

TITLE	Report on Dementia Service Development across the West of Berkshire
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**REPORT ON DEMENTIA SERVICE DEVELOPMENT ACROSS THE WEST OF
BERKSHIRE**

TO: Wokingham Health Overview and Scrutiny Committee

DATE: 24 March 2014

TITLE: **DEMENTIA SERVICES IN BERKSHIRE WEST - UPDATE**

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1. PURPOSE OF REPORT AND EXECUTIVE SUMMARY

- 1.1 This paper provides an update to the Committee on the work in progress in Dementia service development across Berkshire West in support of the National Dementia Strategy. Locally there is a Berkshire West Dementia Stakeholders Group, with representation from health commissioners and providers, Unitary Authorities and the voluntary sector, implementing the strategy at local level as part of the Long Term Conditions Programme.
- 1.2 This paper has had input from all the key partners within the west of Berkshire.

2. RECOMMENDED ACTION

- 2.1 To note the contents of this update report**

3. POLICY CONTEXT

National Dementia Strategy

- 3.1 The National Dementia Strategy (2009) set out a work programme over a five year period to improve dementia care across three main areas - Improved detection; Earlier diagnosis; and Intervention and delivering a higher quality of care and the Revised NHS Operating Framework (2010/11) put clear expectations on NHS organisations to be working with partners on implementing the National Dementia Strategy.
- 3.2 Mental ill health costs some £105 billion each year in England: this includes £21 billion in health and social care costs and £29 billion in losses to business (The Economic and Social Costs of Mental Health Problems in 2009/10. London:

Centre for Mental Health). It was estimated that the financial cost of dementia to the UK will be over £23 billion in 2012.

- 3.3 'Dementia' is used to describe a range of conditions which affect the brain and result in an overall impairment of the person's function. The person may experience memory loss, problems with communication, impaired reasoning and difficulties with daily living skills. This can result in changes in behaviour, which can disrupt their ability to live independently and may affect social relationships. Dementia is a progressive and terminal condition, which will in most cases lead to increasing cognitive difficulties and dependence on others. How long the person will live depends upon the type of dementia, their age and their general health, but many will live with the condition for several years.
- 3.4 During 2012, the Prime Minister launched the 'Dementia Challenge' which set out an ambitious programme of work to push further and faster in delivering major improvements in dementia care and research by 2015, building on the achievements of the National Dementia Strategy (2009). The local health and social care economy worked in partnership to develop and submit 7 proposals, 5 of which were successful in gaining full funding.

Central to the challenge is the requirement that from April 2013, there needs to be a quantified ambition for diagnosis rates across the country. The rates are published annually through the NHS Information Centre and is contained within the NHS Outcomes Framework – domain two. The Dementia Prevalence Calculator Tool enables local areas to account for local factors and establish estimates of their local prevalence rates.

According to the tool the adjusted figures for 2011/12 baseline across Berkshire West are as follows: North & West Reading CCG – 50.63%, South Reading CCG – 46.97%, Wokingham – 44.54% and Newbury & District CCG – 48.18%. All CCGs diagnosis ambition is to be at 67% by the end of 2015/16. There is a national Directly Enhanced Service (DES) encouraging GPs to screen all at risk patients aiming to identify more people with possible dementia and refer them to the Memory Clinics.

The Quality Outcomes Framework (QOF) data for 2012-13 shows the following number of patients on the GP registers: North & West Reading CCG – 583, South Reading CCG – 455, Newbury & District CCG – 618 and Wokingham – 848.

The NHS Outcomes Framework

- 3.5 Domain 2 of the NHS Outcomes Framework, published by the Department of Health identifies four objectives that are of particular relevance. This includes improving the health-related quality of life for people with long term conditions and carers, increasing the proportion of people who feel supported to manage their condition and the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia.

4. LOCAL PICTURE

There is already much joint working between health agencies, local authorities and the voluntary sector. The sections below provide a detailed update on the work in progress within each partner organisation in order to update the Committee.

Berkshire West Clinical Commissioning Groups (CCGs)

- 4.1 As part of the 2013-14 QIPP programme the Berkshire West CCGs prioritised increased investment into their Older People's Mental Health services delivered by Berkshire Healthcare Foundation Trust (BHFT). This investment is in recognition of the costs associated with both the increase in the volume of patients with dementia and the prescribing issues relating to anti-dementia drugs. Capacity in memory clinics is being increased in line with demand. Prescribing of anti-dementia drugs is extending to those with mild dementia in line with NICE guidance. All memory clinics across Berkshire have seen a rise in referrals. Referrals to Memory Clinics have increased on average by 15.8% compared with the same period last year. Across Berkshire 1383 (81%) of the patients referred to Memory Clinics since April 1st, have attended an initial appointment, and of this number 1076 (77.8%) have been seen within 6 weeks of being referred. Of the patients who have attended their first appointment 241 (17.4%) were seen between 7-10 weeks.

Referrals 2013-14 Q1-Q3								
locality	0-3 Weeks	4-6 Weeks	7-10 Weeks	11-14 Weeks	> 14 Weeks	Yet to be seen	Discharge d No Appt	Grand Total
Newbury	51	116	72	6	8	35	18	306
Reading	98	88	37	10	7	49	22	311
Wokingham	81	150	56	6	1	23	32	349
Grand Total	230	354	165	22	16	107	72	966

- 4.2 Shared care has been introduced between specialists and GPs, enabling suitable patients to transfer to GP care once stabilised on their medication and agreed by the clinicians involved.
- 4.3 The ethnicity status of patients attending the memory clinics in each area very closely mirrors the ethnicity profile of the >65 years population in the area. The Berkshire West GP lead for mental health has met with the Nepali community development workers to see if barriers to care/help with education about dementia can be identified and Clare Garley (Alzheimer's Society) has agreed to go and speak to them.
- 4.4 The CCGs have continued to fund the 4 Dementia Care Advisor posts across the west of Berkshire. These provide information, advice, guidance and support to those newly diagnosed with dementia, their family and carers and has a dedicated post for people with early onset dementia. This latter post is pan the west of Berkshire. The other three posts are based in each locality. Wokingham Borough Council part funds its post so that it is full time.
- 4.5 **Home from Hospital Service – Age UK Berkshire.** This is a service part-funded by the Berkshire West CCGs through the Partnership Development Fund, with Reading Borough Council also partially supporting this in the Reading area. Charitable donations to Age UK Berkshire also help support this. The specialist support service is available to clients who have not been in-patients at RBH (i.e. referred by A&E), clients with dementia who are in-patients at RBH and those previously diagnosed with dementia. The specialist service is an extension of Age

UK Berkshire's generic Home from Hospital service run elsewhere in Berkshire, using the expertise built upon that. In addition to referrals from the RBH the service also sees clients in Reading who have been admitted to other hospitals, including Oakwood unit at Prospect Park, The Willows Intermediate Care and patients at private hospitals receiving NHS elective surgeries. Between 1st October and 31st December 2013, the Specialist dementia service supported 16 people with dementia in Reading, and has seen 32 people in total in the Reading area between April and December 2013. The generic Home from Hospital service in Reading has supported 66 older people in addition to those above, between April and December 2013: a total therefore of 98 people.

- 4.6 A number of key improvements were raised for dementia services at the Dementia and Elderly Care Conference hosted by NHS South Reading CCG on 14 May 2013. The Berkshire West Dementia Stakeholder Group reviewed the list of priorities identified by delegates and the updates provided on the South Reading website (<http://www.southreadingccg.nhs.uk/you-said-we-did/dementia>) from partners detail progress made. Key areas were identified: Communication and access to services; Joined up working around training and information; Better integration between hospitals, communities and social care; Lack of integrated ring-fenced funding for care support, respite care, premises, domiciliary care and training; Joined up working across health and social care and Outreach worker for BME community. This report covers the updates against this where this information is available.

Dementia Challenge Projects 2013-14

In response to the Prime Minister's Dementia Challenge launched in 2012, 7 proposals were submitted as part of their bid to the Challenge Fund. These were written by unitary authority partners and BHFT on behalf of all 4 CCGs and the submissions reviewed and co-ordinated by the Berkshire PCT dementia lead. Of these, 5 successfully gained funding. A further one, the 'Berkshire Blue Book' obtained funding by the CCGs themselves and the update is included in this section:

- 4.7 **Patient and Carer's Information** - The project aimed to give patients with dementia and their carers access to the information they want and need via a variety of media, including a local Dementia information website, to inform, empower and improve lives. The approach followed the successful model previously developed in relation to stroke patients in Berkshire West, which involves working closely with service providers, users and carers. The resulting Stroke website has been in existence for over a year with positive feedback and visitor volumes.

The element of the Dementia challenge funding that was received for the development of a website has been delivered. The content includes links to national dementia sites, highlights local support and includes a video talking about Dementia. The content is available on each of the four Berkshire CCG websites and a link as an example as follows: www.wokinghamccg.nhs.uk/long-term-conditions/dementia

- 4.8 **Care Home In Reach Team** – The aims of this project are to deliver improved quality of life for people with dementia living in selected residential and nursing homes; improve the skills of the care home staff, building their confidence and professionalism and improve communication with people with dementia, and

involvement of, carers. This will include their involvement with anticipatory planning for End of Life care.

The team comprises a clinical team lead and 5.5 experienced nurses. There is an equal split between Registered Mental Health Nurses (RMN) and Registered General Nurses (RGN). The team works across the 3 local authority areas in the West of Berkshire with a RMN and a RGN working in each local authority area and all the staff are all employed by Berkshire Healthcare NHS Foundation Trust.

The team began delivering their service in the first wave of identified care homes in May 2013. They have worked in 13 homes so far: 5 in Newbury, 5 in Wokingham and 3 in Reading. The Reading homes tend to be much larger which is why fewer homes have been covered. In total, 411 residents in these homes have been seen by the team. The pattern is that the team will work intensively in 2-3 homes (depending on size) for a period of 3 months and then will move on to a new group of homes. However, links are maintained with the first group of homes which are still visited occasionally and who can approach the team for support. The In Reach staff work alongside the care home staff to model good practice and to observe and identify areas for improvement. The team only goes into homes at the invitation of the manager and the owners.

A variety of training has been delivered as training is a big part of the team's remit. This includes formal training sessions, workshops and informal teaching "on the floor". Care home staff have also been helped and encouraged to access external training. The team is collecting both quantitative and qualitative data to evidence their effectiveness. Initial audits have been completed and follow-up re-audits will take place to gauge the impact of the team's input. The team is building a collection of case studies which illustrate the work they have achieved. Work began in the next wave of homes in January 2014.

- 4.9 **Cognitive Stimulation Therapy (CST)** – this project aims to extend the current provision of CST and will develop knowledge and competency of staff working in non-health settings, to support the initial delivery of CST followed by Maintenance CST in Day Care and Extra Care settings and to expand the local CST network and support continuation and expansion of CST provision within the area.

The project was initially due to start from February/March 2012, however this was delayed due to HR issues and the project consequently became operational on 1st July 2013 when the mental health practitioner (MHP)/facilitator was employed. From the beginning of the project, 9 providers expressed interest in 2 or more of their staff participating in the project. All 3 localities are represented (Newbury, Reading and Wokingham). By delivering formal training to staff working in Day Centres and Extra Care Housing Schemes, and providing them with the opportunity to observe and participate in established CST courses, the project will ensure they have the confidence and capability to run CST in their workplace thereby adopting and extending best practice across care settings in the West of Berkshire and enabling more people with Dementia to engage in this evidence based approach for longer.

A full days training was completed during September with 15 people attending. All providers were represented with at least one staff member from each location. The day based around a programme of explanatory lectures followed

by group workshops and discussion. This first cohort of trainees commenced shadowing the BHFT led CST (3 providers 5 staff). Two providers have now fully completed the shadowing sessions (3 staff). During October the 2nd cohort of trainees shadowing BHFT led CST was delayed due to issues relating to CST sessions. Two providers initially agreed to the training sessions but after a promising start, staff subsequently failed to attend the requisite sessions. On investigation providers stated that demands of workload meant that staff could not be released. Continuing dialogue with the providers has been productive and two participants were due to recommence the course in Dec 2013. The 3rd cohort of shadowing began during November and a fourth commenced during January 2014.

During December 2013 an evaluation of the 1st cohort of trainees was undertaken. The 1st cohort has now finished the shadowing sessions. Woodley Age Concern has marketed maintenance CST sessions and with continuing support from the MHP are due to rollout CST in January 2014. The second provider is currently undertaking a feasibility study and with support from the MHP is looking to begin maintenance CST end of January/ early February 2014. At this stage it is too early to fully assess outcome measures, however qualitative evaluation of staff who have completed the days training and shadowing CST sessions have highlighted that shadowing sessions complimented the theoretical based training day.

At this stage the signs are positive but it is too early to fully evaluate the initiative. Outcome measure used so far have been CST evaluation, staff questionnaire and an attitudes to dementia scale to highlight gaps in participants learning.

- 4.10 **Domiciliary Care Training** – this project seeks to establish the current training provision, identify training needs through a training needs analysis and to identify a future plan of action to meet identified training needs. There is a variable take up of training currently available and this analysis will allow CCGs and UAs to tailor courses based on local need and to more target those agencies who wish to become market leaders.

This project has had a delayed start as the project manager has only recently been appointed. She has developed a work force questionnaire and will be concentrating on working initially with Reading providers and then will be expanding to the other two local authorities. This work is overseen by the Berkshire Care Association.

- 4.11 **Dementia Friendly Communities** – this project aims to assist in building dementia-friendly communities by developing a dementia declaration as outlined by the Dementia Action Alliance in each local authority which would be signed by major employers, the council and voluntary sector. It will commit them to review and change the activities of their organisation in line with the declaration. In addition it involves inter-generational working with schools, colleges and youth groups in partnership with people affected by dementia and their carers. The focus is around engaging young people in a variety of settings. The Dementia Action Alliance includes the championing of the Green Bottle system.

Reading Borough Council – Times of our Lives workshops are being rolled out across primary and secondary schools in Reading to support the intergenerational work. During July and September, the Hands-On Company

researched, devised and rehearsed Times of our Lives (using drama and puppetry) and created the follow-up CD. Marketing the workshops started at the end of the summer term and then during the first two weeks of September. An article in the Reading Chronicle preceded a news story on South Today and a twenty minute studio chat with Drive-time Radio Berkshire. The first workshop was held in September and there have been nine workshops in primary and one in secondary schools up to the end of November. The feedback has been very positive. The workshops will continue in the spring and summer terms.

The first quarter of the Dementia Action Alliance in Reading has been mainly one of establishing contacts, networking, training and forging relationships in order to develop sustainability for the future. In broad terms, all responses from the organisations and people contacted have been very positive with pledges to commit to the alliance in principle, become part of the steering group and /or learn more about becoming a Dementia Friend or Champion. Consultation with people with dementia and their carers is ongoing and a launch of the Alliance is anticipated in February/March.

Wokingham Borough Council – the intergenerational work is progressing very well within Wokingham. The project lead has addressed a number of school assemblies as well as setting up individual projects with schools, young people and day and residential centres. Most of the work to date has concentrated on the upper end of primary education, however, this is now moving into senior schools. This development work has received lots of very positive feedback.

The work for the Dementia Alliance in Wokingham is progressing well and the project team have met with the Chief Executive, Leader of the Council and the Director of Health and Wellbeing and they have signed up to the principle of Wokingham Borough Council being both a member and contributing to the official launch of the Dementia Action Alliance in February 2014. The project manager has also completed several town walks with people with dementia and their carers and will be liaising with the town centre regeneration project.

The two work stream project leads are working as a team and delivered two dementia friends sessions to Wokingham Borough Council staff in February 2014. There has been a recent article in the council's residents' newsletter regarding the project and one is shortly to appear in staff newsletter publicising the dementia friend sessions.

West Berkshire Council – for the Dementia Friendly Communities project in West Berkshire, Sue Butterworth is in post via the Alzheimer's Society to take forward the Dementia Alliance work. A local information forum was held on 4th November 2013 and the Director of Social Care, the Portfolio holder for the Council and the local MP have all given their support to the project. Sue is also working with public health colleagues and local businesses.

The Hands On Company is now up and running and working with local schools to raise dementia awareness with children as has Reading for the inter-generational part of this project. The Dementia Friendly launch event is planned for March/April 2014.

- 4.12 **'Berkshire Blue Book'** - This aims to adapt the Gloucester 'Living Well handbook' to West Berkshire to enhance user participation and ownership from the outset - opinions will be sought from 'experts by experience' (patients and

carers) and 'experts by training' (professionals) to develop a handbook. It draws on a current West Berkshire project to develop online information for people with dementia, utilizing the information currently available from Alzheimer's Society (and other sources) thereby producing a parallel online version to the physical post-diagnosis pack.

As at December 2013 the first prototype 'living' pack was ready. The pack is based on information, input and results from the review of dementia information; the qualitative research to elicit patient/carer information needs; and the parallel research to identify information considered important by healthcare professionals, local authorities and voluntary sector staff.

The process of review and research also included gathering baseline data for evaluating the impact of the pack on patient/carer's reported quality of life, knowledge/skill and service usage. The impact of the pack will also be measured against unplanned admissions and crises requiring intervention.

The next phase due to take place in Jan 2014 is to trial the packs. The sessions are to get feedback on the overall concept and detail of pack components from those who contributed/participated in the preceding research and data collection phase. The packs will then be finalised for launch as part of the final phase.

Local Authorities

The following service is run jointly across the 3 localities.

- 4.13 **Younger People with Dementia (YPWD) Group – Reading Crossroads and Woodley Age Concern.** The Crossroads service is funded by the 3 local authorities and younger people with dementia from across Berkshire West attend. This service which is a combination of workshops and one-to-one sessions is going well. The feedback has been excellent. The Woodley Age Concern service is funded by the Partnership Development Fund. A single programme to co-ordinate the work of Reading Crossroads and Woodley Age Concern with the YPWD outreach service is currently underway. The service covers all three Unitary Authorities.
- 4.14 The YPWD outreach service, hosted by the YPWD Charity, is now operational in West Berkshire providing alternative community based activities for this group of patients.
- 4.15 Singing for the Brain, Walking for the Brain all continue to be provided via the Alzheimer's Society. Crossroads continue to provide a community based respite service to carers.
- 4.16 Dementia Cafés are now in place across the three UAs, funded by the Local Authorities. In addition there is Al's Café in Wokingham for younger people with dementia.

Reading Borough Council

A number of initiatives and ongoing programme of work is in place across Reading led by the council as detailed below:

- 4.17 **Improving the environment of care for people with dementia** - The construction of a dementia friendly garden at The Willows Care Home in Reading started in November 2013. The conservatory has been built and garden areas cleared of paving and overgrown shrubs. The next stage will involve hard landscaping and planting and the development of a programme of activities by Thrive. When finished, the garden will be used as a best practice example for local care homes, extra care and day care settings. It will also feed into the overall programme evaluation and the production of a national dementia friendly environments building design guidance.
- 4.18 **Befriending Service – Alzheimer’s Society.** This is a council funded service which uses volunteers to visit people with dementia and take part in activities with them. Befriending volunteers are paired with people with dementia, having matched them according to interest. This is the third year of operation and after two successful years the service was suffering from a lack of volunteers. This is being addressed by the recruitment of a new manager for the service and the hope is that it will be running at full capacity in the final quarter of 2013/14.
- 4.19 There are a number of groups which provide peer support for people with dementia and their carers. The Alzheimer’s Society runs a weekly drop-in, a monthly Dementia Café and an empowerment group. The latter enables people with dementia to influence and comment on local services. Crossroads holds a monthly carers support group at Hazelwood and the Berkshire Carers Service operates a number of carer support groups in Reading.

West Berkshire Council

- 4.20 An additional 11 bedded unit for people with dementia was opened in one of the West Berkshire Council care homes in June 2013.
- 4.21 **Dementia Support – Age UK Berkshire** - This charged-for service commenced in the West Berkshire Council area with coverage now moving into Reading. Initially started by “seedcorn” funding, the service is now paid for by service users’ families from Personal Budgets, own funds or in a small number of cases, directly by local authorities; there is no ‘subsidy’ or grant from any statutory local authority or NHS body. Trained Age UK Berkshire employees work one-to-one with people living with dementia, enabling them to undertake social or individual activities of their choice, from stimulating activities in their home to trips and visits to place that interest that older person. The service also provides some respite for carers and families and is available from one to eight or more hours per week. The service currently supports 23 older people with dementia or memory loss each week.

Wokingham Borough Council

- 4.22 **Emergency Care for Carers** – Emergency overnight care is available through Crossroads and this is funded by the Council. The progress of this service has been slow due to illness of staff. This service is to be reviewed soon.
- 4.23 **Young Carers work** – Young carers are children or young people under the age of 18 years, whose lives are in some way restricted due to the need to take responsibility for someone who is ill, disabled, experiencing mental health issues or affected by substance misuse. There has been slow progress in this area because the Wokingham Borough Council project manager who led on this work

retired. There are plans to refresh this work in 2014 and this will include providing a service within schools to identify previously hidden young carers.

- 4.24 **Sitting Services** - The service which is provided by Wokingham Crossroads is slowly expanding with the focus on new carers. There is, however, some caution in how the service is provided because of the uncertainties around ongoing funding.
- 4.25 **Dementia Cafes** - The Dementia cafe provides information and support in an informal setting for people with dementia and their carers. There is a Dementia cafe in each of the three UAs, with Optalis just setting up a second café in Wokingham.
- 4.26 **Suffolk Lodge** - £350,000 is set aside to upgrade the sole Wokingham Borough Council residential home to make it dementia friendly. The design company has been appointed and work is planned to start in early 2014.

The Royal Berkshire NHS Foundation Trust (RBHT)

- 4.27 **Staff Training** - As part of the Secretary of State's Health Education England Dementia Mandate the RBH has completed the '*Health Education England Provider Organisation Dementia Scoping Survey*' relating to the provision of dementia awareness training (*National Expectation that 100,000 NHS staff to have received foundation level dementia training by March 2014*).

Dementia awareness training continues to be provided to all Registered Nurses, Allied Health Professionals and Health Care Assistants during Trust Induction. 355 staff received dementia awareness training during their induction period in 2013. Student nurses on placement in elderly care wards are now provided dementia awareness, recognition and management of challenging behaviour, and visuo-perceptual difficulties in dementia training.

The second round of Dementia Champion training took place at the RBH in November 2013. 37 RBHT staff and 14 Student Nurses attended this one day event. There was staff representation from the Urgent, Planned and Networked Care Groups and the day was very well evaluated by attendees.

Dementia Champion training will continue in 2014 with bi-monthly 90 minute training sessions focusing on communication, recognition and management of challenging behaviour, end of life care, the carers' perspective. The award winning DVD 'Barbara's Story' which was created by St Thomas and Guys Hospital was used for the first time at the RBH in the champion training.

As a result of the Francis Report, ward-based simulation scenarios have been implemented as a Pilot Study. Dementia care has been incorporated into these scenarios. In addition, the Older People's Mental Health Service delivered at RBHT by BHFT continues to provide staff training on various subjects.

In November, RBHT sent a representative to the Health Education England gathering of health practitioners, academics, and commissioners to discuss what the learning requirements were for post graduate nurses to improve the level of care received by older people with complex needs. This work is currently being collated by Health Education North East (HENE). This HENE project is proposing to define what the educational requirements are for post graduate

training and how this may be achieved at Foundation, Specialist and Higher Specialist Level (There are almost 500 post graduate courses for nurses relating to caring for older people, however, there are currently no national standards directing the course content).

- 4.28 **Dementia Friendly Wards** – Phase 1 of the enhancing the healing environment work has been completed on four elderly care wards. The new wards incorporate safe flooring, new colour schemes, reduced size of nurses' stations and space made within the bays for staff to work at. This is to encourage staff to be closer to the patients.

The RBH also have a number of future plans in development as detailed below:

- 4.29 **One to One Care Crew** - The Trust is currently in the process of recruiting a team of Health Care Assistants specifically to provide one to one care for patients with cognitive problems. These staff will undergo a special training programme.
- 4.30 **Forget-Me-Not Scheme** – this scheme will be rolled out across the Trust. Forget-me-nots are put behind the beds to aid communication, orientation and reassurance.
- 4.31 **Delirium Screening** – The Trust will implement training related to Confusion Assessment Method (CAM) screening and delirium recognition.

Berkshire Healthcare Foundation Trust

The Older Persons Mental Health Services (OPMHS) teams that operate within each of the Berkshire West localities (Reading, West Berkshire and Wokingham) deliver a number of services to support people with dementia and their carers. Memory clinic accreditation is being sought for each of the 6 clinics in Berkshire. The details are provided below are specific to West Berkshire but all localities run these courses:

West Berkshire OPMHS (Beechcroft)

- 4.32 **Understanding Dementia Course for Carers** – this service will be run six times per year in 2013-14 and five times in 2014-15. Carers are invited to attend following the diagnosis appointment and about 25 carers actually sign up for each course. As a result of feedback from both carers and professionals, one session of the course is being removed in 2014 and will become a stand-alone session to which carers will be invited as and when they feel the time is right. This is a session about the Physical Aspects of Dementia and End of Life care planning. It has been suggested that these two topics will be more relevant further down the line, rather than following diagnosis, so carers will be referred into this final session via the memory clinic at a later stage. In February and March 2013 extra funding has enabled a version of this course to be introduced into one of the local extra-care complexes and delivered to their staff.
- 4.33 **Carers Support Groups** – there are a number of carer support groups that are run in West Berkshire delivered by BHFT. Monthly groups for carers and also specific groups for carers of YPWD are run for anyone who has questions about caring for someone with dementia. The first carers education course was completed in 2013 and a further one is planned for 2014. In order to create synergy across projects outside speakers/project co-ordinators are invited to

access or share the courses/groups/initiatives so that carers can be made part of every process. Sue Butterworth (leading Dementia Action Alliance) has had 2 opportunities to talk to the carers on the Education Course to get their feedback on dementia-friendly communities. The West Berkshire Dementia Care Advisor always attends to talk to the carers about her work, and Mandy Coombes attends to talk about End of Life care planning. Professor Alison Black, who is working with Luke Solomons on the Berkshire Blue Book project for carer information about dementia, has also accessed several education courses - both to get baseline feedback on how information is currently presented and then to continue the action research part of the project by returning to show carers proposed changes in response to their feedback.

- 4.34 **Understanding Dementia Course for Professionals** – This 2-day course is run 6 times per year per year with an average of 20 candidates attending each course with nursing homes, domiciliary agencies and general wards sending attendees. This initiative has run since 2007 and is expected to continue in the future.

BHFT & Local Authority collaboration Young People with Dementia (YPWD) Charity

- 4.35 Younger People with Dementia (Berkshire West) YWPD was launched as a registered charity in June 2012 in order to provide support for younger people with dementia (by definition onset of symptoms before the age of 65) and their carers. The main aims were to raise the profile about the different needs of younger people with dementia, specifically in relation to age appropriate activities, to provide social and emotional support and to raise funds through grants to provide age appropriate support.

The needs of younger people with dementia and their carers differ greatly from older people as the pattern; progression and burden of illness are all different. Loss of employment and with it financial insecurity, marital breakdown and impact on children have far reaching effects. Furthermore behavioural and psychological symptoms associated with the dementia when they occur are very difficult to manage within current care provisions for people with dementia which are geared towards people who are much older and physiologically frailer.

There are no dedicated services for younger people with dementia in Berkshire, as there are in other areas of the country, although nationwide provisions are quite variable. BHFT offers assessment for people with dementia of any age through the Memory Clinics and Community Mental Health Teams for the Elderly, but any interventions offered such as the Understanding Dementia Course for Carers and Cognitive Stimulation Therapy for patients are aimed at people in their seventies, eighties and nineties, as these provide the bulk of the referrals. Whilst carers of younger people with dementia access the current Understanding Dementia Course, feedback has been that these are not age appropriate.

- 4.36 In Wokingham for the past five years BHFT have run a specific adapted Understanding Dementia Course for carers of younger people, but also a parallel psycho education course for people with dementia which has received excellent feedback. The usual follow-on from these interventions is referral to a Dementia Care Adviser and for younger people with dementia there is specifically a Dementia Care Adviser in place.

YPWD employs an Admiral Nurse part-time (3 days per week). This is on a fixed term contract of 18-months according to the funding stream. Admiral Nurses specifically provide intervention, psychological and practical, for carers. Carers of younger people with dementia often have complex needs, often because they are juggling many roles and over 50% of carers of younger people with dementia suffer from mental health problems.

The rest of the activities of the charity are related to fundraising, providing information (via website and quarterly newsletter), carer support, social events and networking. The staff working for YPWD work extremely closely and jointly with the BHFT team and are based in the locality memory clinics, accessing relevant supervision and teaching by BHFT staff, are involved in away days and planning of the service both at a strategic level but also individual care plans of patients and are involved in the support and delivery of the younger people with dementia carer and patient education groups.

Prospect Park Hospital

4.37 BHFT were successful in gaining just under £1 million to improve the environments of two wards in Prospect Park Hospital: Rowan, a specialist 20 bedded dementia ward and Oakwood, a community ward who have patients with dementia as a secondary issue. Rowan ward was opened on 7th January 2014 for the transfer of patients and includes a dedicated cinema room; 'Heal Well' bedrooms - these use a specialist lighting to recreate a gradual sunrise and sunset feel to eliminate the need for night sedation (where possible) as this discourage the day/night reversal so often found with people who have dementia; a 'Garden Room' – this has a drinks machine (donations only), and microwave facilities to encourage families to sit with the patient and eat. The aim is to include the family as much as possible in the care of the patient if that is their desire. There have been noticeable positive effects on the patients if a member of the family sits and eats with them.

End of Life Group

4.38 This group is chaired by Dr Luke Solomon (BHFT) and Alain Wilkes (Wokingham Borough Council) and is running a pilot in a nursing home in Hungerford on advanced care planning. Advance care planning is a sensitive area, but can help improve quality of life for people with dementia and their carers. This project considers a nursing home population of people with dementia and attempted to bring together all parties connected with their care to evaluate the impact of an advance care planning intervention that would be available to emergency services.

Twenty patients with advanced dementia will have an Advanced Care Plan. This plan will be entered onto the Adastral database and remain a live document. The pilot is to map the difficulties and benefits of the scheme which is planned to roll out. The advance care plans will be kept in the care notes if a person is in a care home where GPs can access them. The information on Adastral will be accessible by GPs, A&E, in-reach teams, 111 and 999.

Care Home In-Reach nurses and a Community Psychiatric Nurse (CPN) will begin the pilot in January, inviting families to be involved in an initial session (with Mandy Coombes), monitoring the time required to complete the form,

seeing what can be merged from the Nursing Home's current system and how the information can be input onto AdastrA. The forms being used are in two parts: (i) to be completed by those who have mental capacity; and (ii) to be completed on behalf of those who have lost mental capacity. The qualified nursing home staff will be given an understanding of how to complete the form.

5. NEXT STEPS

The West of Berkshire Dementia Stakeholders Group identified the following future challenges for dementia care locally:

- 5.1 Sustainability of two of the Dementia Challenge Projects: Dementia Friendly Communities and Domiciliary Care Training.
- 5.2 CCGs achieving the 67% diagnosis rate by end of 2015/16. This represents a significant challenge despite all the work undertaken thus far.
- 5.3 The long term sustainability of the work around the funding of the Woodley Age Concern YPWD service. Continuation funding by the Partnership Development Fund has been identified for 14/15. There is a need for tailored age appropriate activities for respite for patients and tailored accommodation needs.
- 5.4 End of Life Care – more focus and attention is needed for people with dementia nearing the end of life.
- 5.5 The standard of care in many local nursing homes – with an increased number of safeguarding incidents and high staff turnover (including managers). Tony Lloyd from the local HealthWatch will feed these concerns back as will Linda Tait to the Thames Valley Strategic Clinical Network for Mental Health.
- 5.6 Co-ordination of the services in the different areas particularly around hospital discharges and how this may be affecting patients' length of stay in hospital.
- 5.7 A conference is planned by the Earley Charity 'Living Well with Dementia' on 31st March at the Reading Hilton and 17th September in Lower Earley (venue to be confirmed).
- 5.8 The Thames Valley Strategic Clinical Network 'Regional Dementia Day' conference was 25th February and this has been circulated via the group members to the wider local health and social care economy.