Review of the Dementia Care Pathway in Camden

(August 2014-February 2015)

Sophie Cottrell and Barbara Wilson

“There was a thing called the big C, today it is the big D. We have got to get rid of that and talk about dementia. How to get people more aware and get rid of the stigma”

“Never get up and think what is going to go wrong today, just get up and think - what can I achieve?”

Two people with dementia speaking up at a Dementia Engagement and Empowerment Project workshop.

Online video: People with Dementia speak out. www.mentalhealthfoundation.com
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This Report

An Interim Report (December 2014) presented the findings of the *Dementia Care Pathway review* and gave an opportunity for further discussion and development of the Pathway.

A draft Final Report was discussed at the Dementia Strategy Implementation Group (DSIG) in February 2015 where the recommendations were agreed. This Final Report is the updated version to be used to inform future strategic direction and commissioning decisions.

Thorough stakeholder engagement has informed the findings and recommendations in this report – for detail see the interim report available from CIPHPAdmin@islington.gov.uk.

We wish to sincerely thank everyone who spoke to us and contributed to this review.

Special thanks go to our Steering Group members: Jane Brett-Jones, Robert Holman, Kathryn Hill and Cameron Hill and for project support from Marian Quartey.

**NB.** We have tried to ensure that there are no inaccuracies in the final report - if you do spot something please email CIPHPAdmin@islington.gov.uk.
1. Executive summary

1.1 Strategic messages

1. Need for leadership and co-production
2. Improvements on timely and sensitive diagnosis
3. A range of support for people to live well with dementia

Dementia is everyone’s business. We need to see the person first, not the dementia.

The onus is on all of us to raise awareness and show that people with dementia can live life to the full as active citizens.

The latest statistics from the Alzheimer’s Society (2014) show:

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<tr>
<th>National Figures</th>
<th>Local (Camden) Figures</th>
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<tr>
<td>850,000 people with dementia are supported by 670,000 carers</td>
<td>There are around 1500 people living with dementia in Camden</td>
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<td>40,000 are young people (i.e. under 65)</td>
<td>31 are young people (i.e. under 65)</td>
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<td>25,000 (2.9%) are from BME communities</td>
<td>13% are from BME communities*</td>
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<td>Two thirds are women</td>
<td>Two-thirds are women *</td>
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<td>1 in 6 people over 80 years will have dementia</td>
<td>1 in 6 people over 80 years will have dementia</td>
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<td>At the moment only 44% receive a diagnosis in England, Wales and N Ireland</td>
<td>At the moment 67% receive a diagnosis in Camden</td>
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*Source: Jan 2015 Dementia prevalence Calculator
* QOF 2012

The Pathway needs to be about more than just health and social care. Whilst the Pathway is seen as a useful document, it is vital to allow and enable people with dementia and their carers to make their own choices in their own time instead of professionals making those choices for them.
1. Need for leadership and co-production

We concur with the All Party Parliamentary Group on Dementia Report conclusions\(^1\) that there is a need for strong leadership, that there must be integration of health and social care and that wherever possible people with dementia should play an integral part in commissioning, training and providing support to other people with dementia.

An evaluation into the effectiveness of Dementia Advisers and Peer Support networks recommended the creation of the organisational space needed for collaborative working and strong leadership. Public Health England and Think Local Act Personal (TLAP) describe in their work with Health and Wellbeing Boards the importance of systems leadership - i.e. leadership that is not invested in people solely through their authority or position. Also that developing strong inclusive communities relies on an asset based model as well as the need for strong political and clinical leadership\(^2\).

At a People with Dementia Speak Out event (run by the Dementia Engagement and Empowerment Project) the consensus was that face to face meetings, pooling knowledge and working together in unison are all vital for people with dementia to be fully engaged.

In terms of Strategic leadership there needs to be high level support for work around dementia from both the Health and the Local Authority and a commitment to working in partnership with people with dementia, carers and voluntary sector partners.

- The DSIG needs a clear reporting structure at a senior level to the CCG and the Health and Wellbeing Board.
- There are many Pathways in health and social care. It is essential to integrate the Dementia Pathway with the Stroke, Diabetes and Palliative Care Pathways.
- Equally important is the need to integrate with the programme for Frail and Elderly (soon to be named Complex Care).

It is important to recognise that what is good for people with dementia is good for everybody.

2. Improvements on timely and sensitive diagnosis

We also know that a timely diagnosis delivered in a sensitive and appropriate way is vital. Camden has met the national target of 67% diagnosis rate and there has been a steady increase in the number of referrals to the Memory Service since 2010. There is still work to do with GPs and the public on the value of a timely diagnosis and Camden needs to have an ambition to meet the 75% rate by 2017 as proposed by the Alzheimer’s Society.

*We want everyone to hear the message that dementia is not a normal part of ageing, that there are treatments and there are things you can do to help yourself. Camden should be more explicit about protective factors (such as diet, general health and avoiding isolation). Individuals who have dementia can live life to the full and have something to offer.*

(Camden Carers)
3. **A range of support for people to live well with dementia**

Our third key message is that people with dementia and their carers need support to live *and die* well. Given that there are a range of dementias with issues developing over time each person with dementia is uniquely affected, as are their families and carers. Living well with dementia is more than just about accessing good health and social care. Camden’s Housing strategy acknowledges the need to increase extra care support to those over 75 and over 85.

The Care Act coming into force in April 2015 is underpinned by a strengths – or asset-based - approach to all assessments. Information and advice needs to be tailor-made. Our research made it clear that both people with dementia and their carers value having someone to talk to throughout the progression of the disease and not just at the point of diagnosis. People with dementia and their carers need to know about what they are entitled to as well as the help available to them.

### 1.2 Pathway Recommendations

**Structural recommendations**

- **Prevention be renamed Awareness and Risk Reduction.**
  
  Although there has been considerable investment into research there is currently no prevention or cure for dementia. However it is crucial to raise levels of awareness, challenge stigma, address the fear and negative assumptions and to inform everyone of what they can do to live healthier lifestyles.

- **End of Life Care be renamed Last Years of Life Care.**
  
  This reflects a change in emphasis with thinking and planning for end of life being considered at an earlier and more appropriate stage rather than simply in the last few weeks or months of a person’s life.

- **Identification element to be removed**
  
  Issues of identification to be incorporated into Awareness and Risk Reduction and/or Assessment and Diagnosis.

**Within the pathway**

This is a summary of the detailed recommendations in section 4 of this report (pages 20-38).

### 1. Awareness and Risk Reduction

- Promote, publicise and support the Camden Dementia Action Alliance.
- Promote, publicise and support the Camden Minds group to encourage more members to join and be proactive in seeking their views on services.
• Promote, publicise and support the Dementia Champions initiative encouraging more people to participate and consideration to be given to placing Dementia Champions in GP surgeries.

2 Assessment and Diagnosis

• Set a new target of a 75% diagnosis rate by 2017 (in line with the Alzheimer’s Society).
• Audit the current data to establish the rate of diagnosis in the BMER communities.
• The Memory Service to lead on a training/information programme for GPs on the benefits of a timely and sensitive diagnosis, prioritising those practices not achieving a 40% diagnosis rate and working with the newly appointed CCG Clinical Lead.
• Ongoing psychological support for those who have been diagnosed with Mild Cognitive Impairment
• Ongoing support for people with dementia who are not being given medication, over and above advice and signposting.
• Improve links with multi-disciplinary teams working with individuals on the Frailty/Complex Needs register to ensure that any dementia related issues are being picked up. Consider scope for outreach in the community hubs.

3. Early Intervention and Treatment

• Devise an information strategy following a review of what currently exists and consider having an over-arching network to keep information up-to-date with a co-ordination role.
• Continue to support a face to face advice and support service for people with dementia and their carers to help them navigate and understand all that is on offer.

4. Living Well with Dementia

• Enable people with dementia and their carers to shape services through Camden Minds, other peer support and voluntary sector groups and involvement in forums such as DSIG.
• All care staff to undergo mandatory dementia awareness training. The training materials to include LGBT case studies.
• Review the 8 Pillars model from Scotlandiii looking at the Dementia Practice Coordinator role compared with the Dementia Adviser and Dementia Navigator roles.

5. Last Years of Life Care

• Work with the Commissioner for End of Life Care on developing the strategy to reflect the needs of people with dementia and their carers. Ensure ways are included to support individuals to be able to die in their own homes rather than in hospital if they so wish and bereavement support for carers.
2. Background

2.1 National Policy Context

Over the last fifteen years we have seen a considerable shift in thinking around dementia from a medical model of seeing people with dementia as suffering, being victims of and a burden/high cost to society to a social model, focusing on a person’s remaining abilities rather than losses (their assets), accepting that people with dementia can, and do, engage in meaningful interpersonal interactions. The importance of tackling the stigma, marginalisation and discrimination of people with dementia by listening to the personal experience, creating wider social awareness and influencing the social and built environment is now well recognised. There have been real challenges around how people with dementia and their carers are enabled to shape services, keep control and have meaningful involvement in the way that services are developed. Given the nature of dementia it may be helpful to think of a shift from dependence to interdependence rather than to complete independence.

Living Well with Dementia 2009

The first national strategy ‘Living Well with Dementia’ was in 2009. Local Authorities were tasked with devising a shared strategic plan with health, the voluntary sector and people with dementia/carers based on 17 strategic objectives with outcomes in 3 areas:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia

In 2010 the Coalition government revised, and built on, this strategy\(^{v}\). There was a call for demonstrator sites to test out new ways of working which led to 40 sites being approved. 22 had a Dementia Adviser model and 18 a Peer Support Network model\(^{v}\).

Dementia Declaration 2009

That same year the national Dementia Action Alliance developed the Dementia Declaration – a major plan of action to change the experience of living with dementia in England for good. People with dementia and their carers outlined seven outcomes, amongst them:

- ‘I have the knowledge and know how to get what I need’
- ‘I have a sense of belonging and of being a valued part of family, community and civic life’

Their report also proposed the idea of creating Dementia Friendly communities.

The Department of Health describes a Dementia Friendly Community as one where:

- ‘more people will be aware of and understand more about dementia; people with dementia and their carers will be encouraged to seek help and support; and people with dementia will feel more included in their community, be more independent and have more choice and control over their lives.’
The first Dementia Action Alliance (DAA) was set up in Plymouth in May 2011. By 2014 we have seen a huge increase in DAAs with 111 across the country, up by 277% since 2013\textsuperscript{ii}. Camden partners registered their Alliance in 2014. There is also a Pan London DAA.

In late 2011 the Department of Health launched a £2 million campaign to raise awareness about early signs and symptoms on television, radio and in the print media. This was part of a response to the Alzheimer’s Society findings that only 40% of people with dementia were receiving a diagnosis. There is now a much higher profile generally in the media with people with dementia and their carers telling their own stories.

**Dementia Challenge 2012**

In March 2012 the Prime Minister issued a Dementia Challenge. He called for an increase in dementia research, addressing the quality of dementia care, an increase public understanding and making communities more dementia friendly. The government pledged to provide extra monies for research, set up 3 Champion Groups, (improvements in health and social care, dementia friendly communities and improvements in research) and 21 School Pioneers.

Later that same year the World Health Organisation declared dementia as a public health issue on a global scale.

The Dementia Engagement and Empowerment Project (DEEP) supports and enables peer support groups. Phase 1 was for one year in 2012 but this was extended to a three year period in 2013. DEEP has funded the Camden Peer Support Network (previously known as CAMEOS now Camden Minds), has issued guidance on use of appropriate language and is supporting a nationwide network of peer support groups.

**Making it Real for People with Dementia 2013**

In May 2013 Think Local Act Personal (TLAP) published the *Making it Real for People with Dementia* guidelines drawing on national good practice through an expert panel. They highlighted that the 800,000 people living with dementia is set to rise to one million by 2021, and that two thirds of these people live in the community. (Statistics from the Alzheimer’s Society 2012. Updated in 2015 to 850,000 people living with dementia and a million people with dementia by 2025). They focussed on 6 areas including information and advice, active and supportive communities and flexible and integrated support.

In 2013 the Royal College of Psychiatry carried out an audit of Memory Services across the country. This was re-run in 2014 (*the 2014 results are not yet available*). They found:

Four times as many patients were being seen in 2013 compared with the audit two years previously. Waiting times for assessment and diagnosis were five and eight weeks respectively, with nearly half of people who were diagnosed at memory clinics being in the early stages (enabling access to post diagnostic support including anti-dementia medication in a timely manner). Three quarters of memory clinics were asking about research.
The 2014 All Party Parliamentary Group

The 2014 All Party Parliamentary Group on Dementia concludes that there is a need for strong leadership, that there must be integration of health and social care and that wherever possible people with dementia should play an integral part in commissioning, training and providing support to other people with dementia.

Opportunities for Change 2014

The Alzheimer’s Society produces an annual state of the nation report. Their 2014 report ‘Opportunities for Change’ makes 14 recommendations, a number of which are for central government inviting them to continue to: provide a strategic lead, have a national debate, integrate care and further invest into research. There is concern that the impetus from the Living Well with Dementia Strategy (2009) and the PM’s Challenge (2012) will dissipate.

There are also seven recommendations for Local Commissioners and service providers to consider:

1. **A target of 75% of people with dementia to be diagnosed by 2017**

   This is higher than the NHS England target of two thirds. Dr Harwood (the London Dementia Ambassador for NHS England) has been supporting Clinical Commissioning Groups and suggests a number of **simple and cost neutral actions**: coding, supporting GPs to make a diagnosis where confident, especially when working with patients in care homes, working with Memory Services to streamline the care pathways and starting to raise awareness in hard to reach, BMER communities.

2. **12 week timescale from referral to diagnosis and an equal service for all**

   NHS England recommends a maximum of six weeks from GP referral to being seen by the Memory Service. The Camden Memory Service aim to make contact within two weeks of a referral and then the actual diagnosis will take some time.

3. **A minimum standard of post diagnostic support (with a guaranteed Dementia Adviser or equivalent)**

   The current Dementia Adviser Service is commissioned from the voluntary sector with a paid Manager and a team of Volunteer Advisers. Their focus is on an holistic assessment, individual support, planning and signposting with some ongoing work if needed.

4. **Fully integrated care**

   There has been a great deal of work done to try and meet the needs of the Frail and Elderly with a borough-wide, multi-disciplinary team approach. Living well with dementia is part of that programme.

5. **For people with dementia and carers to be involved in the commissioning, design and development of services**

   There has been involvement and engagement of people with dementia and their carers in the Housing Strategy, Carers Strategy and the DSIG. The Peer Support Network (Camden Minds) is the obvious place to start. This group wishes to grow membership.
6. **Mandatory training for front line and care staff**

The training programme needs to be reviewed for in-house staff and also an expectation built into contracts with the extra care housing sector and domiciliary care contracts. There is a need to make training LGBT friendly – research shows that these older individuals (estimate of 1.2 million Older LGBT) may be estranged from relatives and have a lack of family support so therefore rely on more formal care.

7. **To become a Dementia Friendly borough – with improved awareness of dementia for businesses and organisations**

We will see the launch of Camden Dementia Action Alliance in 2015. Public Health has a role regarding messages on modifiable behaviours as well as more generally raising awareness. It would be good to see an expansion in the number of Dementia Friends and Champions and to utilise the support of local Pharmacists in the business community. Camden has signed up to the Time for Change initiative tackling awareness raising.

All of these policy changes regarding dementia have to be seen within the wider context of changes to health and social care on personalisation and integration of health and social care.

The aim is for people to remain independent for as long as possible, staying in their own homes with choice and control and cutting down on unplanned hospital admissions. In June 2013 the government announced a £3.8 billion Better Care Fund which is money to be spent on improving integrated working. The Care Act which came into effect this April (2015) enshrines a duty to promote wellbeing, raises the status of carers and puts a duty on local authorities to provide advice, information and advocacy with fairness in access to services.

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**2.2 Local Context**

**Camden Dementia Plan**

The Camden Dementia Care Plan (2012-17) uses the Make it Real ‘I statements’ (see below) as outcomes and tasked the Dementia Strategy Implementation Group (DSIG) to oversee implementation. The Implementation Update Report (May 2014) was informed by the Public Health Intelligence Report on Dementia (May 2013) which amongst other things highlighted the need for a review of all people with dementia on anti-psychotic medication.

The Dementia Care Plan focussed on nine outcomes:

- I was diagnosed early
- I understand, so made good decisions and provide for future decision making
- I get the treatment and support which are best for my dementia and my life
- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- Those around me and looking after me are well supported
- I feel part of a community and I am inspired to give something back
- I am confident my end of life wishes will be respected; I can expect a good death
These I statement outcomes are still the best way to judge the appropriateness and effectiveness of support for people with dementia and their carers.

There have been a number of meetings over the last couple of years around creating a Dementia (and age) Friendly Kilburn based on the four cornerstones of place, people, networks and resources. Over 100 people took part in wide ranging discussions and covered topics such as: access on public transport, crossing times at roads, building up relationships with local businesses, the role of pharmacists, digital exclusion, the need for an Information Pack once diagnosed and carers needing to be treated as expert partners in care.

**Camden Dementia Action Alliance**

A number of partners from all sectors along with people with dementia and their carers have come together to form the Camden Dementia Action Alliance (CDAA). Members met in 2014, the Alliance was registered in late 2014 and will be launched in 2015.

We also spoke to staff at two Innovation projects funded by the council the Tavistock Centre for Couple Relationships (TCCR) Living Together with Dementia intervention and the Somali Cultural Centre which we will cover later in the report. The Innovation funding ends in March 2015.

The Dementia Friends/Dementia Champions’ initiatives are seen as a good thing but are not part of everyone’s consciousness yet. The Alzheimer’s Society has a target to train one million people to be Dementia Friends by 2015. At the time of writing this report there are 1,020,368.

Camden has over 90 Dementia Champions. (Champions are volunteers trained to deliver the 1 hour Dementia Friends training).

Our consultation highlighted the importance of improving dementia awareness for those working in public transport (reinforcing the Kilburn message) and for frontline council staff in leisure services, housing and other universal services. The need for targeted campaigns for the Black Minority Ethnic and Refugee (BMER) communities was also highlighted.

> The Camden Housing Strategy highlights the growing need for sheltered accommodation and extra care housing (with an increase in the numbers of people over 75 and 85) along with an increased need for the provision of intensive support at home after a time in hospital (and use of Careline Telecare). Maitland Park is now open as a care home designed to be dementia friendly.

**Integrated Care**

In April 2012 Camden CCG commissioned a transformational integrated model of care for those defined as frail with a borough-wide, multi-disciplinary approach. Patients who meet all three of the following criteria are considered for this programme:

- 75+ years.
- 1+ long term condition (excluding alcohol misuse and personality disorder).
- 1+ non-elective hospital admissions in a year.
Or alternatively those who are:

- Under 75 with complex health and social care needs and where a patient’s GP has identified, through clinical audit that they would benefit from a case management approach.

The overall vision of the programme is to improve the outcomes and quality of life for all frail and elderly patients and their carers in Camden by:

- Ensuring patients are identified early and receive reliable, holistic (bio-psychosocial) assessment.
- Delivering integrated services which improve the multi-disciplinary planning, coordination and continuity of care for patients.
- Increasing the amount of time patients spend at home through early intervention, prevention and sustained recovery from periods of crisis.
- Promoting excellent communication and collaborative relationships between staff, patients and carers.
- Improving equity of access to frailty services across all Localities to reduce health inequalities.

The CCG have committed £7,657,340 to this work (July 2013-March 2018). The programme works in conjunction with ‘Long Term Conditions’ and the ‘Cancer Programme’.

Frailty will be re-launched in 2015 as Complex Care. Work is delivered through a community hub model and a new Consultant led Clinic will be set up in the West Locality. Opportunities for new clinics, commissioning an integrated (non-medical) health and wellbeing service to provide information; advice and navigation support to frail and elderly people and their carers will also be assessed.

Living well with Dementia

In 2013-14 Camden CCG under its “Living Well with Dementia” initiative invested an extra 505K in services for people with dementia; this included additional staffing to support greater than expected demand in Camden Memory Service and investment in Camden’s mental health crisis teams to enable them to start working with people with dementia who experience a mental health crisis. Camden CCG is appointing a clinical lead on dementia.

Further investment was made in Camden Memory Service (provided by Camden and Islington NHS Foundation Trust) from January 2015 to manage a further increase in referrals and the number of service users receiving ongoing support from Camden Memory Service.
3. Camden – facts and figures

3.1 Dementia population in Camden

Camden has a relatively young population and is home to fewer older people than some outer London boroughs and rural areas. There are currently around 21,800 people aged 65 and over, but this number is predicted to increase by one third over the next 15 years.

The Camden Dementia Plan (2012-17) stated that there were then around 1600 people with dementia in Camden with an expected 25% increase in the 10 years to 2021 along with a sharp increase in those living with dementia aged over 85 and in the black and minority ethnic and refugee (BMER) communities. Of the 1600 people estimated to be living with dementia nearly two thirds were women and nearly half over 85 - only 10% were from BMER communities. The average age at diagnosis is 80. The average number of years since diagnosis was 2.67.

By 2021 41% of people with dementia will be men, the number of people with dementia aged 85 and over will increase by 40% and the number of people with dementia from BMER communities will double. Given that the dementia prevalence ratio increases from 1 in 25 in the 70-79 age range to 1 in 6 for the 80 + age range this will increase the numbers of people with dementia overall.

![Projected number of people with dementia resident in Camden, assuming constant age-specific prevalence, by age group (2014 – 2034)](source: Dementia UK update, 2014 (prevalence); GLA, 2103 (population estimates)
**Expected and diagnosed Prevalence of dementia National 2015, Camden 2012 and 2015**

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<td>80+</td>
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<td>National dementia prevalence</td>
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**Source:** 2015 data - dementia prevalence calculator, primarycare.nhs.uk 2012 data – Camden and Islington GP Public Health dataset

*Given the very low prevalence of dementia under the age of 65, it is not possible to make any informed comment on the number of undiagnosed cases in this age grouping.

Figures from the Public Health Dementia Profile 2013 show the rise in the incidence of dementia with age and a diagnosis rate at that time (based on data from 2012) of 56%.

However the latest data from January 2015 shows a total of 1058 people with a diagnosis of dementia in Camden from an expected number of 1569. This represents an improved overall diagnosis rate of 67%.
3.2 Diagnosis of dementia in Camden

In April 2014 GPs were given the opportunity by NHS England to sign up for a Direct Enhanced Service (DES) on dementia incentivising them to provide extended appointment times and create a care plan covering a person’s physical and mental health and social needs as well as support for any carers. There has been 80% take up across England, whilst in London it is 57% and in Camden 59%.

It will be useful to share learning from those 59% of practices who have signed up, to see what difference this has made to their work with people with dementia and their carers and review the reasons for the other 41% not doing so.

In October 2014 the government announced a further cash incentive of £55 per head to increase diagnosis rates (paid per patient added to the Dementia Register between September 2014 and March 2015). This was not well received by clinicians or the wider community.

The table below shows the size of the gap between expected prevalence and numbers diagnosed. Consideration needs to be given to how to reach those under identified individuals. This would be 119 people to reach a 75% diagnosis rate (Alzheimer’s Society target to reach within the next two years) or 509 people if diagnosis was at a 100 %. (NB This is not expected to be achievable.)

<table>
<thead>
<tr>
<th>Size of the gap</th>
<th>Diagnosed prevalence</th>
<th>Expected prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis rate (% of expected number of dementia cases)</td>
<td>Number of cases to close the gap</td>
<td>Number of cases diagnosed</td>
</tr>
<tr>
<td><strong>Camden</strong></td>
<td>67%</td>
<td>509</td>
</tr>
<tr>
<td><strong>London</strong></td>
<td>58%</td>
<td>29,036</td>
</tr>
<tr>
<td><strong>England</strong></td>
<td>56%</td>
<td>299,611</td>
</tr>
</tbody>
</table>

Note:
The ambition diagnosis rate at November 2014 for England was 67%, Camden has passed this threshold. There are currently no new ambition diagnosis rates for London or Camden.

The graph over the page shows that some 13 practices out of 37 meet or exceed the Camden average. The red line shows the Camden average of 67%. The bars show the diagnosis rate for each practice. The rates are standardised to take into account the differences in population structure of each practice. The practice represented by the bar on the extreme right is associated with a care home.
Percentage of diagnosed over expected dementia cases, age adjusted by practice, Camden registered population, all ages, 2014.

Source: diagnosed cases are from QOF dementia register November 2014. Expected cases are calculated by applying estimated prevalence from the Dementia Society Report, 2014 to the November 2014 GP registered population in Camden. The expected prevalence is adjusted to take into account the differing age and gender populations of individual practices.

This clearly shows the variation across practices with 24 falling below the average and nine of those falling below the 40% rate.

3.3 Co-Morbidity

The Camden Public Heath Intelligence Dementia Profile 2013 (based on data extracted in 2012) highlighted a number of key issues to consider:

Co-morbidity: people with dementia have a higher proportion of co-morbidities compared with Camden’s general population over the age of 65. People with dementia have a significantly higher prevalence of most long-term conditions and in particular stroke, atrial fibrillation and kidney disease.

<table>
<thead>
<tr>
<th></th>
<th>Stroke/TIA</th>
<th>Atrial fibrillation</th>
<th>Chronic kidney disease</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.3 times more likely</td>
<td>2.2 times more likely</td>
<td>1.8 times as likely</td>
</tr>
</tbody>
</table>

Risk-factor screening and Quality Outcomes Framework (QOF)

- People with dementia aged 65 and over are less likely to smoke and more likely to be of a healthy weight compared with the general registered population aged 65 and over.
There are also 64 people over 65 with dementia recorded as being underweight.

- A review the care of people with dementia (QOF indicator DEM2) was not carried out for 26% (213) of people on the dementia QOF register in Camden in 2012. The percentage whose care has been reviewed varies from 63% to 100% in different GP practices.
- Blood pressure recording and regular checks of HbA1c levels for those at high risk are higher amongst people with dementia than in the general population aged 65 and over. Screening rates for depression and flu vaccination are similar to those in the general population aged 65 and over.

These findings indicate a clear need for collaborative and integrated working especially amongst health care professionals such as diabetic nurse specialists, acute and hospital care teams (Stroke, Cardiology, Kidney function) and any dementia advisers or other support staff, volunteers or services. GPs had not carried out annual care reviews for just over 200 people with dementia. This needs scrutiny – especially in those practices showing considerable variation from the Camden average. It may be that the person with dementia has moved away, into supported housing, are in hospital, are isolated with no family carers or perhaps from BMER communities and therefore hard to reach.

### 3.4 Services for people with dementia

The Camden Memory Service has seen a significant increase in the number of referrals with nearly 2.5 times more people in 2013-14 than in 2009-10.

This rise is not expected to continue year on year once diagnosis rates are higher, although the makeup of the group will alter with more men, people from the BMER communities and people over 85 being referred. The overall numbers of people with dementia being supported should then reflect the overall prevalence rates.

<table>
<thead>
<tr>
<th>Year</th>
<th>Referral numbers to Memory Service (MS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009-10</td>
<td>283</td>
</tr>
<tr>
<td>2010-11</td>
<td>433</td>
</tr>
<tr>
<td>2011-12</td>
<td>477</td>
</tr>
<tr>
<td>2012-13</td>
<td>608</td>
</tr>
<tr>
<td>2013-14</td>
<td>667</td>
</tr>
</tbody>
</table>

The Memory Service carried out an audit in the last quarter of 2014 and found that 21% of people referred to them were diagnosed with Mild Cognitive Impairment (MCI). These individuals are signposted onto other services (such as psychological support) and are discharged from the Memory Service.
Referrals to the Dementia Adviser Service (DAS) a service provided by AgeUK Camden.

The DAS take referrals from a variety of sources including the Memory Service, the statutory and voluntary sector as well as self referrals and from family and friends. Their first year of operation was 2010-11.

<table>
<thead>
<tr>
<th>Year</th>
<th>Referrals to the Dementia Adviser Service (AgeUK Camden)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-11</td>
<td>101</td>
</tr>
<tr>
<td>2011-12</td>
<td>224</td>
</tr>
<tr>
<td>2013-14</td>
<td>295*</td>
</tr>
</tbody>
</table>

* 61% of the referrals in 2013-14 were from the Camden Memory service.

Patients with a diagnosis of dementia for which there is no pharmaceutical treatment or who are unsuitable or unwilling for such treatment are discharged from the Camden Memory Service and referred to DAS. A high proportion of people seen have vascular dementia. A smaller proportion of people have an untreatable dementia such as Frontal temporal Dementia. The Memory Service continues working with those with Alzheimer’s disease (who receive medication) in a role similar to DAS.

Cognitive Stimulation Therapy (CST) 2013-14

The Memory Service referred 125 people for CST of which just over half (66) attended. Carers of people going to CST were also offered attendance at a series of workshops. 10 people took up this offer. The service also offers non-access CST to carers of people unable to attend CST for various reasons, such as a language barrier or because they are unable to leave their home. These sessions give carers information about how they can use some of the ideas behind CST with the people with dementia at home. 26 carers were referred of which just over a third (9) attended.
4. The Pathway

4.1 The current pathway

Pathways began to be used in clinical health settings as a way to describe how a person experiences services or how services should work or connect. A Pathway is about what can happen and expected standards. They are now in standard use for health and social care.

The current Pathway: in the Camden Dementia Plan has six elements:

<table>
<thead>
<tr>
<th>Prevention</th>
<th>• Raising awareness, vascular check and promotion of healthy lifestyle. Health and Wellbeing Checks.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification</td>
<td>• Identifying people in hospital or community, enabling people to self identify. GPs to discuss the possibility of dementia, carry out routine investigations, take a focused history with person and carer, assess cognition, provide information and refer to the Memory Service if necessary.</td>
</tr>
<tr>
<td>Assessment and Diagnosis</td>
<td>• Memory service – or other specialist – carries out full assessment. An investigation, blood tests, scans. If the person has dementia the Memory Service will explain the diagnosis to the person and their carer(s) and family.</td>
</tr>
<tr>
<td>Early Intervention and Treatment</td>
<td>• Each person with dementia (pwd) to have an annual review – pwd offered medication where appropriate. Post diagnostic support and counselling to pwd / carer - carers have needs assessed and met and have easy access to services (e.g. GP).</td>
</tr>
<tr>
<td>Living Well with Dementia</td>
<td>• Pwd to have access to regular reviews of needs and interventions, opportunities to plan their future care, support and coping strategies for carers. Psychological and creative therapies, social activities, Reablement, long term care. Support is offered to the carer.</td>
</tr>
<tr>
<td>End of Life Care</td>
<td>• Pwd is added to the Palliative Care Register when approach end of life and are offered specialist palliative care with a named Key worker. Liverpool Care Pathway (no longer in use). Bereavement support.</td>
</tr>
</tbody>
</table>


4.2 Views on the Pathway

In the main people were happy with the overall Pathway. The key message was that the Pathway will be experienced in different ways by everyone – it is not intended as a step by step, linear progression. The important thing is to allow and enable people with dementia and their carers to make their own choices in their own time rather than professionals making those choices for them. Each person will have a different experience and ‘journey’.

There are a variety of different health and social care Pathways but given what we know about co-morbidities there must be integration with the Stroke, Diabetes and Palliative Care Pathways and the Frail and Elderly Programme.

The NICE Clinical Guideline CG42 (Supporting people with dementia and their carers in health and social care) offers this Pathway

| Person with suspected dementia | investigation of suspected dementia | specialist assessment services | diagnosis and assessment | diagnosis of subtype | needs arising from diagnosis | interventions |

As a result of this review (please see Appendix A for methodology details) we are proposing to alter the Pathway by renaming the first and last elements and removing the stage of Identification.

- **Instead of Prevention** we propose ‘Awareness and Risk Reduction’. Although there has been considerable investment into research there is currently no prevention or cure for dementia. However it is crucial to raise levels of awareness, challenge stigma and negative assumptions and inform everyone of what they can do to live healthier lifestyles.

- **Instead of End of Life Care** we propose ‘Last Years of Life Care’. This change emphasises that thinking and planning for end of life can be considered at an earlier (and more appropriate) stage, rather than simply in the last few weeks or months of a person’s life.

Thinking has changed regarding end of life care since the Dementia Plan was written, for instance the Liverpool Care Pathway tool is no longer in use. There was a view that it may help to be more explicit about the latter, more advanced stage of dementia with it being seen as a terminal illness.

- **Consideration was given to whether there needs to be a separate element of the Pathway for Identification**. This was an issue at the time of devising the original Dementia Plan as nationally diagnosis levels were not reflecting expected population prevalence. Camden has now met the target of 67%. It is now more appropriate for Identification to become part of both Awareness and Risk Reduction and Assessment and Diagnosis.

Feedback highlighted that the Living Well with Dementia stage covers the majority of someone’s journey following on from Early Intervention and Treatment and covers everything up until the last years of life. This is the stage with the most complexity and variance for the individual with dementia and their carers as needs will change over time.
Gaps were identified around help with: challenging behaviour, crisis support and during key transitions such as at hospital discharge or moving into more supported care. There was also a low take up of Telecare and assistive technology and issues with access to continence aids.

However DSIG members did not want to see a new section of the pathway added for the more advanced stages of dementia but rather have those issues of support needed around times of major decisions/changes or complexity incorporated into the living well or last years of life care elements of the existing pathway.

This needs a trained and skilled workforce which is able to be responsive, flexible and to work in a multi-disciplinary way with the people with dementia (and their carers) at the centre of their care.
4.3 Revised PATHWAY

**Awareness and Risk Reduction**
- Important to raise awareness at all three levels — community/society (creating a *Dementia Friendly Camden*), individual/carer and professional/support service level. Provide advice on lifestyle especially any modifiable behaviours. Key for the individual or their carer to pick up early indication of issues and feel able to talk to their GP. Health Checks.

**Assessment and Diagnosis**
- All GPs to be pro-active in responding, screening and referring onto the Memory Service or the NHNN (for those under 65) to enable timely and sensitive diagnosis. Those identified with MCI to be advised of networks and support and to be enabled to re-refer themselves. Provide information to the person with dementia/carer about the diagnosis considering the impact for them.

**Early Intervention and Treatment**
- Memory Service to discuss any medication options, refer to CST, DAS or signpost on to appropriate service as well as inform the person with dementia/carer about the CDAA, Camden Minds group, support services and the importance of future-proofing (Advance Care Plan (ACP), Lasting Power of Attorney (LPA), writing a will). Work with GPs on reviews.

**Living Well with Dementia**
- Support for Peer Support Networks – people with dementia/carer to have opportunities to connect, take part in groups/activities/research. Ideally have a named person and know what to do in a crisis. Be offered CST, counselling and befriending. Opportunities to get involved in service design. Support for ACP etc. Prevent unnecessary hospital admissions and offer Reablement on discharge. Advice and support on major decisions.

**Last Years of Life Care**
- Assist with decision making about any move into more supported/residential care – can the person with dementia remain independent/in control in their own home? Should they be on the Complex Care register?
- Review ACP. Offer appropriate palliative/specialised care.
- Bereavement support.
4.4 Good practice and recommendations within the pathway

In this section of the report we look at the five stages of the pathway highlighting good practice as well as any issues and recommendations.

A more complete set of findings can be found in the Interim Report (also please see Appendix A for methodology). This report is available from CiPHAadmin@islington.gov.uk.

4.4.1 Awareness and Risk Reduction

✓ I feel part of a community and I am inspired to give something back

NB: This stage has been renamed ‘Awareness and Risk Reduction’ from Prevention. Although there has been considerable investment into research there is currently no prevention or cure for dementia. However it is crucial to raise levels of awareness, challenge stigma, address the fear, negative assumptions and inform everyone of what they can do to live healthier lifestyles.

`The more you involve people with dementia the less stigma there will be. We need to challenge assumptions as people will see and hear for themselves what the reality is for people with dementia and their carers.’

Commissioner for Older People (Camden).

People with dementia told us that they felt welcome in their own neighbourhoods and communities and were mostly able to enjoy life. The carers we spoke to agreed that in familiar surroundings and where the person with dementia was known or where they were able to advocate for them that there was no stigma or discrimination.

In addition to the stigma and fear attached to having dementia, research shows that as people get older their other greatest fears are dependence and a diminishing role in life xi. People need a role, whether in public or private life, however small as it ‘adds value, meaning and a sense of purpose to older peoples’ lives’. This is reinforced by the New Economic Foundation research into the Five Ways to Wellbeing (Connect, Be Active, Take Notice, Keep Learning and Give). Evidence shows that these actions help keep people resilient, healthy and mentally well xi.

Good practice in Camden on Awareness

Camden Minds: This peer support network of people with dementia meets regularly and hopes to expand. Members’ views are sought on a range of issues (such as how the Royal Free Hospital can be more dementia friendly), raise issues and are kept informed about initiatives and projects. They have facilitation and support from two leading voluntary sector providers (Camden Carers and AgeUK Camden) and are funded through the Dementia Engagement and Empowerment Project (DEEP).

Camden Dementia Action Alliance has registered with the national body and will be launching early in 2015.
**Camden has over 90 Dementia Champions**, who come from all backgrounds, can deliver a one hour course run by the Alzheimer’s Society and make a pledge to support the community. **There is a need for some coordination and planning to enable the most to be made of this resource, especially at key times such as Dementia Awareness Week (in May) and targeting specific hard to reach communities.**

**AgeUK Camden Dementia Befrienders** who enable people with dementia to access arts and other cultural events or to find new interests. Befrienders can book ipads loaded up with tools and access to the internet. They are partnering with UCH Museum on Prescription which has access to museums’ objects across London. Last year they took part in a joint arts research project with University College London and the Bloomsbury Festival. They experience high referral rates and operate a waiting list.

**Home Instead** offer awareness raising workshops once a month. They are attended by people with dementia, carers, OTs, social workers, physiotherapists, GPs and voluntary sector staff.

“The council are listening to the harder to reach communities to co-produce solutions to the health inequalities”.

The Director and Social Work Lead of the Camden Somali Cultural Centre

**The Camden Somali Cultural Centre** runs an awareness raising service offering workshops for the Somali community inviting organisations such as the Alzheimer’s Society and AgeUK Camden to talk to people about dementia. They are trying to help people understand dementia, how to identify if they have a problem and what to do if they are worried. They are also training 10 people of Somali descent to be Dementia Champions.

**Dr Anya Ahmed (Directorate of Social Sciences, University of Salford)** has been commissioned by the Camden Somali Cultural Centre to carry out research to help understand how dementia is understood in BME communities. She is interviewing carers and those diagnosed with Dementia to develop a Language of Dementia in Somali (there is no word for Dementia in Somali language). The work will increase the evidence base for the replicable process of engagement and service development, to meet the needs of other BME or hard to reach communities. They will share learning once their report is complete (in May 2015) which will incorporate academic developments in the field and other work currently being undertaken by the Salford Institute for Dementia at Salford University and will make recommendations for commissioners and other providers such as having a Dementia Cafe and creating a digital tool that helps with memory work so images and sounds from Somalia aid reminiscence work.

The Salford Institute for Dementia was a regional finalist in the Alzheimer’s Society Dementia Friendly Awards 2014. They include people with dementia in setting priorities for research, and encourage all organisations who work in dementia-related fields to ensure that they include people with dementia at all stages as this has such a positive impact on the work.

For more information visit www.salford.ac.uk.
Good practice in Camden on Risk Reduction.

“There is no doubt that people living with dementia do better if they have access to regular structure, socialisation and routine as is provided by day centres. This will help with minimising a number of challenging symptoms such as night day reversal which may be a precipitant to the admission to 24 hour care. A couple of recent studies have also demonstrated a link between depression and the onset of dementia. We do know that day centres can contribute to a reduction of depression in older adults.”

Dr Suzanne Joels (Camden Memory Service)

There are known risks associated with hypertension, diabetes and obesity in mid-life and some weak positive evidence for a Mediterranean diet. Early life factors such as a high level of educational attainment are known to be a protective factor but there is no hard evidence at the moment for the benefits of specific ‘brain training’ exercises. Individuals who regularly drink harmful levels of alcohol are at risk - this is modifiable behaviour but needs a whole service approach.

There are a range of staff carrying out health checks aiming to screen for and advise individuals on prevention of heart disease, stroke, diabetes and kidney disease. Health checks include prompt questions on memory and cognition. The dementia element is a national mandatory part of the NHS Health Check for those aged 65 – 74 (This is an awareness raising component and does not include any memory testing). If there are issues or concerns people will be referred to their GP.

Pharmacists are well placed to notice any deterioration or changes to their customers and can advise on taking medication and aids to daily living. They also carry out health checks. The newly funded ABC project (see box below) will capitalise on this unique position Pharmacists have in each neighbourhood by training Community Pharmacy Healthy Living Champions.

Ageing Better in Camden (ABC) is a partnership of older people and Camden organisations managed by older people and a variety of different groups and organisations. Funded by the Big Lottery it is due to start work in summer 2015 (subject to confirmation by Lottery). It is a six year £4.5 million programme focused on tackling isolation and loneliness. Older people will be central to the delivery of programme which will include: digital inclusion, men's activities, intergenerational work, community connectors, Community Pharmacy Healthy Living Champions, an internet access portal for accessing local activities, community neighbourhood action, work with the Bangladeshi community and the lesbian, gay, bisexual and transgender community.

Good practice elsewhere on Awareness and Risk Reduction

The Alzheimer's Society’s leaflet ‘How could I reduce my risk of dementia?’ touches on physical and mental activity, dealing with high blood pressure and high cholesterol from your 40s onwards, diet, obesity, smoking, alcohol and depression.

Our desk research into award winning projects on raising awareness highlighted work involving whole communities in sports activities and reminiscence (starting from the person with dementia’s own interests and background) as well as those using specific tools in intergenerational awareness raising in schools such as The Archie Project (a scarecrow character who goes from exclusion to inclusion). This project encourages pupils to think about the issues and work with care homes, hosting tea parties to see what community interest there is and inviting local businesses along.
In Yorkshire and Humberside they worked on street signage for public toilets \textit{(in a similar way to the campaigning work of Kilburn Older Voices Exchange)} and raised awareness about dementia for ambulance crew staff.

In all libraries in Shropshire they have a leaflet under the Reading Well Books on Prescription initiative for books on dementia. Titles have been pre-selected by health professionals and by people with dementia and their carers and appear under sections such as Living Well with Dementia, Support for relatives and carers and Personal Stories (reading-well.org.uk).

In one of the country’s Pioneer Primary Schools the Year 5 pupils attended a course on \textit{the Brain and Dementia} as part of their science curriculum. People with dementia shared their first hand experiences. The school also opened up a community \textit{Living Room} where a whole range of activities including a Dementia Cafe and Singing for the Brain were offered. This provided opportunities for music and singing with the pupils.

\textbf{(NB: The Alzheimer’s Society have online resources for raising awareness with children and young people and the Dementia Action Alliance has many examples of different approaches.)}

**Recommendations on Awareness and Risk Reduction**

- Promote, publicise and support the Camden Dementia Action Alliance.
- Promote, publicise and support the Camden Minds group to encourage more members to join and be proactive in seeking their views on services.
- Promote, publicise and support the Dementia Champions initiative encouraging more people to participate – consideration to be given to placing \textit{Dementia} Champions in GP surgeries.
- Circulate the Dementia Engagement and Empowerment Project (DEEP) documents on preferred language for professionals to use.
- Develop a co-ordinated plan for Dementia Friends awareness sessions initially targeting universal provision such as transport services (staff working on busses, trains and underground) and front line council staff at leisure centres, housing estates and those working on reception.
- Dementia awareness training to be stepped up to BMER communities in Camden by building on existing work and expanding to new communities.
- Public Health to lead on risk reduction and modifiable behaviour messages around diet, smoking, exercise and alcohol, working closely with all partners and changing approaches as needed for BMER communities. Those carrying out Health Checks to be networked to share learning on working with people with dementia and their carers.
- Housing providers to review how dementia friendly their built environment is and be encouraged to become more proactive in promoting health and wellbeing lifestyle changes.
- Explore with schools if there is scope for any dementia friendly projects that can be linked to the curriculum.
- Check in with library services whether there is the Reading Well Books On Prescription for dementia available.
4.4.2 Assessment and Diagnosis

✓ I was diagnosed early
✓ I understand, so made good decisions and provide for future decision making

“We want it to be normal to talk about memory problems and to encourage people to come forward for an assessment if they or their families have concerns.”

Professor Alistair Burns, National Clinical Director for Dementia, NHS England

Professor Burns went on to say that there can be a dip post assessment and diagnosis if there is no follow up support.

As part of the review many people talked about the need for a timely diagnosis as opposed to just an early diagnosis. This involves everyone seeing the benefit of having a diagnosis and people receiving their diagnosis at the right time in the right way for them.

Carers had a range of responses when asked if they felt the person they cared for had been diagnosed at the right time for them depending on how their GP had responded and their experience of the Memory Service. Many carers were frustrated at the length of time that diagnosis took given that they were very clear there was a problem. They also felt at times that they were not being listened to as an expert care partner.

Concern was expressed as to whether the screening tools that practitioners were using were effective, especially for those for whom English is a second language or who have different cultural references. It is the view of the Memory Service that the best approach is to take a detailed history, listening to the person and their carers. There is no one recommended universal tool or checklist. People with dementia and their carers need reassurance on this matter as many have had frustrating experiences.

Camden has a 67% diagnosis rate (at December 2014) this means that 33% remain undiagnosed, compared with 42% for London and 44% for England.

Diagnosis rates are lower for people aged 65-69 at only 33%. (Data from 2012 – prevalence rates are 1 in 100.) Raising awareness and promoting risk reduction should encourage more people to come forward in this younger age band. Any initiatives targeting BMER communities may well increase the numbers in this age group too as they may have co–morbidities such as hypertension, diabetes or stroke.
GPs were divided as to the value and ethics of pushing for a diagnosis (given the limited treatment options and issues of patient choice).

We conducted an exercise at an open event asking the mixed group of participants to consider what the benefits were. They said:

- access to treatment, drugs, and talking therapies etc.,
- access to other support, such as support groups, assistive technology etc.,
- ability to plan ahead in terms of housing, Lasting Power of Attorney, developing a will, family etc.,
- ability to discuss anxieties, doubts and fears,
- ability to plan for emergencies and to look into services that may be needed after hospital discharge, for home set-up etc.

The Nothing Ventured Nothing Gained guidance specifies the evidence on good practice is for a stepped approach to disclosure of a diagnosis. This involves ascertaining the person’s desire to know and exploring their reaction to a possible diagnosis. It suggests involving family members where possible, emphasising that progression can be slow; that a good quality of life is possible and offering ongoing support.

**Good practice in Camden on Assessment and Diagnosis**

The Camden Memory Service has seen a significant increase in the number of referrals with nearly 2.5 times more people diagnosed in 2013-14 than in 2009-10. (See page 16).

There are clear working protocols between the Memory Service and the Service for Adults with Learning Disability. As the Learning Disability Service generally knows the individuals involved they carry out the assessment and only ask the Memory Service for specialised advice and input.

Individuals with early onset dementia (i.e. those under 65) are referred to the National Hospital for Neurology and Neurosurgery. The NHNN are happy with all their current protocols and ways of working and find Camden excellent in terms of commissioning interesting, innovative services. For instance they have done some work with the Somali Cultural Centre. As they are a national tertiary service they receive a lot of their referrals via Consultants.

Camden Integrated Digital Records (CIDR) goes some way to addressing the issue of professionals being able to access notes in a shared system. The Memory Service sends a front summary sheet on their reports back to GPs although some GPs expressed a desire for more concise notes.

We can expect to see higher numbers coming through from those 59% of GP practices who have signed up to the Dementia DES.

The Frail and Elderly programme is setting up a community hub model and a new Consultant led Clinic in the West locality (as well as looking for opportunities for new clinics).

**Good practice elsewhere on Assessment and Diagnosis**

Dr Ian Greaves and his colleagues received an Enterprise Award in 2010 (Royal College of GPs) for their specialist dementia service within a Staffordshire GP Practice (running since 2006). One of the rationales was to get around patients’ ‘reluctance to be referred to the Memory Service’. They host one half day clinic a month and see on average 6-9 patients (and any carers). These patients are all
identified ahead by the clinicians who present their case to the Dementia Adviser who ensures a full
history is available (for instance living conditions, have there been any recent hospital admissions,
health of the carer, significant alcohol consumption levels etc.). A Consultant Psychiatrist provides
specialist expertise. They are able to diagnose dementia in 3 out of 4 cases and are then able to
signpost people onto support services in the local area and offer regular reviews.

**Recommendations on Assessment and Diagnosis**

- Set a new target of a 75% diagnosis rate by 2017 (in line with the Alzheimer’s Society
  recommendation).
- The Memory Service to lead on and develop a training and information programme for GPs
  on the benefits of a timely and sensitive diagnosis, prioritising those practices not achieving
  a 40% diagnosis rate, working with the newly appointed CCG Clinical Lead.
- Direct work with practices falling below a 40% diagnosis rate helping them address any issue
  of miscoding and checking if there are particular issues of hard to reach communities within
  the practice populations such as those from BMER communities, those misusing alcohol or
  living alone (the District Nursing team may well be visiting these older people or they may be
  known to the pharmacists). Are there supported or extra care housing schemes in the area,
  or care homes? Does there need to be some targeted dementia awareness training or
  intervention from Memory Clinic staff to improve understanding?
- Carry out an audit of the data relating to BMER communities.
- Ongoing psychological support for those who have been diagnosed with Mild Cognitive
  Impairment
- Ongoing support to those people with dementia who are not being given medication, over
  and above advice and signposting (possibly through a Dementia Adviser/Navigator Service).
- Improve links with multi-disciplinary teams working with individuals on the Frailty/Complex
  Needs register to ensure that any dementia related issues are being picked up. Consider
  scope for outreach in the community hubs.

**4.4.3 Early Intervention and Treatment**

✓ *I get the treatment and support which are best for my dementia and my life*

‘Dementia is an organic disease of the brain and it affects everyone differently.
We need to advise people on keeping well, diet, cutting down on excessive alcohol and on
smoking as well as taking regular exercise etc.’

(AgeUK Camden)
In the main carers felt that the person they care for was getting the right treatment for them although many acknowledged that the treatment options were very limited.

The biggest issue was getting the right information, at the right time and in the right way.

People with dementia and their carers wanted information about what is on offer locally and nationally. They wanted this on a website and in paper format so they can absorb, revisit and digest it at their own pace. Some had found the level of information they had been given overwhelming.

They agreed that a forum would be a good place to swap tips. Of course any forum would need to be moderated. Talking Point (the national online forum run by the Alzheimer’s Society) was not felt to provide this exactly.

The evaluation of the Dementia Adviser and Peer Support pilots concluded that if information is to be provided in a way that is appropriate to the individual, this requires a knowledge of that person’s needs. They found that Peer Support Networks or Dementia Advisers filled the gap that often exists between diagnosis and the need for more intensive services and support.

We know that face to face, word of mouth communication is effective. It would also be useful to have a system to send out regular e-bulletins (or special e-bulletins) that could be disseminated in a timely way to groups and via Dementia Champions. There would need an over-arching network to keep information up-to-date and to have a co-ordination role.

People would like information detailing the process following referral by the GP to the Memory Service about what to expect (in leaflet format). Several Pharmacists and GPs we spoke to also felt that this would be helpful.

GPs would like to integrate information about relevant local and national services into their practice information websites. The National Hospital for Neurology and Neurosurgery expects GPS to signpost people under 65 onto any relevant local services.

**Merton has a new Dementia Hub run by Alzheimer’s Society.**

It is described as ‘a unique community based service for people with dementia, their family and carers. The Hub provides a beautifully calming environment specifically designed around people with dementia. People using the Hub will be able to access different health and social care professionals and 3rd sector organisations under one roof.’

**The following services are available at the Hub and also at a number of locations around the borough:**

Memory Clinic ~ Carers’ Information and Support Programme (CrISP) ~ Support groups for individuals post diagnosis ~ Support groups for people with dementia ~ Support groups for carers - daytime and evenings ~ Therapeutic services (e.g. massage, podiatry and dentistry) ~ Weekly hub cafés on Tuesday mornings and afternoons ~ South Asian community café ~ Dementia Adviser service ~ Dementia Support Workers ~ Information services.

**Services Organised by the Hub in addition to the newsletter (email and print)**

- Blue Sky Café in Raynes Park – First Saturday of every month
- Rainbow Café in Colliers Wood – Fourth Friday of every month
- Sunshine Café in Pollows Hill – Second Friday of every month
- Singing for the Brain (Raynes Park)
There was some discussion around the benefits of a dementia hub/s or even a virtual hub. A visit by DSIG members to the Hub in Merton highlighted that whilst it was a well equipped facility it was tucked away from the community and was not well used on the day of the visit.

There is a lack of early take up of assistive technology in Camden. The Alzheimer’s Society Charter on Assistive Technology describes how this technology falls into 3 broad categories:

- safety
- health
- enhancing or improving someone’s quality of life.

The Charter goes on to say that whatever technology is provided it has to support and complement and not replace personal contact. Some people will have had help before diagnosis and then will have more help after – help is also needed in a crisis\(^v\).

**Good practice in Camden**

**Camden Telecare** offers some excellent options for people with dementia. These need to be publicised better at an earlier stage. Their sense is that they are seen as a last resort. The basic offering is a pendant and a smoke detector. They also have other packages and equipment such as:

- Bed sensors to detect if someone has been out of bed in the night for a longer that pre-agreed time – this will alert them if someone has fallen in the bathroom for example or has left the property in the night. Two way speakers enable staff to understand what has happened.
- Property exit sensors to alert them if someone leaves the property inappropriately – again they have two way speakers to see what is happening in this instance.
- Falls detectors.
- Medication dispensers. *The use of these needs joint work with Pharmacists.*

**The Memory Service** has been doing some work on Advance Care Planning and some GPs have asked if they could have copies of a person’s ACP. The Dementia Adviser Service has been working with a Muslim volunteer who wanted to look at Lasting Power of Attorney so they worked with him, the Imam and other professionals on this. The National Council for Palliative Care in Capacity, Care Planning and Advance Care Planning in Life Limiting Illness (2011) suggests dementia is a life limiting condition in the same way as cancer or motor neurone disease.

**Advanced care planning**

Early stage discussions are needed to enable people with dementia to future proof. One of the members of Camden Minds said that she ‘did not like to think about the future’ as she had an image of someone just sitting in a chair staring, needing assistance with everyday activities and unable to communicate. It is important to raise the topic of Advance Care Planning (including Lasting Power of Attorney) in a sensitive way early on and then offer ongoing support over time responding to the individual’s circumstances.
**Good practice elsewhere**

The Social Care Institute for Excellence (SCIE) have published guidance on use of ICT with people with dementia that talks of using ICT to help keep people connected, do life story work or reminiscence activities as well as the benefits of assistive technology\(^{xvi}\).

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**Recommendations Early Intervention and Treatment**

- Devise an information strategy following a review of what currently exists (including outcomes of the visit to the Merton Dementia Hub). *Would it be best to have an overarching network to keep information up-to-date with a co-ordination role?*
- Work with Practice Managers on integrating information about local services onto their IT systems - do they currently access Camden’s Care Choices and CINDEX directory?
- Discuss with lead pharmacist, other health care professionals and carers the use of Medication Administration Record (MAR charts) taking care to ensure that there is sufficient training in place to make the use of these charts safe.
- Telecare to be part of the DSIG and everyone to promote what is on offer. Explore the incentivisation of Pharmacists to fill Telecare medication dispensers (or blister packs) and offer home delivery.
- Let people with dementia and their carers know about opportunities to be part of any research projects into the condition.
- The Memory Service and Dementia Advisers to share learning so far on Advance Care Planning with colleagues, people with dementia and carers drawing on good practice.
- Continue to support a face to face advice and support service for people with dementia and their carers to help them navigate and understand all that is on offer.

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**4.4.4. Living well with dementia**

- I am treated with dignity and respect
- I know what I can do to help myself and who else can help me
- Those around me and looking after me are well supported

> “I want to do what I have always done, continue as it always was”

> Linda Sinclair, person with dementia interviewed on Radio 4

> “I have to do all the jobs - shopping, washing. She’s had sixty-six years experience, but I only have experience of a few years.”

> (Athma, husband of Vidya, Bradford (Women’s Experience of dementia report 2014)

People with dementia did tell us that they were treated with dignity and respect and carers appreciated it when GPs addressed the individual directly.
The evaluation of the Dementia Adviser and Peer Support pilots \textsuperscript{xvii} describes the impact of a dementia diagnosis and how the individual and family need help with dealing with that transition into an uncertain future.

People may experience a feeling of isolation and other mixed emotions on receiving a diagnosis. These are followed by the challenges of getting appropriate services and support, the way that person copes with the situation, the impact on close personal relationships and mediating the differing assumptions of family carers and practitioners. The family carer’s inclination tends to be to think into the past whilst practitioners tend to think into the future. The person with dementia may well take each day as it comes. The Dementia Adviser is ‘listening and learning about the people living with dementia and is also working in and around other services’. The key to a successful service is to occupy a space that complements existing services and avoids duplication of effort – or setting a service up that undermines each other’s roles.

It is vital that services and support are tailor-made at an individual level.

The review raised issues of carer support and a lack of access to highly skilled, specialist staff on an ongoing basis. People wanted to be able to discuss changes in behaviour and key transitions phases (such as a move into residential care or from one day centre to another). There were particular problems with personal care around managing continence, a lack of out of hours support and not always being seen as an expert care partner.

The Risk Guidance for people with dementia issued by the Department of Health in 2010 \textsuperscript{xviii} suggests that it is more useful to think of vulnerable situations that people with dementia are in rather than of them as vulnerable people. And the critical times identified regarding risk are around diagnosis, if changes occur to the person with dementia’s behaviour, a decline in physical health and a loss of social and life skills resulting in increased dependence.

There was serious concern expressed about how to reach and support those individuals with dementia who had no networks of support or family carers and who may be isolated and living alone.

**Good practice in Camden**

**Camden Carers** offer support to carers through a support group and a range of other services including the Remembering Yesterday and the Caring Today group (reminiscence with an arts/creative focus). During the lifetime of the group people with dementia reveal talents, abilities and skills that their carer may not have not known they had (such as an ability to teach others to crochet). People find it a very positive experience to accept and witness this.

**Age UK Camden** offers a Dementia Adviser Service. The Advisers are all volunteers and the manager is based with the Memory Service at the Peckwater Centre. This enables effective multi-disciplinary communication and access to NHS records and expertise. The Manager offers an initial assessment in the person with dementia’s home and explains the role of the Advisers. They provide information and advice with signposting but not ongoing or long term support. *They have two well established volunteers who sometimes work over a longer period and more intensely with someone if there is a particular need.*
**Tavistock Centre for Couple Relationships (TCCR)** has trained 17 practitioners from a variety of settings in Camden to deliver the *Living Together with Dementia* intervention. Couples are offered 8 sessions (free of charge) focusing on their everyday interactions. There is a training manual and fortnightly supervision groups. There is capacity for more referrals. This two year pilot is funded through Innovation Fund monies by Camden CCG and the funding ends in March 2015. TCCR are actively seeking continued funding.

**The Somali Cultural Centre** currently have two drop-ins - one in the North and one in South of the borough and see about 50 people a week. People are signposted to other services. One offers welfare benefits advice at Cypriot Women’s Centre and one general advice at Kingsgate. They would like to expand this service to a Dementia Café one day a week looking more broadly at the issues of ageing and frailty perhaps. They are trying to help people understand dementia, how to identify if they have a problem and what to do if they are worried. They are also training 10 people of Somali descent to be Dementia Champions.

### Good practice elsewhere

**Islington** re-commissioned their Dementia Adviser Service and now have Dementia Navigators. This involved a move from an advice model to a non-clinical case management model. The Dementia Navigators offer people help to access services, information and advice, sign posting and assist people to attend appointments etc. Their role is to help the person maintain physical and mental health, their home and tenancy, to plan for the future, help with financial matters, social interaction and relationships. They produce a short simple action plan. A secondary aim is to facilitate engagement in the Dementia Friendly Community and Action Alliance. They link up with the Stroke Navigators and the Carer’s Navigators recognising that people with dementia may well have other conditions including depression. They have received 300 referrals since August 2014 - 40% are ongoing and 60% have been signposted on.

**The Alzheimer’s Society** runs a telephone helpline for those who have concerns about Alzheimer’s disease or any other form of dementia. They provide information, support, advice and referrals to other appropriate organisations. Simultaneous translation can be set up for callers to the helpline for whom English is not their language of choice. They can provide confidential interpreters, in many languages, within minutes of the call.

The Alzheimer’s Society is developing a service called the Communities Project. This is being piloted in Islington and Lambeth and is offering something between a befriending service and home care. There will be two aspects to it:

- a telephone service to reduce isolation that people can call
- an opportunity for people to go to an activity or outing either on a one off basis or more regularly.

Clinicians from the Memory Service piloted Support to Carers in Islington helping them understand the disease and develop coping mechanisms. They ran a course and this was really well received – the peer support element of it was particularly valued. It was academically evaluated to assess the benefit in terms of increased resilience and this was shown to be the case.
An evaluation of the Admiral Nurse two year pilot in Norfolk demonstrated that as well as qualitative benefits to the family living with the effects of dementia there was a saving made to the health and social care economy worth 440k over 10 months. The pilot covered 7 surgeries. A lead nurse worked at a strategic level and two nurses worked directly with carers. They had 230 referrals over 10 months. Admiral Nurses are specialist dementia nurses who support the whole family enabling them to deal with the complexities of living with dementia. There are currently some 124 Admiral Nurses in the UK.

In Scotland they are testing the ‘8 Pillars’ model of community support (Lindsay Kinnaird).

This is aimed at supporting people with dementia at home in the moderate to severe stages of the illness. The overall aim is to build the resilience of the person with dementia and their carers. They offer a one year post diagnostic support guarantee. They have identified the gap between a person’s actual function and their potential.

The first pillar is a Dementia Practice Coordinator-the other 7 are:

Therapeutic interventions related to the impact of the condition, general health care and treatment, mental health care and treatment, personalised support, support for the carer, environment and community connections.

**Recommendations on Living Well with Dementia**

- Enable people with dementia and their carers to shape services through Camden Minds and involvement in forums such as DSIG.
- All care staff to undergo mandatory dementia awareness training and for this to include awareness of issues affecting LGBT older people.
- Review current day care use and transition between generic services (such as Kingsgate) and specialist services (such as Raglan and Netherwood) offering support to people in the later stages of dementia. Include those centres run by AgeUK Camden.
- Expand on the capacity for volunteer befriending.
- Streamline the current arrangements for continence aids supplies.
- Identify those practitioners within health, social care and the voluntary sector who can provide more specialised advice, information and support on an ongoing basis.
- Share learning from the 2 Innovation funded projects (led by TCCR & Somali Cultural Centre)
- Review the 8 Pillars model from Scotland looking at the Dementia Practice Coordinator role compared with the Dementia Adviser and Dementia Navigator roles.
4.4.5 Last Years of Life Care

✓ I am confident my end of life wishes will be respected; I can expect a good death.

NB: This stage has been renamed ‘Last Years of Life Care’ reflecting a change in emphasis - thinking and planning for end of life can be considered at an earlier (and more appropriate) stage, rather than simply in the last few weeks or months of a person’s life.

54% of patients with dementia died at home (including care homes) compared with 30% of the general population.

(End of Life Care profile. Camden CCG 2009-10)

Cancer is the underlying cause in only 25% of all deaths, yet 95% of those accessing specialist palliative care services are people with cancer.

Dying Matters

The Camden Dementia Care Plan acknowledges the need for a person with dementia to have access to specialist palliative care, to receive joined up care, to have their levels of pain assessed and managed and to be supported to die at home wherever possible and appropriate.

There is also a need for support to family carers to help them understand what is happening and for follow up bereavement care.

When discussing the Last Years of Life stage of the Pathway at the open event participants stated:

- This needs to be person centred and not diagnosis centred.
- We need to talk about dementia as a terminal illness* – ‘parity of esteem with cancer’ (do we want to talk about dementia as a terminal disease or a long term condition?).
- We need to think about care breakdowns and acute crises as needs can change very quickly.
- Could carers be allowed to stay in hospitals as with children and then people might not deteriorate so rapidly – they might also get better faster with the reduced fear and anxiety?
- Following a stay in hospital dementia patients often lose skills – a programme of ‘Reablement’ to recapture skills that are lost due to a break in routine using homecare and volunteers would help.
- We need to link with AgeUK Camden ‘planning for later life’ services well here.
- Don’t leave wills, Lasting Power of Attorney and Advanced Care planning to this stage – we need to think about recording wishes when people still have capacity.
- Recognising when it has become an end of life situation.
- If people have experienced trauma when they were younger (in a refugee experience for example) this may come to the fore as their dementia progresses. Work around this requires sensitivity.

*In the advance stages dementia is essentially a terminal condition*

xxi
Good practice in Camden

District Nurses are being trained in the use of a pain detection tool suitable for people with moderate to severe dementia called the Abbey Pain Scale. They use it as part of their dementia training for their ‘train the trainer’ package to detect if someone with dementia is in pain as they may not be able to express this clearly. This is not a list of questions – more a list of observations such as:
- Are they grimacing?
- Are they moaning or groaning?
- Are they crying?
- Has there been any physical change in the person?

AgeUK Camden offer advice sessions at the Charlie Ratchford Centre offering help with wills etc. – they also run peripatetic sessions at a variety of other organisations.

Camden Carers have responded to requests from carers by hosting specific events giving information and advice on this topic.

The Commissioner for End of Life Care is refreshing Camden’s strategy and will be making the link with dementia care and good practice in this area. She is working with the hospice movement and palliative care specialists.

Good practice elsewhere

The National Council for Palliative Care (NCPC) provide guidance at all levels, from commissioning services to good practice for practitioners xxii as well awareness raising and information for the individual and their families.

NCPC are members of the Dying Matters Coalition and have signed up to the End of Life Care Manifesto. The Dying Matters website has a great deal of resources available to help raise awareness and improve practice.

Recommendations on Last Years of Life Care

- Work with the Commissioner for End of Life Care on developing the strategy to reflect the needs of people with dementia and their carers. Ensure ways are included to support individuals to be able to die in their own homes rather than in hospital if they so wish and bereavement support for carers.
- Medication dosage and prescriptions can be changing frequently at this stage and pharmacists, GPs, hospitals and carers need to work closely together to ensure pain management etc. is effective.
- Sharing information through the use of Camden Integrated Digital Records Camden Integrated Digital Records (CIDR), case reviews etc., including any advanced care decisions is vital.
- Bereavement support for carers must be available and publicised.
5. APPENDIX

The review methodology

In July 2014 we (Barbara Wilson and Sophie Cottrell) met with Jane Brett-Jones (Public Health Strategist – Mental Health) Robert Holman (Camden Joint Commissioner for Older People) and Kathryn Hill (Programme Manager for Frail and Elderly for the Clinical Commissioning Group /CCG) to agree on the scope of this review, the overall approach and who we needed to consult.

In addition to the tender document for the work they provided us with background information and agreed to act as the Steering Group (SG) for the work. Cameron Hill replaced Kathryn Hill part way through.

We attended the DSIG meeting on the 28.08.14 to outline the review process. We produced an e-bulletin for wide distribution and began contacting people on the stakeholder list to arrange face to face meetings, telephone interviews or make email contact. We also carried out desk research into innovative and good practice in the field of dementia care including the Healthbridge Evaluation Report on the 40 Demonstrator sites for Dementia Advisers and Peer Support Networks.

Working from one basic question framework we devised four different surveys for:

1. GPs – this was put onto Citizen’s Space, the CCG online platform,
2. pharmacists – this was sent out via a main contact though Survey Monkey,
3. other stakeholders,
4. people with dementia and their carers – here we used the ‘Make it Real I Statements’.

We interviewed or met with 30 external stakeholders, 23 GPs and hosted 3 focus groups – with Dementia Carers, KOVE (Kilburn Older Voices Exchange) and Camden Minds (previously known as CAMEOS). In addition the Alzheimer’s Society kindly agreed that we could pose a set of I Statement questions to members of the Rest Bite Group to answer on hand held devices. We spoke to 13 people with dementia and 13 carers.

Of the 30 stakeholder interviews 19 were conducted as telephone interviews and the rest were face to face – this included a visit to the Memory Service.

We have spoken to:

- Day Services – Managers at Netherwood and Kingsgate
- District Nurses
- Pharmacists
- The former lead Social Worker in Camden
- Commissioners /Public Health in Islington & Camden
- Commissioner for Last Years of Life Care Camden
- Commissioner for Older People Camden
- Voluntary Action Camden (VAC)
We had 7 responses to the online GP Survey and have seen or spoken to 23 GPs from 7 practices – we had hoped to include an eighth practice before the end of the review but this has not been possible. We had no responses to the pharmacist’s survey – feedback was that it needed to be easier to fill in with yes/no boxes and drop down menus.

We also took part in a NHS webinar on good practice in Peterborough regarding improving health checks and attended an open dementia awareness meeting hosted in London by Home Instead.

At the DSIG meeting on the 27.11.14 we were able to give a brief overview of feedback raised by GPs and those present reflected on the Living Well with Dementia aspect of the Pathway.

We held an open event on the 11.12.14 to present the Interim Findings and to further develop the pathway. 15 people attended. We made corrections for accuracy to the Interim Report, took into consideration people’s comments and following discussions with the SG created this Final Report for the DSIG. We produced a final e bulletin with our findings.
6. References

i Healthbridge Evaluation Report  
ii Developing the power of strong, inclusive communities - a Framework 2014  
iii ‘8 Pillars’ model of community support (Lindsay Kinnaird)  
iv Quality Outcomes for People with Dementia, Department of Health  
v Healthbridge Evaluation Report  
vi DAA Annual Report 2014  
vii Building on the National Dementia Strategy Report (2014) – All Parliamentary Group on Dementia  
viii Caring for Our Future 2012 HM Government  
ix NHS England Outcomes Framework  
ix Healthbridge Evaluation Report  
xi LGA & Innovations in Dementia –Developing Dementia Friendly communities -Learning and Guidance 2012  
xiii Foresight Project, New Economics Foundation 2008  
xiv Mitchell et al 2009, Nothing Ventured Nothing Gained Risk Guidance Department of Health  
xv Healthbridge Evaluation Report  
xvi Dementia Friendly Technology – the Charter – the Alzheimer’s Society 2014  
xvii Using ICT in activities for people with dementia – a Short Guide for Social Care providers October 2012  
xviii Healthbridge Evaluation Report  
xxii www.dementiauk.com  
xxx ’8 Pillars’ model of community support (Lindsay Kinnaird)  
xxiii Mitchell et al 2009 Nothing Ventured Nothing Gained Risk Guidance Department of Health  
xxiv Difficult Conversations for Dementia and Capacity, Care Planning and Advance Care Planning in Life Limiting Illness NCPC

Other recommended reading

- Dementia: workers and carers together Guide Spring 2012 Dementia UK, Skills for Care, Skills for Business.  
- Making It Real For People with Dementia May 2013. Think Local Act Personal (TLAP).  
- Audit of Memory Services Royal College of Psychiatry 2013  
- Women’s Experiences of Dementia JR Foundation, Innovations in Dementia. SPRU & University of York 2014.  
- Better Domiciliary Care for people with dementia Skills for Care 2014.  
- Running self-help groups in sheltered and extra care accommodation for people who live with dementia –a guide. Mental Health Foundation 2014  