Dementia needs assessment

May 2014

Brighton and Hove Clinical Commissioning Group

Brighton & Hove City Council
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<td>MDT</td>
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<td>MH</td>
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<td>MRC</td>
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<td>Magnetic Resonance Imaging</td>
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<td>Acronym</td>
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<td>NICE</td>
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<td>NIHR</td>
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<td>ONS</td>
<td>Office for National Statistics</td>
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<td>PCT</td>
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<td>PM</td>
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<td>Preferred Priorities for Care</td>
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<td>SCIE</td>
<td>Social Care Institute for Excellence</td>
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1. Introduction and background
Dementia is a syndrome that can be caused by a number of progressive disorders. It affects memory, thinking, behaviour and the ability to perform everyday tasks. Alzheimer’s disease is the most common type of dementia. Others include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.1 It mainly affects older people. One in 14 people over 65 years and one in six over 80 years in the UK have a form of dementia. It is estimated people live on average 7-12 years after diagnosis.

Dementia is an important issue because it affects a large proportion of people and the numbers are increasing as the population is ageing. It places pressure on all aspects of the health and social care system: An estimated 25% of hospital beds are occupied by people with dementia, who have longer lengths of stay, and more readmissions. Approximately two-thirds of care home residents are estimated to have dementia and one in three people will care for someone with dementia in their lifetime.1

Nationally, there is increasing focus on dementia as an issue, including prevention, treatment, demand for services and creating dementia friendly communities. The National Dementia Strategy was published in 2009 and the Prime Minister launched his Dementia Challenge in 2012.

Dementia costs society an estimated £19 billion a year.2 In 2010 Brighton & Hove Older People’s Mental Health Services (of which dementia forms a part) cost an estimated £21.347 million.3

This needs assessment will inform the Brighton & Hove Dementia Implementation Group about current and future unmet needs, assets and gaps in relation to dementia care, enabling it to develop local action plans to meet these needs. The main focus of this needs assessment will be the development of dementia in people aged 65 and over, as other reviews of young onset dementia in the city have recently taken place.

2. Methodology
This needs assessment was undertaken between September 2013 and April 2014. The work was co-ordinated by the Dementia Needs Assessment Steering Group, which was a sub-group of the multi-agency Dementia Implementation Group. The Steering Group was chaired by Alistair Hill, Public Health Consultant. Other members of the group included: Barbara Hardcastle (Public Health Specialist), and Russell Carter (Public Health Specialist Trainee) who led the work and Simone Lane (Brighton & Hove Clinical Commissioning Group), Jane MacDonald (Adult Social Care, Brighton & Hove

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2 Prime Minister’s challenge in dementia, based on Alzheimer’s Society (2007), Dementia UK, Alzheimer’s Society, London.
3 Revised dementia planning framework 2010. Sussex Dementia Partnership.
City Council), Pam Windsor and Sheila Killick (Carers Centre), Sophie Mackrell (Alzheimer's Society), Lucy Frost (Brighton & Sussex University Hospitals), Jacky Austen (Sussex Partnership Foundation NHS Trust), Claire Newman (Sussex Partnership Foundation NHS Trust) and Michele Hembling (Sussex Community NHS Trust).

The contents of the needs assessment has been consulted on with members of the Dementia Needs Assessment Steering Group, Dementia Implementation Group, JSNA City-wide Group, and interviewees. The final version of the needs assessment was agreed and signed off by the Dementia Implementation Group in May 2014.

3. Key issues and gaps
The key issue in relation to data in Brighton & Hove is the under-reporting of the prevalence of dementia due to its under diagnosis. In 2012/13, there were only 1,310 people on GP dementia registers compared to an estimated prevalence of 3,046.

Another data gap is the lack of accurate recording of the number of people diagnosed with dementia living in care homes, receiving home care or self-funding their dementia care. Many of the people using these services will have dementia but no formal diagnosis.

Where data has been available protected characteristics groups have been included in the needs assessment, in the “Who’s at risk and why?” section. This mainly relates to age and gender. There is no local data on ethnicity, sexual orientation, transgender, religion/belief, or marital status.

Due to Brighton and Hove’s unique population profile with a higher proportion of people aged 16-64 years and a lower proportion of 65 years and over (13%) compared to 17% in the South East and 16% in England, dementia needs are not on the same level as other parts of the country. However, a predicted 24% increase in 70-74 year olds and 48% increase in the 90 plus age group by 2021 will put increasing demands on services. This will be particularly felt in the parts of the city where a higher proportion of the older population live i.e. Rottingdean Coastal, Woodingdean, Hangleton & Knoll, Hove Park and Patcham wards.

4. Recommendations for consideration
Where possible the recommendations have been placed under the same headings as those used in the End of Life Care in Dementia Care Pathway.

4.1. Recognising there is a problem

4.1.1 Develop a single dementia information point to signpost the public, professionals and care home/home care workers to, for information on: referral and diagnostic pathways, services available, community support, out
of hours crisis support, and information for self-funders on how to choose a care home. This is something that the Alzheimer’s Society currently does, but with limited capacity.

4.1.2. Establish a Dementia Action Alliance to lead and co-ordinate the development of dementia friendly initiatives, including public education campaigns to increase awareness of the risk factors for dementia and develop a local network of dementia friends.

4.1.3. The wider older people’s workforce needs dementia awareness training (including those working with older people in the learning disability services). This should include information on the memory assessment process and information resources.

4.1.4. Commissioning Plans for Older People’s services should include the requirement they are dementia friendly.

4.2. Discovering that the condition is dementia

4.2.1. People with the symptoms of dementia and awaiting diagnosis should be offered pre-diagnostic counselling, to help them discuss their fears, start the process of self-management and develop therapeutic relationships.

4.2.2. Consider the appointment of specialists like dementia care managers/Admiral Nurses/dementia practice co-ordinator in primary care to provide continuity of care going forward from the point of diagnosis. At the moment the Alzheimer’s Society Dementia Advisers are only available for the first year after diagnosis and the Alzheimer’s Society dementia support workers have limited capacity.

4.2.3. The capacity of the voluntary sector counselling service should be increased, so that people who have recently been given a diagnosis of dementia and their families/carers are offered counselling support to cope with the changes and loss arising from diagnosis.

4.2.5. Scope the potential for developing post diagnostic interventions to educate the recently diagnosed and their families/carers, about dementia and the steps they can take to self-manage the condition to delay progression. Interventions may include: Cognitive Stimulation, Memory Management, Reminiscence, Music and wellbeing, dance and movement and art-based activities – similar to the East Sussex model or a Recovery College (therapy and education jointly led by professionals and peer educators).

4.2.6. Support all people recently diagnosed with Mild Cognitive Impairment and Dementia to access evidence based activities available at the different stages of disease progression e.g. Active for Life, Health Walks, Healthy Eating, Singing For The Brain, Dancing, Dementia Cafes.
4.2.7. Increase the capacity of the CrISP training so that people with dementia and their families/carers are aware of how to access financial assistance and support with legal issues. Make financial and legal advice available to self-funders.

4.3. Living well with dementia

4.3.1. Allow people with a dementia diagnosis to access the Wellbeing Service if they can still benefit from talking therapies. Not doing so is a barrier to achieving NICE quality standard 6.

4.3.2. Ensure all people with dementia have a named key worker to develop a care plan and act as a single point of contact. This should link into the model of frailty being used by Better Care.

4.3.3. People with dementia, including those not eligible for Adult Social Care, need to be made aware of the support services, activities and information available for them at each stage of their illness.

4.3.4. Develop the role of the voluntary sector to provide buddies/befrienders who can outreach to support people with memory loss and take isolated people, including those in sheltered/extra care housing to engage in community activities.

4.3.5. Extra Care Housing and Sheltered housing schemes should become more of a focus for systematic preventative work with residents. Scheme managers should be trained in the early signs and symptoms of dementia and arrange for health promotion interventions for residents, which could also be opened up to the local community.

4.3.6. Optimise the use of Extra Care Housing so that they are able to support people with higher level needs for longer thus easing the pressure on specialist dementia beds.

4.3.7. Increase and develop the capacity of home care to support the increasing number of people with dementia, and develop joint working with health to reduce social isolation and decrease delayed discharges of care from hospital.

4.3.8. Ensure home care providers are included in dementia training.

4.3.9. Ensure all care homes have a named senior member of staff leading on improving dementia care.

4.3.10. Encourage care homes to use memory tools like memory boxes and reminiscence rooms.
4.3.11. Make Direct Payments and Personal Budgets more attractive and easier to use for people with dementia.

4.3.12. Ensure those living alone with dementia are identified as in need of support to avoid residential care and make links to Better Care/Frailty initiatives.

4.3.13. Support the development of dementia specialist forums (for practitioners, providers, care homes, to focus on good practice and care).

4.3.14. Ensure the needs of people with dementia are linked into the Age Friendly City work. e.g. better signage and transport initiatives

4.3.15. Ensure the Dementia Friendly Toolkit being developed by the Trust for Developing Communities is implemented.

4.4. Getting the right help at the right time

4.4.1. Provide access to an emergency back-up scheme for carers not eligible for Adult Social Care.

4.4.2. Need to ensure residential, day and emergency respite is included systematically as a part of care planning.

4.4.3. Increase awareness of council provided respite service, including amongst those not eligible for Adult Social Care.

4.4.4. Adult Social Care to consider possible options and financial implications of developing planned respite.

4.4.5. Promote telecare and telehealth to all who could benefit, including those who live alone and self-funders.

4.4.6. All front line workers to assess if living environments need adaptations for persons living with dementia

4.5. Data sharing to inform strategic decision making

4.5.1. Pool data to develop a dementia dashboard for regular review by a strategic monitoring group. This would monitor QOF Dementia Registers, MAS data, Dementia DES, and prescribing data to assess the effectiveness of interventions to increase early diagnosis of dementia and enable targeting of interventions on areas that need improvement.
5. Timeframe
This needs assessment was undertaken between September 2013 and April 2014. The Dementia Implementation Group will be updating its Action Plan to take account of the needs assessment findings and recommendations and will cover the three year period from September 2014.

6. The role of legislation and policy
Dementia is a key national priority for the Department of Health. Key policy documents have included NICE guidance and policy standards, a National Dementia Strategy (2009) and the Prime Minister’s Challenge on Dementia (2012). These aim to improve dementia services across three areas – awareness, earlier diagnosis and intervention, higher quality of care and research.

National Policy
The key national policy documents and links are as follows:

6.1. Quality standard for supporting people to live well with dementia – NICE April 2013
List of 10 quality standards. These should be read alongside Quality Standard 1 published in 2010.

1. People concerned about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.
2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.
4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.
5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
7. People with dementia live in housing that meets their specific needs.
8. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
10. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.
6.2. Dementia 2013: The hidden voice of loneliness – Alzheimer's Society 2013

Annual survey reporting on the quality of life of people with dementia


6.3. Dementia without Walls – Joseph Rowntree Fellowship July 2012

- Empowering people with dementia
- Dementia-friendly communities
- Thinking differently about dementia

http://www.jrf.org.uk/work/workarea/dementia-without-walls

6.4. Prime Minister’s Challenge on Dementia – March 2012

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

Delivering major improvements in dementia care and research by 2015
1. Increased diagnosis rates through regular checks for over 65s
2. Financial rewards for hospitals offering quality dementia care
3. An Innovation Challenge Prize of £1m
4. A Dementia Care and Support Compact signed by leading care home and home care providers
5. Promoting local information on dementia services
6. 20 dementia friendly communities across the country
7. Support from leading businesses for the PMs Challenge on Dementia
8. An awareness raising campaign
9. More than doubling overall funding for dementia research to over £66m by 2015
10. Major investment in brain scanning
11. £13m funding for social science research on dementia (NIHR/ESRC)
12. £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients
13. Participation in high-quality research

6.5. Dementia Commissioning Pack launched – July 2011

- Practical resource for health and social care commissioners to help improve quality of care for specialist and generalist services for people with dementia and their carers

http://www.dementiapartnerships.org.uk/commissioning/dementia-commissioning-pack/

6.6. Quality outcomes for people with dementia: Building on the work of the national dementia strategy – September 2010

- Outcomes focused implementation strategy for the 2009 national dementia strategy


- List of 10 quality statements

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<tbody>
<tr>
<td>1. People with dementia receive care from staff appropriately trained in dementia</td>
</tr>
<tr>
<td>2. People with suspected dementia are referred to a Memory Assessment Service</td>
</tr>
<tr>
<td>3. People newly diagnosed with dementia and/or carers receive written and verbal information about their condition and treatment and support options in their local area.</td>
</tr>
<tr>
<td>4. People with dementia have an assessment and ongoing personalised care plan, agreed with health and social care that identifies a named care co-ordinator and addresses their individual needs.</td>
</tr>
<tr>
<td>5. People with dementia, while they the capacity, have the opportunity to discuss and make decisions about advance statements and directives and lasting power of attorney and preferred priorities of care</td>
</tr>
<tr>
<td>6. Emotional, psychological and social needs of carers are assessed and care plan drawn up</td>
</tr>
<tr>
<td>7. Non-cognitive symptoms and behaviour that challenges are assessed at an early stage and interventions recorded in care plan.</td>
</tr>
<tr>
<td>8. Dementia specialist liaison services in acute hospitals</td>
</tr>
<tr>
<td>9. Palliative care needs are identified in later stages of dementia</td>
</tr>
<tr>
<td>10. Carers should have access to a comprehensive range of respite and short break services</td>
</tr>
</tbody>
</table>

http://publications.nice.org.uk/dementia-quality-standard-qs1


- Highlighted the overuse of antipsychotic medication for people with dementia.
6.9. Living well with dementia: a National Dementia Strategy. DH 2009

- Aims to improve dementia services across three key areas: improved awareness, earlier diagnosis and intervention and higher quality of care
- Identifies 17 objectives to be delivered at a local level to deliver improvements.

1. Improving public and professional awareness and understanding of dementia
2. Good quality early diagnosis and intervention for all
3. Good quality information for those diagnosed with dementia and their carers
4. Enabling easy access to care, support and advice following diagnosis
5. Development of structured peer support and learning networks
6. Improved community personal support services
7. Implementing the Carers’ Strategy
8. Improved quality of care for people with dementia in general hospitals
9. Improved short term services for people with dementia
10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
11. Living well with dementia in all care homes
12. Improved end of life care for people with dementia
13. An informed and effective workforce for people with dementia
14. A joint commissioning strategy for dementia
15. Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.
16. A clear picture of research evidence and needs
17. Effective national and regional support for implementation of the Strategy


- Examined the prevalence and cost of dementia, early intervention, access to and quality of support services and experiences of people with dementia in hospitals and care homes.

http://www.publications.parliament.uk/pa/cm200708/cmselect/cmpubacc/228/228.pdf
- Review of dementia services, critical about the quality of care received by people with dementia and their families.


- Report on the prevalence and economic costs of dementia in the UK.


- NICE and SCIE guideline on management of dementia

Local Policy

This needs assessment undertaken by Brighton & Hove City PCT includes an epidemiological section on dementia. This gives an estimate of 2-300 new cases of dementia per year.

Many older people show signs of cognitive impairment but fail to meet the criteria for dementia. Mild cognitive impairment increases with age and up to 12% with the condition may progress to develop Alzheimer’s disease in a year.

The needs assessment used an MRC Cognitive Functioning and Aging Study’s (1998) estimates of levels of dementia severity to extrapolate the likely level of support that would be required. It estimated 645 (27%) people 65 and over in Brighton & Hove would have mild dementia; 1046 (44%) moderate dementia; and 697 (29%) severe dementia. 915 people (38%) would require institutional care (most of these people would have moderate to severe dementia).

These figures were applied to the estimated possible range of people with dementia (2,000 to 3,600) and estimated that 1500-2630 (73%) would have moderate to severe dementia and 570-1000 (38%) would require institutional care.

care. The remaining 930-1630 (62%) would be at home where they would need support.

6.15. Scrutiny Select Committee on Dementia (2010)\(^5\)
Following the publication of the National Dementia Strategy in 2009 and the imminent redesign of the dementia care pathway, Brighton & Hove City Council established a Scrutiny Select Committee on dementia. In view of the concurrent changes in local dementia services the committee made practical recommendations for service redesign, rather than strategic ones. Fourteen recommendations were made:

1. Frontline health care workers including GPs and acute hospital staff to be trained in dementia awareness to aid early diagnosis.
2. Proposed Memory Assessment Service should have a homely setting for diagnostic assessment; timely referral management; maintain focus if part of an integrated team.
3. Dementia services to provide ongoing support to recently bereaved.
4. Reflect dementia service users and carers’ views in end of life care planning
5. Commissioners to ensure own staff and those of providers treat bereaved people with sympathy and understanding.
6. Inpatient acute dementia beds should not be located outside the city, unless there are overriding therapeutic benefits for this
7. Capacity planning by commissioners should enable all those requiring a residential or nursing home bed in the city to have one.
8. NHS Brighton & Hove to promote use of Access Point to primary care/GPs
9. Access Point to promote its services via council/city initiatives
10. Support services capacity and anticipated increase in demand should be addressed as part of service redesign work
11. New service care pathway should be easy to navigate, reducing need for advocacy and advice services
12. Commissioners should engage with local communities to encourage them to support people with dementia and their carers
13. Service redesign should address needs of people with early onset dementia
14. Issues of dementia should inform the work programmes of the Adult Social Care & Housing Overview and Scrutiny Committee and the Health Overview and Scrutiny Committee.

6.16. Sussex Dementia Partnership Pathway Development Work 2010
In 2010, the Sussex Dementia Partnership was formed to take a joint approach to dementia care and support pathway redesign. This held a series of workshops involving both professionals, people with dementia and their

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carers. This identified assets and gaps in the then care pathway and identified priorities for service development. These were

- Workforce development
- Dementia friendly general hospital environment
- Dementia friendly general nursing environment
- Carer support including respite
- One stop memory assessment and support services
- Dementia liaison in acute hospitals
- Crisis support
- Care home in-reach
- End of Life Care for people with dementia

### 6.17. Dementia Action Plan 2012-13

As part of the NHS Brighton & Hove/ CCG service redesign work an action plan has been developed. This included 10 key areas.

| 1. Good quality early diagnosis and intervention for all – Development and launch of Integrated Memory Assessment and Diagnosis Service at Aldrington House by April 2013 |
| 2. Improved quality of care in general hospitals - a) Developing sustainable resourcing for Older People’s Mental Health Liaison Service at Royal Sussex County Hospital by April 2013. b) Appointing a Dementia Champion and developing dementia implementation plan by June 2013. c) Improved diagnosis in acute hospitals via CQUIN by March 2013. |
| 3. Dementia Crisis and Short Term Support – Review services and agree models for the future by June 2013 |
| 4. Living well with dementia in care homes – a) Review and develop Care Home In-Reach Team by December 2012. b) Improve Care Home provision by increasing capacity, improving quality and developing role of Ireland Lodge in reducing delayed transfers of care by April 2013. |
| 5. Reduced use of antipsychotic (AP) medication – prescribing of APs in acute and MH Trusts in line with EQ/CQUIN; implement response to Prescribing Observatory for Mental Health UK audit; Next steps after end of prescribing incentive scheme in primary care; audit of AP use in care homes; education for GPs on APs by May 2012. |
| 6. A clear picture of research evidence and needs – Update Whole System Partnership dementia modelling work to include localised data from audit By April 2012 |
| 7. Development of structured peer support and learning networks – Peer support implemented via Memory Assessment Service by April 2013 |
8. An informed and effective workforce for people with dementia – On
going training for local authority and independent sector, and primary care.

9. Improved end of life care for people with dementia – End of life pathway
for people with dementia, develop learning network and specialist resource in
2012/13

10. Improved dementia services for people with specific needs including
young onset, learning disability, dual diagnosis and Korsakoff’s
Syndrome – review Towner Club; needs assessment for young onset
dementia by June 2012; Care home in-reach team to support residential
homes for people with learning disability and dementia; integrate dual
diagnosis pathway with general pathway.

The Shadow Health and Wellbeing Board carried out an exercise in 2012 to
identify high impact areas in terms of health, for the city, identified by the
JSNA Summary. One of these was dementia and this was included as a
priority in the Health and Wellbeing Strategy. This identified the lack of local
information about people with dementia in the city, and the need for a joint
strategic needs assessment to assist with the development of commissioning
plans. It also set out outcomes for the successful implementation of the

- Levels of diagnoses to reach 70% of expected levels by 2016
- Improved access to information, support and advice at point of
diagnosis
- Reduced prescribing of antipsychotics for people with dementia
- Accreditation as a Dementia Friendly Community
- Increased numbers of Carers Assessments completed at an early
stage
- A Dementia Board to take forward developments.
7. Who’s at risk and why?

This section considers fixed and modifiable risk factors which may determine whether or not someone is likely to develop dementia. Where data is available this has included the likely impact on the protected characteristics groups, by way of meeting our duties under the Equalities Act 2010.

7.1. Demography

7.1.1. Population of Brighton & Hove

According to the latest mid year population estimates for 2011, there are 273,000 people resident in Brighton & Hove and this is predicted to increase to 291,000 by 2030. The population structure is somewhat unique compared to that of the South East and England with a much higher proportion of people aged 16-64 years. There are also smaller proportions of children and older people aged 65-74 although there is a similar proportion of the population that are aged 85 years or over as in England at 2.2% of the population.

Average life expectancy in Brighton & Hove is 77.7 years for males and 83.2 for females. Whilst females in the city can expect to live on average six months longer than nationally, life expectancy for males is almost one year lower. Healthy life expectancy is 67.9 years for males and 72.9 years for females meaning that, on average, around 10 years of life is spent in ill health.

7.1.1.1. Population structure

7.1.1.2 Age

Dementia disproportionately affects people aged 65 and over and risk continues to increase as people get older. The 2011 mid year estimates show that 13% of the population of Brighton & Hove are aged 65 years or over which compares to 17% in the South East and 16% in England. The Brighton & Hove ward area with both the highest number and proportion of people aged over 65 years is the Rottingdean Coastal ward with 3,046 people in this age group which is 22% of the population. The Hangleton & Knoll and Patcham wards also have high numbers of over 65s at 2,645 and 2,580 people respectively, both of which constitute 18% of the population. The need for dementia care is likely to be greater in these areas. Table 1 shows the breakdown of over 65 age groups according to the Office for National Statistics mid-year estimates for the number and proportion of over 65s in each ward of the city in 2011.
Table 1. Mid-year estimates for the number and proportion of over 65s in each ward of the city in 2011
<table>
<thead>
<tr>
<th>Neighbourhood</th>
<th>All ages</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85+</th>
<th>Total 65+</th>
<th>% 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brunswick and Adelaide</td>
<td>10,080</td>
<td>236</td>
<td>162</td>
<td>125</td>
<td>101</td>
<td>99</td>
<td>723</td>
<td>7%</td>
</tr>
<tr>
<td>Central Hove</td>
<td>9,276</td>
<td>343</td>
<td>251</td>
<td>222</td>
<td>224</td>
<td>301</td>
<td>1,341</td>
<td>14%</td>
</tr>
<tr>
<td>East Brighton</td>
<td>14,085</td>
<td>556</td>
<td>423</td>
<td>341</td>
<td>253</td>
<td>231</td>
<td>1,804</td>
<td>13%</td>
</tr>
<tr>
<td>Goldsmid</td>
<td>15,644</td>
<td>499</td>
<td>346</td>
<td>352</td>
<td>346</td>
<td>517</td>
<td>2,060</td>
<td>13%</td>
</tr>
<tr>
<td>Hangleton and Knoll</td>
<td>14,745</td>
<td>605</td>
<td>660</td>
<td>528</td>
<td>427</td>
<td>425</td>
<td>2,645</td>
<td>18%</td>
</tr>
<tr>
<td>Hanover and Elm Grove</td>
<td>16,014</td>
<td>319</td>
<td>278</td>
<td>211</td>
<td>144</td>
<td>136</td>
<td>1,088</td>
<td>7%</td>
</tr>
<tr>
<td>Hollingdean and Stanmer</td>
<td>15,690</td>
<td>437</td>
<td>381</td>
<td>318</td>
<td>249</td>
<td>203</td>
<td>1,588</td>
<td>10%</td>
</tr>
<tr>
<td>Moulsecoomb &amp; Bevendean</td>
<td>17,489</td>
<td>464</td>
<td>402</td>
<td>317</td>
<td>233</td>
<td>196</td>
<td>1,612</td>
<td>9%</td>
</tr>
<tr>
<td>North Portslade</td>
<td>10,053</td>
<td>502</td>
<td>394</td>
<td>299</td>
<td>195</td>
<td>145</td>
<td>1,535</td>
<td>15%</td>
</tr>
<tr>
<td>Patcham</td>
<td>14,261</td>
<td>653</td>
<td>605</td>
<td>486</td>
<td>428</td>
<td>408</td>
<td>2,580</td>
<td>18%</td>
</tr>
<tr>
<td>Preston Park</td>
<td>14,881</td>
<td>362</td>
<td>246</td>
<td>199</td>
<td>214</td>
<td>242</td>
<td>1,263</td>
<td>8%</td>
</tr>
<tr>
<td>Queens Park</td>
<td>14,957</td>
<td>528</td>
<td>488</td>
<td>348</td>
<td>320</td>
<td>408</td>
<td>2,092</td>
<td>14%</td>
</tr>
<tr>
<td>Regency</td>
<td>9,925</td>
<td>254</td>
<td>178</td>
<td>167</td>
<td>125</td>
<td>120</td>
<td>844</td>
<td>9%</td>
</tr>
<tr>
<td>Rottingdean Coastal</td>
<td>13,581</td>
<td>821</td>
<td>643</td>
<td>590</td>
<td>463</td>
<td>529</td>
<td>3,046</td>
<td>22%</td>
</tr>
<tr>
<td>St Peters and North Laine</td>
<td>18,275</td>
<td>360</td>
<td>243</td>
<td>198</td>
<td>139</td>
<td>152</td>
<td>1,092</td>
<td>6%</td>
</tr>
<tr>
<td>South Portslade</td>
<td>9,545</td>
<td>414</td>
<td>307</td>
<td>289</td>
<td>199</td>
<td>167</td>
<td>1,376</td>
<td>14%</td>
</tr>
<tr>
<td>Hove Park</td>
<td>10,576</td>
<td>540</td>
<td>386</td>
<td>357</td>
<td>271</td>
<td>324</td>
<td>1,878</td>
<td>18%</td>
</tr>
<tr>
<td>Westbourne</td>
<td>10,043</td>
<td>327</td>
<td>268</td>
<td>256</td>
<td>283</td>
<td>461</td>
<td>1,595</td>
<td>16%</td>
</tr>
<tr>
<td>Wish</td>
<td>9,627</td>
<td>334</td>
<td>318</td>
<td>273</td>
<td>229</td>
<td>318</td>
<td>1,472</td>
<td>15%</td>
</tr>
<tr>
<td>Withdean</td>
<td>14,440</td>
<td>591</td>
<td>470</td>
<td>448</td>
<td>412</td>
<td>397</td>
<td>2,318</td>
<td>16%</td>
</tr>
<tr>
<td>Woodingdean</td>
<td>9,765</td>
<td>570</td>
<td>413</td>
<td>373</td>
<td>317</td>
<td>224</td>
<td>1,897</td>
<td>19%</td>
</tr>
<tr>
<td>Brighton &amp; Hove</td>
<td>272,952</td>
<td>9,715</td>
<td>7,862</td>
<td>6,697</td>
<td>5,572</td>
<td>6,003</td>
<td>35,849</td>
<td>13%</td>
</tr>
</tbody>
</table>
Although there is no good quality data currently available on the prevalence of dementia in different ethnic groups, it is likely that dementia will be more common among Asian and Black Caribbean elders. This is because high blood pressure, diabetes, stroke and heart disease, which are risk factors for dementia, are more common in these communities. Numbers of Black and Minority Ethnic (BME) populations are expected to increase in coming years, particularly in the over 65 age group as these populations age. Nationally it is estimated that dementia will increase seven-fold by 2051 in BME groups, compared to the two-fold increase in the rest of the population. Ethnicity is also an important issue in relation to dementia because of the additional challenges faced in providing culturally sensitive services and raising awareness of dementia among populations that evidence shows often have low levels of knowledge and understanding of the condition.

In Brighton & Hove, the most recent population estimates (2011) show that 80.5% of the city's population are White British and 19.5% are from a BME group (compared to 12% in 2001). This is a lower proportion than England (20.2%), but higher than the South East (14.8%). A larger proportion of BME residents are currently in the younger adult age groups of 15-39 years compared to the White British population while a larger proportion of white British residents are in the older age groups aged 40 and over. (Figure 1)

Figure 1. Percentage of BME and White British people by age groups in Brighton & Hove, 2011

Source: ONS, Census 2011

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7.1.1.4. Gender

Dementia prevalence is higher in women, especially for Alzheimer’s disease, and although incidence rates for vascular dementia are higher in men aged 65-70 years, this disparity evens out in older ages for women aged 85-90 years. The difference in prevalence of dementia between women and men for Alzheimer’s disease is largely due to women’s longer life expectancy although some incidence studies also confirm higher rates of new cases in women, suggesting additional factors are involved.\(^8\) In 2011 there were fairly equal proportions of males and females living in Brighton & Hove with mid year estimates suggesting there were 136,800 females and 136,200 males. In the South East and England as a whole there are slightly more females than males at 51% to 49% in both.

7.1.1.5. Learning disabilities

It is known that people with learning disabilities are at increased risk of developing dementia and this is particularly true for people with Down’s syndrome who have a lower age of onset than the general population, at 54

years.\(^9\) This is of increasing importance as advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities.

Based on national prevalence rates, there were an estimated 4,400 adults aged 18-64 years with a learning disability living in Brighton & Hove in 2011, with around 6% with a severe learning disability. It is estimated that there will be a 3% increase in the number of adults with a learning disability in the next 5 years and a 5.1% increase in the next 10 years, with the highest increase amongst people aged 55 and over and those with more severe learning disabilities.

In terms of people known to services with dementia and a learning disability, there are currently 13 individuals on the Community Learning Disability Team’s dementia care pathway aged between 45 and 80 years. Of these 8 are women and 5 are men and of these 7 have Down’s Syndrome. Eight live in learning disability residential care homes and the rest in general care homes for older people, nursing homes, with a family and shared lives placement.\(^10\)

7.1.1.6. Sexual orientation

Lesbian, gay and bisexual people with dementia are at risk of health inequality and face challenges that people in heterosexual relationships don’t. Older LGB people are more likely to be single and live on their own than heterosexual people.\(^11\) They are less likely to have children or see family members, so that without this support as they get older they are more likely to need Adult Social Care. They may also fear prejudice and discrimination from support groups and residential care staff, which may put them off from seeking help with their dementia.\(^12\)

This is a pertinent issue for Brighton & Hove where up to 40,000 (16%) of the population may be LGBT, the highest proportion outside London.\(^13\) Older people’s services including care homes will need to ensure that staff are trained to meet the needs of LGBT people, including those with dementia.

7.1.2. Population projections

The overall population of Brighton & Hove is predicted to increase from 273,000 people in 2011 to 288,600 by 2020 (a 6% increase). POPPI does not include population projections beyond 2020. However, the number of over 65s is estimated to rise by around 12%, which is about 40,000 people by 2020.\(^14\) The biggest increases are expected to be in the 70-74 age group with an

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10 Email communication from David O’Neil SPFT Community Learning Disability Team 2014
12 Alzheimer’s Society. Supporting lesbian, gay and bisexual people with dementia. Alzheimers.org.uk.
increase of 1,900 people (24% increase) and in the 90+ age group with an increase of 1,100 people (48% increase). These increases highlight the future challenge of providing adequate dementia care in Brighton & Hove.

Table 2. Population projections for Brighton & Hove for 2012-20

<table>
<thead>
<tr>
<th>Age/year</th>
<th>2012</th>
<th>2014</th>
<th>2016</th>
<th>2018</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>65 - 69</td>
<td>10,600</td>
<td>11,100</td>
<td>11,100</td>
<td>10,100</td>
<td>10,100</td>
</tr>
<tr>
<td>70 - 74</td>
<td>7,700</td>
<td>8,000</td>
<td>8,500</td>
<td>9,600</td>
<td>9,800</td>
</tr>
<tr>
<td>75 - 79</td>
<td>6,700</td>
<td>6,700</td>
<td>6,700</td>
<td>6,700</td>
<td>7,100</td>
</tr>
<tr>
<td>80 - 84</td>
<td>5,500</td>
<td>5,400</td>
<td>5,400</td>
<td>5,400</td>
<td>5,600</td>
</tr>
<tr>
<td>85 - 89</td>
<td>3,700</td>
<td>3,700</td>
<td>3,700</td>
<td>3,800</td>
<td>3,800</td>
</tr>
<tr>
<td>90+</td>
<td>2,400</td>
<td>2,700</td>
<td>2,900</td>
<td>3,100</td>
<td>3,300</td>
</tr>
<tr>
<td>Total 65+</td>
<td>36,600</td>
<td>37,600</td>
<td>38,300</td>
<td>38,700</td>
<td>39,700</td>
</tr>
</tbody>
</table>

| Total population | 275,300 | 279,300 | 282,800 | 285,800 | 288,600 |
| % of total population 65+ | 13.3% | 13.5% | 13.5% | 13.5% | 13.8% |

Data: ONS population projections

7.2. Modifiable risk factors for dementia

Prevention of dementia is a crucial aspect of a comprehensive dementia strategy and key to this is an understanding of the modifiable factors that increase the risk of developing dementia. Non modifiable risk factors for dementia are covered above in population structure.

The Cognitive Function and Ageing Study in 2011 (CFAS II) suggested that the prevalence of dementia in over 65s has decreased over the preceding 20 years since CFAS I was published. While the actual numbers of people estimated to have dementia increased from 664,000 to 670,000, this represented a decrease in prevalence from 8.3% to 6.5%. This decrease is thought likely to be due to changes in health behaviours and improved management of cardiovascular risk factors which have prevented or delayed the onset of dementia at a population level. This is an important finding as it suggests that prevention of dementia is possible.15

Furthermore, while identical twin studies have linked several genes to an increased risk of Alzheimer’s disease, it is not uncommon for one twin to suffer with dementia but the other not to. This suggests that other factors including lifestyle and environmental ones are also important in determining development of the disease.16 Many of these factors are related to cardiovascular health.

15 http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61579-2/fulltext
7.2.1. Smoking
Smoking has been clearly demonstrated to be a risk factor for dementia although quitting is thought to reduce risk back to normal background levels. In 2012, the Health Counts survey gave a smoking prevalence figure of 23.1% in Brighton & Hove which is similar to the Integrated Household Survey which gave a prevalence of 22.9% for 2011/12. Both give a local prevalence which is higher than England (20%).

There is a clear relationship between smoking and age, with smoking prevalence generally falling with age and by the age of 75 years or over, for males and females, smoking prevalence in Brighton & Hove reaches its lowest point (5% for males and 10% for females).

7.2.2. Obesity
There is evidence that overweight and obesity in mid-life can increase the risk of dementia. In the 2012 Health Counts survey, 14% of respondents who self-reported their height and weight were classified as obese. However, this is considerably lower than estimates for Brighton & Hove based upon the Health Survey for England of 20%. The England prevalence is 24%.

There was however a significant increase in obesity prevalence in Health Counts from 2003 (10%) to 2012 (14%), but no significant change in the prevalence of overweight (33% vs. 30%).

Obesity levels are predicted to increase from approximately a quarter of the population in England to 41-48% in men, and to 35-43% in women by 2030 which would equate to 11 million more obese adults by 2030, 3.3 million of whom would be older than 60. This increase is likely to offset any recent reductions in prevalence due to improved cardiovascular health.

7.2.3. Diabetes
Diabetes is a risk factor for cerebrovascular disease and the subsequent development of dementia with growing evidence linking Type 2 diabetes with an increased risk of dementia. In 2012, 3.3% of people aged 17 years or over in Brighton & Hove were recorded as having diabetes by their GP and this figure is increasing each year. Modelled data suggests that the actual prevalence is far higher with an estimate of 6.3% prevalence in 2013.

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19 http://www.bmj.com/content/330/7504/1360
21 Professor Banerjee, stakeholder meeting 2013.
7.2.4. Physical activity
Physical activity has been shown to prevent cognitive decline with ageing and
the progression of dementia at all stages of the disease.23 According to the
Health Counts Survey, a quarter of adults in Brighton & Hove are achieving
recommended levels of physical activity and this is similar to the proportion
estimated by Sport England’s Active People Survey (28%). This is higher than
the Active People Survey figure for the South East and England of 22%. Health
Counts also suggests that the proportion of people in Brighton & Hove
doing the recommended levels of physical activity is increasing, with levels at
only 15% in the 2003 survey. This is similar to national levels which are also
reported to be increasing.

Despite well documented benefits of physical activity, participation drops with
increasing age with the Active People Survey showing only 22% of adults
aged 55+ engage in three 30 minute sessions per week. The Health Counts
Survey also suggests that the proportion of women doing recommended
levels of physical activity is lower than for men.

7.2.5. Alcohol consumption
Drinking more than the recommended levels of alcohol significantly increases
the risk of developing dementias such as Alzheimer's and vascular dementia.
In addition, people who regularly drink excessive amounts of alcohol over a
long period of time are at risk of developing Korsakoff's syndrome which is a
dementia specifically related to alcohol. However, research suggests that
light-to-moderate amounts of alcohol may protect the brain against dementia
and keep the heart and vascular system healthy.24

The 2012 Department of Health Profiles provide an estimate of 24% of adults
in the city drinking at increasing risk or higher risk levels, which is not
significantly different to the 22% across England (modelled data based upon
2008/09 data from the General Lifestyle Survey). According to Health Counts,
the percentage of people drinking at increasing or higher risk levels in the City
has actually fallen significantly since 2003 but is higher than 1992 levels.

7.2.5. Residential status
7.2.5.1. Living alone
Living alone has implications for dementia care. The further the disease
progresses, the more intensive the care required becomes. People living
alone are at risk of accidents in the home due to memory loss and are likely to
be admitted to a care home earlier than those living with another person.

The 2011 Census found the following proportions of men and women living
alone in the age ranges 65-74 and 75+:

23 http://www.alzheimers.org.uk/factsheet/529
Table 3. Proportion of males and females living alone by age, Census 2011.

<table>
<thead>
<tr>
<th>Age range</th>
<th>% males</th>
<th>% females</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-74</td>
<td>22%</td>
<td>30%</td>
</tr>
<tr>
<td>75+</td>
<td>35%</td>
<td>58%</td>
</tr>
</tbody>
</table>

These proportions can be applied to the ONS population projections for Brighton & Hove for 2012 – 2020 to give an estimate of the number of men and women aged 65 years and over living alone. The figures suggest that there are large numbers of women aged 75 and over living alone in the City. However these may be an underestimate as the 2011 Census showed that Brighton & Hove has above the national average of single person households: 36% compared to 30% for England as a whole.

Table 4. People aged 65 and over living alone, by age and gender, projected to 2020

<table>
<thead>
<tr>
<th>Age range</th>
<th>2014</th>
<th>2016</th>
<th>2018</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males 65-74 predicted to live alone</td>
<td>2,090</td>
<td>1,940</td>
<td>2,134</td>
<td>2,156</td>
</tr>
<tr>
<td>Males 75+ predicted to live alone</td>
<td>2,516</td>
<td>2,618</td>
<td>2,686</td>
<td>2,822</td>
</tr>
<tr>
<td>Females aged 65-74 predicted to live alone</td>
<td>2,964</td>
<td>3,057</td>
<td>3,088</td>
<td>3,119</td>
</tr>
<tr>
<td>Females aged 75+ predicted to live alone</td>
<td>6,438</td>
<td>6,438</td>
<td>6,496</td>
<td>6,612</td>
</tr>
<tr>
<td>Total population 65-74 predicted to live alone</td>
<td>4,054</td>
<td>4,997</td>
<td>5,222</td>
<td>5,275</td>
</tr>
<tr>
<td>Total population 75+ predicted to live alone</td>
<td>9,056</td>
<td>9,056</td>
<td>9,182</td>
<td>9,434</td>
</tr>
</tbody>
</table>

Source: Census 2011 applied to ONS and POPPI population projections.

**Recommendation**

*Ensure those living alone with dementia are identified as in need of support, to avoid residential care and make links to Better Care/Frailty initiatives.*
8. The level of need in the population of Brighton & Hove

8.1. Prevalence of dementia

8.1.1. Estimated prevalence

The Alzheimer's Society report "Dementia UK" (2007), used an expert Delphi consensus method to estimate national dementia prevalence. This involved a panel of experts who reviewed all relevant published information on the prevalence of dementia in the UK before individually preparing an estimate of the prevalence rates by age and gender. These rates were collated and the full list was reviewed by the group to produce an agreed set of National Dementia Prevalence Rates. An NHS dementia prevalence calculator has been developed by the Alzheimer's Society which allows users to estimate the prevalence of dementia for their own local area based on these national estimates while additionally applying the aggregated age and gender profiles of their General Practice patient lists, and taking into account the number of older people living in local residential care and nursing homes.

The estimates suggest that prevalence of dementia in the UK is relatively low in 65-69 year olds (1.3%), increasing with age to almost a third of the population aged 95 and over. The prevalence is also slightly higher in females than males. In Brighton & Hove this would mean there are approximately 988 males and 1,992 females over 65 with dementia.25

Table 5. Estimated prevalence and number of dementia in people over 65

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Prevalence estimate based on national figures</th>
<th>Estimated number in Brighton &amp; Hove</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female %</td>
<td>Male %</td>
</tr>
<tr>
<td>65-69</td>
<td>1.0</td>
<td>1.5</td>
</tr>
<tr>
<td>70-74</td>
<td>2.4</td>
<td>3.1</td>
</tr>
<tr>
<td>75-79</td>
<td>6.5</td>
<td>5.1</td>
</tr>
<tr>
<td>80-84</td>
<td>13.3</td>
<td>10.2</td>
</tr>
<tr>
<td>85-89</td>
<td>22.2</td>
<td>16.7</td>
</tr>
<tr>
<td>90-94</td>
<td>29.6</td>
<td>27.5</td>
</tr>
<tr>
<td>95+</td>
<td>34.4</td>
<td>30.0</td>
</tr>
<tr>
<td>All 65+</td>
<td>9.4%</td>
<td>6.0%</td>
</tr>
<tr>
<td>Whole population</td>
<td>1.4%</td>
<td>0.7%</td>
</tr>
</tbody>
</table>

Data: based on Alzheimer’s Society, Dementia UK. The full report, 2007 applied to Brighton & Hove population using the Dementia Prevalence Calculator. (Figures may not sum due to rounding)

25 http://www.dementiaprevalencecalculator.org.uk/calculator/estimated_prevalences.html?type=LA&organisation_id=00ML
As stated previously, the CFAS I and II studies have suggested a decrease in prevalence over the past two decades. This means that the prevalence estimates based on the Alzheimer’s Society report in 2007 upon which the figures in Table 5 are based are considered likely to be overestimates. The decrease in prevalence in over 65 year olds from 8.3% in CFAS I to 6.5% in CFAS II represents a decrease of 22% and were this to apply to the estimated number of people 65 years and over in Brighton & Hove in 2012 with dementia of 2980, this would reduce to approximately 2300 people. However, the important point to note is that even with a small decrease in incidence and prevalence, increasing and ageing populations are still expected to double the number of people with dementia in the next generation.  

8.1.2. Quality and Outcomes Framework data

According to 2012/13 Quality and Outcomes Framework (QOF) data for Brighton & Hove, there were a total of 300,503 people registered with GPs in the area and 1,310 of these had been diagnosed with dementia. This equates to 0.4% of the people registered with local GPs and compares to 0.6% in England and 0.6% in the South of England Commissioning Region. It is also lower than each of the other 12 Surrey and Sussex Clinical Commissioning Groups (Figure 3). The QOF data is not available by different age groups so it is not possible to adjust it to take account of the differences in the age structures of practices. Therefore care should be taken when comparing Brighton & Hove to other CCG areas, particularly those within the Surrey and Sussex Area Team where it is known that Brighton & Hove has a lower proportion of over 65s.

It should also be noted that the fact that QOF data is not available by different age groups also means that these figures include cases of diagnosed early onset dementia although these numbers are likely to be very small compared to late onset dementia. For example the dementia prevalence calculator estimates there are 40 men and 25 women under the age of 65 with dementia in Brighton & Hove.

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27 http://www.hscic.gov.uk/catalogue/PUB12262
The GP Practice with the highest proportion of dementia patients is Wish Park (Evans) and the practice with the greatest number of dementia patients is Sackville Road (McMinn). There are seven practices with less than five patients.
GPs in Brighton & Hove are grouped into three localities; East, Central and West. The dementia register figures for these localities are displayed in Table 6.

Table 6. Dementia registration with GPs in localities 2011/12.

<table>
<thead>
<tr>
<th>Locality</th>
<th>Total registered</th>
<th>patients</th>
<th>Dementia register</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>89,280</td>
<td>344</td>
<td>0.4%</td>
<td></td>
</tr>
<tr>
<td>Central</td>
<td>106,997</td>
<td>276</td>
<td>0.3%</td>
<td></td>
</tr>
<tr>
<td>West</td>
<td>105,764</td>
<td>512</td>
<td>0.5%</td>
<td></td>
</tr>
<tr>
<td>Brighton &amp; Hove</td>
<td>302,041</td>
<td>1,132</td>
<td>0.4%</td>
<td></td>
</tr>
</tbody>
</table>

8.1.3. Dementia diagnosis rates

It is known that nationally many cases of dementia are undiagnosed and these figures appear to show that this is the case in Brighton & Hove with only 1,310 people on GP registers in 2012/13 with a diagnosis compared to an estimated total of 3,046. This means that 43% of the expected cases have been diagnosed. However, this is higher than the same figure for 2011/12 of 37.2% diagnosed. This figure in 2011/12 was lower than the East Coast figure of 40.3% and also England as a whole at 44.2%. Without a diagnosis, people are unable to gain access to specialist dementia services and get the support they need during the early stages of the disease. Primary Care should aim to diagnose as large a proportion of the expected dementia cases as possible. However, in 2011/12 Brighton & Hove ranked 159 out of 176 PCTs in the country on this measure. The dementia prevalence calculator provides estimates of the number of undiagnosed and diagnosed cases within Local Authority areas28 (Figure 5).

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Figure 5. Estimated number of undiagnosed and diagnosed cases of dementia in Brighton & Hove and other ONS Regional Centres Local Authorities 2011/12.

Figure 6 gives the proportion of the estimated number of cases of dementia that have been diagnosed in each practice. The ranges of percentages are from 191.9% to 1.6%. The one practice that has a figure over 100% has more diagnosed cases than their estimated number (School House Surgery, 192%). No data is available for five practices.

Figure 6. Proportion of estimated cases diagnosed by Practice 2011/12.

Source: Dementia Prevalence calculator: http://www.dementiaprevalencecalculator.org.uk/calculator/organisations.html

Following Department of Health guidance the Better Care Plan for the city has recently set an ambition diagnosis rate of 56% for 2014 and 67% by 2015. In view of this it is recommended that those GP Practices with a diagnosis rate
of fewer than 50% are targeted to increase their rates. An initial audit of QOF dementia registers may contribute to an increased rate of diagnosis.

8.2. Dementia prevalence trends and projections

Dementia has been included in the QOF measures since 2006/07. Since that time the proportion of the GP registered population in Brighton & Hove diagnosed with dementia has increased slightly from 0.3% to 0.4% in 2012/13 (Figure 7). This reflects an increase in actual numbers from 937 to 1,310.

The estimated national dementia prevalence rates can be applied to the ONS population projections displayed in Table 2 to provide predictions of the number of people with dementia in 2020. These are displayed in Table 7.

Table 7. Projected dementia prevalence in Brighton and Hove 2012-2020

<table>
<thead>
<tr>
<th>Age/year</th>
<th>2014</th>
<th>2016</th>
<th>2018</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>65 - 69</td>
<td>139</td>
<td>139</td>
<td>126</td>
<td>126</td>
</tr>
<tr>
<td>70 - 74</td>
<td>219</td>
<td>233</td>
<td>263</td>
<td>269</td>
</tr>
<tr>
<td>75 - 79</td>
<td>394</td>
<td>392</td>
<td>399</td>
<td>415</td>
</tr>
<tr>
<td>80 - 84</td>
<td>647</td>
<td>647</td>
<td>644</td>
<td>657</td>
</tr>
<tr>
<td>85 - 89</td>
<td>767</td>
<td>744</td>
<td>744</td>
<td>761</td>
</tr>
<tr>
<td>90+</td>
<td>807</td>
<td>865</td>
<td>924</td>
<td>982</td>
</tr>
<tr>
<td>Total 65+</td>
<td>2,972</td>
<td>3,020</td>
<td>3,100</td>
<td>3,211</td>
</tr>
</tbody>
</table>

Source: NHS Dementia prevalence calculator and ONS. Accessed on www.poppi.org.uk

These figures do not take account of the anticipated decrease in dementia due to the decline in the number of people at risk from cardiovascular disease.

Figure 7. Proportion of diagnosed dementia on GP registers in Brighton & Hove, South East Coast SHA and England 2006/07 – 2012/13.
**Recommendation**

Pool data to develop a dementia dashboard for regular review by a strategic monitoring group. This would monitor QOF Dementia Registers, MAS data, Dementia DES, and prescribing data to assess the effectiveness of interventions to increase early diagnosis of dementia and enable targeting of interventions on areas that need improvement.

8.3. Dementia related deaths

In 2012, 155 deaths from dementia were recorded in Brighton & Hove which accounted for approximately 7% of all deaths that year. Out of these 155 deaths, 147 (95%) were in people aged 75 or over which accounted for approximately 10% of all deaths in that age group.

There appears to have been a sharp increase in the number of deaths with dementia as the primary cause in 2011 which may be due to a change in recording of dementia as the primary cause of death, rather than an actual increase in the number of people dying from dementia. Death certificates record an additional secondary diagnosis field but no dementia codes were recorded in this field during the period 2001 to 2011.

**Figure 8. Deaths from all types of dementia, 2001-2011.**
9. Views of public

The views of people with dementia and their carers were captured to inform the needs assessment findings, using a variety of methods. These included a literature review. Incorporating the findings of a number of focus groups run by the Trust for Developing Communities as part of work they were doing on developing a Dementia Friendly Toolkit. The Carers’ Centre Dementia Needs Assessment Worker also undertook an analysis of the unmet needs identified by carers as part of their assessment process. Extensive consultation work was also conducted with people with dementia and their carers in 2010 by the Sussex Dementia Partnership as part of its work on reviewing and identifying gaps in the care pathway. The reports of these consultation events were analysed for recommendations.

9.1. Literature Review

A literature review of qualitative evidence from a national level was undertaken to ascertain any key issues identified by users and carers in studies about their experiences of dementia services. Google Scholar was searched using the terms: dementia carers survey; dementia patient views on unmet need; qualitative dementia studies in the UK; quality outcomes for people with dementia.

The following key issues were highlighted in the studies:

9.1.1. Pre-diagnosis care

The period before a diagnosis is made is a time of fear and uncertainty, and can place stress on relationships. The person being diagnosed fears becoming incontinent, having to go into a care home and the affect of the diagnosis on their spouse and children. During this period counselling would give people the opportunity to voice their fears and expectations and imparting knowledge and information may help people with their fears. Pre-diagnostic visits may also help start the process of self-management and develop therapeutic relationships.

9.1.2. Diagnosis

Diagnosis was often a frustrating, disorganised and uncertain process and needed to be sensitively and appropriately disclosed. The earlier a diagnosis was made the easier subsequent transitions would be. The reactions to receiving a diagnosis could either be shock if an individual was unaware of their memory loss or validating if it helped to explain experiences. Getting a

29 Steeman E, Dierckx de Casterle, Godderis J, Grypdonck M. Living with early stage dementia a review of qualitative studies. Integrative Literature Reviews and Meta-analysis. 2006 Blackwell Publishing Ltd.
32 Alzheimer’s Society survey 1995
diagnosis could also reduce a person’s self-confidence, reduce daily activities and produce a sense of loss. Proactive care needs to begin early in the diagnostic process to reduce disability, dependency and suffering.

9.1.3. Accessing supports and services
Primary care has a lack of knowledge and support which can make it difficult to get help. They need to be able to refer people to specialist statutory and voluntary sector services and provide on going support and advice. Memory clinics and specialist services are positive but there could be delays in accessing these. Users and carers wanted supports or services to be appropriate for their stage of the illness and current needs. In general support needed to give people a sense of belonging and being loved; being understood, accepted and valued as an individual; being included in enjoyable and meaningful activities and feeling supported.

9.1.4. Addressing information needs
Carers feel they have to push for information. They want clear written information on cognitive testing, medications, disease progression, finances and behaviour.

9.1.5. Disease management
Patients and carers want physicians to be knowledgeable about dementia and its management. They don’t want to have to approach providers to initiate aspects of management such as medication discussions and concerns about driving.

9.1.6. Communication and attitudes
Poor communication can act as a barrier to treatment. Carers and patients want to have their perspectives valued at every stage of the treatment and want to be treated with dignity and respect.

9.1.7. Recommendations to health care providers
Prorok and Horgan et al.’s (2013) meta-ethnographic analysis of qualitative studies made the following recommendations for health care providers to improve the dementia patient/carer experience.

- Improve communication and attitudes around dementia
- Primary care to be aware of person centred approaches to care
- Educate providers in dementia management and skills
- Outreach and public education strategies to increase awareness of dementia and early recognition of signs of cognitive changes
- Increase early detection in primary care and community settings, through screening programmes for those at risk
- Educate people in self-management skills
- Appoint specialists like dementia care managers in primary care.
- Psychoeducation for care givers via primary care or links to Alzheimer’s society.
9.1.8. Systematic review on subjective experiences of people living in the community with dementia.\textsuperscript{33}

This systematic review aimed to study the needs, demands and coping strategies of people living in the community with dementia. It included all types of dementia and took evidence from qualitative, quantitative and mixed research methods. Six reviews of 220 studies published between 2002 and 2009 were included in the final analysis. The findings showed that most people with dementia had needs similar to those with other long term conditions, as well as feelings of loss related to impaired cognition. Few demands were found, apart from a demand to be involved with the diagnostic process, as they felt excluded by professionals and carers. Coping strategies identified included writing lists, seeking information on the disease, health promotion or prevention activities such as memory training. The review concluded that a relevant proportion of people with dementia are able to express their needs and demands and should be included in research and decision making.

9.1.9. Residential care and End of Life Care

Two studies were reviewed in relation to residential care and end of life care for people with dementia. Key issues for patients, relatives and staff in residential dementia care included: privacy, dignity and choice around personal possessions, food and money; relationships in the care environment and how vulnerability, abuse, complaints and protection issues were managed; access to activities tailored to the individual’s needs; dementia friendly physical environment; expectations of the care environment by families and carers; formal structures in the home for user and carer views at all levels.\textsuperscript{34}

A qualitative study of 7 carers and 50 professionals involved in providing End of life Care found the following barriers in caring for dementia patients: out of hours/night time – lack of out of hours care and access to notes; difficulties with night time emergency calls and hospital admission; lack of night time support for residential homes. Training – lack of skills in dementia care among ambulance crews, hospital and care home staff. Advanced care planning not being implemented; carers feeling unsupported after bereavement, particularly if loved one died in care home. Good practice in overcoming these barriers was felt to be Care Home In-reach services.


**Recommendations**

People with the symptoms of dementia and awaiting diagnosis should be offered pre-diagnostic counselling, to help them discuss their fears, start the process of self-management and develop therapeutic relationships.

Support all people recently diagnosed with Mild Cognitive Impairment and Dementia to access evidence based activities available at the different stages of disease progression e.g. Active for Life, Health Walks, Healthy Eating, Singing For The Brain, Dancing, Dementia Cafes.

People with dementia, including those not eligible for Adult Social Care, need to be made aware of the support services, activities and information available for them at each stage of their illness.

**9.2. Focus Groups**

During December 2013, the Trust for Developing Communities carried out a series of focus groups and individual interviews with people with dementia and their carers to help inform the development of a Dementia Friendly Toolkit. Interviews took place with approximately 33 people, including 7 carers at a variety of locations: Bevendean De Café, Dyke Road De Café, Mad Hatters Lunch Club, Alzheimer’s Society Carers Support Groups, Hove Group, Sanders House, Brighton Group, Bread Street, St. John’s Community Centre.

Questions covered whether the carer or cared for had stopped taking part in something due to the dementia; what could be done to help them take part in activities and what a dementia friendly society would look like and whether they would like more groups to take part in.

Some of barriers identified that prevented participation in activities included:

- **The needs of people with dementia changing as their condition develops** – This meant previously accessible activity such as Singing For The Brain was no longer suitable after a certain point in the condition’s development.
- **Factors that affect participation** - being in a wheelchair, incontinence, forgetting when activities take place
- **Carers restricted in pursuing own interests** - behaviour of cared for meant some previously shared activities were no longer possible. e.g. shopping, gardening, theatre.
- **Communication difficulties** – difficult to hold a conversation
- **Loneliness and isolation**
- **Need for clear signposting and information**
- **Need for supportive transport** – blue badges for people with dementia and dementia friendly taxi firms.
• **Ability to take part in mainstream activities** - e.g. Adult Education during early stages of dementia
• **Dementia services not always appropriate** – some individuals did not feel they were at the stage of needing specialist services i.e. dementia day care centre
• **Stigma surrounding dementia and lack of awareness**
• **Good practice needs to be supported by adequate funding**
• **Need for buddies to meet, greet and support person with memory loss**
• **Need for more support for respite care** – carers need support with financial issues

Positive factors mentioned by the focus groups and interviews included the Dementia cafes and Singing For The Brain. They provided a safe space where people understood dementia.

### Recommendations

*Develop the role of the voluntary sector to provide buddies/befrienders who can outreach to support people with memory loss and take isolated people, including those in sheltered/extra care housing to engage in community activities.*

*Ensure the needs of people with dementia are linked into the Age Friendly City work. e.g. better signage and transport initiatives*

*Ensure the Dementia Friendly Toolkit being developed by the Trust for Developing Communities is implemented.*

*Commissioning Plans for Older People’s services should include the requirement they are dementia friendly.*

*Need to ensure residential, day and emergency respite is included systematically as a part of care planning.*

*Increase awareness of council provided respite service, including amongst those not eligible for Adult Social Care.*

### 9.3. Carers’ Needs Assessment Worker findings.

Carers’ Needs Assessment Workers are employed by the Carers’ Centre and receive referrals for assessment from the Memory Assessment Service for the carers of people diagnosed with dementia. Analysis was undertaken in February 2014 by the Carers’ Needs Assessment Worker of 44 assessments carried out between June 2013 and February 2014.

Analysis of the carers’ needs assessments found the following common themes.
• Information and support - need for information about disease progression, how to manage behaviour, signposting and emotional support. How to access care packages.
• Peer support – meeting other carers was important to share experiences and provide mutual support
• Free home based respite – a particular need for working or non-resident carers
• Emergency Back-up Scheme – opportunity to register with the council’s scheme for alternative home-based support for a disabled person for 48 hours, should an emergency arise preventing the carer providing care and placing the cared for person at risk.
• Importance of a flexible approach to accessing the Carer’s Grant for activities such as adult learning, a break, transport costs
• Importance of counselling opportunities and MBCT course for carers
• The need for good back care advice for carers
• The need for good legal advice for carers, particularly on Powers of Attorney, wills and trusts

Recommendations

The capacity of the voluntary sector counselling service should be increased, so that people who have recently been given a diagnosis of dementia and their families/carers are offered counselling support to cope with the changes and loss arising from diagnosis.

Increase the capacity of the CrISP training so that people with dementia and their families/carers are aware of how to access financial assistance and support with legal issues. Make financial and legal advice available to self-fundeders.

Provide access to an emergency back-up scheme for carers not eligible for Adult Social Care.

9.4. Consultation work

9.4.1. Assets and gaps identified by Sussex Dementia Partnership Service redesign workshops

The following assets in dementia services delivered by the voluntary sector were identified in 2010.
• Good information from internet
• Good support from the Alzheimer’s Society
• Family and friends support
• Good generic national information leaflets on services you can expect to receive from Alzheimer’s society
• PCT (CCG) making good links between dementia and end of life services

Gaps
• Few services for people with dementia who live alone e.g. accessing Alzheimer's Society respite.
• Alzheimer's Society can only accept referrals for their respite service if Adult Social Care eligibility requirements are met. People not reaching this threshold have to self-fund
• Respite service has a waiting list and funding is being reduced.
• Delays in being signposted to voluntary sector
• Repeat process sometimes required to detect diagnosis, leading to delays in treatment and support
• Low level dementia not referred to CMHT
• Lack of information on how to access financial assistance for carers and lack of information on legal issues
• Alzheimer's Society have insufficient capacity to provide information, support and signposting to all that could benefit from it.
• Martlets Home Respite Service and Palliative Care Team are under utilised as people don’t associate them with dementia.

The introduction of the Memory Assessment Service, Dementia Advisers and Carer Support Workers, as well as the work on the End of Life with dementia pathway has addressed the following gaps:
• Memory Assessment Service now provides a diagnostic pathway with early identification and everyone with a dementia diagnosis receives support from a Dementia Adviser for a year.
• The End of Life Care Work and Dementia has increased the uptake of the Martlets Home Respite Service and Palliative Care Team by people with dementia.

9.5. Care Homes and Home Care Surveys

9.5.1. Care Homes Dementia Survey
To help inform any unmet needs in relation to care home dementia care for this needs assessment, a survey was carried out at a meeting of the Brighton & Hove Care Homes Forum in September 2013, by the Public Health Department. A total of 20 managers who attended completed a questionnaire. Although this is a small sample out of the 111 homes in the City it still provides some useful information on the care home services provided for people with dementia. The full details of the survey can be found in Appendix 1.

Results
The most common dementia specific facility provided by care homes was an enclosed secure outside space (90%) but all homes provided at least one dementia specific facility. Very few homes stated they were using memory boxes or reminiscence rooms.
Only 70% of homes indicated that they have a senior member of staff identified with the role of improving dementia care in their homes and this is a recommendation from the national dementia strategy.

Overall there was no one single service that managers felt people with dementia were not receiving enough support from. It is notable that 80% of the managers felt that they received enough support from GPs either fully or to some extent.

The national dementia strategy identifies the importance of person-centred care planning. Eighty-five percent of care homes that answered this question indicated that they complete an assessment of the needs of people with dementia when they are admitted and make a care plan based on this assessment.

Having something meaningful to do is an important part of quality of life and is as true for people with dementia as it is for the rest of the population. Out of the care homes surveyed, 90% indicated that they provide residents with the opportunity to take part in everyday activities which were part of their lifestyles prior to admission. Gardening and tending plants was the most common (70%).

All care homes indicated that they provide at least one regular activity for their residents. These included creative, social and physical activities with life story, singing, art, physical exercise and outings all commonly provided. Again, these activities are key to a good quality of life for people with dementia in care homes.

Voluntary organisations were the most common source of information on dementia care accessed by the care homes (80%).

Training was the most common request for additional support to improve dementia care in the homes.

**Recommendations**

Ensure all care homes have a named senior member of staff leading on improving dementia care.

Encourage care homes to use memory tools like memory boxes and reminiscence rooms.

**9.5.2. Home Care Dementia Survey**

In addition to the care homes survey, a similar survey was conducted of the home care providers in the City. In 2013 there were 43 domiciliary home care

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providers in the city that are registered on the CQC website. 12 of these independent providers hold a contract on the council’s framework, which was awarded through a competitive tender process. Surveys were completed by ten of the Council contracted providers at a Home Care Forum meeting in September 2013. Full details are in Appendix 1.

The ten organisations surveyed provided care for approximately 1,622 people in Brighton & Hove and their combined estimations suggested 812 (50%) of these had diagnosed or undiagnosed dementia. Out of these estimated 812 people, 423 (52%) were diagnosed and 389 (48%) undiagnosed. These findings suggest that the overall prevalence of dementia is lower in home care clients than care home residents (50% vs 64%) although it is important to note that these figures are based on rough estimates only and we cannot be certain they are representative of all care homes or home care.

**Results**
The majority of home care staff (60%) had a Qualifications and Credit Framework (QCF) level award, certificate or diploma in dementia.

Four out of the ten home care managers felt that their clients did not receive enough support from GPs and only three felt that they did.

The main sources of information on dementia care were from voluntary organisations and NHS Choices website.

Suggestions for improving the level of care for residents with dementia were:

- More training that we can pass onto our staff
- Stronger partnership working with other organisations
- The support services - GP, Social work, dentists, OTs, Speech Therapists, Physios, Psychiatrists, Nurses - work in silo but need to work jointly and communicate much more closely
- Better understanding from GPs of the benefits of people remaining in their own homes for as long as possible.
- Improved public awareness of the condition.
- Mandatory basic dementia awareness training provided more regularly
- More training and workshops

**Recommendation**

*Ensure home care providers are included in dementia training*
10. Views of professionals

A series of semi-structured interviews were undertaken to ascertain the views of key stakeholders about how well dementia services were working and to identify any gaps in services or improvements that needed to be made. Eighteen interviews took place, the majority were face to face and one was by telephone. Key staff from the following services were interviewed: Memory Assessment Service (BICS), Age UK, Carers Centre, Alzheimer’s Society, Sussex Partnership NHS Trust Deputy Service Director, Professor Banerjee Brighton and Sussex Universities Medical School, Dementia Specialist Team BSUH (Head of Nursing Older People, Dementia Nurse, Lead Dementia Nurse Specialist, Lead Consultant in Dementia), Mental Health Liaison Nurse Community Rapid Response Service, Mental Health Liaison Nurse Community Short Term Services, Care Home In Reach Service, End of Life Care in Dementia Adviser, St John’s Day Centre, Somerset Day Centre, Ireland Lodge, Wayfield Avenue, Older Person’s Housing Manager, Extra Care Housing Scheme Manager, Assistive Technology Commissioner.

The qualitative data from the interviews was transcribed and analysed by using the constant comparative method to identify emergent themes.

Assets
Interviewees described the following positive factors in relation to the delivery of local dementia services.

a) Joint working - There is a commitment to joint working across agencies. Strategic level discussions work well and the Dementia Implementation Group is felt to be useful. The provision of mental health services “under one roof” enables integrated care to take place. i.e. social care staff are seconded into the mental health team and can provide care packages.

b) Specialist NHS dementia services – The restructuring of the Living Well With Dementia Team was felt to be a positive change and would offer a more specialist service than the CMHTs and had good links with other organisations. NHS dementia services were felt to be working better with social care. The Care Home In-reach and Psychiatric Liaison services were cited as assets. Other positives were the early identification of dementia by the Community Rapid Response Service and introduction of the Butterfly Scheme to BSUH.

c) Day care – Day centres were felt to offer a sense of community and friendship. Activities were needs led offering choice and independence. They offered access to a range of services e.g. CAB, bathing, chiropody, fruit and vegetable van. Flexible attendance hours could be offered. The Alzheimer’s society and Dementia Cafes were cited as assets and Ireland Lodge was felt to benefit from low staff turnover and specialist knowledge from the attached RMN.

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36 The Butterfly Scheme has been adopted by over 100 hospitals across the UK and provides a system of hospital care for patients with dementia. See page 75 for more details
d) Staff development – A range of networks for dementia professionals are either being planned or already exist. The End of Life Care in Dementia Adviser is developing a forum for dementia practitioners in Brighton and Hove. Monthly good practice forums are run by the Care Home In-Reach service for Care Home Managers and Activity Workers that they have previously worked with. Age UK is facilitating an Older People’s Provider Group which would be open to providers of dementia services.

Training in dementia and end of life care has been delivered to GPs and practitioners and will be ongoing. A Namaste workshop of compassionate care has also been delivered. All the staff in local authority commissioned day centres, sheltered and extra care housing schemes interviewed for the needs assessment had received basic dementia awareness training. Age UK Crisis staff had received training in dementia and the Carers Centre and Memory Assessment centre staff had received training in telecare.

e) Dementia Advisers – Dementia Advisers were felt to be an asset being accessible at the point of diagnosis and accepting people with complex needs from the Living Well with Dementia Team.

f) Support for carers – Supports identified for carers included: signposting to services by day centres; receiving information and support from Dementia Advisers at point of diagnosis; peer support and information from the Alzheimer’s Society Carer Information and Support Programme (CriSP); specialist carer workers to carry out Carers needs assessments; IPCT Carers Support Workers identifying “hidden” carers of people with dementia and referring to the Carers Centre; Alzheimer Dementia Carer Support group running in tandem with a client group, thus providing some respite; the Dementia cafes providing a social outlet for carers; the BSUH Dementia Specialist Nursing Team developing a Carers Pack.

g) Information and advice – Alzheimer’s Society Carer Information and Support programme (CriSP) was cited as a good source of information and advice. The Memory Assessment Service was good at getting information to people at the early stages of diagnosis. The Mind Advocacy service was good. Dementia cafes gave information via informal talks from health professionals and It’s Local Actually website was also cited as good.

h) Increasing community awareness – Interventions to increase community awareness of dementia were taking place with the Alzheimer’s Society “Worried about your memory” campaign. The National Alzheimer’s Society had also run awareness sessions to recruit Dementia Friends in the city, workplaces are a target area for recruiting Dementia Friends e.g. BICS staff have received Dementia Friends training.

i) Other – A successful bid to the Department of Health for funding pilots to improve the caring environment for people with dementia, is enabling SPFT to refurbish an acute dementia ward and for RSCH to make A&E more dementia friendly, including a dementia care area. Dementia Friendly colour standards
are used in the routine decoration of council sheltered housing. The Adult Social Care Commissioning Prospectus has improved joint working in the third sector as day centres have collaborated on making joint bids to deliver dementia care. The end of life care in dementia pathway has been developed and identified the needs of clients and carers. The Alzheimer’s Home Support Service provides continuity of staff due to low turnover. Singing for the Brain is beneficial being very social and uplifting.

**Gaps**

Interviewees described the following gaps or areas for improvement in local dementia services.

a) **Need for community support services** – More early support in the community would help to prevent dementia patients reaching crisis point. This is a role which could be provided by Admiral Nurses but there is only one in Brighton & Hove linked to a BUPA nursing home. It was also felt Befriending Services could help fulfil this role.

b) **NHS Dementia Services** – The absence of neuropsychology in the MAS could lead to patients being referred from service to service. The CRRS is concerned that waiting for a GP to refer a patient to MAS, rather than making direct referrals, risks patients dropping out. Some patients with functional mental health issues/co-morbidities referred to MAS require instant care but primary care is unable to access this quickly. It was also felt that the number of previously undiagnosed people awaiting assessment for early diagnosis by MAS was already outstripping its capacity.

It can be difficult to access some services, for example the LWWDT had high eligibility criteria and limited staff capacity, which could lead to delays in reviews.

c) **Lack of affordable Adult Social Care funded specialist beds** - The lack of affordable specialist dementia beds means that some patients have delayed discharges of care from hospital; it also means at times there aren’t local beds for dementia patients to be admitted to and they have to go elsewhere in Sussex, leading to a negative impact on continuity of care, delayed discharges and difficulties for carers.

d) **Crisis** - There is no dementia crisis team in Brighton & Hove, this function is provided by the LWWDT and the Enhanced Duty Team but this service is only available until 7pm. It was felt that if there were a dementia crisis team, patients could be discharged earlier. It was also felt that some Care Homes did not know where to go for support in a crisis.

e) **Gaps in joined up working** – There is a need for more joined up working by community services, particularly offering post discharge support to enable people to stay at home and avoid readmission to hospital or admission to a care home. Housing and health services needed to work closer together, so that sheltered housing are better able to support those with higher level needs.
f) Utilisation of day services – At the time of visits for the needs assessment some of the day services were working at approximately half to a third under occupancy. Some interviewees also felt there was not enough provision for day opportunities for people with dementia.

g) Transport limitations – The capacity of the day centres visited was limited by the accessibility of transport to convey users to the centres. For one centre this could be a very long trip for some centre users, a round trip of up to 3 hours (this is not for a dementia specific day centre). This could be a barrier for older people including those with dementia to accessing day centres.

h) Respite – Access to respite is very important to carers but the three main residential respite providers in Brighton & Hove all have waiting lists, so that those who can afford it pay for a respite service, rather than waiting. Ireland Lodge felt there had been an increase in demand for residential respite over the previous 4 years.

Demand for day time respite showed a different pattern, with lack of demand for the specialist Dementia Crisis Sitting Service leading it to being widened to a general sitting service. A view was also expressed that the need for day time respite may be declining.

i) Support for Care Homes – Homes face their greatest difficulty in supporting people with challenging behaviour and don’t know where to get support from in a crisis. Information could be shared through the range of care home forums.

j) Lack of staff training in dementia – At one older people’s day centre visited for people with low to moderate needs, the staff hadn’t received dementia awareness training. It was felt domiciliary care services needed more knowledge about dementia. Pharmacists are often a source of information for people with early stage dementia and should have dementia training. Staff involved with End of Life Care also need to be trained to recognise the signs of when someone with dementia is dying.

k) Accessing Information – It’s difficult getting people to know about information that is available, as there is no specialist information point or one single point of access for information or resources. There was a view that the Alzheimer’s Society should be the core place for people to go to for information. There needs to be signposting to local services, including comprehensive, up to date lists of activities, services and organisations available. It was felt “It’s Local Actually” and “Information Prescriptions” could be difficult for some carers to navigate.

Specific information and/or training carers required included what to look for in a good care home. Self funded carers/clients needed signposting and information about carers groups.
l) Support for Carers – The biggest gap is education for the carer and person with a dementia diagnosis – they don’t know what to do and carry on getting overwhelmed. There is not enough support, particularly when the cared for goes into a care home. A systematic method of up skilling carers at the point of diagnosis needs to be developed. Carers also need access to legal advice.

The IPCT Carers Support Workers are identifying carers of people with dementia, who have previously been unknown to local services. One day centre visited for older people with low to moderate needs didn’t provide any support services for carers.

m) Primary Care – Primary Care plays a key role in the dementia care system by referring patients to the MAS for diagnosis and treatment, however some GPs are reluctant to make referrals because they don’t believe anything can be done for dementia, which is reflected in a low level of dementia diagnoses in the city. Also GPs don’t always follow-up on requests to make referrals for diagnosis by MAS, made as a result of dementia CQUIN assessments in the acute hospital. Community Short Term Services also felt it would be useful to get systematic feedback from GPs as to whether they were making appropriate referrals for memory assessment. It was felt that Practice Nurses should be more involved in managing dementia patients and that primary care should offer patients more support after diagnosis.

One day centre visited for older people with low to moderate needs didn’t receive any referrals from GPs.

n) Home care – Independent providers aren’t able to provide enough home care, which can impact on hospital discharges and length of stay. It was felt there wasn’t enough home support and some that was currently provided free by the Alzheimer’s Society would soon have to be means tested by users.

o) Stigma/awareness – The community needs to increase its awareness of dementia and in particular people who visit older people at home should be aware of the signs. The voluntary sector has a role to play in increasing awareness. The national Alzheimer’s Society trains people to become Dementia Friends but there is no co-ordination with the local society, so that they are unable to contact people locally who have been trained as Dementia Friends who may wish to become involved in supporting their service in raising awareness.

p) Inequalities – Some GPs aren’t referring those with low to moderate needs to day care and some aren’t referring those with the symptoms of early stage dementia for diagnosis, which will prevent them and their carers from accessing specialist services and support. A lack of affordable specialist dementia beds for those funded by the local authority means they have a lack of choice in comparison to self-funders. Under supply of affordable provision in the city means that between 150-200 people are placed in accommodation by the council outside the city at any one time. Some will have chosen this
option to be nearer relatives.\textsuperscript{37} People with severe dementia also have less choice of care homes. People who can’t afford to pay for their own respite also have to wait longer to access it. And those without access to independent transport can face a long journey travelling to and from day centres.

\textbf{q) People with Learning Disabilities and Dementia} – Staff within the Community Learning Disability Team don’t routinely receive training in dementia awareness. This may be beneficial for people who work with older people with Down’s syndrome in particular. Conversely as people with learning disabilities may use mainstream dementia services or care homes as they get older, it may be beneficial for these staff to receive training about people with learning disabilities.

\textbf{r) Sheltered housing} – Sheltered Housing Managers aren’t utilised enough as a resource for health promotion with their residents and local community.

\textbf{s) Extra Care Housing} - Some residents with dementia can be at risk of isolation because they are unable to access trips out, or attend appointments in the community without someone to accompany them. This is not part of the role of the support workers, who spend a lot of time trying to signpost people to find this type of support. Lifelines “Health Link” volunteers could perform this role but reduced funding means less volunteers are available.

\textbf{t) Assistive technology} 
Primary care, SPFT and Care Homes and new build housing for older people could make more use of telecare for people with dementia.

\textbf{u) Other} – Other issues identified that needed improvement included: long waits for Access Point to answer the telephone; managing personal budgets could be stressful; there were waiting lists for dementia counselling services; the Incontinence Service has a waiting list and provides poor quality pads so people buy their own. Advanced Care Planning needs to happen earlier for end of life care dementia patients; hospitals don’t always have time to pick up that people have dementia when they are admitted to hospital; better signage is needed to make the city dementia friendly.

\textbf{Recommendations}

\textit{Develop a single dementia information point to signpost the public, professionals and care home/home care workers to, for information on: referral and diagnostic pathways, services available, community support, out of hours crisis support, and information for self-funders on how to choose a care home. This is something that the Alzheimer’s Society currently does, but with limited capacity.}

\textsuperscript{37} Communication from Older People’s Commissioner. BHCC. April 2014.
Consider the appointment of specialists like dementia care managers/Admiral Nurses/dementia practice co-ordinator in primary care to provide continuity of care going forward from the point of diagnosis. At the moment Alzheimer’s Society Dementia Advisers are only available for the first year after diagnosis and Alzheimer’s Society dementia support workers have limited capacity.

Optimise the use of Extra Care Housing so that they are able to support people with higher level needs for longer thus easing the pressure on specialist dementia beds.

Increase and develop the capacity of home care to support the increasing number of people with dementia, and develop joint working with health to reduce social isolation and decrease delayed discharges of care from hospital.

Adult Social Care to consider possible options and financial implications of developing planned respite.

Support the development of dementia specialist forums (for practitioners, providers, care homes, to focus on good practice and care).

The wider older people’s workforce needs dementia awareness training (including those working with older people in the learning disability services). This should include information on the memory assessment process and information resources.

Scope the potential for developing post diagnostic interventions to educate the recently diagnosed and their families/carers, about dementia and the steps they can take to self-manage the condition to delay progression. Interventions may include: Cognitive Stimulation, Memory Management, Reminiscence, Music and wellbeing, dance and movement and art-based activities – similar to the East Sussex model or a Recovery College (therapy and education jointly led by professionals and peer educators).

Extra Care Housing and Sheltered housing schemes should become more of a focus for systematic preventative work with residents. Scheme managers should be trained in the early signs and symptoms of dementia and arrange for health promotion interventions for residents, which could also be opened up to the local community.

Promote telecare and telehealth to all who could benefit, including those who live alone and self-funders.
11. Evidence of effectiveness in addressing needs
This chapter looks at national and local evidence on what works well when commissioning dementia care. It includes an overview of the effective models of care and gives a “local view” of how far this has been achieved in Brighton and Hove.

11.1. Models of care

11.1.1. Support for Commissioning Dementia Care  NICE April 2013
Effective implementation of NICE dementia guidance requires the following steps to be implemented by commissioners.

1. Integrated care and service provision
   - Whole –systems approach to commissioning
   - Integrated health and social care needs assessments and commissioning plans
   - Integrated health and social care commissioning functions
   - Involvement of public, people with dementia, and carers in commissioning services
   - Long term conditions approach to supporting people with dementia
   - Personalised care
   - Ensure all health and social care professionals who may come into contact with people with dementia are aware of the condition and where people can access diagnosis
   - Commission multi-agency teams

Local View
The Dementia Implementation Group is looking at ways of involving the public, people with dementia and carers more in the commissioning of services. The other approaches to integration are already taking place.

2. Early Identification, assessment and diagnosis
   - Local target to increase proportion of people with dementia who receive an early diagnosis
   - Commission dementia diagnosis service
   - Initial management of dementia to include information about condition and consideration of medical and social care

Local View
The Memory Assessment Service has been commissioned and the Dementia DES and CQUIN will increase proportion of people getting an early diagnosis. A local target for dementia diagnosis has been set based on national advice.

3. Promoting choice
   Define responsibility for
   - Initiating a care plan and carers assessment
   - Periodic reviews
• Care coordination
• Support people to make Advanced Care Plans for End of Life care
• Access to independent advocacy services

Local View
These aspects are included in the current dementia care pathway.

4. Promoting independence
• Community and residential providers to demonstrate how they enable people with dementia to participate in leisure activities, maintain relationships and contribute to the community
• Invest in support for people to live independently

Local View
Day services reprovision with activity hubs will have an impact but this is an area which will need further development.

5. Providing support
• Increase access to behavioural and social interventions, which can reduce inappropriate antipsychotic prescribing
• Mental health liaison services in hospitals

Local View
These aspects are included in current care pathway.

6. Palliative and end of life care
• Make end of life care commissioners aware of needs of people with dementia
• Support primary care to identity people with dementia to add to palliative care register

Local View
End of life care in dementia pathway addresses these aspects.

11.1.2. 8 Pillars Model of Community Support
Alzheimer’s Scotland has identified eight evidence based approaches for post-diagnostic support for people with moderate to severe dementia living in their own home.

1. Dementia Practice Co-ordinator – a named, skilled practitioner who will lead the care, treatment and support for the person and their carer on an ongoing basis, co-ordinating access to all the pillars of support and ensure effective interventions across health and social care.

Local View
A Dementia Adviser offers support for the first year after diagnosis but there is no on-going role in support as the dementia progresses and no named key worker to act as a single point of contact on anon-going basis.
2. Therapeutic interventions to tackle symptoms of the illness–dementia specific therapies to delay deterioration, enhance coping, maximise independence, and improve quality of life.

**Local View**
Living Well with Dementia Team offer therapeutic interventions but there is no Memory Support Service like the East Sussex model commissioned from the Alzheimer’s Society, which delivers: cognitive stimulation therapy, memory management, reminiscence, music and wellbeing, dance and movement and art-based activities. These are all included as effective interventions in NICE guideline 42, apart from art-based activities.

3. General healthcare and treatment – regular and thorough review to maintain general wellbeing and physical health.

**Local View**
GPs review physical health of those on the QOF dementia register on an annual basis, but those without a formal diagnosis will not be getting this review.

4. Mental health care and treatment – access to psychiatric and psychological services to maintain mental health and wellbeing

**Local View**
Patients with a diagnosis of dementia are not currently eligible to receive mental health support from the Wellbeing Service.

5. Environment – adaptations, aids, design changes and assistive technology to maintain the independence of the person and assist the carer

**Local View**
Dementia Friendly Environment initiative has been taken up by BSUH, SPFT, some GP Practices and Care Homes and assistive technology is available. Both of these interventions could have wider take up.

6. Community connections – support to maintain and develop social networks and to benefit from the peer support for both the person with dementia and the carer.

**Local View**
Dementia cafes fulfil this role and carers support groups but more support from the voluntary sector could reduce social isolation.

7. Personalised support – flexible and person centred services to promote participation and independence

**Local View**
Limited use of direct payments amongst people with dementia.
8. Support for carers – a proactive approach to supporting people in the caring role and maintain the carer’s own health and well being

Local View
Memory Assessment Service offers people a Carers’ Needs Assessment, providing a gateway to generic carers’ services and one year’s support from the Carers Needs Assessment Workers and Dementia Advisers.

**Recommendations**

*Ensure all people with dementia have a named key worker to develop a care plan and act as a single point of contact.*

*Scope the potential for developing post diagnostic interventions to educate the recently diagnosed and their families/carers, about dementia and the steps they can take to self-manage the condition to delay progression. Interventions may include: Cognitive Stimulation, Memory Management, Reminiscence, Music and wellbeing, dance and movement and art-based activities – similar to the East Sussex model or a Recovery College (therapy and education jointly led by professionals and peer educators).*

*Allow people with a dementia diagnosis to access the Wellbeing Service if they can still benefit from talking therapies. Not doing do is a barrier to achieving NICE quality standard 6.*

*All front line workers to assess if living environments need adaptations for persons living with dementia*

*Make Direct Payments and Personal Budgets more attractive and easier to use for people with dementia.*

11.1.3. **Assistive technology**

The evidence base for assistive technology to support people with dementia is small. Woolham (2006) reported improved quality of life and cost-effectiveness from the evaluation of one scheme. Technology for safer walking has the potential to offer benefits to people with dementia and their carers but this should only be used in conjunction with good design of the

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living environment, appropriately trained care givers and stimulation and activity appropriate to the individual. 41

11.1.4. Dementia Friendly Communities
Dementia Friendly Communities do as much as possible to remove barriers to everyday living for people with dementia and their carers. The concept has grown as an offshoot of the WHO Age-Friendly Movement and the development of dementia friendly communities was included in the Prime Minister’s Challenge on Dementia (2012).

The Alzheimer’s Society has identified 10 key areas that can lead to a dementia friendly community.

- Challenging stigma and building understanding of dementia
- Accessible community activities
- Acknowledge potential
- Ensure an early diagnosis
- Practical support to enable engagement in community life
- Community based solutions
- Consistent and reliable travel options
- Easy to navigate environments
- Respectful and responsive businesses and services

The four cornerstones model has been advocated for adoption by local authorities. 42 This gives consideration to Place (housing, neighbourhood, access), People (Family, paid carers, GPs, wider family, friends, neighbours and regular contacts) Resources (natural, physical, cultural, commercial, educational and personal resources) Networks (effective in sharing understanding, practical in solving problems, inclusive in crossing boundaries, discreet in respecting confidentiality).

Housing LIN has developed a checklist for dementia friendly environments. This relates to six design principles of familiarity, legibility, distinctiveness, accessibility, safety and comfort. 43 Sunderland Council has developed a design guide “Enabling Independence for Independent Living” (2013). The West Midlands has developed a pioneering project to create a dementia friendly generation by developing teaching resources and events to teach children about dementia. 44 Hampshire County Council has developed a dementia friendly toolkit 45 and York, Sheffield, Doncaster, Plymouth and Crawley have all been leading work in this area.

42 Local Government Information Unit. Policy Briefing. Dementia Friendly Communities (2013)
44 http://www.dementiaaction.org.uk/dementiafriendlyschools
Brighton and Hove CCG has commissioned The Trust for Developing Communities to develop a Dementia Friendly Toolkit; the Alzheimer’s Society (national) trains Dementia Friends, and some resources were recently allocated to hospitals, GPs and nursing/care homes to develop dementia friendly environments but apart from these initiatives there is currently no co-ordinated programme across the four cornerstones areas highlighted to develop a dementia friendly community. Setting up a Dementia Action Alliance would be a first step towards achieving this. Dementia Action Alliances are multi-agency steering groups of health, social, voluntary, commercial and public sector organisations. They are set up to sign the National Dementia Declaration, which has seven outcomes for people with dementia and their families and includes an action plan. They aim to achieve dementia friendly communities and could focus on initiatives such as developing a “kitemark” scheme for shops and facilities that want to attract customers and be part of a “Memory Aware” scheme to develop a dementia friendly High Street. There are 11 Dementia Action Alliances in the South East, including Crawley, Bexhill, Hampshire, Reading and Oxfordshire. Alliances only have cost implications if they become independent legal entities and employ a co-ordinator.

**Recommendation**

*Establish a Dementia Action Alliance to lead and co-ordinate the development of dementia friendly initiatives, including public education campaigns to increase awareness of the risk factors for dementia and develop a local network of dementia friends.*

**11.1.5. Specialist Community Nursing Service**

Admiral Nurses are RMN specialists in dementia care who are employed by the NHS or other care provider e.g. BUPA and professionally supported by Dementia UK. They offer ongoing support to people with dementia and their carers from the point of diagnosis. They provide education for carers offering comprehensive information programmes on understanding the disease progress, behaviour changes and support around the emotional impacts. Case loads can be up to 75 people. The service has been in parts of the UK for about 20 years but RCTs of effectiveness have not been published. Although a comparative study carried out in 2003 comparing outcomes for usual care and Admiral Nursing care found no differences in survival in the community by the two groups. There was support though for a dementia specialist service which engages the care giver and continues involvement for as long as required, rather than simply carrying out an assessment and referring the person back to social services or primary care.

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Dementia UK has undertaken qualitative studies with carers using the Admiral Nursing Service in Hull\textsuperscript{47} and Hillingdon\textsuperscript{48} in 2013. These both found the carers valued the service for being a dedicated service able to offer them one to one support, peer support, and social elements. Although in Hillingdon some carers said they would have liked more hands on care and a sitting service for the person with dementia and in Hull it was felt the service was working at full capacity so that the needs of the entire population could not be addressed.

11.1.6. Brighton University Research findings

Dance and Dementia Project – A pilot study ran for 3 months in 2011, to explore the role dance played in maintaining and developing relationships between people with dementia and their carers. It found participants became increasingly confident with movement as the sessions progressed. Reminiscence and embodied movement encouraged the recall and expression of memories. Interactions between group members increased but weren’t sustained outside the sessions. The experience was positive for participants and there was some evidence that the impact was sustained after the sessions.\textsuperscript{49}

11.1.7. Evaluation of the Alzheimer’s Society Carer Information and Support Programme (CrISP)

An evaluation of the Alzheimer’s Society CrISP programme found that carers valued the new information they received and the peer support environment in which it was given. A better understanding of the effect of dementia on perception and behaviour increased their confidence as a carer and made them more assertive in seeking services. They valued visual and written information, solving of practical problems, and hearing the experiences of others. The timing of the information received in relation to the stage of dementia the cared for person was at was important, as it could be distressful if received at too early a stage. Many were disappointed to lose the contact and support offered by the course.\textsuperscript{50}

\textsuperscript{47}Maio L, Illiffe S and Botsford J. Carer Satisfaction Questionnaire. Hull Report. Dementia Uk and UCL.
\textsuperscript{48}Maio L, Illiffe S and Botsford J. Carer Satisfaction Questionnaire. Hillingdon Report. Dementia Uk and UCL.
\textsuperscript{49}Research findings. Dance and Dementia Project: findings from the pilot study. University of Brighton. January 2012.
12. Services in relation to need

There are a wide range of services provided by different agencies for people with dementia and their carers. Some are specifically for people with dementia and some are more general. Services have been included under headings for the different stages of the care pathway: concerns about memory loss, diagnosis and treatment, living well with dementia, crises and challenging times, approaching the end of life.

12.1. Concerns about memory loss

12.1.1. Dementia DES
In 2013/14, NHS England introduced a new directly enhanced service (DES) to encourage GPs to identify patients at clinical risk of dementia, offer an assessment to detect possible signs of dementia in those at risk, offer a referral for diagnosis where dementia is suspected and support the health and wellbeing of carers for patients diagnosed with dementia. All but four of the Brighton and Hove GP Practices are participating in this DES but no data is available, as the annual audit has not yet taken place.

Recommendation
Monitor uptake of the Dementia DES as part of a dementia dashboard and encourage an increase in the number of GP Practices participating.

12.1.2. NHS Health Checks
NHS Health Checks include a question for 65-74 year olds asking patients whether they have any of the signs and symptoms of memory problems and if they would like a referral to their GP to follow this up. There is also a national NHS Health Check dementia leaflet available and a web based dementia training tool for staff. Locally this dementia element is gradually being integrated into the NHS Health Check. There is no data available on the number of referrals being made as a result of the health check as there is currently no data collection or reporting requirement, but this may be introduced as Public Health England are looking to more outcomes data from these checks.

12.1.3. Memory Assessment Service
The Brighton and Hove Memory Assessment Service (MAS) is provided by Brighton Integrated Care Services (BICS), Sussex Partnership NHS Foundation Trust (SPFT), The Carers Centre for Brighton & Hove and The Alzheimer’s Society. It started receiving referrals in June 2013. It accepts referrals from GPs, BSUH and SPFT for patients suspected of having mild cognitive impairments or undiagnosed dementia. Patients are assessed at clinics at Portslade GP Practice, County Oak Medical Centre, with another satellite clinic to be set up in Saltdean.
Assessments are carried out by specialist mental health nurses who are part of a multidisciplinary team (MDT). The MDT consists of: 1 session of Psychiatrist, 19 hours RMN, 2 GPs; 1.5 wte Dementia Advisers, and 0.5 wte Carers Needs Assessment Worker. The nurses conduct an assessment of cognitive function using the ACE3 test, take a medical/social history, risk assess for safety and safeguarding of vulnerable adults and alcohol use. Patients also have an MRI scan.

The MDT does not include a neuropsychiatrist, referrals for this have to be made to the SPFT secondary care service.

If a patient receives a diagnosis of dementia they will be offered a Dementia Adviser, for up to a year regardless of the degree of severity. The Dementia Advisers are employed by the Alzheimer’s Society and help with planning for the future and accessing support and information. Carers are also offered a Carer’s Assessment by the Carers Needs Assessment Worker, who is managed by the Carers’ Centre and can signpost to these carer services. Diagnosed patients are also offered a place in a medical trial or are started on anti-dementia drugs. After 6 months of medication initiation with MAS, patients are discharged to shared care by GPs. Complex dementia cases and those who have been on Aricept for a year are referred on to the Living Well with Dementia Team.

**Service activity data** – As the service has only been in operation since June 2013 there is limited data available.

A performance report to the CCG in December 2013, reported that there was a backlog of assessments due to 40 patients being referred prior to commencement of the service, higher than expected referrals and a reduced number of available assessment slots (as the decision was made at service launch to increase assessment time allowed and nurses attending weekly MDTs in person, rather than submitting a report). This had led to 94 patients having an 8 week wait for assessment, rather than the 10 day target set in the KPI. This is followed by a further wait of up to 7 weeks for referral to diagnosis, in other words up to 15 week wait from referral to diagnosis, rather than the KPI wait of 10 weeks. This compares to an English average of 5.2 weeks wait from point referral to assessment and an additional 8.4 week wait from memory clinic assessment to diagnosis. An action plan is being implemented to speed up the assessment process and reduce the backlog by June 2014. This will include a request to over perform on the contract and the appointment of 2 MAS assessment trained Bank nurses or OTs.

Data for June 2013 to March 2014 shows some improvement in reducing the service backlog. With 87 patients waiting for an assessment compared to 116 in previous months but there is still a 7 week wait from GP referral to MAS assessment, rather than a 10 day wait. During the same period 236 assessments have been completed and 180 dementia diagnoses have been

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made by MAS (against a KPI target of 310 per annum). 56 carer assessments have also been completed.

**Recommendation**

*Monitor the reduction of the waiting time for a MAS assessment against the expected KPI as part of a dementia dashboard.*

12.1.4. **Information, Advocacy and Advice – Age UK.**

Age UK provides a range of services for older people but are not dementia specific. They have a role in signposting people with early memory loss to services and providing them with information.

12.2. **Diagnosis and Treatment**

**Primary Care** – see under concerns about memory loss

**Memory Assessment service** – see under concerns about memory loss

12.2.1. **Alzheimer’s Society**

Brighton and Hove Alzheimer’s Society provides a range of services for people with dementia and their families.

**Dementia Support Service** – Two Dementia Support Workers (28 hours per week each) provide support to carers in their own homes. They provide personalised casework which includes giving information on dementia, benefits advice, liaising with health professionals, information on maintaining independence and signposting to other relevant services. They deliver 200 separate contacts for casework per year.

**Home Support Respite Service** – 11 Home Support Workers provide carers with free respite in the home or community for 3 hours a week. The support workers provide activities including reminiscence work and trips out. This is currently a free service but will be means tested by Adult Social Care in the future at £18 an hour. This means that people with a substantial or critical need and eligible for Adult Social Care will have a financial assessment and contribute to the service in line with this, unless they have a substantial care package costing over £900, when they will not have to pay for the service. A private service is available for people not eligible for Adult Social Care.

**Carers Support Groups** – Free monthly carers support group and respite (activity) groups run alongside each other at Belbourne Court with the activity group at Alfred Davey Court in Brighton and Sanders House in Hove.

**Carers Information and Support Programme** – A 6 week basic dementia information course is run for up to 15 carers of people recently diagnosed. There is also a 4 week course for up to 15 carers of people with more advanced dementia. Historically these courses were undersubscribed but now MAS is available and courses are full.
Singing for the Brain – A structured group for patients and their carers involving music therapy and singing. A very social group which runs for 24 people in 8 week blocks at Brighton Museum. It is very popular and in April 2014 had 10 couples on a waiting list.

Dementia Cafes – These have been running since August 2012, with one café in Hove and one in Bevendean, another is due to be established in Brighton. One café is held in the evening and one during the day. Each cafe has up to 25 people, offering a social experience, entertainment, refreshments and informal talks from health professionals. The Dementia Cafes have one part time co-ordinator.

12.2.2. Carers’ Centre
The Carers’ Centre provides support to carers of people with dementia, primarily those still living in the community but also sometimes for people in care homes. There are a variety of support options offered to carers including:

Carers Needs Assessor role in the new Memory Assessment Service. This is a part time role (23 hours pw) and provides a route of referral for the Carers Centre and can provide support for up to a year. There are currently 81 dementia carers assigned to the Carer’s Needs Assessment Worker (managed by the Carers Centre) for Carer’s Assessment and one-year follow up. (April 2014)

Carers groups. Carers of people with dementia can access any of the Centre’s groups which provide social support and information on being a carer.

The Cornerstones Group. A 6 weekly course for carers of people with a life limiting illness. Specialist speakers invited to present. The group is run in partnership with the Martlets.

Legal surgeries. These are free 30 minute sessions introducing the legal aspects of issues relevant to caring for people with dementia such as power of attorney, making wills etc.

Route into counselling. Provide limited funded sessions with Relate and The Rock Clinic

Case work support for carers. Includes a small number of sessions (usually 3–4), providing emotional support information provision, advocacy and individual grant fundraising. Dementia carers amount to 14% of caseloads, and the majority of these have another health condition as well. (April 2014) 127 dementia carers are on the mailing list to receive the quarterly Carers News magazine and 24 dementia carers access the quarterly coffee mornings.

Bereavement support. The Carers Centre organises and runs fun/therapeutic activities 5 times a year for carers who have been bereaved 1
year or less. They can also provide one or two individual sessions of support for carers who are bereaved, including information and signposting to other opportunities, groups and networks.

12.3. Living Well with Dementia

12.3.1. Sussex Partnership NHS Foundation Trust (SPFT)

**12.3.1.1. Young onset dementia**
Sussex Partnership NHS Foundation Trust provides the Young Onset Dementia Service at Buckingham Road on Tuesdays and Fridays and an outreach service one day a week. 12 people use the service, which provides Cognitive Stimulation Therapy, reminiscence therapy, physical activity, groups and outings. Most patients are in their 50s and are referred from the Living Well with Dementia Team or Memory Assessment Service. Carers offer each other informal support.

**12.3.1.2. Living Well with Dementia Team**
Sussex Partnership NHS Foundation Trust has provided the Living Well with Dementia Service since summer 2013. This is a multi-disciplinary team consisting of psychiatry, neuropsychology, occupational therapy, nursing, social work, dietician, physiotherapy and Speech and Language Therapy. The service is provided 7 days a week for 365 days a year from 9am to 7pm. Most patients have complex dementia, challenging behaviour and treatment and care co-ordination issues. The target client group include:

- On-going and active involvement with those individuals who are known (or will be taken on) by the team, but who are currently receiving acute in-patient care.
- People who have complex diagnostic needs referred on from the MAS
- Individuals assessed by the MAS whose conditions have deteriorated and/or need a more comprehensive intervention and treatment portfolio as agreed by service specification requirements
- Existing clients with complex dementia-related needs and other concurrent mental health problems

The team is integrated with Adult Social Care so that seamless packages of care can be provided.

The team aims to:

- Support/review patients receiving a community care funded service either by a managed package of care or a Self Directed Support package.
- Provide crisis support and interventions for those with dementia of any age
- Provide psychosocial interventions, behavioural management and educational programmes for carers and other professionals.
- To ensure appropriate prescribing of anti-psychotics and cholinesterase inhibitors.
12.3.1.3. Relief Service
SPFT and Brighton & Hove Council jointly funded the Alzheimer’s Society to provide a Home Support Respite service. This is not a sitting service. A full programme of activities, tailored to the person with a dementia, is delivered by highly trained support staff. This service is currently funded by Carer’s Grant funding from the Council. From September 2014 this will be spot purchase funding from the Community Care budget.

12.3.1.4. You and Me Group
SPFT run a group to increase understanding of the diagnosis of dementia and a behavioural management approach.

12.3.1.5. The Centre for Dementia Studies
Launched in 2013 by Professor Sube Banerjee, this is a partnership between Brighton and Sussex Medical School and SPFT. It is a centre for dementia research, enabling people to access a range of dementia trials if they wish to do so. It also delivers a range of educational opportunities, including an MSc in Dementia Studies and a Primary Care Dementia Fellowship Programme.

12.3.2. Day Care

12.3.2.1. Ireland Lodge
Ireland Lodge is a Local Authority provided residential care home and day care centre in Woodingdean, for people with organic mental health needs i.e. vascular dementia, Alzheimer’s disease. The day care service has 20 places and provides day time respite. A place costs approximately £40 with meals and transport. In November 2013 the day service had a 50% occupancy, the manager felt this may be because people are using more community resources rather than buildings based services. This requires further investigation, as it may also be due to the referral system.

12.3.2.2. Wayfield Avenue
Wayfield Avenue is a Local Authority provided residential care home and day centre in Hove, for people with functional mental health needs to the west of the city. Where a person has a functional mental health need and dementia, they are referred to Wayfield Avenue rather than Ireland Lodge. The day centre is open 7 days a week for 25 people from Monday to Friday, and for 15 people at weekends (when Ireland Lodge is closed). In November 2013 it had a 70% occupancy rate at weekends, it was felt this may reflect a decline in need for day time respite. This requires further investigation, as it may also be due to the referral system. Day care costs £28 plus meals and transport.

During 2013, 57 out of 62 (92%) day centre users had dementia. After an initial assessment users are reviewed at 6-8 weeks and then at 6 months. The day centre signposts users to other services in the community they may benefit from. Of the 6 day care centre staff all have the council’s basic
dementia awareness training and 3 have completed a diploma in dementia care. The seconded RMN in the team also provides training in dementia.

12.3.2.3. St. John’s Day Centre
Impact Initiatives are commissioned by Brighton and Hove City Council to provide St. John’s Day Centre for Older People aged 60 and over with low to moderate needs. It covers the Brunswick area of the city but will be spreading to north, central and west Brighton from April 2014 in conjunction with services provided by TDC and Hangleton and Knoll Project. The day centre has a capacity for up to 60 people and currently takes up to 30 people a day, with 15 supported places for people referred from Adult Social Care. The service and café is available 7 days a week, with a lunch club at weekends, but three days a week no transport is provided. Attendance costs £2 per morning, £2 per activity, £6 for lunch, £4 for transport and £3-£4 for classes (costs correct December 2013). A wide range of social activities and trips are offered to users, as well as offering a drop-in. The centre also acts as an information hub for local services. It doesn’t currently offer specialist support services to carers. They also run a small befriending service which could be used by housebound people and help reacquaint them with their neighbours.

Approximately 10% of the day centre users have dementia. The service doesn’t receive many referrals from GPs. They have 13 staff members (mainly part time) none of whom currently receive dementia training

12.3.2.4. Somerset Day Centre
Somerset Day Centre is commissioned by Brighton and Hove City Council to provide day care and personal services to 40 older people over the age of 60 years. Up to 28 spaces are available each day for 4 days a week - 8.30am to 4.45pm. There are currently 8 vacancies (December 2013). The Centre serves residents to the East of the city and all staff have received Basic Dementia Awareness Training. As well as providing a range of social activities, the centre also provides a bathing service. Less than a quarter of users are self-funded.

Referrals are made by Adult Social Care Access Point, the IPCT, LWWD Team, CRRS and GP Practices. Approximately a third of centre users are in the early stages of dementia. They are able to continue using the centre until their dementia reaches a stage where they become unmanageable. The centre staff provide support to carers and help single users with dementia make plans for their future. Carers are involved in giving feedback on the service through a questionnaire and users via a bi-monthly meeting.

12.3.3. Direct Payments
National research on direct payments and personal budgets in England for people living with dementia has found that there appears to be no data being collected for this group.\(^\text{52}\)

When compared to similar local authorities the city has an above average performance in relation to the number of direct payments used. In 2012/13, 479 people received direct payments, but the number of older people receiving these was low and of the 479, 9% had mental health issues including dementia. It is envisaged that in the future this proportion will increase as the process of making direct payments is made easier for users and social care and mainstream services will be more flexible and creative in meeting needs through the direct payments route.

12.3.4. Telecare
Brighton & Hove City Council’s CareLink Plus service provides a telecare service to 5,500 residents in the city. This includes the provision of a community alarm service and awareness raising amongst the public and professionals of the assistive technology available. This includes: emergency alarm button, provision of keysafe, medication reminders, bed sensors, floor sensors, flood sensors, smoke and carbon monoxide detectors and exit sensors. Smart technology has also introduced GPS devices that can plot the movement of vulnerable people who wander and raise alerts for help should they go beyond a predetermined area. Ten people in the city are using this device. The service aims to keep people, including those with dementia, living independently and safely at home for as long as possible. The service also supports people being discharged from hospital. Similar technology can also be used in residential homes. Costs vary from £3.35 to £5.12 per week. Services including the Carers Centre Staff and IPCT Team have received training at the Daily Living Centre in the use of telecare. Not many referrals are currently received from GPs. If CareLink staff have concerns about users they can make referrals for follow up via Access Point.

12.3.5. Home care
The council spent £15.7 million on home care in 2012/13, 67% of which was spent on services provided by the independent sector. In 2013, there were 43 CQC registered home care providers in the city, 14 of which are contracted to provide services for the council. In 2012/13 they supported 2,012 people at home, with most people receiving more than 10 hours of care a week. According to Comas-Herrera et al (2007) by 2031 the number of hours of home care needed for older people with cognitive impairment will need to rise by 67% to keep pace with demographic pressure. There are no figures available on the proportion of these clients with dementia, but most home carers will be supporting people with memory loss.

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Table 8. Home Care Client Categories 2012/13

<table>
<thead>
<tr>
<th>Home Care Client Categories 2012/13</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Physical disability, frailty and sensory impairment 65+</td>
<td>62%</td>
</tr>
<tr>
<td>Physical disability, frailty and sensory impairment 18-64</td>
<td>16%</td>
</tr>
<tr>
<td>Mental Health 65+</td>
<td>8%</td>
</tr>
<tr>
<td>Learning disability (all age)</td>
<td>10%</td>
</tr>
<tr>
<td>Mental Health 18-65</td>
<td>4%</td>
</tr>
</tbody>
</table>


The council also provides its own Independence at Home short term reablement service, which supports one Extra Care Housing Team. An element of future commissioning will include home care providers encouraging people who are socially isolated to be aware of activities taking place in their local area and to be actively engaged with activity hubs. 32

12.3.6. Sheltered Housing

There are 23 sheltered housing schemes in the city. As well as living accommodation, Scheme Managers are on hand to give support to people who live there. Approximately a third of the residents are in their 80s. People who develop dementia are offered support to enable them to stay in their home for as long as possible. Four housing schemes in the city have redecorated to be more dementia friendly (Sloan Court, Elwyn Jones Court, Lindfield Court and the lobby area of Walter May House). Staff in council provided sheltered schemes are trained in dementia awareness but would benefit from more tailored dementia training, so that they could be a resource for early detection and signposting to local services. They could also help to delay the onset of dementia by working in a more preventative role – health promotion sessions on smoking cessation, healthy weight and oral health. They could also act as a community base for other health initiatives.

12.3.7. Prescribing

NICE guidance (CG42) 2011.

AChE and Memantine can improve symptoms or temporarily slow down their progression in some people. Three acetylcholinesterase (AChE) inhibitors are recommended as options for managing mild to moderate Alzheimer’s disease: donepezil, galantamine, and rivastigmine. They work by preventing an enzyme (acetylcholinesterase) from breaking down a nerve cell that acts as a chemical messenger in the brain. The loss of these nerve cells is related to the severity of symptoms that people experience. 55 They may only be effective at improving symptoms from between 6 – 12 months. Improvements noted include improvements in motivation, anxiety levels and confidence, in addition to daily living, thinking and memory. 52 Memantine is recommended for people with moderate Alzheimer’s disease who are intolerant of or have a contraindication to AChE inhibitors or severe Alzheimer’s disease. Memantine protects brain cells by blocking the effects of a chemical messenger glutamate

that can damage them.\textsuperscript{52} There is evidence that memantine can temporarily slow down the progression of symptoms, including every day function, in people in the middle to later stages of the disease. It also helps behavioural symptoms including aggression and agitation.\textsuperscript{52} AChE inhibitors and memantine should not be prescribed for people with vascular dementia and AChE should not be prescribed for people with Mild Cognitive Impairment (MCI) unless as part of a properly constructed clinical study.\textsuperscript{56}

The Committee on safety of Medicines (CSM) in 2004 published guidance highlighting that regular use of anti-psychotics in elderly patients with dementia is associated with a three-fold increase in stroke and a two-fold increase in mortality. In 2009, an independent review of anti-psychotics as part of the National Dementia Strategy concluded that associated risks of prescribing anti-psychotics for these patients far outweighed the benefits. This led to a government pledge to reduce prescribing by by two-thirds by November 2011.\textsuperscript{57}

Antipsychotics should only be used to treat non-cognitive symptoms, such as psychosis and/or agitated behaviour causing significant distress or immediate risk of harm to the person with dementia or others. Risperidone is the only licensed antipsychotic for Behavioural and Psychological Symptoms in Dementia (BPSD). It is only licensed for short term treatment of BPSD of up to 6 weeks. No other antipsychotic is licensed for this indication.

\section*{12.3.7.1. Prescribing in Brighton & Hove}

\textbf{Anti–dementia drugs}

Since 2010/11 the number of anti-dementia drug items prescribed in primary care has doubled from 7,250 to 14,211 in 2012/13. This is likely to be due to changes in prescribing practice as NICE guidance lifted restrictions on these drugs which limited them to patients with moderate to severe dementia and extending its prescribing to include those with the early stages of dementia. See Figure 9. The cost was £304,980.48 in 2010/11, £391,651.70 in 2011/12 and decreased to £218,677.72 in 2012/13. The decrease in cost can be accounted for by some drugs coming off patent.

\textsuperscript{56} NICE clinical guideline 42. Dementia.
\textsuperscript{57} Banerjee S. The use of antipsychotic medication for people with dementia: Time For action. DH 2009.
Figure 9. Primary care anti-dementia drug prescribing 2010-13

Figure 10 shows the total number of anti-dementia drug items prescribed by GP Practices in 2012/13.

Figure 10. Anti-dementia drugs prescribed by GP Practice 2012-13

It should be noted that the practice data in the above figures has not been adjusted for practice population size or characteristics such as number of care home patients registered.

Sussex Partnership NHS Trust has developed an Effective Share Care Agreement with primary care for the prescribing of AChE and Memantine anti-dementia drugs. These are initiated by the Consultant/specialist with potential for the prescribing to be transferred to primary care once the patient’s condition has stabilised.
**Antipsychotics**

Antipsychotic drugs are prescribed for behavioural and psychological symptoms in dementia. There have been concerns that antipsychotic drugs were being over prescribed in people with dementia to control behaviour. The report “Time for Action” (2009) called for a decrease in prescribing of these medications to be made a priority.\(^{58}\)

The National Dementia and Antipsychotic Prescribing Audit ran from 2006-11. This covered all people in Brighton & Hove PCT with a diagnosis of dementia, a prescription for anti-psychotic medication or alternative medication, including drugs for dementia, hypnotics and anxiolytics. Only 16 practices in Brighton and Hove submitted data. These showed a rise in people being diagnosed with dementia between 2006 - 2011 but a downward trend in antipsychotic prescribing over the same period. Indicating that the “Time for Action” recommendations were being acted upon.

In 2009/10 and 2011/12, Brighton & Hove PCT ran a Prescribing Incentive Scheme to reduce the level of prescribing of antipsychotics by GP practices. Practices were asked to audit patients over 65, with an antipsychotic prescription and exclude those with a diagnosis of schizophrenia or other psychosis. Dementia was not used as a search term, to highlight potential cases of misdiagnosis. In 2009/10, 25 practices participated in the audit and had prescribed antipsychotics for 167 patients, by 2011/12, the number of patients being prescribed antipsychotics had fallen to 154 patients out of 30 practices audited.

In 2011/12, 63% of the patients in the audit prescribed an antipsychotic had a record of Challenging Behaviour.

In 2009/10 and 2011/12 the most commonly prescribed antipsychotics were:

**Table 9. Most frequently prescribed antipsychotics 2009/10 – 11/12**

<table>
<thead>
<tr>
<th>Antipsychotic</th>
<th>2009/10</th>
<th>2011/12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risperidone</td>
<td>41%</td>
<td>24%</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>23%</td>
<td>33%</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>21%</td>
<td>14%</td>
</tr>
<tr>
<td>Other</td>
<td>15%</td>
<td>29%</td>
</tr>
</tbody>
</table>

In 2011/12, prescriptions for antipsychotics were most commonly initiated by the CMHT.

By 2011/12, 52% of patients were having their medication reviewed at least every 12 weeks, compared to 18% in 2009/10 and the cases where there was no evidence of follow up or an ongoing review had reduced to 48% in 2011/12 from 82% in 2009/10.

The audit suggested that by 2011/12, patients were just as likely to be prescribed antipsychotics if they lived at home, compared to a nursing or residential home.

The audit results suggest that in line with NICE guidance there are now relatively low levels of antipsychotic prescribing compared to 2009. However, it is not possible to give an accurate figure on the size of the decrease due to methodological concerns with the national audit and the lack of a reliable measure. In addition, not all GP Practices participated in the national audit so the findings are not generalisable. Good practice has also been encouraged through the development of an online GP Resource Pack for reducing antipsychotics in people living with dementia, by the Sussex Partnership NHS Trust in September 2013 and other educational opportunities.
12.4. Crises and Challenging times

12.4.1. Secondary Care
Nationally, it is estimated that a quarter of hospital beds are occupied by people with dementia over 65 at any one time. A report by the Alzheimer’s Society on the care of people with dementia in general hospitals found that:

- Half of people with moderate dementia admitted with acute illness such as hip fracture or pneumonia will die within 8 months
- People with dementia are at high risk of complications such as pressure sores, falls and incontinence
- Rehabilitation works just as well if not better for patients with dementia compared to those without co-morbidities such as fractures

Data on hospital admissions for people with dementia in Brighton and Hove was taken from SUS data. This is likely to be an underestimate because it relies upon accurate clinical coding, and will only include those with a formal dementia diagnosis. Also dementia is unlikely to be the primary reason for admission for the majority of people and data on it as a secondary condition may not always be recorded.

Between 2010/11 and 2012/13 there were 136 admissions with a primary diagnosis of dementia. This increases to 522 admissions if dementia as one of the top ten secondary conditions for admission is included. During this period, 124 were emergency admissions for dementia. The most frequent primary diagnosis of dementia was “vascular dementia, unspecified” and “unspecified dementia”.

Repeat admissions for dementia have fallen since 2010/11 from 14% of all dementia admissions to 6% in 2012/13.

Data on admissions where dementia is a secondary diagnosis shows the extent of inpatient cases who have dementia and the need for the whole hospital environment to be dementia friendly and not just specialist dementia wards. Nationally the top five reasons why carers report the person with dementia is admitted to hospital are: following a fall (14%); broken fracture hip or hip replacement (12%); urine infection-including urinary tract infection (9%); chest infection (7%); stroke/minor stroke (7%). These reasons are reflected locally in Table 11.

The top 10 primary diagnoses for people admitted to hospital with a secondary diagnosis of dementia between 2009-2013 are shown in Table 11

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60 Alzheimer’s Society. Counting the Cost. 2009.
Table 11. Most common primary admissions for people with a secondary diagnosis of dementia to BSUH (B& H residents) 2009-2013.

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>Admissions to BSUH 2009-2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urinary tract infection, site not specified</td>
<td>376</td>
</tr>
<tr>
<td>Fracture of neck of femur closed</td>
<td>160</td>
</tr>
<tr>
<td>Syncope and collapse</td>
<td>152</td>
</tr>
<tr>
<td>Unspecified acute lower respiratory infection</td>
<td>131</td>
</tr>
<tr>
<td>Pneumonia, unspecified</td>
<td>121</td>
</tr>
<tr>
<td>Lobar pneumonia, unspecified</td>
<td>96</td>
</tr>
<tr>
<td>Senility</td>
<td>91</td>
</tr>
<tr>
<td>Disorientation, unspecified</td>
<td>74</td>
</tr>
<tr>
<td>Chest pain, unspecified</td>
<td>59</td>
</tr>
<tr>
<td>Superficial injury of other parts of the head</td>
<td>57</td>
</tr>
</tbody>
</table>

Source: SUS data Brighton and Hove local authority residents 2009-2013

Efforts should be focused on preventing these conditions and staying out of hospital where possible.

The average length of stay (LOS) for those with a primary diagnosis of UTI and secondary diagnosis of dementia was 8.9 days, for someone without the dementia diagnosis it was 6.4 days. The average LOS for those with a primary diagnosis of fractured neck of femur and secondary diagnosis of dementia was 22.3 days, for someone without the dementia diagnosis it was 18.5 days.

12.4.1.1. Dementia Specialist Nursing Team - Brighton and Sussex University Hospitals (BSUH)

The specialist nursing team has evolved out of the dementia champion nurse role which receives referrals of patients with dementia from all the non-dementia wards in the hospital. They provide dementia training to staff in the Trust and promote the philosophy that dementia is everyone’s business, they will be opening up the delivery of their training to include community based staff from June 2014. Training offered includes ward level, one day and three day programmes. The training is co-facilitated by a person who lives with dementia. The one day training was attended by 92 staff in 2013 and in 2014, they have capacity to offer the one day training to 200 staff, focusing on those in the frontline. 130 staff attended the 3 day programme in 2013 and there will be capacity for 300 staff to attend in 2014.

Poynings ward at Princess Royal Hospital, is an 8 bed specialist dementia inpatient unit. Emerald ward opened at Royal Sussex County Hospital in April 2014 as a 15 bed specialist shared-care dementia unit consisting of separate female and male wards, specially designed to help patients with dementia and co-morbid conditions.
A census was carried out on elderly medical wards on June 17th 2011, to quantify the proportion of patients with dementia, the number on antipsychotic medication and whether the mental health teams were involved with their care. This found that out of 4 wards at RSCH 30 out of 68 patients (44%) had a dementia diagnosis in their notes. The mean age of these patients was 89 and 18 were women and 12 men. The majority had been admitted from their own homes. Of the 30 with a dementia diagnosis, 3 had been given a new diagnosis on admission to hospital and 14 did not have a full diagnosis documented. Five of the dementia patients were on an antipsychotic or benzodiazepine or antidepressant for behaviour management and were known to the mental health team. Only one dementia patient was on an AChE. Ten (33%) of the patients had previously been seen by the mental health team or Mental Health Liaison Nurse on admission. Only one had a “This is Me” bag. This is a communication aid which includes a profile of the person, a photograph from their prime, information on preferred priorities of care, booklet on future end of life care planning and a “Lions” message in a bottle.

The census concluded that almost half the care of the elderly medical beds at RSCH were occupied by dementia patients – this situation should change with the opening of the specialist Emerald ward. There appeared to be poor documentation and recognition of the types of dementia and the lack of full diagnosis meant that patients who may have benefitted from AChE inhibitors weren’t being prescribed them. Recognition and documentation of patients with dementia should be improved by the introduction of the CQUIN. The level of antipsychotic prescribing could be improved further if the RSCH environment were improved – the Dementia Friendly Environment funding should have a positive impact on this. Poor levels of dementia awareness and lack of use of behavioural interventions such as the “This is me” bag should have improved, following the work of the End of Life Care in dementia adviser during 2012/13. It is planned to repeat the elderly ward census in the future and there will be a repeat of the national dementia audit.

12.4.1.2. Dementia Diagnosis CQUIN (Commissioning for Quality and Innovation Framework)

A CQUIN has been developed nationally to financially incentivise the diagnosis/identification of dementia patients on acute wards. Since October 2012 every patient over 75 admitted for at least 72 hours has been assessed for dementia using a case finding question and diagnostic assessment tool. Targets have been set for 90% of eligible patients to receive an assessment, and for 90% of positive assessments to be referred to the Memory Assessment Service. The Department of Health Dementia Map reports BSUH performance against the CQUIN in April/June 2013/14 as 92% of cases identified in hospital; of these 99% are diagnosed in hospital with dementia and 99% of these cases are referred on for memory assessment. This compares to 91% identified and 93% diagnosed and 95% referred for memory assessment in both Eastbourne and Hastings CCGs. In 2013/14 the CQUIN

61 Dr L Pack. Dementia Survey Results Summary. BSUH. 05.07.11
will include an additional element asking whether carers felt supported during the inpatient admission; the hospital must confirm they have a lead clinician for dementia and an appropriate staff training programme.

12.4.1.3. Dementia Friendly Environment Grant
A grant has been received as part of Prime Minister’s Dementia Challenge funding to improve the environment for people with dementia. This will be used to improve A&E and create a dementia care area with softer lighting.

12.4.1.4. Butterfly Scheme
The Butterfly Scheme which runs in 100 hospitals in the UK was introduced in June 2013 and is being rolled out across BSUH. With patients’ consent, a blue butterfly sticker on patient notes or a metallic butterfly behind the bed signifies someone with dementia. Together with key fobs these remind staff of the steps they need to take to communicate with someone with dementia.

12.4.1.5. Inpatient activity data
A review of the impact of the role of the Dementia Nurse Specialist based on a sample of 172 patients admitted to BSUH between July 1st 2012 and June 30th 2013, includes the following activity data:

- The majority of patients seen by the specialist nurse were admitted from their own homes (81%)
- The majority of patients admitted and referred were seen either on the same day or by one day after referral by the Dementia Specialist Nurse.
- The main presenting condition given for admission to hospital were Falls (31%), increased confusion (17%) and chest infection (14%). 6% of admissions were for UTIs. This is a lower proportion of admissions for UTIs than reported for primary admissions with dementia as a secondary diagnosis from 2009-13, but this may be due to the three year’s rather then one year’s data.
- The majority of patients had a length of stay (LOS) of 34 days or less (71%). The average LOS is in line with the national average but with a lower median LOS. The Dementia Nurse Specialist reports that there has been a potential reduction in LOS on Poynings ward, due to earlier discharges following her facilitation of discharge planning.\(^{59}\)
- 43% of patients admitted from their own home were discharged to their own homes. The next most frequent discharge destinations were specialist dementia residential or nursing homes (12%).\(^{62}\)

The Dementia Nurse Specialist service has increased the level of support offered in hospital to people with dementia and their carers. Patients are being identified and seen by the service within one day, with earlier discharge (to their own homes in a third of cases) being facilitated, which will mean cost

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\(^{62}\) Frost L and Dixon G. The Impact of Dementia Champion Role at BSUH and development of a Dementia Specialist Service. BSUH NHS Trust. February 2014 (unpublished)
savings to the Trust. The education programme, Butterfly Scheme and Dementia Friendly Environment funding is embedding dementia awareness across the Trust and enabling the CQUIN target to be achieved.

The Butterfly Scheme should continue to be rolled out and the Dementia Care Pathway implemented across the Trust. The education programme should be offered to external partners and the effectiveness of the Dementia Specialist Team should continue to be evaluated.

12.4.2. Liaison Psychiatry – Sussex Partnership Foundation NHS Trust
SPFT provides Liaison Psychiatry input into dementia services at RSCH. This work is undertaken by psychiatrists, specialist nurses and a clinical neuropsychologist, to provide rapid assessment, diagnosis and advice on optimum management of patients with dementia and other causes of confusion in an acute hospital setting.

12.4.5. Dementia Friendly Environment – Brunswick Ward – Sussex Partnership Foundation NHS Trust
Funding from the Department of Health Enhancing Healing Environments bid is being used to refurbish Brunswick ward (Nevill Hospital site) as the Lindridge Nursing Home. This will include ambient Healwell lighting, a secure landscaped garden with lift access, and dementia friendly furnishings. A service improvement plan is being implemented. Staff are receiving dementia training and will be involved in evaluating the new environment with service users and carers.

12.4.6. Community Rapid Response Service – Sussex Community NHS Trust
The Community Rapid Response Service (CRRS) aims to avoid hospital admissions by contacting and assessing patients within 2 hours of referral and closing the case within 3 days. The service is provided by a multidisciplinary team of 33 staff, including a mental health liaison nurse, who assesses patients with suspected memory loss. If assessment tools suggest memory loss, the patient is either
- referred to the GP for onward referral to MAS (CRSS feel this introduces an unnecessary delay as they can complete all tests required for referral and a delay may lead to the patient dropping out of the care pathway but MAS won’t assess patients while still acutely ill)
- referral to BICS for mental health assessment and triage or Wellbeing Service
- referral to Brighton Urgent Response Service (BURS) for suicidal patients.

From June to October 2013, the CRRS received referrals for 121 patients diagnosed with dementia. The Mental Health Liaison Nurse made 21 referrals for mental health assessment and triage during this period, 7 referrals to the Wellbeing Service and 5 referrals to the MAS. Patients not referred on were already being managed by the CMHT or GP for their mental health issues. The Mental Health Liaison Nurse says she has been seeing more patients
with mental health problems since the Integrated Community Advice and Support Team (ICAST) service was disbanded. There is no longer a dementia crisis service in Brighton and Hove, with out of hour’s patients being seen by the Living Well with Dementia Teams’ Enhanced Duty Team.

12.4.7. Community Short Term Services – Sussex Community NHS Trust
Community Short Term Services facilitate early hospital discharge by supporting people in their own homes or in community beds for up to 6 weeks. The service is provided by a multi-disciplinary team of 120 staff including a RMN. The average team case load is 150-180 patients. Approximately 40% of clients have dementia and are treated in community beds. Patients with an existing dementia diagnosis are managed by the LWWDT and those with undiagnosed memory/cognitive problems are referred to their GPs for referral to MAS. Approximately 30 referrals have been made to GPs for dementia diagnoses since June 2013.
12.5. Adult Social Care

12.5.1. Extra Care Housing
Extra care housing aims to enable older people to live independently for as long as possible in their own homes through the provision of purpose built accommodation with some care and support services on site including the provision of hot meals. Brighton and Hove has 153 units of extra care housing. Patching Lodge is one of main providers. It has 76 tenants with an average age of 73 years, 90% of the places are social rents via the council. Of these residents 20 are thought to have dementia but not all will have a diagnosis. The scheme was built to be dementia friendly e.g different floors having different colours. The staff are having awareness training to become Dementia Friends and there is a Dementia Champion. Training is also offered to residents to increase their awareness of dementia. If a person develops dementia after they have become a tenant efforts are made to support them through regular reminders for activities, appointments, medication etc. A joint approach is taken to assessing the individuals’ level of risk and whether their needs can still be met in the extra care environment. The Lifelines voluntary service organises various health promotion activities for residents and the local community, which take place at Patching Lodge including a reminiscence group, singing group, gentle exercise and health walk. They are also going to start a gardening group.

12.5.2. Care Homes
There are an estimated 432,000 older and physically disabled people in approximately 20,000 homes in the UK63 and the Alzheimer’s Society estimates that two thirds of people living in care homes have a form of dementia.64 However, recent studies have suggested that up to 80% of people in care homes have dementia or significant memory problems.65 Ensuring the provision of appropriate, high quality care for people in care homes is therefore of great importance to local dementia strategies.

Although there are many examples of good practice and care there is evidence of ongoing challenges to the provision of high quality care for people with dementia living in care homes. The recent Alzheimer’s Society report “Low Expectations” highlighted some of these challenges which include lack of training and support for staff, need for meaningful occupation and activities for residents and use of antipsychotic drugs in care homes. The report also identifies broader issues around funding for care, supporting people to make choices in their care, promoting care homes as part of the community and a lack of confidence that people with dementia in care homes can enjoy a good quality of life.

In Brighton & Hove there are 111 registered care homes with a total of 2,326 beds. Ten care homes have people with dementia as their primary client type and provide 304 beds. In total, including dementia beds in homes not primarily for people with dementia, 335 beds (14%) are registered specifically for people with dementia, some people with undiagnosed dementia will also be occupying non-dementia beds. As part of a recent application process for funding to improve the environment for people with dementia in care homes, managers were asked to report the number of residents currently in their homes with dementia (diagnosed or undiagnosed). 43 homes applied which between them had a total of 1,239 beds and out of these, 854 residents were reported to have dementia (69%). However this is almost certainly an underestimate as many homes will not have been at 100% capacity when they reported these figures. The proportion of people with dementia in each home ranged from 10% to 100%.

A survey of care homes was conducted in Brighton & Hove in 2013 and this also provided some information on the proportion of care home residents with dementia. 20 care homes reported the number of residents currently in their home and an estimate of the number of diagnosed and undiagnosed dementia cases. Out of 518 people reported to be in these homes, 38% had a diagnosis of dementia and 26% were reported to have undiagnosed dementia making a total of 64%. Although this is a lower figure than the estimate from the funding applications it is also very similar to the Alzheimer’s Society estimate of two thirds of people in care homes having dementia and does not appear to support more recent estimates of 80% (e.g. Lithgow et al., 2012).

12.5.3. Ireland Lodge
Ireland Lodge is a Local Authority provided residential care home and day care centre in Woodingdean, for people with organic mental health needs i.e. vascular dementia, Alzheimer’s disease. It has 23 residential short stay beds, 13 are for planned and emergency respite and 10 are CCG funded transitional beds for assessment of needs. Average stays are approximately 12 weeks. An RMN is attached to the care home 4 days a week which enables direct referrals to secondary care and specialist knowledge of medication. The manager felt demand for respite has increased over the last 4 years. Respite care costs £756 per week for self funders or a minimum of £120 per week for those that are eligible for financial support (costs correct November 2013).

12.5.4. Wayfield Avenue
Wayfield Avenue is a Local Authority provided residential care home and day centre for people with functional mental health needs to the west of the city. Where a person has a functional mental health need and dementia, they are referred to Wayfield Avenue rather than Ireland Lodge. Wayfield Avenue has 24 beds. An RMN is attached to the home and provides training to staff in dementia.

12.5.5. Care Home In-reach Services – Sussex Partnership NHS Trust
The Care Home In-reach Service works with Care and Nursing Homes in Brighton and Hove to improve quality of life for people with dementia. They
develop an action plan for time limited work of up to 16 weeks, which can include staff training, dementia awareness and safety issues. The service aims to reduce anti-psychotic prescribing and hospital admissions. The service also provides a monthly good practice forum for Care Home Managers they have previously worked with and an Activity Workers Forum. The service signposts people without a formal dementia diagnosis to the MAS for a diagnosis.
12.6. Approaching the end of life

Early conversations with people with dementia are important so that people can plan ahead for their future care, including palliative and end of life care.

One in three people over the age of 65 will die with dementia. It is one of the top five underlying causes of death.66

12.6.1. End of Life Care in Dementia project

This short term project was established in 2012 for 20 months using Regional Innovation Funding to appoint a Dementia Adviser to improve End of life Care in dementia and develop an integrated Sussex wide pathway.

A pathway has been developed comprising of 6 phases. The needs of people with dementia, their relatives and carers have been identified at each stage and the services that need to be made available to meet these.

1) Recognising there is a problem – Need increased public awareness; increased professional knowledge of dementia care pathway; culture of positivity; single point of access for assessment; counselling offered at an early stage; early access to carer support and their recognition as partners in care; routine dementia screening for over 60s and early diagnosis for learning disabilities.

2) Discovering that the condition is dementia – Need increased professional knowledge of sources of support, signposting and access to medication and treatment; requirement for MAS to confirm diagnosis; access to counselling and carers’ assessments; improved agency information sharing; allocated key worker; support from professionals; one stop shop for specialist dementia care; information checklist; post-diagnostic review; inclusion on dementia or long term conditions register; initiate Advanced Care Planning.

3) Living well with dementia – Need Advanced Care Planning (opportunity to discuss plans for future care) included as routine practice and as part of the GP annual dementia review; regular holistic health checks; clear information from professionals and data sharing, including information in a variety of formats; support for carers; access to services based on needs not labels; use of “This is Me” bags; access to respite care; dementia friendly communities; consistent emergency out of hours support and appropriate safeguarding.

4) Getting the right help at the right time – Need for Advanced Care Planning and contingency arrangements; treat person with dementia, relatives and carers as partners in care; training of professionals to increase skills and knowledge of support services; information in different formats and advocacy support; normalising life; support services available 24/7; use of technology to...

support independence; access to specialist practitioners; annual wellbeing checks; dementia friendly wards; education, information and support for carers, with access to websites and help at GP practices; Advanced Care Planning upon admission to residential and nursing homes.

5) **Nearing the end of life, including the last days of life** – Need professionals to improve ability to recognise the “dying phase;” co-ordinated care led by named professional; understand emotional and spiritual needs and who to contact for support; review Advance Care Plans/Lasting Power Attorney/Advance Decision to Refuse Treatment/Do Not Attempt Coronary Pulmonary Resuscitation/Preferred Priorities for Care and implement; hospital discharge with clear advice, information and contact details; timely assessment and response for Continuing Care Funding; access to specialist services including EOLC Adviser and information. Retain GPs in Nursing Homes. Pre death course and pre bereavement counselling; review funeral options.

6) **Care after death** – Bereavement services for family/carers; support with practical arrangements; referral to counselling/support groups; follow-up from care co-ordinator.
13. Funding
As the cost of care for people with dementia is embedded across the whole of the health and social care system, including acute hospitals, mental health services, residential and nursing homes, it is difficult to determine the costs of dementia care.
14. Issues related to workforce
Brighton & Hove City Council provides a range of training courses on dementia for staff working in Older People’s services - both its own staff, independent sector, Sussex Community NHS Trust and Sussex Partnership NHS Trust. During 2012-2013 dementia training was attended by 519 staff, the majority of whom were from the council or independent sector.

Table 13. Attendance at Dementia Awareness Training by Older People's Services, 2012-2013.

<table>
<thead>
<tr>
<th>Training Course</th>
<th>BHCC Older People’s Services (includes assessment teams, provider services, OTs)</th>
<th>Housing (Older People’s Services BHCC)</th>
<th>Independent Sector (includes older people’s residential, home care, informal, carers, CVS)</th>
<th>Older People’s Services Sussex Community NHS Trust</th>
<th>Sussex Partnership NHS Foundation Trust</th>
<th>Total number of people receiving training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advanced skills for supporting people with dementia</td>
<td>15</td>
<td>68</td>
<td>1</td>
<td>1</td>
<td></td>
<td>85</td>
</tr>
<tr>
<td>Dementia-Advanced Skills for OTs</td>
<td>16</td>
<td>5</td>
<td>2</td>
<td></td>
<td></td>
<td>23</td>
</tr>
<tr>
<td>Dementia and the Environment in OT</td>
<td>11</td>
<td></td>
<td>3</td>
<td>1</td>
<td></td>
<td>15</td>
</tr>
<tr>
<td>Dementia Awareness</td>
<td>81</td>
<td>10</td>
<td>248</td>
<td>1</td>
<td>1</td>
<td>341</td>
</tr>
<tr>
<td>Managing Medicines for people with dementia</td>
<td>1</td>
<td></td>
<td>24</td>
<td></td>
<td></td>
<td>25</td>
</tr>
<tr>
<td>Older people and mental health</td>
<td>18</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td></td>
<td>30</td>
</tr>
<tr>
<td>Grand Total</td>
<td>142</td>
<td>18</td>
<td>343</td>
<td>10</td>
<td>6</td>
<td>519</td>
</tr>
</tbody>
</table>

Brighton & Hove City Council Dementia Qualification Programmes
Level 2 Unit in Dementia Awareness: 13 people have completed this workbook – all BHCC staff
Level 3 Certificates in Dementia Care: 8 people completed this – all BHCC staff
Level 3 Diploma Health and Social Care Dementia Pathway: 9 altogether: 6 x BHCC and 3 x External.

The wider workforce of front line workers including sheltered living scheme and extra care housing scheme managers need training in the dementia care pathway, so they can signpost people for memory assessment and know about support services that are available once diagnosed.

Every front line worker in older people’s services should also have basic dementia awareness training to identify early signs and symptoms and have an understanding of diagnostic processes and support available. The council provided dementia training is available for this purpose.

The Revised Dementia Planning Framework 2010, identified a need to promote dementia related placements with local medical training schools and the development of competency frameworks for staff working with dementia.
15. Unmet needs, service gaps and over-provision
Since 2013 some of the main gaps in Brighton & Hove’s dementia services have started to be filled with the advent of the Memory Assessment Service, Living Well with Dementia Teams and BSUH Specialist Dementia Nurse. Discussions with stakeholders as part of the needs assessment process and feedback from carers and users have highlighted a number of areas where more could be done to improve dementia services.

- **Under diagnosis of dementia**
  Only 43% of expected cases of dementia are being diagnosed in the city. The estimated prevalence in people aged over 65 years is 2,980 but only 1,310 had been diagnosed in 2012/13.

- **Lack of services to access for each stage of dementia**
  As the MAS starts to systematically identify and diagnose more people with dementia and as the population lives longer, there will be an increase in the number of people in the city living with mild, moderate and severe dementia. Dementia prevalence is projected to be 3,211 by 2020. This will place increased pressure on health and social care for services. At the moment there is felt to be a gap in appropriate services to access, for the different stages of dementia.

- **Provision of respite**
  Some aspects of respite care such as residential respite have waiting lists, whilst other aspects such as day time respite are under utilised. It is also difficult for carers to access planned respite.

- **Lack of support for people recently diagnosed with dementia or mild cognitive impairment and their families.**
  There is no one specialist information point to signpost carers to for more information on local services, once a family member has been diagnosed. Existing information and support services such as the Alzheimer’s CrISP programme will need to increase their capacity if they are to be able to support the increasing number of people being diagnosed going forward. Carers and cared for need education about evidence based activities they can engage in at each stage of the condition, to help delay further progression. Access to counselling and bereavement support is needed to help support families with the changes and loss arising from the diagnosis. Newly diagnosed dementia patients only get the support of a Dementia Adviser for a year.

  There is no provision for post diagnostic interventions similar to the East Sussex model, which includes cognitive stimulation, memory management, reminiscence, music and wellbeing, dance and movement and art.
People with dementia and some mental health co-morbidities are not currently eligible for Wellbeing Services for anxiety or depression, even though their level of dementia may be mild.

- **Lack of key worker support in the community to help prevent people with dementia reaching a crisis.**
  People with dementia do not currently have a single, named key worker to co-ordinate their care. There is no befriender/buddy or an Admiral Nurse type role in the community which can intervene at an early stage after diagnosis to provide support and information to the person with the condition and the family, and to continue to offer them this support as the condition progresses. This is particularly important for people who live on their own.

- **Need to develop a Dementia Friendly City**
  More could be done in terms of environmental adaptations including signage, and transport in the public realm, and use of telecare in both private and social housing and residential care homes and health settings.

  Although there is dementia awareness training available for council approved providers and hospital staff, more training needs to be made available to front line workers, including GPs, Practice Nurses, Pharmacists, domiciliary care staff, sheltered and extra care housing providers, and generic older people’s services staff in the community.

  On a wider scale there needs to be more Dementia Friends as part of the city becoming a dementia friendly environment.

  There is no Dementia Action Alliance in the city, which could lead and co-ordinate the development of dementia friendly initiatives, including links to Better Care/frailty agenda, Age Friendly City initiatives, Age Concern’s Big Lottery bid and campaigns.

- **Lack of affordable dementia beds**
  There is a lack of affordable dementia beds in the city, which means some people with dementia live in residential homes outside the city.

- **Lack of support and advice for people not eligible for Adult Social Care funding**
  People who are not eligible for Adult Social Care Services are at risk of missing out on support from services they can access, such as Emergency Back-up, Support Groups and accessing home care because they are not made aware of them.

- **Not enough focus on interventions to delay onset of dementia**
  Existing resources such as Sheltered Housing Scheme workers do not have enough of a preventative focus.
16. Recommendations for further needs assessment

There were a number of areas with data gaps in this needs assessment, which could be included as areas for further evidence gathering as part of any future needs assessment.

- There is no accurate data on the number of people with a diagnosis of dementia living in care homes in the city. The figures used in the needs assessment were based upon a self-report survey of council commissioned care homes. As many people with dementia do not have a formal diagnosis, any figure given is likely to be an underestimate.
- Similarly there is no accurate data on the number of home care clients with dementia.
- No data is kept on the number of people with dementia specifically who have personal budgets or direct payments.
- There is no data on the number of people with dementia self-funding their dementia care in the city because they are not eligible for Adult Social care Funding.
- There is no local data on the extent of dementia amongst the BME population and other protected characteristic groups, apart from gender.
- Due to under diagnosis of dementia in primary care the prevalence of people with dementia on Dementia Registers will be an underestimate.
- No Dementia DES data from primary care was available at the time of the needs assessment and not all GP Practices were offering the DES which could be an inequality for some patient. DES data should be reviewed as part of the proposed dementia dashboard.
- No outcomes data was available from the dementia questions which form part of the NHS Health Checks. If this data were recorded we could measure how effective Health Checks are in encouraging people with memory concerns to make a follow-up appointment with their GPs.
- At the time of the needs assessment the Memory Assessment Service had been in operation for less than a year, so that there was no complete annual data. MAS data should be reviewed as part of the proposed dementia dashboard.
- Data on acute hospital admissions for people with dementia is an underestimate due to a reliance on accurate clinical coding and dementia usually being recorded as a secondary condition on admission.
- Future needs assessments could review whether the introduction of the specialist dementia ward at RSCH and training delivered by the Dementia Specialist Nurses, has an impact on reducing the difference in length of stay between those admitted with and without dementia for the same conditions.
- The proposed dementia dashboard should review the number of anti-psychotic and anti-dementia drug items prescribed and who by, to see whether the MAS increases the number of anti-dementia items prescribed as more patients are diagnosed with Alzheimer’s disease.
• A weakness in the needs assessment is that there is no recent funding data. It is very difficult to separate out the costs of dementia care as it crosses so many services. Future needs assessments should review funding costs.
17. Key contacts

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Dementia Needs Assessment Steering Group. Chair Alistair Hill Public Health Consultant. Alistair.hill@brighton-hove.gcsx.gov.uk 01273 296560
APPENDIX 1

Dementia in care homes
There are an estimated 432,000 older and physically disabled people in around 20,000 homes in the UK (Laing and Buisson, 2013) and the Alzheimer’s Society estimates that two thirds of people living in care homes have a form of dementia (Alzheimer’s Society, 2007). However, recent studies have suggested that up to 80% of people in care homes have dementia or significant memory problems (e.g. Lithgow et al., 2012). Ensuring the provision of appropriate, high quality care for people in care homes is therefore of great importance to local dementia strategies.

Although there are many examples of good practice and care there is evidence of ongoing challenges to the provision of high quality care for people with dementia living in care homes. The recent Alzheimer’s Society report Low Expectations highlighted some of these challenges which include lack of training and support for staff, need for meaningful occupation and activities for residents and use of antipsychotic drugs in care homes. The report also identifies broader issues around funding for care, supporting people to make choices in their care, promoting care homes as part of the community and a lack of confidence that people with dementia in care homes can enjoy a good quality of life.

In Brighton & Hove there are a total of 111 registered care homes with a total of 2326 beds between them. Ten of the care homes have people with dementia as their primary client type and between them provide a total of 304 beds. In total, including dementia beds in homes not primarily for people with dementia, 335 beds (14%) are reserved specifically for people with dementia although clearly many of the beds not reserved for people with dementia will be occupied by people with the condition. As part of a recent application process for funding to improve the environment for people with dementia in care homes, managers were asked to report the number of residents currently in their homes with dementia (diagnosed or undiagnosed). A total of 43 homes applied making a total of 1239 beds and out of these, 854 residents were reported to have dementia (69%). However this is almost certainly an underestimate as many homes will not have been at 100% capacity when they reported these figures. The range of proportion of people with dementia in each home was from 10% to 100%. A survey of care homes was conducted in Brighton & Hove (see below for full analysis) and this also provided some information on the proportion of care home residents with dementia. In this survey, 20 care homes reported the number of residents currently in their home and an estimate of the number of diagnosed and undiagnosed dementia cases. Out of 518 people reported to be in these homes, 38% had a diagnosis of dementia and 26% were reported to have undiagnosed dementia making a total of 64%. Although this is a lower figure than the estimate from the funding applications it is also very similar to the Alzheimer’s Society estimate of two thirds of people in care homes having dementia and does not appear to support more recent estimates of 80% (e.g. Lithgow et al., 2012).

Care Homes Dementia Survey
A survey was carried out at a meeting of the Brighton & Hove Care Homes Forum in September 2013. A total of 20 managers who attended completed a
questionnaire. Although this is a small sample out of the 111 homes in the City it still provides some useful information on the care home services provided for people with dementia.

**Question 1.** Does your care home provide any of the following for people with dementia?

<table>
<thead>
<tr>
<th>Facility</th>
<th>Number of homes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enclosed, secure, outside space</td>
<td>18</td>
<td>90%</td>
</tr>
<tr>
<td>Specially designed garden</td>
<td>6</td>
<td>30%</td>
</tr>
<tr>
<td>Name plaques on residents’ doors</td>
<td>12</td>
<td>60%</td>
</tr>
<tr>
<td>Personalised bedrooms (e.g. photos)</td>
<td>17</td>
<td>85%</td>
</tr>
<tr>
<td>Memory boxes</td>
<td>6</td>
<td>30%</td>
</tr>
<tr>
<td>Signposting around the home</td>
<td>8</td>
<td>40%</td>
</tr>
<tr>
<td>Reminiscence room</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Carpet zoning and guidance</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Snoezelen rooms</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Overnight facilities for relatives</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>10%</td>
</tr>
</tbody>
</table>

Summary: All homes indicated that they provided at least one of the facilities for people with dementia, and particularly common was the secure outside areas. However it is noticeable that relatively few homes stated that they were using memory boxes or reminiscence rooms.

**Question 2.** Do you have a senior member of staff identified with the role of improving dementia care in your home?

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>14</td>
<td>70%</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>Not answered</td>
<td>1</td>
<td>5%</td>
</tr>
</tbody>
</table>

Summary: Only 70% of homes indicated that they have a senior member of staff identified with the role of improving dementia care in their homes and this is a recommendation from the national dementia strategy. (*Living Well With Dementia: A national dementia strategy*)

**Question 3.** Do you think residents with dementia in your care home get enough support from the following services?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>To some extent</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>8 (40%)</td>
<td>8 (40%)</td>
<td>3 (15%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Social workers</td>
<td>6 (30%)</td>
<td>11 (55%)</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Dentists</td>
<td>10 (50%)</td>
<td>7 (35%)</td>
<td>2 (10%)</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>3 (15%)</td>
<td>13 (65%)</td>
<td>2 (10%)</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>
Summary: Overall there was no one single service that managers felt people with dementia were not receiving enough support from. It is notable that 80% of the managers felt that they received enough support from GPs either fully or to some extent.

**Question 4. Do you complete an assessment of the needs of people with dementia when they are admitted?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17</td>
<td>85%</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>--</td>
</tr>
<tr>
<td>Not answered</td>
<td>3</td>
<td>15%</td>
</tr>
</tbody>
</table>

**Question 5. If ‘yes’, do you make a care plan for each service user based on this assessment?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17</td>
<td>85%</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>--</td>
</tr>
<tr>
<td>NA / Not answered</td>
<td>3</td>
<td>15%</td>
</tr>
</tbody>
</table>

Summary: The national dementia strategy (*Living Well With Dementia: A national dementia strategy*) identifies the importance of person-centred care planning. The majority of care homes indicated that they complete an assessment of the needs of people with dementia when they are admitted and make a care plan based on this assessment. None of the homes stated that they did not do either of these although three declined to answer the questions.

**Question 6. Are people with dementia offered the opportunity to take part in everyday activities which were part of their lifestyles prior to admission?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>18</td>
<td>90%</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Not answered</td>
<td>1</td>
<td>5%</td>
</tr>
</tbody>
</table>
**Question 7. If ‘yes’, please specify...**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number of homes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tending plants / gardening</td>
<td>14</td>
<td>70%</td>
</tr>
<tr>
<td>Food preparation</td>
<td>10</td>
<td>50%</td>
</tr>
<tr>
<td>Laundry</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleaning</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Admin/paperwork</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Laying tables</td>
<td>2</td>
<td>10%</td>
</tr>
</tbody>
</table>

Summary: Having something meaningful to do is an important part of quality of life (Ball et al., 2000) and is as true for people with dementia as it is for the rest of the population (Alzheimer’s Society, Home from Home report, 2007). Out of the care homes surveyed, 90% indicated that they provide residents with the opportunity to take part in everyday activities which were part of their lifestyles prior to admission. Gardening and tending plants was the most common (70%).

**Question 8. Are any of the following provided as regular activities in your home?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number of homes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reminiscence / life story work</td>
<td>19</td>
<td>95%</td>
</tr>
<tr>
<td>Singing sessions</td>
<td>19</td>
<td>95%</td>
</tr>
<tr>
<td>Art sessions</td>
<td>17</td>
<td>85%</td>
</tr>
<tr>
<td>Physical exercise classes</td>
<td>16</td>
<td>80%</td>
</tr>
<tr>
<td>Outings away from the home</td>
<td>16</td>
<td>80%</td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bingo</td>
<td>8</td>
<td>40%</td>
</tr>
<tr>
<td>Crafts</td>
<td>3</td>
<td>15%</td>
</tr>
<tr>
<td>Walks</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Music</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Knitting</td>
<td>2</td>
<td>10%</td>
</tr>
<tr>
<td>Animals</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Quizzes</td>
<td>2</td>
<td>10%</td>
</tr>
</tbody>
</table>

Summary: All care homes indicated that they provide at least one regular activity for their residents. These included creative, social and physical activities with life story, singing, art, physical exercise and outings all commonly provided. Again, these activities are key to a good quality of life for people with dementia in care homes. The National Minimum Standards for Care Homes for Older People (Department of Health, 2003) states that service users, particularly those with dementia, should have opportunities for stimulation through leisure and recreational activities which suits their needs, preferences and capacities. A report by the Alzheimer’s Society (Home from Home, 2007) suggested that many care homes were failing to implement this
recommendation with a survey of carers finding that over half felt that their relative did not have enough to do during the day. Although the survey of care homes cannot provide detailed information on how often residents engage in activities or how beneficial they find them, it does suggest there is an understanding of the need to provide meaningful, social activities for residents of care homes and that in most homes there is at least a basic level of opportunity provided.

**Question 9. Where do you look for information on dementia needs?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number of homes</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary organisations (e.g. Alzheimer's Society, Age UK, Dementia UK etc.)</td>
<td>16</td>
<td>80%</td>
</tr>
<tr>
<td>NHS Choices website</td>
<td>10</td>
<td>50%</td>
</tr>
<tr>
<td>Local Authority Care Homes Forum</td>
<td>8</td>
<td>40%</td>
</tr>
<tr>
<td>CQC</td>
<td>4</td>
<td>20%</td>
</tr>
<tr>
<td>Other care home managers</td>
<td>12</td>
<td>60%</td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia in-reach team</td>
<td>5</td>
<td>25%</td>
</tr>
<tr>
<td>Distance learning course</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Parent company</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Online</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Local Authority Training</td>
<td>1</td>
<td>5%</td>
</tr>
<tr>
<td>Social Care Institute for Excellence</td>
<td>1</td>
<td>5%</td>
</tr>
</tbody>
</table>

Summary: Voluntary organisations were the most common source of information on dementia care accessed by the care homes (80%) followed by a range of additional sources. Although the survey does not provide detail on which voluntary organisations exactly are utilised, it suggests that the care home community find the third sector a useful source of support and information in their work.

**Question 10. Please tell us what would help you improve the level of care for residents with dementia in your home...**

- “More bespoke training for staff including spotting signs of neglect”
- “More training freely available”
- “More provision of free training for staff”
- “Availability of more staff training and easy access to relevant professionals”
- “Reduce fees to enable provision of more one to one support”
- “Improved dementia awareness in the community”
- “Local free transport access to facilitate outings (some homes cannot afford their own mini-busses etc)”
- “More staff (i.e. more money)”
• “More staff – therefore more money”

Summary: Training was the most common request for additional support to improve dementia care in the homes with four managers writing this.

Question 11. If there are any other services provided by your establishment for people with dementia or additional comments you would like to make please write them in the space below...

Few responses were received to this request for additional comments although two managers stated that the recent funding received for improving the dementia environment would help them to provide a better service for people with dementia in the future.

Home Care Organisations Dementia Survey

In addition to the care homes survey, a similar survey was conducted of the home care providers in the City. There are approximately 36 home care providers in Brighton & Hove and surveys were completed by ten of these at a Home Care Forum meeting in September 2013.

The ten organisations surveyed provided care for approximately 1622 people in Brighton & Hove and their combined estimations suggested 812 (50%) of these had diagnosed or undiagnosed dementia. Out of these estimated 812 people, 423 (52%) were diagnosed and 389 (48%) undiagnosed. These findings suggest that the overall prevalence of dementia is lower in home care clients than care home residents (50% vs 64%) and slightly more of those with dementia in care homes were diagnosed (52% vs 59%) although it is important to note that these figures are based on rough estimates only and the non-random nature of the survey means it is vulnerable to selection bias.

Question 1. Please indicate the dementia related training available to your staff...

<table>
<thead>
<tr>
<th>Training level</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No specialist dementia training</td>
<td>0</td>
<td>--</td>
</tr>
<tr>
<td>Informal training with a senior staff member</td>
<td>2</td>
<td>20%</td>
</tr>
<tr>
<td>QCF Level 2 or 3 awards in dementia</td>
<td>4</td>
<td>40%</td>
</tr>
<tr>
<td>QCF Level 3 Certificate in Dementia</td>
<td>2</td>
<td>20%</td>
</tr>
<tr>
<td>QCF Level 2 or 3 Diploma in Health and Social Care with a dementia pathway</td>
<td>2</td>
<td>20%</td>
</tr>
</tbody>
</table>

Question 2. Do you think people with dementia you provide care for receive enough support from the following services?

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>To some extent</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
</table>
| GP                    | 3 (30%) | 3 (30%) | 4 (40%) | 0 (--)
| Social workers        | 1 (10%) | 8 (80%) | 1 (10%) | 0 (--)
| Dentists              | 0 (--)| 0 (--)| 3 (30%) | 7 (70%)
| Occupational Therapists | 1 (10%) | 7 (70%) | 2 (20%) | 0 (--)
| Speech therapists      | 0 (--)| 5 (50%) | 2 (20%) | 3 (30%)
| Physiotherapists      | 1 (10%) | 6 (60%) | 3 (30%) | 0 (--)|
Summary: Again there was no one single service that managers felt people with dementia were not receiving enough support from although four out of the ten home care managers felt that their clients did not receive enough support from GPs and only 3 felt that they did.

**Question 3. Where do you find information on dementia care?**

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Voluntary organisations (e.g. Alzheimer’s Society, Age UK, Dementia UK etc.)</td>
<td>10</td>
<td>100%</td>
</tr>
<tr>
<td>NHS Choices website</td>
<td>7</td>
<td>70%</td>
</tr>
<tr>
<td>Local Authority Home Care Forum</td>
<td>5</td>
<td>50%</td>
</tr>
<tr>
<td>CQC</td>
<td>3</td>
<td>30%</td>
</tr>
<tr>
<td>Other home care organisations</td>
<td>3</td>
<td>30%</td>
</tr>
</tbody>
</table>

**Question 4. Please tell us what would help you improve the level of care for residents with dementia?**

- “More training that we can pass onto our staff”
- “Stronger partnership working with other organisations”
- “The support services listed in question 2 work in silo but need to work jointly and communicate much more closely”
- “Better understanding from GPs of the benefits of people remaining in their own homes for as long as possible”
- “Improved public awareness of the condition”
- “Mandatory basic dementia awareness training provided more regularly”
- “More training and workshops”

Russell Carter
Public Health Specialist Trainee