, dairy or meat, and includes plenty of fish and fresh fruit and vegetables.

All these healthy lifestyle choices will also reduce the risk of other serious conditions such as stroke, heart disease and cancer.

It also seems that keeping socially and mentally active into later life may help lower the risk of dementia. Being socially active could include visiting friends or going to a place of worship, while being mentally active could include doing puzzles or reading.

#### **Recommendation 1**

The Panel recommends that Ealing CCG and Ealing Council raises public and professional awareness about lifestyle changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks as preventative activities for reducing the risk of dementia, within their health promotion campaigns.

### 6.2 Raising Awareness and Early Diagnosis

Raising the public's awareness of dementia is crucial to ensure that people with dementia are identified as early as possible and can be offered the most appropriate care.

An All Party Parliamentary Group on Dementia (2012) Unlocking diagnosis: the key to improving the lives of people with dementia, found that one-third of people with dementia had waited longer than a year to go to their GP with their symptoms. The reasons for this are complex and may include an assumption that memory problems are normal in older age, a fear of the diagnosis, a view that little can be done to help or the perceived stigma of dementia.

The Panel heard from the Alzheimer's Society that whilst the 'stigma' of dementia was unfortunately still seen amongst all sectors of society, it was particularly prevalent amongst some Black and Minority Ethnic (BME) communities where there was not a full understanding of what dementia is. Some communities did not have a word for dementia and still associated it as a form of 'madness'.

The Panel were advised by the Clinical Lead for Dementia, Ealing CCG that several strands of work were being undertaken with BME communities in Ealing, including getting to know community leaders, giving talks within communities, and providing nationally available Alzheimer's Society leaflets and factsheets in various languages. There were however cultural and social barriers within some of the BME communities which still needed to be overcome.

### **Recommendation 2**

The Panel recommends that Ealing CCG and Ealing Council develop an awareness raising campaign about dementia targeting those Black and Minority Ethnic communities in the borough where cultural and language barriers needed to be overcome in order to increase diagnosis rates.

The Panel noted from the Better Health Briefing, 'Black, Asian and Minority Ethnic Communities – where are we now?' that there are increasing indications that the prevalence of dementia in Black African-Caribbean and South Asian UK populations is greater than the white UK population. Since these groups are also more likely to experience high blood pressure, it is suggested that the increased risk of vascular dementia contributes to increased prevalence.

### **Recommendation 3**

That the Dementia Programme Board reviews 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.

Currently only 42% of people with dementia in England have a formal diagnosis. The diagnosis rate varies – from 27 % in the worst performing areas to 59% in the best. Too often, diagnosis comes too late – during a crisis or beyond the point where people can plan for the future and make informed choices about how they would like to be cared for.

Diagnosing dementia, especially at an early stage, has a number of benefits. It provides someone with an explanation for their symptoms, gives access to treatment, advice and support, and allows them to prepare for the future and plan ahead. Knowing the type of dementia may allow appropriate drug treatments to be offered. Surveys show that people with dementia would like early diagnosis and with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.

A review by the Care Quality Commission (CQC) in 2012/13 found that in almost a quarter of hospital admissions there was no record of the person's dementia. The review also found that people with dementia have longer stays in hospital, more re-admissions and higher mortality rates than similar people without the condition. A report by the Alzheimer's Society says that 25% of hospital beds are filled by people with dementia and that poor care of people with dementia leads to unplanned emergency admissions.

Ealing CCG is working with primary care to improve the diagnosis of dementia. All 79 GP practices have been advised on how to search for patients who may have dementia but do not have a formal diagnosis. Ten GP practices have had more intensive support and this is being extended to another 10 practices. 57.2% of people estimated to have late onset dementia in Ealing have a recorded diagnosis, although the panel were encouraged to note that diagnosis rate for Ealing had increased in recent years, members were concerned that it remained below the target of 67%.

<b>Recommendation 4</b>
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That Ealing CCG takes action to improve diagnosis rates for people with dementia.
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The Panel heard how providing support to GP practices has increased identification of possible dementia diagnoses. Training for community health, social care staff, and staff within care homes also helps to increase awareness of the early warning signs enabling more effective support to be put in place. There are real opportunities to improve our understanding of the way dementia affects local communities, including identifying and supporting more people with dementia in a timely way, for example by harnessing the knowledge and experience of those regularly working with older people in the community. This is looking wider than the pivotal role of GPs, for example to, district nurses, health visitors, home care workers, occupational therapists, social care staff and voluntary organisations.

<b>Recommendation 5</b>
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That the Dementia Programme Board supports the development and roll out 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.
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### **6.3 Better Information and Advice**

The Panel were informed by the Alzheimer's Society and Dementia Concern that there is considerable confusion in the London Borough of Ealing as to who provides which services. There appeared to be a lack of coherence and aligned signposting by different care facilitators in the borough. What was needed was a comprehensive information guide outlining types of support, care pathways, and giving general information to allow people to feel more in control.

A carer told the panel that when he became his mother's carer, there was a 'paucity of information available on what I was entitled to, I had to do most of my research online and there was nothing in plain English to say what was out there'.

The Panel noted that Dementia Concern was working with the Public Health Department and the Alzheimer's Society on providing easy to understand information for people with dementia and their carers. This will make it much clearer on what the roles of the different organisations are and what help there is available for carers.

#### **Recommendation 6**

The Panel endorses the work being undertaken by Dementia Concern and the Alzheimer's Society working with Public Health England to produce comprehensive but easy to understand information for people with dementia and their carers.

The Panel reviewed the information on Dementia provided on Ealing Council's website and agreed that a dedicated page providing broadly essential information for residents might help to alleviate some of the confusion over the provision of dementia services in the borough.

#### **Recommendation 7**

Ealing Council to add a dedicated page to its website so that residents are able to access direct links for general advice on dementia and are signposted to key contacts.

The Panel heard from Carers about their experiences in trying to arrange short term care, panel members were informed that carers would find it useful to have information on which organisations they could approach. One carer informed the Panel that getting the information on how to access care was like 'making your way through a minefield'.

#### **Recommendation 8**

That Ealing Council signpost residents to information regarding paid carers specifically for people with dementia

### **6.4 Living Well with Dementia**

Two-thirds of all people with dementia live in their own homes in the community. Some will be in the early stages of their illness, and others near the end of their lives. The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them.

Apart from family members or friends, who provide the vast bulk of care and support, the panel heard that home care is probably the single most important service involved in supporting people with dementia in their own homes. The Commission for Social Care Inspection (CSCI) has found that good-quality, flexible home care services contribute significantly to maintaining people's independence, reducing

social isolation, preventing admissions to care homes and hospitals, and supporting carers.

Care services need to take account of the special needs and sensitivities of providing personal care to people with dementia. It is essential to engage with an individual on each occasion before sufficient trust can be established to give the necessary care. If adequate time is not allocated then care interventions, such as showers, medication or meals, may be refused.

The Panel heard evidence from Dementia Concern that assessments for care packages often do not take into account the additional time needed for the care worker to develop a relationship with the person with dementia in order to win their trust. The care worker may need half an hour to engage with the person with dementia and if this is the time limit for giving a wash or a meal the service is likely to be turned down. This is shown in records saying, 'refused shower, medication or meal. The Panel were informed by the son of a person with dementia that the carers did not appear to care for his mother's wellbeing, ' they had failed to ensure that she took her medication and due to the time constraints on them did not have time to prepare proper meals, usually just providing a sandwich'.

<b>Recommendation 9</b>
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That Adult Social Services provides an enhanced domiciliary care service which meets the needs of people with dementia. Care services need to take account of the special needs and sensitivities of providing personal care to people with dementia. It is essential to engage with an individual on each occasion before sufficient trust can be established to give the necessary care. If adequate time is not allocated then care interventions, such as showers, medication or meals, may be refused.
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Carers informed the Panel that respite care was crucial to enable often elderly carers to undertake everyday tasks. One carer stated that the lack of respite care available to her was a primary concern and that her living situation would be improved simply by having someone available during the week to check in on them, make sure everything was ok and allow her a few hours to have a degree of social life.

<b>Recommendation 10</b>
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That Ealing Council and Ealing CCG explore the feasibility of developing alternative models of respite care other than bedded respite care for people with dementia, such as domiciliary care.
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Carers also stated that there was a lack of information about respite care amongst some carers and health care professionals, including GPs.

Members heard carers' concerns about the perceived lack of long-term planning, which led to funding for respite care running out early within the municipal year and a lack of consistency. One carer stated that when he was looking to make holiday arrangements, social services would not provide him with dates for respite unless it was within four weeks of the date of request, making planning in anything other than the short-term difficult.

A respondent to the Dementia Concern Carers' Survey, which was undertaken in December 2014, stated 'I have recently enquired about respite and was told that it would not be available until the end of March 2015. I am a carer and have had no respite for over 4 years. It is cumbersome trying to get anything remotely like respite'.

#### **Recommendation 11**

That Ealing Council and Ealing CCG 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.

In 2012 the Health and Adult Social Services Scrutiny Panel received a report on the development of Ealing's Joint Dementia Strategy 2013-16. One of the objectives of the strategy was to improve the availability of high quality home care places for people with dementia.

In December 2013, when considering a report on Dementia Services Redesign, the panel heard that there was a shortage in the number of care homes in the borough able to look after people with challenging behaviour and complex needs. This results in admissions to hospital which may be preventable and also contributes to delayed discharges, as well as limiting the availability of respite care.

#### **Recommendation 12**

That the Dementia Programme Board seeks to increase the number of care homes in the borough able to look after people with challenging behaviour and complex needs.

The Panel heard from Dementia Concern, a local charity, about the services they provide for people with dementia and their carers in the London Borough of Ealing. This includes assessment, advice & information, monitoring and support, advocacy, day care, short breaks for carers, dementia cafes, and carers' information evenings. Roger Beckett, Chief Executive, Dementia Concern informed the panel that the service receives direct referrals from West London Mental Health Trust and that the services offered by Dementia Concern could help more people with post diagnosis support if GPs and Intermediate Care Ealing also made direct referrals..

#### **Recommendation 13**

Ealing CCG to consider whether GPs and Intermediate Care Service could make direct referrals to Dementia Concern.

The Panel recognises that dementia is one of the biggest challenges the UK faces today. The number of Ealing residents with late onset dementia (over the age of 65) is currently estimated to be 2,630 with this figure being set to rise to over 5,000 by 2038.

Appointing a non-executive councillor with responsibilities for championing high quality dementia services would ensure that the Council remains focussed on this issue and would reaffirm to the public that the needs of residents continue to guide the Council's actions. The responsibilities of this role would not just be about supporting the development of a dementia friendly community, but about making sure that there is a focus on providing the health and social care required to help people with dementia live well and helping to break down the barriers which prevent certain communities from accessing dementia services.

<b>Recommendation 14</b>
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That Ealing Council appoints a non-executive councillor to act as a champion for high-quality dementia services.
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Members noted from presentations from the Alzheimer's Society and Dementia Concern that demand for the services provided by the voluntary sector was growing. Dementia Concern informed the Panel that the number of people on their database had increased by 50% over the last four years. In the last 9 months they have recruited several new workers – two dementia advisers, a welfare benefits officer, and three community support workers in order to meet the increased need.

The Alzheimer's Society also told the Panel that there was a need for an increased range of activities to suit all individuals and provide a wider range of choice. There was also a need for more Support Work capacity to support the increasing numbers of people with the diagnosis.

Members of the panel attended a Dementia Café in Michael Flanders Centre which is run once a month by volunteers. It is open to all whether or not they are known to social services and is a way that those with dementia and their carers can enjoy a social event, have contact with others experiencing the same issues, and have contact with social services staff who can provide information or signpost them to other forms of assistance. Members noted that there were two other Dementia Cafés run in the borough by voluntary groups and meeting in local community centres and Ealing Town Hall.

The Panel agreed that the Council should look at how it could offer more help to the voluntary organisations in the community who were providing this much needed support.

<b>Recommendation 15</b>
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That the Cabinet takes into consideration the increasing pressure on those voluntary sector organisations that deliver services to people with dementia by supporting access to low cost community facilities, effectively managing facilities with partner organisations, and when developing its budget proposals for 2016/2017 onwards.
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As part of the Panel's wider activities, members scrutinised the council's plan for implementing the Care Act 2014. For the first time carers are recognised in the law in the same way as those they care for. Under the Care Act 2014, local authorities have a responsibility to assess carers' eligible needs for support. This will mean

more carers, including carers of people with dementia, are able to have an assessment, comparable to the right of the people they care for, and a support plan setting out how their needs will be met.

Carers of people with dementia undoubtedly provide a vital role and the availability of appropriate care and support and the quality of services has a significant bearing on whether carers feel able to take a break from their caring responsibilities. There is evidence that providing carers with better information, training and coping strategies, including emotional and psychological support, improves their quality of life and is also cost-effective, with costs being off-set by reduced use of services

As the primary purchaser of social care services, local authorities will be under a duty to promote and shape a diverse and high quality market of care and support services (including prevention services) in its area, with a view to ensuring that people have a variety of providers and high quality services to choose from.

Local authorities must consider certain factors when exercising this duty including the importance of ensuring the sustainability of the market, the current and future demand for services and the importance of carers and service users being able to undertake work, education and training. The Government has suggested that the enhanced duty to cooperate between the NHS and local authorities' means that some of the costs of support for carers might fall to the NHS and that improved services to carers might reduce their need to use NHS services.

#### **Recommendation 16**

That Ealing Council and Ealing CCG actively facilitates and shapes the local market for dementia care and support with the aim of developing a market that delivers a wide range of sustainable high quality care and support services, that will meet the needs of the local community.

### **6.5 Creating a Dementia Friendly Community**

In March 2012, the Prime Minister launched his 'challenge on dementia' with a series of commitments to action. Creating dementia-friendly communities is one of the commitments in the challenge. The health and social care system has a vital role to play in improving support for people with dementia, but alone it cannot combat the stigma attached to dementia. Lack of awareness among the public and poor understanding in communities has a major impact on the experience of people with dementia.

The concept of dementia-friendly communities is an emerging one and there is not yet an extensive body of literature. Definitions from national and international attempts to explore the concept's dimensions include descriptions put forward by people with dementia and their carers.

A dementia-friendly community may be defined as being a place:

- in which it is possible for the greatest number of people with dementia to live a good life
- where people with dementia are enabled to live as independently as possible and to continue to be part of their community

- where they are met with understanding and given support where necessary.

It is a place where the society or community acts consciously to ensure that people with dementia (along with all its citizens) are respected, empowered, engaged and embraced. People living with dementia want to remain independent for as long as possible, and they want to have a choice and control over their lives through all stages of their dementia. Dementia-friendly communities can better support people in the early stages of their illness, maintaining confidence and boosting their ability to manage everyday life.

The Panel noted that that the Council is committed to working towards making the borough dementia friendly. The Panel considered that having a theme for a future mayoralty which focuses on creating a dementia friendly community would help to raise the profile of the Council's commitment. With the support of officers, the planning of a proactive programme would help the Mayor to devote their valuable and limited time to those activities which would make a real difference to raising awareness of dementia. Adopting a theme would also enable the Mayor to be specific from the outset about what they wished to achieve and to aim for a clear set of results to demonstrate successes at the end of the civic year.

#### **Recommendation 17**

The Panel encourages a future Mayor to adopt the theme for their mayoralty of supporting Ealing to become a dementia friendly community, acting as ambassador, facilitator, promoter, encourager and fund raiser.

Establishing a local structure is the key to the success and sustainability of creating a dementia-friendly community. A Local Dementia Action Alliance is the recommended model for this as it enables the bringing together of individuals and organisations with shared aims to help the community to become more dementia friendly. They will usually include police forces, fire and rescue services, retailers, local authorities, local transport providers, charities, community groups, businesses, care providers, health trusts, and people living with dementia and their carers.

Members were informed that Ealing Council were working with the Alzheimer's Society to establish a Dementia Action Alliance (DAA), made up of organisations working across the borough to make the lives of people living with dementia and their carers better.

Regular reports from Ealing Dementia Action Alliance will enable the scrutiny panel to follow the progress of the borough in becoming dementia-friendly.

#### **Recommendation 18**

The Panel supports Ealing Council's commitment to becoming a dementia-friendly borough, and will monitor progress in delivering this outcome by receiving regular updates from Ealing Dementia Action Alliance.

The Panel noted that Ealing DAA which is due to be launched in May 2015 had received start-up funding from Ealing Council. The Panel hopes that Ealing Council will continue to support the DAA with ongoing funding, until it is up and running and able to be self-supporting.

#### **Recommendation 19**

The Panel asks that Ealing Council will continue to support Ealing Dementia Action Alliance with ongoing funding, until it is able to be self-supporting.

Members of the Panel visited Reading Dementia Action Alliance on the 4 December 2014 to find out how they got their DAA up and running, and the approaches being taken by the local businesses and organisations involved to working with people with dementia and their carers

Members were informed that Reading DAA thought that it was important to get a prominent business person who was enthusiastic and knew lots of people involved from the start. In Reading's case this was the CEO of the local bus company. Bus drivers were the first to undertake Dementia Friends training. This helped them recognise the signs, such as trouble paying or staying on the bus for a long time, so that they could offer help.

Reading's Oracle shopping centre, which has over 80 businesses, has signed up to the DAA along with local voluntary sector organisations. There are 14 people on the Steering Group and these include representatives from transport, Citizens Advice Bureau, CCG, Reading Council (an officer and member), a local solicitor, a person with dementia and a carer. The Steering Group also includes one or more people from the local BME groups within Reading.

Businesses who join commit to follow the terms of reference of the DAA which includes allocating time to attend the steering group, becoming a Dementia Friend and champion and ensuring their business is dementia friendly.

When members asked about how the DAA measures its impact they were told that this largely came from the number and range of organisations involved and feedback from the community.

#### **Recommendation 20**

Ealing Dementia Action Alliance should invite members of Ealing Business Partnership to be actively involved in Dementia Action Alliance.

The Panel heard that Public Health England and the Alzheimer's Society have joined forces in a campaign to encourage people to become Dementia Friends. Anybody can become a Dementia Friend; it's about understanding a bit more about dementia and the small things you can do to help people with the condition. Dementia Friends learn a little bit about what it's like to live with dementia and are supposed to turn that understanding into action. This could be helping someone find the right bus or being patient in a till queue if someone with dementia is taking longer to pay. Every action counts.

The Panel were pleased to note that Ealing council has run some information sessions for staff where they learn about dementia and how they can help to create dementia friendly communities; however this training did not appear to be ongoing. Members felt that it was important that front line staff and managers had an understanding of dementia, so that they could turn that understanding into action to help improve the delivery of front-line services.

#### **Recommendation 21**

That the Council increases the provision of 'How to become a Dementia Friend' courses and encourages front line service officers, managers and councillors to attend. This course is run by the council however there are no training dates currently scheduled and there is a waiting list.

#### **Recommendation 22**

Scrutiny Panel members to use their links with resident and community groups to encourage people to become 'Dementia Friends' and participate in the training being offered by the Alzheimer's Society.

Information from the Alzheimer's Society shows that younger people are more educated and aware about dementia than ever before. Hundreds of schools have taken part in the dementia friendly schools programme and awareness is gathering pace within youth movements around the country.

Whilst visiting the Michael Flanders Centre, staff informed members that they were working to establish links with the local community and hoping to have short assembly slots at various local schools to help raise awareness and breakdown fear and stigma around individuals with dementia.

#### **Recommendation 23**

London Borough of Ealing's Family and Children's Services to encourage and support work with schools as part of the strategy to develop a dementia friendly community.

### **6.6 Developing a Centre of Excellence**

During this review, members of the panel visited three day centres in Ealing which provide care for people with dementia; Sycamore Lodge, Elm Lodge and Michael Flanders Centre. As part of the Panel's wider activities, the Panel considered the consultation on the proposal that customers from the Sycamore Lodge and Elm Lodge Day Centres would have their services delivered at the Michael Flanders Centre in Acton.

Members were informed that the Michael Flanders Centre would offer the same level of support and number of placements currently available across the three centres. There would be an increase in staffing to provide a service to the increased number of customers and some staff from Elm Lodge Centre and Sycamore Lodge Centre

would transfer to the Michael Flanders Centre providing continuity of care for the customers and continuity for families. All of the staff at all of the day centres receive the same training and are all qualified to NVQ Level 3 and Dementia Level 3

The Panel were pleased to note that there were plans to transform the Michael Flanders Centre into a Centre of Excellence for Dementia in line with examples of best practice across the country. The plans would include expanding the availability of specialised therapy services and access to other specialist support available in the community and provided by the voluntary sector.

<b>Recommendation 24</b>
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The Panel supports the development of the Michael Flanders Centre as a dementia centre of excellence and encourages the Council to progress this work.
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<b>Recommendation 25</b>
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That the Dementia Programme Board arranges for appropriate officers to visit the Southwark Dementia Care Centre of Excellence, when opened, to learn from any innovative practice.
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## 6.7 Ealing Dementia Programme Board

Although the Panel was given assurance by the Head of Integrated Commissioning and the Joint Commissioning Manager for Older People Services, Ealing Council/Ealing CCG that considerable progress had been made against all the Dementia Programme Board Action Plan areas, the Panel was disappointed to learn that the multi-agency Dementia Programme Board had not met since early 2014 due to staff changes and difficulties synchronising diaries for the wider range of members.

Members were concerned that without meeting regularly the Board would not be able to provide strategic, clinical and operational leadership and direction to the Dementia Programme or ensure that the Dementia Programme is progressed to meet agreed milestones, targets and timescales.

Members were informed that a Dementia Programme Board meeting was being arranged for February 2015, when the action plan would be fully reviewed and a fresh action plan for 2015-2016 would be prepared.

<b>Recommendation 26</b>
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That the Dementia Programme Board meets regularly with meeting dates scheduled for the year ahead, and provides regular updates on the progress of its action plan to the Scrutiny Panel.
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<b>Recommendation 27</b>
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That the Dementia Programme Board invites Age UK to be a member of the Board.
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## **7. BACKGROUND INFORMATION**

There are many sources of information available – below are some of the key sources used in this review:

1. Living well with Dementia: a national dementia strategy, Department of Health, February 2009
2. Prime Minister's challenge on dementia, Department of Health, March 2012
3. Prime Minister's challenge on dementia 2020, Department of Health, Cabinet Office and Prime Minister's Office February 2015
4. Joint Dementia Strategy for Ealing 2013 – 2016, Public Health Ealing October 2013
5. Corporate Plan 2014-2018, Ealing Council
6. Ealing Health and Wellbeing Strategy, 2012 – 2016
7. Better Health Briefing, Black, Asian and Minority Ethnic Communities and Dementia – where are we now? David Truswell, November 2013
8. Foundation criteria for the dementia-friendly communities recognition process, 2014-15, Alzheimer's Society
9. Developing dementia-friendly communities-Learning and guidance for local authorities, Local Government Association, May 2012
10. Creating a dementia friendly York, Joseph Rowntree Foundation, October 2012
11. Reading Dementia Action Alliance Report August 2013 – July 2014, Alzheimer's Society
12. Ten questions to ask if you scrutinising services for people with dementia, Centre for Public Scrutiny

## 8. RECOMMENDATIONS WITH OFFICER / PARTNER COMMENTS

Conclusions or Recommendations		Officer / Partner Comments
1	The Panel recommends that Ealing CCG and Ealing Council raises public and professional awareness about life-style changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks as preventative activities for reducing the risk of dementia within their health promotion campaigns.	The Dementia Programme Board will consider asking Public Health to take the lead in responding to this recommendation and consider how such information could be included in the Annual Health Checks for older people
2	The Panel recommends that Ealing CCG and Ealing Council develop an awareness raising campaign about dementia targeting those Black and Minority Ethnic communities in the borough where cultural and language barriers needed to be overcome in order to increase diagnosis rates.	The CCG is working with all GPs to increase dementia diagnosis rates, in line with national targets and is committed to identifying people likely to have dementia from all communities. The CCG is seeking advice on best practice from a number of other London Boroughs who have been successful in reaching black and ethnic minority communities to ensure that cultural or language barriers are not preventing early diagnosis and support. Through active participation in the Dementia Action Alliance we aim to increase awareness among hard to reach communities encouraging people to come forward for dementia diagnosis in order to obtain ongoing treatment and support.
3	That the Dementia Programme Board reviews 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 Dementia Programme Board will consider asking Public Health to include this review in their update of the Dementia chapter in the Joint Strategic Needs Assessment to inform recommendation 2 above.

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments</b>
4	That Ealing CCG takes action to improve diagnosis rates for people with dementia.	As indicated above, the CCG is working with all practices to increase dementia diagnosis rates and was close to reaching the national target in 2014/15. Further action will be taken during 2015/16 to extend and sustain this improvement.
5	That the Dementia Programme Board supports the development and roll out 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.	The Dementia Programme Board will consider asking all member organisations and local providers about their plans for dementia training and seek updates on implementation. A successful education session for GPs was held on 14 <sup>th</sup> January and more is already planned for primary care. Adult social care staff are already trained in dementia. Care homes have a duty to ensure that all their care staff are trained to work with people with dementia.
6	The Panel endorses the work being undertaken by Dementia Concern and the Alzheimer's Society working with Public Health England to produce comprehensive but easy to understand information for people with dementia and their carers.	In addition to information produced by the voluntary and community sector on the services which they offer, council officers in adults' services and public health are preparing a wider "living well with dementia" leaflet which should be available by the summer 2015. They are also updating a previously published Dementia Awareness handbook for use as a dementia information booklet more widely.
7	Ealing Council to add a dedicated page to its website so that residents are able to access direct links for general advice on dementia and are signposted to key contacts.	The council website is currently being revised and officers will be delighted to take forward this action and put information and advice on dementia on the site again once a robust system is place.

	<b>Conclusions or Recommendations</b>	<b>Officer / Partner Comments</b>
8	That Ealing Council signpost residents to information regarding paid carers specifically for people with dementia	<p>An information pack on services available for people with dementia is being prepared, including home care. All Ealing's contracted home care providers are specifically trained to provide support to people with dementia.</p> <p>Information on care and support services can be found at <a href="http://www.careplace.org.uk">www.careplace.org.uk</a> and in the Ealing Resource Directory. This will include information on the registration of the service and whether carers are trained in dementia.</p>
9	That Adult Social Services provides an enhanced domiciliary care service which meets the needs of people with dementia. Care services need to take account of the special needs and sensitivities of providing personal care to people with dementia. It is essential to engage with an individual on each occasion before sufficient trust can be established to give the necessary care. If adequate time is not allocated then care interventions, such as showers, medication or meals, may be refused.	<p>Each service user (and carer) receives an individual assessment and the package of care identified is designed to meet their particular needs. If it is felt that not enough time or frequency has been allowed within the package it can be reviewed and adjusted. The additional time required for people with dementia is understood by care assessors, but the point will be reinforced with the care management team.</p> <p>All Ealing's contracted home care providers are specifically trained to provide support to people with dementia.</p> <p>Information on care and support services can be found at <a href="http://www.careplace.org.uk">www.careplace.org.uk</a> and in the Ealing Resource Directory.</p>

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments</b>
10	That Ealing Council and Ealing CCG explore the feasibility of developing alternative models of respite care other than bedded respite care for people with dementia, such as domiciliary care.	Home care is already available for people with dementia; the Council will be extending services for carers in 2015/16 in line with the requirements of the Care Act and will take account of feedback from carers of people with dementia in the Dementia Concern survey and from the Carers' Conference in developing the specifications. Officers recommend that any financial implications should be met from existing local authority and NHS budgets.
11	That Ealing Council and Ealing CCG 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.	The Council and CCG will take account of this recommendation in developing respite care for people with dementia.
12	That the Dementia Programme Board seeks to increase the number of care homes in the borough able to look after people with challenging behaviour and complex needs.	Public Health are currently updating the dementia needs assessment which will inform the Council and CCG's development of the market for care places. West London Mental Health NHS Trust are proposing changes to improve the services available for people with challenging behaviour and complex needs. These proposals will be presented to the Dementia Programme Board in May.
13	Ealing CCG to consider whether GPs and Intermediate Care Service could make direct referrals to Dementia Concern.	Ealing CCG will consider this recommendation in discussion with other partners about the development of the dementia care pathway
14	That Ealing Council appoints a non-executive councillor to act as a champion for high-quality dementia services.	The Dementia Programme Board would welcome this appointment

<b>Conclusions or Recommendations</b>	<b>Officer / Partner Comments</b>
15 That the Cabinet takes into consideration the increasing pressure on those voluntary sector organisations that deliver services to people with dementia by supporting access to low cost community facilities, effectively managing facilities with partner organisations, and when developing its budget proposals for 2016/2017 onwards.	
16 That Ealing Council and Ealing CCG actively facilitates and shapes the local market for dementia care and support with the aim of developing a market that delivers a wide range of sustainable high quality care and support services that will meet the needs of the local community.	The need to develop the market for dementia services has been recognised in the Council's Market Position Statement and will be reinforced in discussion with providers in the coming years.
17 The Panel encourages a future Mayor to adopt the theme for their mayoralty of supporting Ealing to become a dementia friendly community, acting as ambassador, facilitator, promoter, encourager and fund raiser.	The Dementia Programme Board welcomes this recommendation.
18 The Panel supports Ealing Council's commitment to becoming a dementia-friendly borough, and will monitor progress in delivering this outcome by receiving regular updates from Ealing Dementia Action Alliance.	The Dementia Programme Board welcomes this recommendation.
19 The Panel asks that Ealing Council will continue to support Ealing Dementia Action Alliance with ongoing funding, until it is able to be self-supporting.	The Dementia Programme Board will consider how the Dementia Action Alliance can continue to be developed with both statutory and non-statutory support.
20 Ealing Dementia Action Alliance should invite members of Ealing Business Partnership to be actively involved in Dementia Action Alliance.	Initial contacts have been made and will be followed up, making use of corporate business relationships and perhaps with the support of the non-executive champion recommended in 15 above.

<b>Conclusions or Recommendations</b>	<b>Officer / Partner Comments</b>
21 That the Council increases the provision of 'How to become a Dementia Friend' courses and encourages front line service officers, managers and councillors to attend. This course is run by the council however there are no training dates currently scheduled and there is a waiting list.	The Dementia Programme Board will consider how to extend the programme of Dementia Friend courses across all council departments and members. Officers recommend that the cost of this training be contained within existing Children's and Adult's Training Budgets.
22 Scrutiny Panel members to use their links with resident and community groups to encourage people to become 'Dementia Friends' and participate in the training being offered by the Alzheimer's Society.	The Dementia Programme Board welcomes this recommendation.
23 London Borough of Ealing's Family and Children's Services to encourage and support work with schools as part of the strategy to develop a dementia friendly community.	The Dementia Programme Board welcomes this recommendation.
24 The Panel supports the development of the Michael Flanders Centre as a dementia centre of excellence and encourages the Council to progress this work.	This is welcomed. Adults' Services will be taking forward this proposal during 2015/16.
25 That the Dementia Programme Board arranges for appropriate officers to visit the Southwark Dementia Care Centre of Excellence, when opened, to learn from any innovative practice.	The Dementia Programme Board will follow up this recommendation.
26 That the Dementia Programme Board meets regularly with meeting dates scheduled for the year ahead, and provides regular updates on the progress of its action plan to the Scrutiny Panel.	The multi-agency Dementia Programme Board has since February 2015 been meeting every 2 months and has meeting dates scheduled for the year ahead. The Board has refreshed its terms of reference and its action plan and will provide regular updates on progress to the Scrutiny Panel.
27 That the Dementia Programme Board invites Age UK to be a member of the Board.	The Dementia Programme Board has already included Age UK in the membership of the board under its revised Terms of Reference.

## Appendix 1

### Overview of Dementia

Dementia is a disease characterised by deterioration in the mental functions of an individual including memory, language, orientation and judgement. Symptoms vary and initially can be minor but for someone with dementia they often become severe enough to affect daily life.

Dementia is caused when the brain is damaged by diseases or a series of strokes. Alzheimer's disease is the most common cause of dementia but not all dementia is due to Alzheimer's. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia. Some of the common cognitive issues include:-

- day-to-day memory – difficulty recalling events that happened recently
- concentrating, planning or organising – difficulties making decisions, solving problems or carrying out a sequence of tasks (e.g. cooking a meal)
- language – difficulties following a conversation or finding the right word for something
- visuospatial skills – problems judging distances (e.g. on stairs) and seeing objects in three dimensions
- orientation – losing track of the day or date, or becoming confused about where they are.

A person with dementia will often also have changes in their mood, becoming frustrated or irritable, withdrawn, anxious, easily upset or unusually sad. With some types of dementia, a person may experience hallucinations or believe things that are not true (delusions).

Dementia is progressive, the symptoms gradually get worse over time. It progresses differently for each individual. However as dementia progresses, individuals may develop behaviours that seem unusual or out of character. These may include repetitive questioning, pacing, restlessness or agitation. A person with dementia, especially in the later stages, may have physical symptoms such as muscle weakness or weight loss, with changes in sleep pattern and appetite also common. The effects of dementia on an individual can be distressing or challenging for not just the person affected but also for their family and friends.

### Dementia: Types & Causes

Many different diseases can result in dementia. The most common types of dementia are:

- **Alzheimer's disease** – The most common cause of dementia, accounting for 60% of cases<sup>1</sup> Brain cells are surrounded by an abnormal protein and their internal structure is also damaged. In time, chemical connections between brain cells are lost and some cells die. Problems with day-to-day memory are often noticed first, but other symptoms may include difficulties with: finding the right words, solving problems, making decisions, or perceiving things in three

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<sup>1</sup> Work, Mental Health and Welfare, London Mental Health and Employment Partnership, NHS, pg 7

dimensions. Individuals may also have difficulty with eating, swallowing, continence and experience loss of communication skills.

- **Vascular dementia** – If the oxygen supply to the brain is reduced because of narrowing or blockage of blood vessels, some brain cells become damaged or die. This causes vascular dementia. The symptoms either occur suddenly following one large stroke, or over time through a series of small strokes or damage to small blood vessels deep in the brain. The symptoms of vascular dementia vary and may overlap with those of Alzheimer's disease. Many people have difficulties with problem-solving or planning, thinking quickly and concentrating. They may also have short periods when they get very confused.
- **Mixed dementia** – Is when someone has more than one type of dementia, and a mixture of symptoms. It is common for someone to have Alzheimer's disease and vascular dementia together.
- **Dementia with Lewy bodies** – Here tiny abnormal structures (Lewy bodies) develop inside brain cells. They disrupt the brain's chemistry (affecting the person's memory, concentration and language skills) and lead to the death of brain cells. Early symptoms can include fluctuating alertness, difficulties with judging distances and hallucinations. Day-to-day memory is usually affected less than in early Alzheimer's. Dementia with Lewy bodies is closely related to Parkinson's disease and has some of the same symptoms such as tremors and slowness of movement.
- **Frontotemporal dementia (including Pick's disease)** – Here, the front and side parts of the brain are damaged over time when clumps of abnormal proteins form inside nerve cells, causing them to die. At first, changes in personality and behaviour may be the most obvious signs. Depending on where the damage is, the person may have difficulties with fluent speech or may forget the meaning of words or objects. This dementia includes Pick's disease and most commonly affects people under 65.

The symptoms of these types of dementia are often different in the early stages but become more similar later on. This is because more of the brain becomes affected as the different diseases progress.

In the later stages of dementia, an individual will need increasing support to carry out everyday tasks.

### **Rare causes of dementia**

There are many other diseases that sometimes lead to dementia though only accounting for only about 5% of all dementia. They tend to be more common among younger people with dementia (under the age of 65).

These include alcohol-related brain damage (including Korsakoff's syndrome), corticobasal degeneration, progressive supranuclear palsy, HIV infection, Niemann-Pick disease type C, and Creutzfeldt-Jakob disease (CJD).

Some people with Parkinson's disease or Huntington's disease develop dementia as the illness gets worse. People with Down's syndrome are particularly at risk of developing Alzheimer's disease as they age.

## **Mild cognitive impairment**

Some people have problems with their memory or thinking but these are not severe enough to interfere with everyday life. In this case, a doctor may diagnose mild cognitive impairment (MCI). Research shows that people with MCI have an increased risk of developing dementia; about 10–15 per cent of this group will develop dementia each year.

However, MCI can also be caused by other conditions such as anxiety, depression, physical illness and side effects of medication. Because of this, some people with MCI do not go on to develop dementia, and a small number of people will get better.

## **Dementia: Differential Elements / Who gets dementia?**

There are around 800,000 people in the UK with dementia. It mainly affects people over the age of 65 (one in 14 people in this age group have dementia), and the likelihood of developing dementia increases significantly with age. Most cases of dementia are late-onset and therefore affect people aged 65 and over. However, dementia also affects younger people with at least 17,000 people in the UK who developed dementia before they were 65. It is suggested that this figure has been underestimated and the real number may be up to three times higher. Dementia can affect anyone regardless of gender, ethnicity, socio-economic situation and residential status. Nearly two-thirds of people with the disorder live in the community, while the other third reside in a residential home. A smaller number of people with dementia are from black and minority ethnic (BME) groups. This reflects the current younger age profile in London's BME communities. As this population ages, with a higher prevalence of physical conditions which may contribute to dementia, the rate of dementia is expected to increase. Approximately one in 40 cases is early-onset dementia and occurs before the age of 65. Many factors, including age, genetic background, medical history and lifestyle can combine to lead to the onset of dementia.

Dementia can also develop as a result of family genetics. In a very small number of people, certain types of dementia are inherited as a single gene that causes the disease, usually before age 65. A much larger number of people will inherit a combination of genes that increases or decreases their risk of developing dementia in much less direct ways.

## **Dementia: Diagnosing dementia, Causes & Proactive Measures**

Diagnosing dementia especially at an early stage, has a number of benefits. It provides someone with an explanation for their symptoms, gives access to treatment, advice and support, and allows them to prepare for the future and plan ahead. Knowing the type of dementia may allow appropriate drug treatments to be offered.

Dementia will usually be diagnosed by a specialist doctor, a psychiatrist, a geriatrician or a neurologist. Occasionally a GP or specialist nurse will make the diagnosis, depending on their expertise and training.

There is no single test for dementia. A diagnosis is based on a combination of things:

- taking a 'history' – by the doctor talking to the person and someone who knows them well about how their problems developed and how they are now affecting their daily life
- cognitive tests of mental abilities (eg memory, thinking) – simpler tests will be carried out by a nurse or doctor, more specialist tests by a psychologist
- physical examination and tests (eg blood tests) – to exclude other possible causes of the symptoms
- a scan of the brain – if this is needed to make the diagnosis.

Usually a GP makes the initial assessment and then refers the person to a memory clinic or other specialist service for more detailed assessment. A specialist with expertise in dementia will be able to arrange more detailed tests and brain scans if needed.

### **Dementia: Treatment**

The vast majority of causes of dementia cannot be cured, although research is continuing into developing drugs, vaccines and other medical treatments.

### **Non-drug treatments and support**

A range of support, therapies and activities that do not require medication can help someone to live well with dementia. Support for the person and their carer after a diagnosis gives them a chance to talk things over with a specialist, ask questions about the diagnosis, and think about the future. Information should be given on where to get help if needed in the future and how to stay physically and mentally well.

Talking therapies, such as counselling, can help someone come to terms with their diagnosis. Cognitive behavioural therapy (CBT) may also be offered to help with depression or anxiety.

Cognitive rehabilitation can enable an individual to retain mental skills and raise their confidence. There is also much that can be done at home to help someone with dementia remain independent and live well with memory loss. Support ranges from devices such as pill boxes or calendar clocks to practical tips on how to develop routines or break tasks into simpler steps.

Activities that help to keep the mind active, such as cognitive stimulation, are popular. As the condition progresses, many people with dementia enjoy reminiscence and life story work (in which the person is encouraged to share their life experiences and memories). Such activities may help improve someone's mental abilities, mood and wellbeing.

It is vital that people with dementia stay as active as they can – physically, mentally and socially. This is helpful in bringing confidence and self-esteem to someone with dementia.

## **Drug treatments**

There are drugs that can help to improve the symptoms of dementia or that, in some cases, may stop them progressing for a while.

A person with mild to moderate Alzheimer's disease or mixed dementia may be prescribed donepezil, rivastigmine or galantamine. These may temporarily relieve memory problems and improve alertness, level of interest and daily living. In the moderate or severe stages of Alzheimer's disease someone may be offered memantine. This may help with mental abilities and daily living, and ease distressing or challenging behaviours and delusions.

Donepezil, rivastigmine and galantamine can be helpful for someone with dementia with Lewy bodies who has distressing hallucinations or delusions, or who has behaviours that challenge.

For those with vascular dementia, drugs will be offered to treat the underlying conditions. These often include high blood pressure, high cholesterol, diabetes or heart problems. Controlling these may help slow the progression of dementia.

A wide range of other drugs may be prescribed at different times for a person with dementia. These include drugs for depression or anxiety, sleeping tablets or antipsychotics. Note that some of these drugs can have severe side effects. Not all are recommended for all types of dementia. Health professionals will generally advise that a non-drug approach is tried first before prescribing medication.

## **Dementia: Prevention**

It is not usually possible to say for sure why an individual has developed dementia. It is known that high blood pressure, lack of physical exercise and smoking – all of which lead to narrowing of the arteries – increase the risk of developing Alzheimer's disease and vascular dementia. There is evidence that a healthy lifestyle, especially in mid-life, can help reduce the risk of dementia. Regular physical exercise, maintaining a healthy weight, not smoking, and drinking only in moderation are all linked to a reduced risk of dementia.

It is important that conditions such as diabetes, heart problems, high blood pressure and high cholesterol are all kept under control. Getting depression treated early is also important.

A balanced diet may help to reduce risk. A balanced diet is one which is low in saturated fat, does not have too much salt, dairy or meat, and includes plenty of fish and fresh fruit and vegetables.

All these healthy lifestyle choices will also reduce the risk of other serious conditions such as stroke, heart disease and cancer.

It also seems that keeping socially and mentally active into later life may help lower the risk of dementia. Being socially active could include visiting friends or going to a place of worship, while being mentally active could include doing puzzles or reading.

## Appendix 2

### Extracts from the Prime Minister's "Challenge on Dementia"

#### **Challenge: Driving improvements in health and care**

##### **Reason- Better diagnosis**

Currently only 42% of people with dementia in England have a formal diagnosis. The diagnosis rate varies – from 27% in the worst-performing areas to 59% in the best. Too often, diagnosis comes too late – during a crisis or beyond the point where people can plan for the future and make informed choices about how they would like to be cared for.

Surveys show that people with dementia would like early diagnosis and with early intervention, and access to the right services and support, people with dementia can continue to live well for many years.

The people most at risk of developing dementia (the over-75s) see their GP at least once, if not several times, a year. Around 97% of people aged over 75 go to their GP surgery at least once a year, and around 87% at least once every six months.

##### **Commitment 1**

*Increased diagnosis rates through regular checks for over-65s We will ensure GPs and other health professionals make patients aged 65 and older aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.*

##### **Reason: Improving care in hospitals**

A quarter of all hospital beds are occupied by someone with dementia, and many hospitals struggle to provide the high-quality care that meets the needs of people with dementia. There are examples of excellent and innovative practice across care settings. We need to support this good practice and encourage it to develop and spread.

##### **Commitment 2**

*Financial rewards for hospitals offering quality dementia care From April 2012, £54m will be available through the Dementia CQUIN to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also for April 2013, access to CQUIN rewards will be dependent on delivering support for carers in line with NICE/SCIE guidelines.*

##### **Commitment 3**

*An Innovation Challenge Prize of £1m NHS staff can win up to £1m for innovative ideas for transforming dementia care.*

##### **Reason: Improving standards in care homes and domiciliary care**

While many care homes and care-at-home services offer excellent support for people with dementia, some are not doing enough. We need to make sure that whether people are being cared for in their own home, or in care homes, the staff who work with them have the knowledge and skills to help them lead as fulfilling a life as possible.

#### **Commitment 4**

*A Dementia Care and Support Compact signed by leading care home and home care providers. Ten leading organisations have set out their commitment to deliver high-quality relationship-based care and support for people with dementia, and to engage and involve the wider community in this work.*

#### **Reason: Better information for people with dementia and their carers**

People with dementia and their families and friends would like better information about health and care services. They want to know what they are entitled to, so that they can be sure they are getting all the support they need. Greater transparency in health and care services can also drive up quality and empower people with dementia and their carers.

Currently, the quality of advice and information people receive is variable. In all too many areas, it is extremely difficult for people with dementia to find out what support is available and to what they are entitled to.

In 2011/12, primary care trusts were asked to work with their local authorities to publish dementia plans which set out the progress they were making locally towards implementing the National Dementia Strategy.

#### **Commitment 5**

*Promoting local information on dementia services. We will promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012. From April 2013, similar information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure that all people receiving care and support get better information to support their care choices.*

#### **Reason: Better support for carers**

There are around 550,000 people in England acting as the primary carers for people with dementia. Carers for people with dementia save the nation nearly £7 billion every year. Research shows that carers of people with dementia experience greater strain and distress than carers of other older people.

We want to see better support for carers. The NHS is now required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources and make sure that carers get the support and break they deserve. We have provided an additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role. The NHS should also ensure that a range of psychological therapies and support is available to carers of people with dementia in line with NICE/SCIE dementia guidelines.

#### **Challenge: Creating dementia-friendly communities that understand how to help**

#### **Reason: Dementia-friendly communities**

The health and care system has a vital role to play in improving support for people with dementia. But alone it cannot combat the stigma attached to dementia. Lack of awareness among the public and poor understanding in communities has a major impact on the experience of people with dementia.

People living with dementia want to remain independent for as long as possible, and they want to have choice and control over their lives through all stages of their dementia. With an early diagnosis and the right support they can achieve this.

But this is not the experience of the vast majority of people living with dementia. Not only do they frequently have to battle for diagnosis and support, but everyday things we all take for granted – getting to the shops, spending time with friends and family, getting money from the bank, and going on holiday – are made difficult because of the limited understanding of dementia in their communities.

People with dementia talk about stigma and social isolation. They report losing friends following their diagnosis, seeing people cross the street to avoid them, feeling lonely, and struggling to use local services. Research with the general public has shown that this is often down to the fear, misunderstanding and helplessness people feel in the face of dementia. They simply do not understand enough to support someone to live well with dementia.

### **Commitment 6**

*Dementia-friendly communities across the country by 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly.*

### **Commitment 7**

*Support from leading businesses for the PM's Challenge on Dementia. Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.*

### **Reason: Public understanding**

Despite the rising numbers of people living with dementia, public understanding of the condition is limited and populated with misconceptions. Poor understanding of dementia has a fundamental impact on the health and well-being of people with dementia. It can lead to their rights not being recognised and families and the economy being put under serious strain. People with dementia, their carers and families struggle to remain independent in a society that does not understand dementia or how to support those affected by dementia to live well with it.

### **Commitment 8**

*Awareness-raising campaign from autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned*

## Appendix 3

### **Ealing Dementia Strategy (2013-16) Action Plan Priorities**

1.1 The multi agency Dementia Programme Board was set up in 2012 to deliver the priorities set out in Ealing's Dementia Strategy guided by the recommendations contained in the Joint Strategic Needs Assessment and consultation with service users.

#### **1.2 Improving diagnosis rates for people with dementia**

51.9% of people estimated to have late onset dementia in Ealing have a recorded diagnosis. This diagnosis rate has increased in recent years and is higher than the national diagnosis rate, but remains lower than the target rate of 60% which is to be achieved by 31<sup>st</sup> March 2015. Ealing is intending to address this via continued dementia awareness work and primary care training.

#### **1.3 Preventing crises and hospital admissions by improving support for people with dementia in the community**

Work on reducing reliance on in patient mental health beds is continuing, however going forward increased attention is being given to other hospital admissions. In 2012/13 there were 1781 admissions to general hospital for Ealing residents recorded as having a diagnosis of dementia. 85% of these were admitted through accident and emergency. The top causes of admission were urinary tract infections, respiratory complaints, falls and fractures, all of which are potentially preventable. The best means by which to intervene and reduce admissions are currently being considered in the context of re-design work with the voluntary sector, domiciliary care, day care, care homes, crisis resolution and home treatment services, and primary care. An important aspect of this will involve work with carers to support them in knowing when and how to seek appropriate assistance.

#### **1.4 Improving care for people with dementia in the general hospital**

In 2012/13 the mean length of stay for people with dementia admitted to general hospital was 13 days. 18.4% of admissions were for 21 days or longer compared with 7% for England as a whole. Ealing's Dementia Programme Board has proposed a local target to reduce the proportion of patients with a length of stay of 21 days or more to 10% by 2015/16.

#### **1.5 Improving residential and nursing home care for people with dementia**

The Programme Board has identified a shortage in the number of care homes able to look after people with challenging behaviour and complex needs. This results in admissions to hospitals which may be preventable. It also contributes to delayed discharges. This is being addressed through a number of avenues including contract negotiations with Ealing Council's PFI provider to increase the number of beds designed to support people with dementia, enhanced primary

care provision to nursing homes via new contractual arrangements with the CCG, and ongoing support with training and promotion of dignity in care

#### **1.6 Developing a dementia friendly community**

This is an area for development outlined in the Prime Minister's Challenge issued in March 2012. Ealing's Programme Board is proposing to pilot a dementia friendly community project. It will involve the identification of dementia friends and dementia champions in non-traditional service areas such as local businesses, leisure and educational services.

#### **1.7 Dementia and learning disabilities**

People with learning disabilities have an increased likelihood of developing dementia at an early age. The Community Team for People with Learning Disabilities (CTPLD) assesses and supports people with a possible or confirmed dementia diagnosis, however not all people with a learning disability are known to CTPLD. Consequently work is beginning to take place with WLMHT to explore further options for this client group

## APPENDIX B

### RECOMMENDATIONS WITH OFFICER / PARTNER COMMENTS

Conclusions or Recommendations		Officer / Partner Comments (Including any resource and legal implications)	Officer Recommended Response to Cabinet (Accept/Reject)
1	The Panel recommends that Ealing CCG and Ealing Council raises public and professional awareness about life-style changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks as preventative activities for reducing the risk of dementia within their health promotion campaigns.	The Dementia Programme Board will consider asking Public Health to take the lead in responding to this recommendation and consider how such information could be included in the Annual Health Checks for older people	Accept
2	The Panel recommends that Ealing CCG and Ealing Council develop an awareness raising campaign about dementia targeting those Black and Minority Ethnic communities in the borough where cultural and language barriers needed to be overcome in order to increase diagnosis rates.	The CCG is working with all GPs to increase dementia diagnosis rates, in line with national targets and is committed to identifying people likely to have dementia from all communities. The CCG is seeking advice on best practice from a number of other London Boroughs who have been successful in reaching black and ethnic minority communities to ensure that cultural or language barriers are not preventing early diagnosis and support. Through active participation in the Dementia Action Alliance we aim to increase awareness among hard to reach communities encouraging people to come forward for dementia diagnosis in order to obtain ongoing treatment and support.	Accept

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments (Including any resource and legal implications)</b>	<b>Officer Recommended Response to Cabinet (Accept/Reject)</b>
3	That the Dementia Programme Board reviews 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 Dementia Programme Board will consider asking Public Health to include this review in their update of the Dementia chapter in the Joint Strategic Needs Assessment to inform recommendation 2 above.	Accept
4	That Ealing CCG takes action to improve diagnosis rates for people with dementia.	As indicated above, the CCG is working with all practices to increase dementia diagnosis rates and was close to reaching the national target in 2014/15. Further action will be taken during 2015/16 to extend and sustain this improvement.	Accept
5	That the Dementia Programme Board supports the development and roll out 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.	The Dementia Programme Board will consider asking all member organisations and local providers about their plans for dementia training and seek updates on implementation. A successful education session for GPs was held on 14 <sup>th</sup> January 2015 and more is already planned for primary care. Adult social care staff are already trained in dementia. Care homes have a duty to ensure that all their care staff are trained to work with people with dementia.	Accept
6	The Panel endorses the work being undertaken by Dementia Concern and the Alzheimer's Society working with Public Health England to produce comprehensive but easy to understand information for people with dementia and their carers.	In addition to information produced by the voluntary and community sector on the services which they offer, council officers in adults' services and public health are preparing a wider "living well with dementia" leaflet which should be available by the summer 2015. They are also updating a previously published Dementia Awareness handbook for use	Accept

Conclusions or Recommendations		Officer / Partner Comments (Including any resource and legal implications)	Officer Recommended Response to Cabinet (Accept/Reject)
		as a dementia information booklet more widely.	
7	Ealing Council to add a dedicated page to its website so that residents are able to access direct links for general advice on dementia and are signposted to key contacts.	The council website is currently being revised and officers will be delighted to take forward this action and put information and advice on dementia on the site again once a robust system is place.	Accept
8	That Ealing Council signpost residents to information regarding paid carers specifically for people with dementia	An information pack on services available for people with dementia is being prepared, including home care. All Ealing's contracted home care providers are specifically trained to provide support to people with dementia. Information on care and support services can be found at <a href="http://www.careplace.org.uk">www.careplace.org.uk</a> and in the Ealing Resource Directory. This will include information on the registration of the service and whether carers are trained in dementia.	Accept

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments (Including any resource and legal implications)</b>	<b>Officer Recommended Response to Cabinet (Accept/Reject)</b>
9	That Adult Social Services provides an enhanced domiciliary care service which meets the needs of people with dementia. Care services need to take account of the special needs and sensitivities of providing personal care to people with dementia. It is essential to engage with an individual on each occasion before sufficient trust can be established to give the necessary care. If adequate time is not allocated then care interventions, such as showers, medication or meals, may be refused.	<p>Each service user (and carer) receives an individual assessment and the package of care identified is designed to meet their particular needs. If it is felt that not enough time or frequency has been allowed within the package it can be reviewed and adjusted. The additional time required for people with dementia is understood by care assessors, but the point will be reinforced with the care management team.</p> <p>All Ealing's contracted home care providers are specifically trained to provide support to people with dementia.</p> <p>Information on care and support services can be found at <a href="http://www.careplace.org.uk">www.careplace.org.uk</a> and in the Ealing Resource Directory.</p>	Accept
10	That Ealing Council and Ealing CCG explore the feasibility of developing alternative models of respite care other than bedded respite care for people with dementia, such as domiciliary care.	<p>Home care is already available for people with dementia; the Council will be extending services for carers in 2015/16 in line with the requirements of the Care Act and will take account of feedback from carers of people with dementia in the Dementia Concern survey and from the Carers' Conference in developing the specifications.</p> <p>Officers recommend that any financial implications should be met from existing local authority and NHS budgets.</p>	Accept

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments (Including any resource and legal implications)</b>	<b>Officer Recommended Response to Cabinet (Accept/Reject)</b>
11	That Ealing Council and Ealing CCG 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.	The Council and CCG will take account of this recommendation in developing respite care for people with dementia.	Accept
12	That the Dementia Programme Board seeks to increase the number of care homes in the borough able to look after people with challenging behaviour and complex needs.	Public Health are currently updating the dementia needs assessment which will inform the Council and CCG's development of the market for care places. West London Mental Health NHS Trust are proposing changes to improve the services available for people with challenging behaviour and complex needs. These proposals will be presented to the Dementia Programme Board in May.	Accept
13	Ealing CCG to consider whether GPs and Intermediate Care Service could make direct referrals to Dementia Concern.	Ealing CCG will consider this recommendation in discussion with other partners about the development of the dementia care pathway	Accept
14	That Ealing Council appoints a non-executive councillor to act as a champion for high-quality dementia services.	The Dementia Programme Board would welcome this appointment	Accept
15	That the Cabinet takes into consideration the increasing pressure on those voluntary sector organisations that deliver services to people with dementia by supporting access to low cost community facilities, effectively managing facilities with partner organisations, and when developing its budget proposals for 2016/2017 onwards.	The Council is sympathetic to the accommodation needs of voluntary sector organisations delivering services to people with dementia and does currently provide such facilities within Adults Services. However, officers would need to consider on a case by case basis what additional access can be provided, in light of competing demands and the challenging financial context.	Accept

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments (Including any resource and legal implications)</b>	<b>Officer Recommended Response to Cabinet (Accept/Reject)</b>
16	That Ealing Council and Ealing CCG actively facilitates and shapes the local market for dementia care and support with the aim of developing a market that delivers a wide range of sustainable high quality care and support services that will meet the needs of the local community.	The need to develop the market for dementia services has been recognised in the Council's Market Position Statement and will be reinforced in discussion with providers in the coming years.	Accept
17	The Panel encourages a future Mayor to adopt the theme for their mayoralty of supporting Ealing to become a dementia friendly community, acting as ambassador, facilitator, promoter, encourager and fund raiser.	The Dementia Programme Board welcomes this recommendation.	Accept
18	The Panel supports Ealing Council's commitment to becoming a dementia-friendly borough, and will monitor progress in delivering this outcome by receiving regular updates from Ealing Dementia Action Alliance.	The Dementia Programme Board welcomes this recommendation.	Accept
19	The Panel asks that Ealing Council will continue to support Ealing Dementia Action Alliance with ongoing funding, until it is able to be self-supporting.	The Dementia Programme Board will consider how the Dementia Action Alliance can continue to be developed with both statutory and non-statutory support.	Accept
20	Ealing Dementia Action Alliance should invite members of Ealing Business Partnership to be actively involved in Dementia Action Alliance.	Initial contacts have been made and will be followed up, making use of corporate business relationships and perhaps with the support of the non-executive champion recommended in 15 above.	Accept

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments (Including any resource and legal implications)</b>	<b>Officer Recommended Response to Cabinet (Accept/Reject)</b>
21	That the Council increases the provision of 'How to become a Dementia Friend' courses and encourages front line service officers, managers and councillors to attend. This course is run by the council however there are no training dates currently scheduled and there is a waiting list.	The Dementia Programme Board will consider how to extend the programme of Dementia Friend courses across all council departments and members. Officers recommend that the cost of this training be contained within existing Children's and Adult's Training Budgets.	Accept
22	Scrutiny Panel members to use their links with resident and community groups to encourage people to become 'Dementia Friends' and participate in the training being offered by the Alzheimer's Society.	The Dementia Programme Board welcomes this recommendation.	Accept
23	London Borough of Ealing's Family and Children's Services to encourage and support work with schools as part of the strategy to develop a dementia friendly community.	The Dementia Programme Board welcomes this recommendation.	Accept
24	The Panel supports the development of the Michael Flanders Centre as a dementia centre of excellence and encourages the Council to progress this work.	This is welcomed. Adults' Services will be taking forward this proposal during 2015/16.	Accept
25	That the Dementia Programme Board arranges for appropriate officers to visit the Southwark Dementia Care Centre of Excellence, when opened, to learn from any innovative practice.	The Dementia Programme Board will follow up this recommendation.	Accept

<b>Conclusions or Recommendations</b>		<b>Officer / Partner Comments (Including any resource and legal implications)</b>	<b>Officer Recommended Response to Cabinet (Accept/Reject)</b>
26	That the Dementia Programme Board meets regularly with meeting dates scheduled for the year ahead, and provides regular updates on the progress of its action plan to the Scrutiny Panel.	The multi-agency Dementia Programme Board has since February 2015 been meeting every 2 months and has meeting dates scheduled for the year ahead. The Board has refreshed its terms of reference and its action plan and will provide regular updates on progress to the Scrutiny Panel.	Accept
27	That the Dementia Programme Board invites Age UK to be a member of the Board.	The Dementia Programme Board has already included Age UK in the membership of the board under its revised Terms of Reference.	Accept