

## Appendix 2. Health Well Being Board Update – Dementia

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### 1. Overview:

The purpose of the report is to provide the Health and Wellbeing Board with an update on developments in dementia services in Brighton & Hove since the last report provided to the HWBB in March 2013 highlighting progress against the outcomes in the joint Health and Wellbeing Strategy.

#### 1.1 National Context

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. 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.<sup>1</sup>

Nationally, there is increasing focus on dementia as an issue, including prevention, treatment, and 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.

#### 1.2 Local Context

Dementia disproportionately affects people aged 65 and over and risk continues to increase as people get older. Brighton & Hove has a lower proportion of people aged 65 years and over (13%) compared to 17% in the South East and 16% in England, so dementia needs are not on the same level as other parts of the country. However, the number of over 65s is estimated to rise by around 12%, to about 40,000 people by 2021.<sup>1</sup> The biggest increases are expected to be in the 70-

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<sup>1</sup> Department of Health. Dementia. A state of the nation report on dementia care and support in England. November 2013

74 age group with an increase of 1,900 people (24% increase) and in the 90+ age group with an increase of 1,100 people (48% increase).<sup>2</sup> This will be particularly felt in the parts of the city where the older population is concentrated i.e. Rottingdean Coastal, Woodingdean, Hangleton & Knoll, Hove Park and Patcham wards. These increases highlight the future challenge of providing adequate dementia care in Brighton & Hove.

A key issue in Brighton & Hove has been the under diagnosis of dementia. In 2012/3, there were only 1,310 people on the GP dementia registers, compared to an estimated prevalence of 3,046. There is also a lack of accurate reporting of the number of people diagnosed with dementia living in care homes, receiving home care or self funding their dementia care.

### 1.3 Key outcomes

#### 1.3.1 PHOF / NHSOF / ASCOF

- Estimated diagnosis rate for people with dementia (Public Health and NHS Outcomes Framework)
- Dementia –a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life (Adult Social Care Outcomes Framework, Placeholder (not yet available) and NHS Outcomes Framework)

#### 1.3.2 Brighton & Hove Health and Wellbeing Strategy 2012 - outcomes for successful implementation of the Dementia Action Plan 2012/3

1. Levels of diagnosis to reach 70% of expected levels by 2016
2. Improved access to information, support and advice at point to diagnosis
3. Reduced prescribing of antipsychotics for people with dementia
4. Accreditation as a Dementia Friendly Community
5. Increased numbers of Carers Assessments completed at an early stage
6. A Dementia Board to take forward developments

## 2. Developments over the last year and improvements in outcomes

Brighton & Hove developed a Joint Dementia Action Plan in 2012 that sets out the strategic vision for improving care and support to people with dementia and their carers. The central aim of the plan is to increase awareness of the condition, ensuring early diagnosis and intervention as well as improving the

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<sup>2</sup> <http://www.poppi.org.uk/index.php?pageNo=314&areaID=8330&loc=8330>

quality of care for people with dementia and their carers. Key updates since the last report follows.

In the last year, as a result of the initiatives outlined below, **there have been significant improvements in awareness of dementia, early diagnosis and intervention as well as improvements in the quality of care for people with dementia and their carers.**

Numbering of this section corresponds to 1.3.2 above - Brighton & Hove Health and Wellbeing Strategy – Dementia. Sections in bold relate to the PHOF outcomes.

## 2.1 Levels of Diagnosis

Good quality early diagnosis is vital for all, without a diagnosis many people may not be able to access the right care and support, so increasing the rate of diagnosis is a priority. A new Memory Assessment Service was started in 2013, to increase the number of people in the city diagnosed with dementia and provide improved support to people with dementia, as well as their carers.

The service started in June 2013 and is now fully operational. This service is delivered from three local GP surgeries in Portslade, Patcham and Saltdean as well as in patients' homes. Patients can be referred to this service by their GP and the service does accept self-referrals.

**In 12/13 Brighton & Hove's dementia diagnosis rate was 44.4%, up from 38.9% the previous year. While this is some way off from 70% of expected levels by 2016, it is moving in the right direction. (Data on the diagnosis rate for 13/14 should be available in October 14).**

Issues raised by the CVS Forum are addressed in the Action Plan.

<b>CVS Forum: Dementia Gaps</b>	<b>Increased diagnosis rates</b>  CVSF members felt that currently, there is a lack of publicity about the memory service, although we are aware of plans for the new development worker.
<b>Update</b>	The Memory Assessment Service (MAS) ran an advertising campaign to coincide with dementia week in May 2014 to advertise the services further.
<b>Future Actions from JSNA for strategic</b>	Develop a single dementia information point to signpost the public, professionals and care home/home

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<b>plan (*)</b>	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
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## 2.2 Improved access to information and support

<b>CVS Forum: Dementia Gaps</b>	Improved access to information, support and advice at point of diagnosis
<b>Update</b>	<p>The MAS service does offer support from Dementia Advisers at point of diagnosis for up to 1 year.</p> <p>As Part of End Of Life work the “This is me bag” was produced and widely distributed across the city</p>
<b>Future Actions from JSNA for strategic plan</b>	<p>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).</p> <p>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.</p>

### 2.2.1 Improved support via the MAS

In addition to increasing levels of diagnosis, the MAS also offers advice and support to patients and their carers for up to a year after diagnosis via Dementia Advisers.

The new action plan arising from the JSNA will take on board the need for a single dementia information point as outlined below (\*) to ensure improved access to information, support and advice more broadly for the city.

### 2.2.2 Improved support to people with dementia admitted to general hospitals

- A Dementia Champion post is based at the Royal Sussex County Hospital and is driving forward improved services for people with dementia across the hospital. In addition this year, a specialist Dementia Nurse role to support the Champion has been funded.
- **90% of people who are over the age of 75, and are in hospital for 72 hours or more have received a memory screen, to identify if they have symptoms of memory loss and refer on to the Memory Assessment Service**
- The hospital has adopted the Butterfly scheme and this was launched in June on the Sussex County and Princess Royal sites. The Butterfly scheme provides a framework for rolling out education and an approach to caring for patients with dementia across the whole Trust. It allows people whose memory is permanently affected by dementia to make this clear to hospital staff and provides staff with a simple, practical strategy for meeting their needs.
- The Emerald Unit on the Royal Sussex County site opened in May 2014, with the aim of providing specialised nursing, therapies and mental health care for people with a dementia. The Dementia Champion and nurse specialist are based within this unit. It is envisaged that through the Emerald Unit, BSUH will establish a 'hub' for dementia care, to ensure that patients and staff can access appropriate advice, care and expertise. The development of the ward was supported by the Trust securing capital funding from the Department of Health, as part of the Dementia Friendly environments partnership bid.
- BSUHT has recently produced a 2 year clinical strategy for dementia.

### 2.2.3 Crisis Support Dementia Crisis & Short Term Support

Additional resource has continued to be put into the Community Rapid Response Service (CRRS), to enable more people with dementia to be supported at home and avoid unnecessary admissions to hospital. This service has also employed a mental health liaison nurse.

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#### 2.2.4 Living Well with Dementia Team

The services that Sussex Partnership NHS Foundation Trust provided for dementia were reviewed in 12/13 and the Living Well with Dementia Service was put in place in 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.

#### 2.2.5 Care Homes

- The Care home in-reach service provides support to care homes to improve their ability to care for and support their residents who have dementia. This service was reviewed in 2013; the service is now permanently funded with a change in staff mix to provide additional occupational therapy.
- Two new large care homes have recently opened in the city, Maycroft Manor and Dean Wood and a third is currently being developed. These care homes all have capacity to admit patients with memory loss and dementia. However, because of the comparatively high level of fees at these new providers, generally places in these new care homes are available to people who are able to fund their own care

#### 2.2.6 Younger Onset Dementia

- Day services for people with young onset dementia have been supported to move to new premises at Buckingham Road.

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- The Alzheimer's society also received funding in 2012/13 to "Provide Singing for the Brain" sessions and "Dementia Cafes". They have received further funding for 13/14 and are now looking at the providing target sessions for patients with younger onset dementia.

### 2.2.7 End of Life

In 2013 the regionally funded Sussex End of Life (EoL) dementia project was used to develop a care pathway for people with dementia at the end of life. Specialist resources for EoL including the "This is me bags" were developed and a range of training for professionals was delivered.

### 2.3. Reduced prescribing of antipsychotics for people with dementia

Since 2012/3 there have been 2 main initiatives to address this:

- A Care Home In-Reach team supports person-centred approaches to dementia, in particular identifying alternatives to antipsychotic medication.
- In April 2012 a resource pack for GPs to assist them in reducing the use of antipsychotics in people living with dementia was produced, and this has been improved and updated in the last 18 months. It has a variety of resources with the latest version including information for carers on how to help avoid challenging behaviour.

### 2.4 Dementia Friendly Community

- **Dementia Friendly Environment Capital Bid**  
A £1 million capital funding application to support improving the environment of care for people with dementia was awarded in June 2013. This was a partnership bid which aimed to adapt the environment in a number of settings accessed by people with dementia. This work included improvements to BSUH to create a dedicated space in Accident and Emergency, and 2 inpatient wards; funding to improve 6 GP surgeries in the city; dementia friendly improvements to Brunswick Specialist Dementia ward in the Neville Hospital and residential short term services units and Ireland Lodge and Wayland Avenue day care centres. Funding grants were also given to 38 mainstream residential care homes.
- **Dementia Challenge Fund**  
Brighton and Hove received a small funding grant for 1 year from the National Dementia Challenge Fund and this was used to fund the Trust for

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Developing Communities to work on supporting the voluntary and community sector. In partnership they have developed a toolkit to support voluntary and community groups in making the city more dementia friendly, which will be launched in September 2014.

- **Dementia Friendly City**  
The new action plan arising from the JSNA will take on board how to make the city an accredited Dementia Friendly Community. One option could be to align this approach with the Age Friendly City programme.
- **Dementia Friendly Toolkit**  
Trust for Developing Communities (TDC) has been developing a toolkit for voluntary sector organisations to help them become more dementia friendly. The toolkit is in the process of being finalised and will then be rolled out across the voluntary sector in the city, using a range of communication/marketing strategies. There is the potential to adapt this toolkit for organisations in other sectors.

<b>CVS Forum: Dementia Gaps</b>	<b>Accreditation as a dementia friendly community - housing</b> It was felt that large housing providers could improve their knowledge of and willingness to work in partnership with other organisations in the community and voluntary sector, especially regarding new service developments. A more collaborative culture should be fostered. To achieve the accreditation, better information around dementia would be needed with raised awareness about the availability (or lack thereof) of dementia housing.
<b>Update</b>	Work has started to develop dementia friendly communities; however this has not been targeted at housing providers specifically.
<b>Future Actions from Needs Assessment for strategic plan</b>	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 3.6. Optimise the use of Extra Care Housing so that they are able to support people with higher level needs for

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	longer thus easing the pressure on specialist dementia beds.
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## 2.5 Carers Assessments

There is a team of Carer Support Workers in Adult Social Care who offer information, advice, support and carers assessments to all carers of adults in Brighton & Hove. Over the last year, they have been working closely with the Integrated Primary Care Teams (IPCTs) and the Living Well with Dementia service to raise awareness of the needs of carers and the support available. The Carers Centre also has a carers needs assessment worker as part of the Memory Assessment Service, so that carers are offered an assessment of their needs at the point of diagnosis.

Telecare and Carers Services information sessions have been run at Ireland Lodge and Wayfield Avenue for carers of people attending the day centre, and 2 information workshops were held with Sussex Partnership Trust to help raise awareness of the support available for carers of people with dementia.

The Carers Register was launched in June 2014 and is being promoted across the city and in partnership with voluntary sector colleagues, to improve access to the appropriate level of assessment and support.

As a result of all this activity, the number of carers of people with dementia accessing carers assessments has been increasing year on year.

## 2.6 Dementia Board

The Dementia Partnership Board has been meeting regularly since May 2013 to both take forward the Dementia Action Plan and to steer the Dementia Needs Assessment. Key aims are:

- To provide a cross organisational steering group to take forward improvements in care for people with Dementia. Partners include the Local Authority (Adult Social Care and Public Health), CCG community and acute and mental health settings and third sector.
- To ensure there is a forum for relevant professionals to come together to support and steer services for people with dementia in terms of future developments.

Members include a cross section of representatives from health and social care and the voluntary sector, chaired by Simone Lane, Joint Commissioner for Dementia. Terms of Reference and membership will be updated in line with the delivery of the revised Action Plan.

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### 3. Improvements in outcomes

In the last year, as a result of the initiatives outlined above, there have been significant improvements in awareness of dementia, early diagnosis and intervention as well as improvements in the quality of care for people with dementia and their carers.

In terms of the specific PHOF outcome relating to diagnosis (estimated diagnosis rate for people with dementia (Public Health and NHS Outcomes Framework):

- In 12/13 Brighton & Hove's dementia diagnosis rate was 44.4%, up from 38.9% the previous year. Data on the diagnosis rate for 13/14 should be available in October 14.
- 90% of people who are over the age of 75, and are in hospital for 72 hours or more have received a memory screen, to identify if they have symptoms of memory loss and refer on to the Memory Assessment Service

### 4. Outline proposals going forward.

In May 2014, a Dementia Needs Assessment was undertaken<sup>3</sup> which looked at current and future unmet needs, assets and gaps in relation to dementia care. It included a wide range of recommendations. In response to these, a Joint Strategic Delivery Plan is being drafted and consulted upon. Key to the plan is an aim to treat dementia as a 'long-term condition' and align dementia services with physical health services, so a holistic approach is taken to the care of people with dementia.

The draft plan will be discussed at the Health and Well Being Board on 14th October 2014.

A recent workshop with a wide range of commissioners and providers from across health and social care, including private and voluntary sectors looked at all the recommendations in the draft Joint Strategic Delivery Plan and prioritised the following actions going forward:

- Develop a single dementia information point to signpost the public, professionals and care home / home care workers to 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.
- Support all people recently diagnosed with mild cognitive impairment and dementia to access activities at the different stages of disease progression –

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<sup>3</sup> <http://www.bhconnected.org.uk/content/needs-assessments>

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eg Active for Life, Health Walks, Healthy Eating, Singing for the Brain, Dementia Cafes.

- 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
- 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
- Increase the capacity of home care to support the number of people with dementia and develop joint working with health to reduce social isolation and decrease delayed discharges of care
- Ensure that all care homes have named senior member of staff leading on improving dementia care
- Encourage care homes to use memory tools like memory boxes and reminiscence rooms

It was also recognised that there is a need to strengthen the voice of people with dementia going forward to ensure that their views are integral to the commissioning and service delivery and improvement.