Dementia Services in Buckinghamshire – Everyone’s Responsibility

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Electoral divisions affected: All

Portfolio areas affected: Adults and Family Wellbeing

Executive Summary

Dementia is an illness receiving regular national and media spotlight due to its increasing prevalence and the impact it is having, and is likely to have, on individuals’ lives and the UK as a whole.

People are living longer, and because of this, cases of dementia are expected to rise steadily over the next decade. Currently there are approximately 750,000 people with dementia in the UK. This is expected to rise to 1 million within the next decade.

It is believed that dementia costs the UK around £20 billion per year, with a third of the costs being borne by carers. The greatest proportion of direct costs is on care homes. The overall cost is expected to rise to above £34 billion by 2025.

In Buckinghamshire there are approximately 6000 cases of dementia. It is predicted that around 9000 people in Buckinghamshire will have dementia by 2025. This has severe implications for Health and Social Care resources and increased responsibilities for all those caring for people with dementia.

To highlight these concerns, the Public Health Overview and Scrutiny Committee commissioned a review into dementia services in the county. The Committee appointed a task and finish group to carry out the review, which has focused on identifying the benefits of early diagnosis and services in place to support dementia, once a diagnosis has been made.

Members spoke to a range of contributors and, most importantly, were able to hear first hand the views of those with dementia and their carers. Members welcomed the chance
to engage directly with these service users and have aimed to represent their views accurately and sympathetically within the report.

The findings highlighted in the report identify significant benefits in diagnosing dementia early on in the illness. These include giving the person with dementia a chance to come to terms with their illness and an understanding of what they are going through, a chance to plan effectively for their future, an opportunity to take advantage of anti-dementia medication and access to better care and support. With support at this early stage, people can be helped to live independently for longer, resulting in less resource needed to support dementia in hospitals and care homes. However, it is estimated that only 33% of people in Buckinghamshire with dementia are formally diagnosed.

Members also learned that those with dementia and their carers find out about services and support available in an ad-hoc fashion. No clear signposting routes are in place.

Visible leadership of the challenges of dealing with dementia at every level, and maximising opportunities to work jointly, were identified as key to driving forward improvements articulated in the National Dementia Strategy.

Finally, members recognise that the area of dementia is complex. No two cases of dementia are the same, making it important to remember that one size does not fit all and services need to be flexible to accommodate this. Members have proposed the following recommendations which they believe will help improve the lives of those with dementia and the people who care for them.

Recommendations

1. That the Buckinghamshire Dementia Strategy Implementation Board should lead on the development of a joint communications strategy. The objective of the strategy should be to raise dementia awareness and knowledge amongst communities, the public and professionals so that the early signs of dementia are identified, benefits of early diagnosis are emphasised and appropriate support is signposted. (Paragraphs 36 – 48)

2. That clear targets, based on reducing the gap between the predicted numbers of people with dementia and the numbers of those formally diagnosed, should be included within the communications strategy. Coding and recording, following a diagnosis of dementia, should be consistently applied between all agencies to ensure services can be planned according to actual need. (Paragraphs 24, 36 – 48)

3. For NHS Buckinghamshire to identify an Executive-level dementia champion to ensure that dementia remains a strategic priority in Buckinghamshire, and that, as soon as the new commissioning arrangements are in place, this expectation will pass to the three GP collaboratives. (Paragraphs 49 – 52)

4. To raise awareness and engagement of GPs in identifying dementia, NHS Buckinghamshire to:
   • Assess GPs’ knowledge and awareness of dementia and support services in place, to identify gaps;
   • Develop a programme of training and awareness raising opportunities to address any gaps;
   • Evaluate the impact of awareness raising against the Quality Outcomes Framework register. (Paragraphs 58 – 59)
5. Buckinghamshire County Council and NHS Buckinghamshire joint commissioners, as part of the implementation of the Dementia Commissioning Strategy, to support the development of a community-based service which would provide a single point of access to ongoing signposting, advice and guidance throughout the dementia journey to individuals, who have been diagnosed, and their carers. *(Paragraphs 69–73)*

6. NHS Buckinghamshire to support Buckinghamshire Healthcare Trust to:
   - Improve information sharing about patients with dementia, for example, through the patient passport ‘This is me’;
   - Explore opportunities for joint training and sharing of best practice on effective strategies for recognising and supporting patients with dementia;
   - Ensure the experiences of patients with dementia, including feedback from families and carers, are monitored and acted upon, and for future implementation of good practice for dementia to be reinforced through the contract and Service Level Agreement;
   - Ensure all Health and Social Care professionals reflect the principles of the ‘Dignity in Care’ standard in all activities supporting people with dementia. *(Paragraphs 93–97)*

7. Buckinghamshire County Council and NHS Buckinghamshire joint commissioners to commission a rolling programme of training into all nursing and registered care homes to support the provision of dementia care for all. *(Paragraphs 101–108)*

8. NHS Buckinghamshire to ensure that the ImPACT (Immediate Public Access to Care and Treatment) programme workstream on Care Homes focuses on addressing unnecessary hospital admission for people with dementia and for the detailed plan to be shared with the PHOSC. *(Paragraphs 101–108)*

9. With reference to carers who themselves have been admitted to hospital, Buckinghamshire County Council, in partnership with Buckinghamshire Healthcare Trust, to ensure that,
   - Carers, upon discharge from hospital, are actively encouraged to sign up to the ‘In Case of Emergency’ programme, provided by Carers Bucks, to ensure that their loved ones are taken care of in the event of a future emergency involving the carer;
   - All carers meeting the Social Care eligibility criteria receive a Carers Assessment as part of the discharge planning process when they leave hospital;
   - Carers not meeting the Social Care eligibility criteria should be referred to Carers Bucks for general advice, information and support and should also be encouraged to participate in the ‘In Case of Emergency’ programme. *(Paragraphs 111–114)*

10. That the Public Health Overview and Scrutiny Committee will receive a brief update on progress within six months of implementation of the recommendations and a full report in twelve months time.
1. Introduction

1. Dementia is an illness which undoubtedly is deeply distressing for both the person with dementia and their family and friends. It is estimated that there are approximately 750,000 people in the UK with some form of dementia. The number of people with dementia is expected to increase substantially over the next two decades, and by 2025 it is predicted that the cost of dementia for the UK will be around £34 billion.

2. The Public Health Overview and Scrutiny Committee chose to carry out a review of dementia services as it considers dementia to be a critical issue, particularly given that Buckinghamshire has a growing ageing population and dementia rates are expected to almost double over the next twenty years.

3. The National Dementia Strategy, published in 2009, emphasises the importance of good quality early diagnosis. Given that only 33% of people with dementia in the county are thought to receive a diagnosis, members chose to focus their review on the benefits of early diagnosis and the services in place to support those with dementia, and their carers, once a positive diagnosis has been made.

4. Throughout the course of the review, members worked closely with representatives from NHS Buckinghamshire and the Oxford Health NHS Foundation Trust (formerly Oxfordshire and Buckinghamshire Mental Health Trust), who are working in collaboration to review clinical care pathways for dementia patients, through their Dementia Pathway Project.

2. Methodology

5. A task and finish group was set up in October 2010, to carry out the review on behalf of the Public Health Overview and Scrutiny Committee. Members included:
   - Margaret Aston, County Councillor, Chairman of the task and finish group
   - Mike Appleyard, County Councillor, Chairman of the PHOSC
   - Avril Davies, County Councillor
   - Trevor Egleton, County Councillor
   - Wendy Mallen, County Councillor
   - Jenny Puddefoot, County Councillor
   - Lindsay Rowlands, District Councillor

Brian Gilbert, from the Local Involvement Network, was an invited guest on the group.

6. The group held five evidence gathering sessions with contributions from NHS Buckinghamshire, Buckinghamshire County Council, Oxford Health NHS Foundation Trust, Buckinghamshire Healthcare NHS Trust, Community Mental Health teams, representatives from the Voluntary and Community Sector (the Alzheimer's Society and Carers Bucks), people with dementia and their carers.

7. In addition, members visited a care home, a memory clinic and day hospital, a dementia ward, a show flat demonstrating assistive technology, and various activities offered by the...
voluntary sector, including Singing for the Brain, Memory Cafes and a carers’ support group.

8. Although an invitation was extended to the GP commissioners, via NHS Buckinghamshire, to contribute directly to this review, unfortunately they were unable to do so due to their current workloads. Direct GP input was therefore limited to a single but excellent GP from Wendover, who has a specific interest in dementia, and her views are represented in this report.

3. National context

i. What is dementia?

9. There are many myths surrounding dementia, including that it is a normal part of ageing and nothing can be done about it. Members learned that dementia is a general term describing a global decline in cognition, which is not restricted by age or intelligence. Symptoms include memory loss, personality change, language difficulties, poor insight and behavioural problems.

10. There are different types of dementia, including:

   - Alzheimer’s disease (62% of cases in this country).
   - Vascular dementia (17% of cases in this country).
   - Lewy Body Dementia (10% of cases in this country).\(^3\)
   - Others – frontal dementia and alcoholic dementia.

11. Members understand that, in spite of research, the causes of dementia remain unknown. There is no ‘blue print’ for the condition and each person’s illness is different. Whilst there is no cure for dementia, some dementia symptoms can be alleviated through medication. There are ways to prevent the onset of some types of dementia, through healthy living and a nutritious diet.

12. The figures for dementia are stark:

   - It is estimated that there are currently 750,000 people with dementia in the UK.
   - Two thirds of these people live in the community and one third lives in care homes.
   - The numbers of those with dementia is set to rise to 1 million by 2025.
   - The financial cost of dementia to the UK is thought to be £20 billion per year and is expected to rise to above £34 billion by 2025.
   - 1 in 5 people over 85 have dementia.
   - 1 in 1000 people aged 40 to 65 have a form of dementia.
   - 60,000 deaths a year are attributed to dementia.\(^4\)
   - Up to one in four hospital beds at any one time is occupied by a person over the age of 65 who has dementia. Their stay in hospital can be twice as long as others. The excess cost of this is estimated to be £6m per year for an average general hospital.

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\(^1\) Alzheimer’s Society 2011
\(^2\) PHOSC presentation September 2010
\(^3\) Who Cares Wins Royal College of Psychiatrists 2005
\(^4\) Quality outcomes for people with dementia DH September 2010

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ii. The National Dementia Strategy

13. In 2009, the National Dementia Strategy was published. The Strategy identifies seventeen objectives to help people with dementia and their carers live as well as possible. These objectives include:
   - Awareness-raising
   - Early diagnosis and intervention
   - Information
   - Support for people with dementia and their carers, including peer support.

14. To implement the Strategy nationally, Primary Care Trusts (PCTs) were given £150 million over two years until 2010-11. However, this budget was not ring-fenced and at the time of publication of the National Audit Office’s interim report ‘Improving Dementia Services in England’, the level of funding that PCTs had allocated to dementia was unclear. Local authorities did not receive additional funding. Although the strategy was welcomed, implementation nationally has reportedly been slow and patchy.

15. With costs around dementia care expected to double over the next fifteen years, and increasing numbers of older people, concerns around how local authorities and Health will be able to afford to fund this, are being grappled with nationally. The Commission on Funding of Care and Support is an independent body responsible for reviewing the funding system for care and support in England. The Commission is chaired by Andrew ...
Dilnot, and is expected to provide recommendations and advice on how best to address this issue, to Government by July 2011.\textsuperscript{10}

4. The Buckinghamshire context

16. It is estimated that 6033 people have dementia although only around 33\% have been formally diagnosed.\textsuperscript{11} The number of those with dementia is predicted to rise to around 9000 by 2025.

17. Members learned that there could be as many as 2000 people with dementia currently living in care homes. As the number and complexity of people with dementia increases, there will be a significant impact for Health and Adult Social Care, including increased care costs for long-term placements as a consequence.

18. Members learned that, in Buckinghamshire, no single service has the responsibility of making an early diagnosis of dementia and services must work together to make it possible. The focus for dementia leadership in the county is provided through the Buckinghamshire Dementia Strategy Implementation Board, which includes representatives from Oxford Health NHS Foundation Trust, NHS Buckinghamshire, GP commissioners, Buckinghamshire County Council, the Alzheimer’s Society and Buckinghamshire Healthcare Trust. This Board provides a forum for moving forward the dementia agenda and recognises that, to be effective, all organisations involved will need to understand each other’s constraints, be flexible and avoid working in isolation.


Six priorities have been identified in the strategy:

- Awareness
- Early diagnosis
- Quality
- Working together to provide seamless services
- Self-directed support
- Governance.

20. Buckinghamshire Healthcare Trust has identified a lead for dementia care, whereby a Senior Clinician has to take responsibility for designing and managing the pathway process for those with dementia.

21. Buckinghamshire County Council’s Adults and Family Wellbeing budget for Older people and Older People’s Mental Health, including dementia, for 2011/12, is £26.7 million, with a further £4.2 million on a range of services for people with dementia. Social care is restricted to substantial and critical care and the bulk of its residential care budget is spent on those with dementia.

22. NHS Buckinghamshire spends £24 million annually on Continuing Health Care. Of this, £6.9 million is spent on Mental Health Continuing Health Care and approximately £4.3

\textsuperscript{10}Commission on Funding of Care and Support, Dept. of Health
\textsuperscript{11}Mapping the Dementia Gap Alzheimer’s Society March 2011
\textsuperscript{12}Task and Finish Group Minutes 27.1.11

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23. In addition, NHS Buckinghamshire has commissioned Oxford Health NHS Foundation Trust to provide a range of services for older adults who have mental health issues, including people with dementia. The total contract value for older adults is £8.7 million, and includes memory clinics, psychiatric liaison services, inpatient beds, community mental health teams and day hospitals. Furthermore, there is an unaudited amount of resources that supports people with dementia who are using mainstream health services, for example, one in four hospital beds at any one time is occupied by a person over the age of 65 who has dementia.

24. Members learned that it is not possible to be precise about the spend on dementia in both social care and within the whole health economy, due to the way dementia is recorded. It is thought that there is under recording in both settings. It is difficult to see how specialist care planning for dementia across all the providers can be undertaken accurately if the need is not fully assessed. Members would urge that coding and recording methods are consistently applied, including a diagnosis of dementia from the the appropriate medical professionals, to ensure that the planning of specialist services is based on actual need and spend can be more accurately determined.

5. Findings

5.1 The importance and benefits of early diagnosis

25. It can be devastating for people to discover that they have dementia, which is why many people are fearful of a diagnosis. During the course of this review and speaking to a number of contributors, members learned that the benefits of early diagnosis are significant. To encourage early diagnosis, members believe that the public need to be made explicitly aware of the benefits. One person with dementia described the difference her early diagnosis has made for her, by helping her to adjust to a different life and accessing medication which has ‘helped the fog to lift’.

The benefits of early diagnosis, for people with dementia, can be summarised as follows:

26. Delaying the onset of the illness - Early diagnosis enables people to take advantage of anti-dementia medication which can slow the progress of dementia for a period of time. People can then be helped to stay independent for longer, with the use of support such as assistive technology, advocacy and peer support.

27. Better care and independence - Early diagnosis ensures that patients can access appropriate support and treatment to help them to live better with the condition. It may delay the point of needing to go into a residential home, leading to less demand on the NHS and care homes. It helps the professionals get a much better understanding of the person, their life story and how the care, support, services and advice can be individualised to their needs.
28. Understanding - Early diagnosis can help people to understand the causes of the problems they have been having. It can help to restore a person’s sense of identity, which can often be lost through dementia, and rule out other illnesses which display the same symptoms.

29. Planning - Early diagnosis gives people time to plan effectively for their future whilst they are still able to have a say. It gives them and their loved ones time to make important decisions around practical and legal arrangements, including setting up lasting power of attorney.

5.2 The barriers to early diagnosis

30. Despite the clear benefits of early diagnosis, members learned that only 33% of all people with dementia are diagnosed. In Buckinghamshire, 2062 people have diagnosed dementia although it is estimated that the actual number of those with dementia could be as high as 6033. Members were told by contributors that the reasons for this level of under diagnoses are thought to be:

31. Stigma - Fear and ignorance of dementia amongst the public may mean that people with dementia do not want to confront their condition and stigma remains high. There is also evidence of people wanting to avoid terms such as ‘dementia’ and ‘Alzheimer’s disease’ because of the stigma they carry. This stigma can form a barrier to early diagnosis and intervention.

32. Lack of public awareness: People with dementia and their carers often do not recognise the symptoms or the gradual onset of the illness and this may delay them seeking help.

33. Gaps in awareness and knowledge of some professionals of dementia and support services available. Members learned that GPs are the main source of referrals of patients with possible dementia to memory services, where diagnoses are carried out. However, they learned that whilst some GPs are very good at referring patients, others are not. In a recent national survey of GPs, only 31% believed they had the basic skills to deal with patients suffering from dementia, indicating that 69% of GPs believe that they do not.

34. Difficulties in diagnosis: GPs are often the first port of call for people who may believe that they have a problem and GPs may pick up on dementia problems when the patient presents with other conditions. However, there are difficulties around this as some

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16 www.publicguardian.gov.uk
17 Dementia Out of the Shadows Alzheimer’s Society, October 2008
18 Task and Finish Group minutes 14 January 2011

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medical conditions mirror dementia symptoms and this can make it difficult for GPs to identify dementia accurately. Before a patient is referred to the memory services, a GP has to rule out other possibilities, for example, depression or an underactive thyroid.

35. Therefore, when a diagnosis of dementia is made, it is often late and at a time of crisis. There is currently no national screening programme for dementia. GPs are only able to make a diagnosis if people come forward and highlight their symptoms.

5.3 Raising awareness and understanding

36. Improving both public and professional awareness and understanding of dementia is the first objective of the National Dementia Strategy. Importantly, people need to not only understand the signs and symptoms, but should know where to go for help. They also need to understand what they can expect during the course of the illness.

37. A recent think tank report on dementia and the Big Society, led by the Department of Health, acknowledged the importance of communities and neighbourhoods as places where people with dementia feel safe, both physically and socially. The Think Tank also identified that culture and lifestyle preference may mean that not everyone with dementia wants to take part in community activity. The Think Tank suggests mapping community facilities and the social interactions of people with dementia, to find out where and how people connect with their community. Support can therefore be targeted where support is needed and will make most impact.

38. The Think Tank acknowledges that information about dementia is a vital step in encouraging people with dementia to take part socially in their communities and to encourage other people to act socially in respect of dementia. Lack of knowledge, as well as stigma, are the root causes of exclusion from communities. Local engagement is thought to be necessary to normalise dementia, for example, through intergenerational projects and inviting local people into services for people with dementia, such as memory cafes and care homes, to encourage greater understanding of dementia through learning from people with dementia.

39. The importance of the community in supporting people with dementia is demonstrated in Bournemouth, where the HSBC Branch is at the forefront of the town's fight against dementia. Staff have been trained to spot the early signs of the disease among their customers. When they have concerns, they alert local health staff working in a specialist multi-disciplinary team. They can also signpost information to their customers about local memory services and other forms of support. Staff working in other shops, for example, the dry cleaners and pharmacy, have also been given advice on how to deal with customers with dementia.

40. Members were interested to find out about the role that community pharmacists have in supporting people with dementia. They learned that community pharmacists might be well placed to detect early signs of dementia in people, although their role would be limited to signposting. They were advised that further roles for pharmacists could include advising prescribers on appropriate prescribing, and working with patients and/or carers in care homes to optimise medicines for residents and training staff in safe administration.

19 Dementia and the Big Society Report from Think Tank, DH, Alzheimer's Society, Bradford University, 2011
20 LGID How Bournemouth is tackling dementia November 2010
21 Written response from the Local Pharmaceutical Committee January 2011
41. Members heard that local dementia information events are held in the county from time to time. For example, Aylesbury Vale District Council recently held an event on dementia awareness, involving several partner organisations, to inform the general public. The event was attended by 70 members of the public. The Haddenham Health Centre runs a drop-in session once a month for people recently diagnosed with dementia. The manager of Chiltern View Care Home attends the sessions to give guidance and information on issues around dementia. Unfortunately recent sessions have not been well attended as there has been little publicity and GPs have not picked up on it as a resource.

42. Members welcome the new national joint awareness-raising and fund-raising campaign of the Alzheimer’s Society and Tesco’s to provide buses for dementia road shows. The buses will visit two major Tesco’s stores a week, across the country. In addition, the Alzheimer’s Society has embarked on a ‘Worried About Your Memory’ campaign, by sending information to every GP surgery.

43. Despite these awareness-raising activities, members heard there is still a lack of awareness amongst the public and professionals and it is clear that there is more work to be done to co-ordinate the message.

44. Members were informed that those from Black and Ethnic minority groups are less likely to access services for dementia, partly because of the stigma attached to the illness, language barriers and because they are unaware of services available. There are examples of practice in Buckinghamshire to encourage those from ethnic minority groups to access services. For example, Carers Bucks runs a joint project with the PCT entitled ‘English at the Doctors’. Oxford Health NHS Foundation Trust is working with communities to change negative attitudes to dementia and engage people from minority ethnic communities in physical activities.

45. At the regional Health and Social Care Awards 2010, NHS Buckinghamshire Community Development Team won the mental health and well-being award for their work with the ‘Movers and Shakers’ Groups, which help older people from ethnic communities support each other to stay healthy through activities such as jazzercise.

46. To increase the rates of early diagnosis, the public, and those likely to come into contact with those with early symptoms, need to have more awareness and knowledge of what the symptoms of dementia are and how the illness can progress. The benefits of early diagnosis need to be strongly promoted and myths busted.

47. To be effective, members believe that awareness campaigns need to involve relevant organisations working together in a linked and targeted way. Campaigns need to explicitly promote the benefits of early diagnosis with clear, jargon-free messages. Information should list the early symptoms, include quick memory tests, emphasise the benefits of a healthy lifestyle and diet, signpost people to where they can get help, and, where possible, link into national campaigns. Real case study examples of people living well with dementia would help to get the message across that early diagnosis and intervention can support a far better quality of life for longer. Information needs to be available in a variety of formats and venues.

48. Given the scale of the gap between the numbers of those diagnosed and the actual numbers of people with dementia, there should be clear targets set for reducing this gap.

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27 January 2011
29 November 2010

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5.4 Strong leadership

49. With the publication of the National Dementia Strategy and growing awareness of the impact dementia will have on the future economy and on people’s lives, dementia has become an increasing priority for the leadership across the NHS and the Local Authority.

50. During the course of the review, members of the task and finish group expressed concerns that significant changes in the configuration of commissioners within the NHS, proposed in the Health and Social Care Bill 2011, may result in a loss of leadership around this critical agenda.

51. The County Council will have a pivotal role in ensuring organisations make best use of available resources, by working effectively and imaginatively together, through its commissioning function, its current and proposed future Public Health role, and through the work of the new Health and Wellbeing Board, which will be in shadow form from April 2011.

52. Members welcome the fact that GP commissioners are already actively involved in the Buckinghamshire Dementia Strategy Implementation Board and would encourage their vital and valued continued interest and involvement in this agenda.

5.5 Diagnosing dementia

53. The National Dementia Strategy aims for all people with dementia to have a rapid assessment and an accurate diagnosis which is sensitively communicated to them and their carers.
54. To find out how assessments take place in Buckinghamshire, members visited the memory clinic and day services at the John Hampden Unit and spoke to the Community Mental Health Teams (CMHT), which act as gate keepers to memory services in the first instance. There are three integrated health and social care CMHTs for older people. These services are commissioned by Buckinghamshire County Council and NHS Buckinghamshire from Oxford Health NHS Foundation Trust. The CMHTs in Buckinghamshire cover High Wycombe, Aylesbury and Amersham localities. Each team has a caseload of between 400 – 500 clients. If patients are unable to get to a clinic then assessment, treatment and support may take place at home, carried out by Community Psychiatric Nurses.

55. Once referred, patients are seen within four weeks and various screening assessments (including the Mini Mental State Examination) are carried out. There are a range of options for follow-on care, depending on the score for these assessments. Staff also assess carers and provide them with information on memory problems, strategies for coping and signposting to other resources.

5.6 Signposting post diagnosis

56. The National Dementia Strategy states that good quality information on the illness and on the services available – both at diagnosis and throughout the course of care – should be available to people with dementia and their carers. This can empower people to understand what is happening to them and how they can cope better with what lies ahead.

57. Members learned that signposting individuals to support services is a multi-agency role. Some of the key agencies that members looked at were GPs, Buckinghamshire County Council and the Voluntary and Community Sector.

i. The role of GPs

58. GPs play a pivotal role in the early diagnosis of dementia and members heard from carers of the excellent support many have had from their local GP. However, members also heard that some GPs may be reluctant to give an early diagnosis unless they can offer post-diagnosis support, contacts and services. In some cases, once patients are diagnosed with dementia, GPs are unclear about the next steps and the range of services available.

59. Nationally there is survey data indicating a low level of dementia awareness by GPs, but the picture locally is unclear. Therefore, to successfully increase early diagnosis and to help understand how best to support GPs locally through a joint communications strategy, members recommend that an assessment is carried out of the knowledge and awareness amongst local GPs of dementia and the level of support that needs to be in place.

| Recommendation 4 |
| To raise awareness and engagement of GPs in dementia, NHS Buckinghamshire to:  |
| • Assess GPs’ knowledge and awareness of dementia and support services in place to identify gaps;  |
| • Develop a programme of appropriate training and awareness raising opportunities to address any gaps;  |
| • Evaluate the impact of awareness raising against the Quality Outcomes Framework register. |

24 Task and Finish Group minutes 27 January 2011

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60. Members heard that it is important for information and guidance to be readily available at the point of diagnosis – not just when in crisis. Carers indicated that it is often the period between diagnosis and crisis that they need most advice and support. There is a need to help people with dementia and carers to identify the issues that may arise along the dementia journey and to offer strategies to cope.

61. Members learned of the importance for people with dementia and their carers of post-diagnosis planning, immediately after a diagnosis.

62. However, members heard that those with dementia and their carers often found out about services and support available in an ad-hoc fashion, including information on Council Tax relief and funding through grants.

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ii. The role of Buckinghamshire County Council

63. The government’s vision for social care, published in November 2010, identified that ‘people funding their own care have a particular need for information and guidance to help plan how their care needs are met’. Self-funding covers a range of situations such as buying in a little help for domestic work, live-in full-time staff and choosing a residential or nursing home. Members learned from contributors that, combined with the stress of having dementia, or being responsible for the care of someone with dementia, these tasks can prove overwhelming. One carer was herself a wheelchair user and was expected to visit and choose a care home for her husband with dementia.

64. However, reduced resources and capacity prevent Adult Social Care staff from being able to offer anything more than signposting to those who fund their own care.

65. Cost-effective options are being looked at by Adult Social Care to provide advice on services, such as, for example, the setting up of a website portal, available from August 2011, which will provide advice and information around available services. This will not however be directly accessible to the many elderly people who do not access the Internet.

66. The new 111 telephone service, which will be piloted in Buckinghamshire, will give patients access to urgent care on a 24/7 basis. The provider will assess the needs of callers and refer them to appropriate local services.

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iii. The role of the Voluntary and Community Sector

67. Members recognise the significant role the Voluntary and Community sector plays in supporting and advising those with dementia and their carers and are mindful that they are

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25 A Vision for Adult Social Care November 2010
26 Visit to Carers Support Group 4 January 2011
27 http://www.buckshealthcare.nhs.uk/
unable to give full credit to the myriad of services provided by this sector, within this report. Examples of services commissioned by Buckinghamshire County Council include Age UK, to provide advice and information to older people, and Carers Bucks, to provide dedicated support to older people and people with dementia.

68. The Alzheimer's Society provides a number of dementia-specific services including raising public awareness, providing information, a Dementia Advisory Service, workforce development, peer support, training for carers, a befriending scheme, a 24/7 online support and discussion forum, and home visits.

iv. Single point of access

69. The Department of Health is currently piloting Dementia Advisors models, which provide a single point of access for those with dementia, around the country. Many of the pilots have had the involvement of the Alzheimer's Society. The model is that each dementia advisor has around 200 clients and the dementia advisor stays with the client throughout their dementia journey. Each dementia advisor is supported by, typically, seven volunteers. The cost of a dementia advisor service is £42,000 per annum.

70. In Medway, a Dementia Advisor Service has been set up by the local authority, PCT and the Sunlight Trust. Four specialist dementia advisors act as the first point of contact for 365 people, providing information and signposting to local support groups, day services, help with welfare payments, transport information. The project will be fully evaluated in May including the long term sustainability of the service.

71. Given the current difficulties faced by people with dementia when finding out what is available to support them post diagnosis, members strongly recommend the introduction of a single point of access for GPs and other professionals to refer people to. This point of access could offer advice and information on legal and financial guidance, what the future holds, what can be expected, how to deal with issues as they arise and support available. Guidance and information on support services could be offered on an ongoing basis and in a timely way so that people receive information when they need it.

72. Members recognise that advice needs to be given at varying times during a patient’s dementia journey and may need to be given separately to carers. Although a service of this nature will require additional funding, members believe that early intervention saves money in the long run, as people may be prevented from falling into crisis.

73. Members learned that the voluntary sector, specifically the Alzheimer's Society, has the infrastructure, skills and knowledge already in place to offer a single point of access service, to which people could be signposted to immediately after diagnosis.

Recommendation 5
Buckinghamshire County Council and NHS Buckinghamshire joint commissioners, as part of the implementation of the Dementia Commissioning Strategy, to support the development of a community-based service which would provide a single point of access to ongoing signposting, advice and guidance throughout the dementia journey to individuals, who have been diagnosed, and their carers.

28 Medway Dementia Advisor Service mdasunlighttrust.org.uk
29 Task and Finish Group minutes 9 November 2010

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5.7 Supporting independence

74. Members learned that being able to live at home independently and remain involved in their communities is a key aspiration of those with dementia and their carers, and is also a priority for the providers of services.

75. Evidence suggests that giving the right support at home can reduce the number of people going into care homes by 28%. In Buckinghamshire, members heard that reducing the number of those in nursing homes funded under continuing healthcare by 20%, could potentially reduce annual costs of £3,298,000, by £659,600.

76. The new reablement service, provided by Buckinghamshire County Council’s Adult Social Care, provides individuals with 24 hour support for two weeks after discharge from hospital, enabling them to leave hospital at the right time. Pilots currently underway in Buckingham and Burnham are discovering how best to use funds to support this effectively, for example, basing social care staff and reablement workers in GP surgeries where they can work together, with clinical staff, to support people in their homes, after discharge from hospital.

77. Members were keen to learn how dignity is embedded within the care of people with dementia. The Dignity in Care Campaign is part of a wider Department of Health campaign to promote dignity in care for people in the health and social care sectors, and covers all care provided by paid workers in any setting (hospital, residential, nursing, day centres and in people’s own homes).

78. Adult Social Care’s response to the White Paper ‘Our Health, Our Care, Our Say’ includes a commitment to the Dignity in Care agenda and work is underway to ensure that its principles are reflected within all Health and Social Care activities.

i. Assistive technology

79. Members learned that a small team within the Adults and Family Wellbeing portfolio provides assistive technology for people aged 18 and upwards who may need low to moderate support to live independently. The service provides timely and early intervention support for up to 2000 people in the county. Referrals are increasing each month and the team is currently operating at capacity. The team is nationally recognised as delivering best practice.

80. The team works with other organisations, including acute hospitals. However, members heard that improvements could be made in how effectively they work together, for example, by hospitals providing advance notice of when patients will be discharged from their care, so that equipment can be made available.

81. Examples of equipment successfully tailored for use by those with dementia include:

- The ‘buddi’ system, which is a GPS tracking device linked to a call centre. This can trigger an alarm if the person does not return home when expected. The system can be borrowed for use on holidays, giving carers peace of mind in case their loved ones wander off.
• Automated medication dispenser, which buzzes to remind the person with dementia to take their medication at certain times. A sensor alerts the call centre if a tablet has not been removed.
• The ‘Just Checking’ system provides information on the daily activity of a person with dementia in their own home. The information can be used to help plan and review care packages.

82. Used correctly, this technology can help people with dementia live independently for longer, but success depends on them being referred early enough. The Department of Health is in the process of evaluating the impact of this technology on service users’ lives and costs, and a report is due to be published shortly.

ii. Day centres

83. Day care for people with dementia is provided in a variety of locations and by a range of providers, including the local authority, church groups and the voluntary and community sector. There are currently no specially designed, purpose-built day centres in the county for people with dementia, and buildings may be limited by physical barriers, such as not being able to lock doors to prevent people who are likely to wander and a lack of specialist mental health staff on site.

84. Members heard of the importance of day centres to the lives of people with dementia and their carers. They also spoke to carers who have had difficulties in accessing these services. One carer spoke of a nine month delay in getting his wife a place at a day centre. However, the day centre now makes a huge difference to his life.

85. Buckinghamshire County Council’s business case for transforming Day Services identifies that there are individuals requiring specialist environments and staff. The proposed new Day Opportunities Centres are expected to play an important part in supporting people with complex needs, including people with dementia, providing specialist support and assistance, therapeutic activities, management of difficult behaviours and respite, from which carers will benefit.

86. Carers spoke to members of their real concerns about proposed increased charges for day care provision. In some cases this could lead to having to make a choice between attending a day centre or having daily care during the current review of these services.

5.8 Activities to support independence

87. During the course of the review, members visited a number of activities run by the Alzheimer’s Society, including Singing for the Brain and memory cafes, which are for those with dementia and carers, and a Carers Support Group which is for carers only. Attendance at the general activities on offer varies, with, for example, around 70 people attending the Singing for the Brain session in the south of the county, and around 15 attending the session in Aylesbury. Volunteers running the Aylesbury session are looking at ways to raise the profile of the activity to encourage more people to attend.

33 Visit to Carers Support Group 4 January 2011
34 Transforming of Day Services: The Business Case 21 March 2011
35 Visit to Memory Café 20 January 2011

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88. A number of these activities provide invaluable peer group support. Members learned that these activities can lead to strong friendships and social activities outside of the sessions. By hearing the views of others they are helped to come to terms with the condition and the impact it has on lives.

‘It gives me another perspective. If I have a problem, someone has been there before.’ Husband of person with dementia.

89. The Chairman of the review group spoke at length to a befriender and her befriended. The person with dementia described her befriender as making a difference to her life from being ‘very dull’ to being ‘very good’. She believes that the uniqueness in befriending is the personalised friendship it can offer to people of all ages with the illness, from early onset to the late stages. It is also one of the few activities that is accessed by those with early onset dementia, i.e. those below the age of 65 years.

90. Those attending activities spoke highly of the benefits gained. However, members learned that local branches of the Alzheimer’s Society are only servicing the needs of 5% of people with dementia in the county. Reasons for this are likely to be lack of awareness of the activities and transport difficulties, particularly for those in isolated locations.

5.9 Hospital care

91. The Royal College of Psychiatrists identified that on an average 500 bed district hospital, 330 beds will be occupied by older people, 220 of these will have a mental health disorder and, of these, 102 will have dementia. The majority of people in hospital with dementia have not been diagnosed. Those with dementia are likely to have poorer outcomes, with increased mortality, loss of independent function, higher rates of institutionalisation, and greater length of stay in hospital, blocking beds for those who need to be there.

92. An example of where the specialised management of patients with dementia is being tackled is at the Royal Berkshire Hospital. A dementia care nurse is based in the acute medical/ surgical units for three days per week to advise on the management of people with dementia in an acute hospital setting. In Buckinghamshire, the Older People’s Mental Health Liaison nurses, provided by Oxford Health NHS Foundation Trust, offer a service within the county’s acute hospitals.

i. Skills

93. National evidence shows that over half of nurses in general hospital care, caring for those with dementia, have no specialist training. Members were told that there are pockets of good practice within the acute hospital trust, but gaps exist in the level of skills, knowledge and empathy, and the level of priority given to dementia. Post-registration training for dementia is available but the limited study allowance makes this difficult to access as to specialise in dementia can take several weeks.
ii. The environment

94. Members learned how important the environment is for people with dementia. However, some of the performance targets in place in acute care can present challenges for dementia care, for example, the isolation of infections which involves moving patients to side rooms, which otherwise would be used for people with dementia. People with dementia also become disorientated and, due to confusion of their surroundings, may feel the urge to wander. However, this is often discouraged in a ward setting where staff worry that patients may fall.

95. Significant changes in the workforce from full time to part time present an issue for people with dementia who may find the changeover of staff confusing. It also presents a management challenge in ensuring that the workforce is trained. To ensure that staff can learn directly from the experiences of patients, exit surveys are now being given to people with dementia as they leave a ward so that improvements can be made on an ongoing basis.

iii. Sharing information

96. Members learned of a scheme in place in general hospitals, where important information about vulnerable patients is recorded in a patient passport called ‘This is me’. The passport follows the patient with any move. It is hoped that this will be rolled out Trust-wide in the summer, as part of a Ward education pack.

97. Members were told that services in an acute setting need to work closely with the CMHTs and each other to support dementia, by being prepared to share information, solve key issues around confidentiality and data protection, provide formal and informal opportunities for sharing best practice, think flexibly and challenge care pathways for dementia patients.

Recommendation 6
NHS Buckinghamshire to support Buckinghamshire Healthcare Trust to:

- Improve information sharing about patients with dementia, for example, through the patient passport ‘This is me’;
- Explore opportunities for joint training and sharing of best practice on effective strategies for recognising and supporting patients with dementia;
- Ensure the experiences of patients with dementia, including feedback from families and carers, are monitored and acted upon, and for future implementation of good practice for dementia to be reinforced through the Service Level Agreement;
- Ensure all Health and Social Care professionals reflect the principles of the ‘Dignity in Care’ standard in all activities supporting people with dementia.

5.10 Training and awareness of care home staff

98. It is estimated that there are 6000 care staff working in the Private &Voluntary care sector in the county. About two thirds work for large providers like Fremantle Trust and Heritage Care who provide their own training, with major programmes around dementia.

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99. Members learned that Buckinghamshire County Council has funded dementia training for staff from the Private & Voluntary care sector, as well as for its own Adult Social Care staff. Courses have included dementia awareness and communication skills. This training is not currently mandatory, although there are moves to make it so.

100. Buckinghamshire County Council concentrates on providing training to small to medium size care organisations. Between the period of April 2009 – January 2011, training has been provided to approximately 32% of staff in these smaller organisations. A total of 64 Adult Social Care staff have attended, equating to approximately 16% of the Adult Social Care home care and day care services staff group. Mandatory training events monitored by CQC tend to be promoted above non-mandatory events, such as dementia training.

101. Members visited the Chiltern View Care Home outside of Aylesbury, to see an example of a care home offering excellent, specialist care for those aged over 65 years, with moderate to severe dementia. The behaviour of residents is managed with careful and positive behavioral strategies and staff are taught when to intercept challenging behaviour. The manager is currently working with Buckingham University to develop training for care workers on dementia, which will extend their knowledge beyond NVQ Level 3. Although, in general, staff turnover within care homes can be high, this home has a high staff retention rate.

102. Members visited Cromwell Ward, a 17-bed assessment unit for adults over 18 years of age with dementia, based at the John Hampden Unit, Stoke Mandeville. This facility is commissioned by NHS Buckinghamshire and the provider is Oxford Health NHS Foundation Trust. Staff are trained to deal with the most challenging cases of dementia.

103. Members heard that admissions to Cromwell Ward are often a result of carers reaching a point of being unable to cope, or care homes being unable to manage the complexities of the illness or challenging behaviour. In a few cases, where care home staff do not have the necessary skills to meet the more challenging needs of patients with dementia, the homes may be unwilling to take the patients back into the home once they are ready to be discharged.

104. Members were told that there is often no clearly recorded evidence from care homes about measures taken to avoid admissions of a resident to hospital.

105. The National Dementia Strategy states the need to identify strategies and improvements within the person’s own home to prevent deterioration of the person’s condition. Staff at Cromwell Ward spoke of the need to provide more preventive work and in-reach to care homes to train staff to better manage and support people with dementia, thereby reducing the possibility of an admission to hospital.

106. Members learned that additional investment has been made available by the Department of Health to support the avoidance of hospital readmission during the 30 days after discharge. Health and Social Care are working together to establish effective community-based services, including reablement, which was referred to in paragraph 74.

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40 Learning and Development Data, Adult and Family Wellbeing
41 Visit to Chiltern View Care Home, Brendan Care Home, 26 November 2010
42 Visit to Cromwell Ward, 14 January 2011
107. One of the workstreams of the partnership ImPACT (Improved Public Access to Care and Treatment) programme is to work with care home staff to review how patients with urgent care problems can be supported in care homes, to help them to stay out of hospital.

108. Members are aware of the importance of preventing unnecessary admissions to hospital. To ensure that people with dementia are given the right care in homes, members recognise that collaborative solutions are needed to ensure that care home staff are given sufficient, ongoing opportunities to develop strategies to support those with dementia.

Recommendation 7
Buckinghamshire County Council and NHS Buckinghamshire joint commissioners to commission a rolling programme of training into Nursing and Registered Care Homes to support the provision of dementia care for all.

Recommendation 8
NHS Buckinghamshire to ensure that the ImPACT (Immediate Public Access to Care and Treatment) programme workstream on Care Homes focuses on addressing unnecessary hospital admission for people with dementia and for the detailed plan to be shared with the PHOSC.

5.11 Support for carers

i. Respite care

109. Members learned of the importance of residential respite, which not only gives carers a break but is an opportunity to see how the person with dementia will respond in a care home environment. However, respite is often a crisis call for carers. Carers currently receive one week of respite a year. Members heard that there is a need for a robust respite service to offer placement for short-term residential care. This is an area which members did not have a chance to explore in any depth but acknowledge it to be an area needing further research.

110. Members heard that services such as the Carers Support groups only touch the tip of the iceberg, with many carers not able to attend as they cannot leave their loved ones. The Carers Break Grant, currently worth £10K, is allocated by the Alzheimer’s Society. The view of the Society is that the criteria used for allocating this fund are not flexible enough to provide short respite breaks, such as two or three hours a week to go to the hairdressers or out shopping. Members heard that the Carers’ Break Grant is underspent because it can only be used for holidays. Members were advised that this will be explored further by the Adult and Family Wellbeing portfolio.

ii. Coping in an emergency

111. Carers Bucks, with funding from Buckinghamshire County Council, have developed an ‘In Case of Emergency’ (ICE) comprehensive care plan, which provides a free backup

http://www.buckshealthcare.nhs.uk

44 Visit to Chiltern View Care Home, Brendan Care Home, 26 November 2010
45 Visit to Carers Support Group, Amersham January 2011

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service for carers who cannot provide care because of an emergency. A 24 hour telephone service is provided all year round and trained staff are available and on call to respond immediately to emergency situations.

112. The scheme is currently promoted in a variety of ways, including via the Carers Bucks newsletter, via domiciliary care workers, through organizations such as the Health Living Centre, the Alzheimer’s Society and Age UK. Information has gone out to hospital discharge teams to be distributed to patients although whether this is happening in practice is unclear.

113. Although uptake has recently improved to 550 service users, Carers Bucks have still not reached its target of 800 users by the 1 March 2011. Members consider this to be a vital service for carers, given the dependence people with dementia have on them.

114. Members heard that all carers caring for someone with substantial or critical care needs should receive a Carers Assessment, funded by Buckinghamshire County Council, when discharged from hospital, in order to establish their needs and how they can be supported to carry out their role. In addition, those carers who are not eligible, can be referred to Carers Bucks to receive general advice, information and support. Members believe that it is important that both groups are actively encouraged at this point to participate in the ICE programme.

### Recommendation 9

With reference to carers who themselves have been admitted to hospital, Buckinghamshire County Council, in partnership with Buckinghamshire Healthcare Trust, to ensure that,

- Carers, upon discharge from hospital, are actively encouraged to sign up to the ‘In Case of Emergency’ programme, provided by Carers Bucks, to ensure that their loved ones are taken care of in the event of a future emergency involving the carer;
- All carers meeting the Social Care eligibility criteria receive a Carers Assessment as part of the discharge planning process when they leave hospital;
- Carers not meeting the Social Care eligibility criteria should be referred to Carers Bucks for general advice, information and support and should also be encouraged to participate in the ‘In Case of Emergency’ programme.

### 6. Conclusion

115. During the course of the review, members learned that there are, without doubt, a number of benefits in diagnosing dementia early and they recognise the excellent work, led by passionate and committed teams, to support those with dementia. However, there are frustrations that this area of work is not always given the priority it deserves and the overall approach in the county seems fragmented and needs to be pulled together - ‘There are lots of dots; they just need to be joined together’.

116. Members conclude that to enable people to live better with dementia, diagnosis needs to take place as early as possible. For this to happen, people need to recognise the
symptoms and know where to go to for help. Once diagnosed, they need to be guided through all stages of their illness by professionals with appropriate expertise.

117. To make best use of available resources, organisations providing support throughout the dementia journey need to work closely with each other. Members believe that providing the right support and good quality care early on in a person’s illness will save money in the long run. However, members understand that there will be no ‘quick fix’ and a long term plan needs to be in place to ensure that the anticipated increasing needs can be resourced.

118. Health and Social Services, alongside the voluntary and community sector, play a big part in supporting people with dementia. However, the responsibility for dementia has to be everyone’s. Members heard that a healthy diet and lifestyle can help reduce the risks of some types of dementia and believe there to be a personal responsibility on all of us to adopt healthy lifestyles. However, there is further work to be done to determine how people can be encouraged to do so.

7. Acknowledgements

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Carers Bucks
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