

Agenda

DEMENTIA SERVICES TASK & FINISH GROUP

Date: Tuesday 9 November 2010

Time: 10.15 am

Venue: Mezzanine Room 2, County Hall, Aylesbury

10.00am Pre-meeting for Members of the Task & Finish Group only to discuss key areas of questioning and lines of enquiry.

Agenda Item	Time	Page No
1 APOLOGIES AND CHANGES IN MEMBERSHIP	10.15am	
2 DECLARATIONS OF INTEREST		
3 INTRODUCTION OF THE REVIEW	10.20am	1 - 16

Contributors:

- Margaret Aston, Chairman of the Dementia Services Task and Finish Group

Purpose:

The Chairman of the Task and Finish Group will outline the reasons for the review.

Papers attached:

- Dementia Services Scoping Document
- Living well with dementia – A National Dementia Strategy : Chapter 4: Early diagnosis and support



INVESTOR IN PEOPLE



4 THE BENEFITS OF EARLY DIAGNOSIS AND SERVICES AVAILABLE - VIEWS FROM THE VOLUNTARY AND COMMUNITY SECTOR

17 - 30

Contributors:

Ken Dorling, Locality Manager, Berks, Bucks & Oxon, Alzheimer's Society, and Ann Whiteley, Carers Bucks

Purpose: To specify the benefits of early diagnosis and to outline the services in place in Buckinghamshire to support those with dementia and their carers

Papers attached:

- Alzheimer's Society Services in Buckinghamshire
- Executive Summary – National Dementia Declaration

5 LIVING WITH DEMENTIA - A CARER'S PERSONAL PERSPECTIVE 12.15pm

Contributor:

- Carer of a person with dementia

Purpose: To hear a personal account of how it is to care for someone with dementia, including their experiences following the diagnosis, and support and services available.

6 DATE OF NEXT MEETING 13.00

The next meeting will take place on Friday 26 November 2010 at 10am in Mezz 1.

If you would like to attend a meeting, but need extra help to do so, for example because of a disability, please contact us as early as possible, so that we can try to put the right support in place.

*For further information please contact: Liz Wheaton on 01296 383856
Fax No 01296 382538, email: ewheaton@buckscc.gov.uk*

Members

Mr M Appleyard
Mrs M Aston (C)
Mrs A Davies
Mr T Egleton

Mrs W Mallen
Ms J Puddefoot
Mrs L Rowlands

**Overview and Scrutiny Scoping Paper
2010/11**

Subject of the Review	Dementia Services in Buckinghamshire
Chairman	Task and finish group Chairman to be nominated
Review members, including co-optees	Mike Appleyard, Margaret Aston, Avril Davies, Trevor Egleton (co-opted from OSCC), Wendy Mallen, Jenny Puddefoot, Lindsay Rowlands
Officer contact	Jane Burke
Purpose of the Review (Reasons for undertaking the review, including where the ideas have come from)	<ul style="list-style-type: none"> • To understand the benefits and key challenges of early diagnosis, including patient and carer views and perceptions as well as funding implications. • To explore existing care pathways following a positive early diagnosis and to identify any gaps and inconsistencies in services available in the county. • To identify any improvements that could be made to improve the early diagnosis of dementia and subsequent care pathways for Buckinghamshire residents.
Anticipated outcome(s)	<ul style="list-style-type: none"> • That the review will contribute to raising awareness and understanding of the importance of early diagnosis and how this impacts on the public and providers of services. • Identify areas of good practice in Adult Social Care, Health and partner organisations, eg other authorities, voluntary sector. • Identify any improvements that could be made to help early diagnosis as well as access to subsequent care • Develop recommendations that will be taken forward to appropriate reporting bodies and feed into the implementation of the local dementia strategy.
What is the potential impact of the review on <ul style="list-style-type: none"> • Residents • Equality issues, e.g. access to services, vulnerable groups • Health inequalities • Adding value to the organisation • Partners 	<ul style="list-style-type: none"> • Improve understanding of the importance of early diagnosis and the care and support available for patients and carers. • Improved quality and accessibility to service provision, particularly for disadvantaged groups. • Encourage closer partnership working through integrated teams and pooled budgets with a view to achieving efficiencies in service delivery.
Link to Council Corporate Plan priority	<p>Recommendations resulting from the review should feed into the Local Dementia Strategy and enhance existing plans to help manage the condition in Buckinghamshire. It will endorse the following Council's Corporate Plan priorities:</p> <ul style="list-style-type: none"> • Support people who need our help • Tailor services to meet local need • Deliver effective and efficient services
Consideration of National Performance Framework indicators	To be reviewed when new National Performance Framework indicators are published.

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<p>Link to Sustainable Communities Strategies outcomes</p>	<p>Links to Health and Wellbeing theme</p> <ul style="list-style-type: none"> • Aim: Improve the quality of life for an ageing population • Outcome: the vast majority of older or vulnerable people who wish to remain in their own homes for longer are supported to do so.
<p>Key Issues for the review to address</p>	<ul style="list-style-type: none"> • The benefits of early diagnosis • Care pathways currently in place, once a positive diagnosis has taken place • Effectiveness of the provision of dementia services in Buckinghamshire including quality and accessibility • How gaps in service delivery will be addressed • Long term cost benefits of early diagnosis and the costs to the LA and health services of dementia • Service users and carers views of current service provision and ease of access • How teams across Adult Social Care, Health and Voluntary Organisations are delivering integrated service through joint commissioning, pooling resource and integrated community teams • Further actions to improve and develop partnership working.
<p>Methodology</p>	<ul style="list-style-type: none"> • A member task and finish group from the PHOSC, supported by the policy officer, to carry out evidence gathering sessions including site visits • Consideration of use of co-optees (from the Commissioning Committee/ LINK?) • Evidence and information to be gathered from all those contributing to the Local Dementia Strategy • Desktop research /visits as appropriate to local authorities that perform well in this area • Site visits (i.e. to hospitals /care homes/ community teams/ services users/ dementia café/ memory clinics) • Focus groups with service users and carers
<p>Press & Publicity</p>	<ul style="list-style-type: none"> • Leaflet to public at PCT's Health Fair/AGM on 29 September – information and invitation to contribute • Press release inviting interested parties to contribute their stories – local paper • Scoping Paper November 2010 Cabinet and relevant Trust boards • Public report and press release March 2011 • Leaflet May 2011 • Workshop/ seminar with key stakeholders re implementation of recommendations
<p>Key background papers</p>	<ul style="list-style-type: none"> • Implementation of the National Dementia Strategy in the South East – Baseline Review Report 2010 • National Dementia Strategy – Department of Health 2009 • Paying the Price – Kings Fund 2008 • Local Dementia Strategy – NHS Buckinghamshire 2010

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	<ul style="list-style-type: none"> • Dementia UK Report 2007 • Improving Services and Support for People with Dementia' : National Audit Office 2006/7 • Out of the Shadows: Alzheimer's Society 2008 • Who cares wins, Improving the outcome for older people admitted to the general hospital: 2005 The Royal College of Psychiatrists. • NICE guidance
Use of demographics/ needs data	<ul style="list-style-type: none"> • ONS population data • POPPI Projecting Older People Population Information System • BCC population projection work by ward (not yet published but accessible)
Evidence to be provided by:	<ul style="list-style-type: none"> • Strategic Director for Adults and Family wellbeing • Cabinet Member for Adults and Family Wellbeing • NHS Trust Directors – acute trust, mental health trust • NHS Buckinghamshire (PCT) • Relevant officers • GPs / clinicians • Care home managers • Service Users, patients and carers • Operational Teams • Voluntary organisations i.e. Carers Bucks, Alzheimer's Society, Dementia UK
Potential partners	<ul style="list-style-type: none"> • The Buckinghamshire LINK
Resources required	<ul style="list-style-type: none"> • Officer and member time
Timetable	<ul style="list-style-type: none"> • Overview of national and local context to Health Scrutiny committee September 10th 2010 • October 2010 – Members of Health OSC to broadly agree Scoping Paper; task and finish group to agree finer detail • Press release November 2010 • Evidence gathering to take place October 2010 through Jan 2011 • Draft report to OSC March 2011 • Report to Cabinet April 2011 • Report to NHS Trust Boards May/June 2011 • Report to Bucks Strategic Partnership Board Summer 2011
Reporting mechanism	<ul style="list-style-type: none"> • Cabinet – to respond to recommendations • NHS Trust Boards – to respond to recommendations • Bucks Strategic Partnership Board – for information

Overview and Scrutiny Scoping Paper 2010/11

Indicative Timetable

Target dates	Action
Start up	
Thurs 8 October	Members of PHOSC to agree overall scope
Thurs 21 Oct, am	1 st meeting of T & F group: officer presentation, member agreement on details of scope, determine key lines of enquiry and contributors
Mon 8 Nov	Scoping paper to Cabinet for information
Evidence-gathering	
Tues 9 Nov, 10 - 4	2 nd meeting of T & F group: oral evidence
Fri 26 Nov, 10 - 4	3 rd meeting of T & F group: oral evidence
Fri 3 Dec, 10 - 4	4 th meeting of T & F group: oral evidence
Fri 14 Jan, 10 – 1	Possible evidence gathering meeting
Thurs 27 Jan, 10 - 12	5 th meeting of T&F group: Mop-up meeting, draft recommendations, consider key findings
Report drafting	
28 Jan – 10 Feb	
Thurs 10 Feb	6 th meeting of T&F group: consider and finalise draft report
Report consideration	
11 March	Draft report to PHOSC
w/c 28 March	Circulation of draft report to cabinet, partners, cabinet member response, and press release issued on report
11 April	Report to Cabinet
April/ May	Report to relevant Partner Boards

Chapter 4: Early diagnosis and support

'General practitioners after all are exactly that, general practitioners, and so they can't be expert in everything, but they don't seem to have a general sensitivity to dementia as an illness.' (person with dementia)

'Surely they should be getting more training and then if [they] can't understand it...pass it on to the neurologist or psychiatrist rather than put you on tranquillisers.' (person with dementia)

'We had gone to him [the GP] for a lot of things and he was always telling [the person with dementia] that it was in his mind, he hadn't got these problems, he needed to pull himself together.' (carer)

'I've just been told "You've got Alzheimer's" and they walk out; [it] is absolutely bloody disgusting.' (person with dementia)

'I got the diagnosis on the phone by somebody I had never met telling me, "Your husband has Alzheimer's and vascular dementia." That was probably the worst possible way. That was absolutely infuriating.' (carer)

'I think they need [to be] diagnosing much earlier and take notice of it because I think there are lots of channels that could be avoided if the first time they saw you, they got down to business and meant it. Not just fob you off.' (person with dementia)

'[The GP] has been very positive in supporting both of us really. When this problem occurred he referred [the person with dementia] straight away to the memory clinic and stuff so he obviously saw something in her that he felt he should deal with straight away. When consultants and people have done tests on her and written to him he has always been in touch with us to let us know what is going on. He is very positive.' (carer)

'[The consultant] said it's dementia and I just burst into tears because I was so... I half expected it but it's still a terrible shock.' (carer)

'It was as if the thunder clouds had been taken away because they had given an answer to me why I was treating my family so like a louse that I was.' (person with dementia)

'I was relieved really that what I was trying to convince people of had been verified.' (person with dementia)

'They didn't give me enough information. I came away thinking, "What do we do now, where do we go from here?" I have a prescription in one hand and a note for blood tests in the other and nobody has said what the CAT scan showed...nobody has given me that information. I am the person who is going to deal with [my husband].' (carer)

'It was organised by various people from the Alzheimer's Society and carers, and they explained to the people what kinds of dementia there were, and what happens, and how you can help it by healthy living and all this; it was really good.' (carer)

'Be honest to yourself and to your friends because there is a lot of support if you are open. Some of them will walk away and can't deal with it but an awful lot of people will help.' (person with dementia)

'Today I have met people who are in very much the same boat as I am with things they can and can't do...so for me it's a relief, a bloody relief to find that there are other people in the same boat as me.' (person with dementia)

'I think I've been part of a group that regularly goes together and since I've got to know other people and I think of it as being "We're all in it together", and therefore I don't feel lost...and that's very helpful actually.' (person with dementia)

Good-quality early diagnosis and intervention for all

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

How this can be delivered

- The commissioning of a good-quality service, available locally, for early diagnosis and intervention in dementia, which has the capacity to assess all new cases occurring in that area.

The case for change

Under-diagnosis is the current norm

1. Currently only about one-third of people with dementia receive a formal diagnosis at any time in their illness.¹⁷ When diagnoses are made, it is often too late for those suffering from the illness to make choices. Further, diagnoses are often made at a time of crisis; a crisis that could potentially have been avoided if diagnosis had been made earlier. A core aim of the National Dementia Strategy is therefore to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis. There is evidence that such services are cost effective, but will require extra initial local investment to be established. When established, such services can release substantial funds back into health and social care systems.¹⁸
2. In its Operating Framework for 2008/9,¹⁹ the Department of Health summarised the situation as follows:

“...providing people with dementia and their carers the best life possible is a growing challenge, and is one that is becoming increasingly costly for the NHS. Research shows that early intervention in cases of dementia is cost-effective and can improve quality of life for people with dementia and their families...”

¹⁷ NAO (2007). *Improving services and support for people with dementia*. London: TSO.

¹⁸ Ibid.

¹⁹ DH (2007). *The NHS in England: the Operating Framework for 2008/09*. London: DH.

3. The text went on to state that the Department of Health would publish details of the clinical and economic case for investing in services for early identification and intervention in dementia which PCTs should consider when planning local services. This detailed cost-effectiveness analysis for such services was published as Appendix 4 of the Strategy consultation document.²⁰ It is available for download on the Department's dementia website at www.dh.gov.uk/dementia and also in revised form as a peer-reviewed publication.²¹ This sets out clearly that a 'spend to save' approach as advocated by the National Audit Office (NAO) in their value for money report can both increase the quality of care and save hundreds of millions of pounds of expenditure over a 10-year period. These analyses suggest that such services are clinically and cost effective using accepted measures.

The value of early intervention

4. The evidence available also points strongly to the value of early diagnosis and intervention to improve quality of life and to delay or prevent unnecessary admissions into care homes. According to the best estimates available,²² care home placement of people with dementia costs the UK £7 billion per year with two-thirds paid by social services and one-third by older people and their families themselves. While it is clearly the case that some people will need and benefit from admission to care homes, and that this can be a positive choice, there is also a strong quality argument for the prevention of unnecessary institutionalisation. People with dementia generally want to stay in their own homes, as do their carers. The evidence available indicates that:
 - early provision of support at home can decrease institutionalisation by 22%;²³
 - even in complex cases, and where the control group is served by a highly skilled mental health team, case management can reduce admission to care homes by 6%;²⁴
 - older people's mental health services can help with behavioural disturbance, hallucinations and depression in dementia, reducing the need for institutional care;²⁵

20 DH (2008). *Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy*. London: DH.

21 Banerjee S, Wittenberg R (2008). 'Clinical and cost effectiveness of services for early diagnosis and intervention in dementia.' *International Journal of Geriatric Psychiatry* (ePub in press).

22 Knapp M, Prince, M, Albanese E et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

23 Gaugler JE, Kane RL, Kane RA and Newcomer R (2005). 'Early Community-Based Service Utilization and Its Effects on Institutionalization in Dementia Caregiving'. *The Gerontologist*, 45, 177–185.

24 Challis D, von Abendorff R, Brown P et al (2002). 'Care management, dementia care and specialist mental health services: an evaluation'. *International Journal of Geriatric Psychiatry*, 17:4, 315–25.

25 Gilley DW, Bienias JL, Wilson RS et al (2004). 'Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer's disease'. *Psychological Medicine*, 34:6, 1129–35.

- carer support and counselling at diagnosis can reduce care home placement by 28%;²⁶
 - early diagnosis and intervention improves quality of life of people with dementia;²⁷ and
 - early intervention has positive effects on the quality of life of family carers.²⁸
5. All PCTs currently commission a number of services which might make the diagnosis of dementia. They include general practitioners, old age psychiatric community teams, geriatric medicine and neurology services. Current systems are almost without exception non-prescriptive and lack clarity about where and by whom diagnoses of dementia should be made.

Role of primary care

6. A strong and consistent message emerged from DH's consultation process that the diagnosis of dementia, and in particular mild dementia where the diagnosis is more complex, should be carried out by a clinician with specialist skills. With a disorder as common as dementia it is tempting to assume that this should be completed by primary care. However, this is in effect the status quo which has delivered the low



26 Mittelman MS, Roth DL, Clay OJ and Haley WE (2007). 'Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention'. *American Journal of Geriatric Psychiatry*, 15:9, 780–89.

27 Banerjee S, Willis R, Matthews D et al (2007). 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model'. *International Journal of Geriatric Psychiatry*, 22:8, 782–88.

28 Mittelman MS, Roth DL, Clay OJ and Haley WE (2007). 'Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention'. *American Journal of Geriatric Psychiatry*, 15:9, 780–89.

levels of activity that we have summarised above. A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; risk avoidance; concerns about competency; and concerns about the availability of resources.²⁹ This can be particularly problematic for people from specific groups, such as people with learning disabilities or younger people with dementia.

7. The message from those responding to the consultation exercise was that these are reasonable concerns, and that the primary care role should be that of identifying those with worrisome symptoms that might mean that their patient has dementia, excluding any other explanatory disorder, and referring on to a specialist service for that individual to receive a definitive diagnosis, not only of dementia, but also of the sub-type of dementia. This would require that such services are available for the GP to refer to and, in the large majority of the country, this is not currently the case. The focus of old age psychiatric services is on the severe and complex end of the spectrum, leaving early diagnosis and intervention largely unaddressed. Equally, geriatric and neurology services are saturated at present with their current work with those referred to them with dementia and complex physical co-morbidity and younger and atypical presentations respectively. This strategy is not intended in any way to minimise or undermine the role of primary care in the diagnosis and management of people with dementia. It is instead an acknowledgement of complexities that have become apparent in the last 10 years, and is designed to support primary care by generating services that they can use in a clear explicit care pathway. The primary care role following diagnosis can therefore be informed by the clinically important information as to whether or not that person has dementia, and of what sub-type, and treatment modified to take account of that.

The case for commissioning a specific service for early diagnosis and intervention

8. From our consultation, and based on a successful DH pilot³⁰ and the DH cost-effectiveness case,^{31, 32} it appears that new specialist services need to be commissioned to deliver good-quality early diagnosis and intervention. Such services would need to provide a simple single focus for referrals from primary care, and would work locally to stimulate understanding of dementia and referrals to the service. They would provide an inclusive service, working for people of all ages and from all ethnic backgrounds.

29 Iliffe S, Wilcock J, Haworth D (2006). 'Obstacles to Shared Care for Patients with Dementia: A qualitative study'. *Family Practice*, 23:3, 353–62.

30 Banerjee S, Willis R, Matthews D et al (2007). 'Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model'. *International Journal of Geriatric Psychiatry*, 22:8, 782–88.

31 DH (2008). *Transforming the Quality of Dementia Care: Consultation on a National Dementia Strategy*. London: DH.

32 Banerjee S, Wittenberg R (2008). 'Clinical and cost effectiveness of services for early diagnosis and intervention in dementia'. *International Journal of Geriatric Psychiatry* (ePub in press).



Their sole focus would be on early diagnosis of and intervention for people with dementia. This would include:

- making the diagnosis well;
 - breaking the diagnosis well to the person with dementia and their family; and
 - providing directly appropriate treatment, information, care and support after diagnosis.
9. Such services would not replace the work currently completed by old age psychiatry, geriatrics, neurology or primary care, but would be complementary to their work. The aim is to complete work not currently associated with any service. Instead such a service might be provided by any of a number of types of specialist with diagnostic skills in dementia (eg old age psychiatrists, geriatricians, neurologists, or GPs with a specialist interest) or combinations thereof. Local decisions would be based on existing service provision and where local skills and enthusiasm lie. Those referred with needs other than dementia would be referred on appropriately. There is value in considering commissioning such a service as a joint health and social care venture, with core

involvement of local third sector organisations. Such services could see people in their own homes, or in primary care settings, rather than be hospital-based. The provision of such services locally would have the effect of simplifying the care pathway for the majority, locating responsibility and so enabling easy referral, simple communication and clear performance monitoring. A core set of assessment tools (eg of cognition, behaviour, activity limitation and quality of life in dementia) could be agreed and specified to enable direct regional and national monitoring and comparison of the services provided. Where there are existing memory clinics that have resources associated with them, they may form the core of such a new service, and those resources could be used as part of this service reconfiguration.

10. Local commissioners will wish to consider the extent to which referral to such services are 'open' for the public or rely on referral through primary care or adult social care. There was a genuine divergence of opinion in those responding to the consultation on this. There will be a need to work out how services can be made to work for those from specific groups such as people with learning disabilities. Consistent feedback was received during the consultation process about how difficult it is for this group to receive a diagnosis and appropriate help and support. People with learning disabilities are likely to be in touch already with health and social care services, so close liaison and collaboration between the different professionals involved is essential.

Good-quality information for people with dementia and carers

Objective 3: Good-quality information for those with diagnosed dementia and their carers. Providing people with dementia and their carers with good-quality information on the illness and on the services available both at diagnosis and throughout the course of their care.

How this can be delivered

- A review of existing relevant information sets.
- The development and distribution of good-quality information sets on dementia and services available, of relevance at diagnosis and throughout the course of care.
- Local tailoring of the service information to make clear local service provision.

The case for change

11. The importance of good-quality information, given in such a way as to be accessible to patients and carers in enabling them to direct their own care, is clear. Every person diagnosed with dementia and their carers need to be provided with good-quality, relevant information on the illness and on the availability of local services. The consultation process has provided excellent examples of national and local documents

that could be adapted with ease for use across England. One such example is the booklet *Coping with dementia – a practical handbook for carers*³³ published by Health Scotland and currently available to be given out to carers across Scotland on diagnosis. Information could be made easily available in a range of settings, for example in local libraries.

12. The challenge is to generate an individually tailored comprehensive package of high-quality information. This should be developed nationally to include information on the nature of the condition, and then adapted locally to describe the treatment and the support available. Different materials might be needed as the disease progresses and to cover the evolution and management of different symptoms and situations. Equally, versions would be needed to work across the diverse populations affected by dementia (eg different language groups, minority ethnic groups, people with learning disabilities and people with early-onset dementia). Information should also be available on what options exist for planning ahead for those diagnosed with dementia, to ensure that their desires and wishes are properly considered were they to lose mental capacity. For example, by making a Lasting Power of Attorney and registering it with the Office of the Public Guardian.
13. For this element of the strategy there will therefore be a need centrally to collect the excellent sets of information that have been generated on dementia to date, rather than starting from scratch. The strategy therefore identifies the need for an initial phase involving the central collection of materials and their collation, and the development of key documents for distribution.

Enabling easy direct access to a contact who can signpost and facilitate health and social care input throughout life with dementia

Objective 4: Enabling easy access to care, support and advice following diagnosis.

A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

How this can be delivered

- This is a new role and there will be a need first for the development and generation of demonstrator projects, and the piloting and evaluation of models of service provision prior to implementation.
- Following this, commissioning a local dementia adviser service to provide a point of contact for all those with dementia and their carers, who can provide information and advice about dementia, and on an ongoing basis help to signpost them to additional help and support.

³³ Health Scotland (2008). *Coping with dementia – A practical handbook for carers*. Edinburgh: Health Scotland.

- Contact with a dementia adviser to be made following diagnosis.
- The dementia adviser not to duplicate existing ‘hands-on’ case management or care.

The case for change

14. One of the most clear and consistent messages emerging from discussions with people with dementia and their carers has been the desire for there to be someone who they can approach for help and advice at any stage of the illness – ‘someone to be with us on the journey’. Current health and social care services normally discharge individuals once the case is stable and the care package is being delivered. This is almost always perceived negatively by people with dementia and their carers, who, faced with a serious illness where there is inevitable long-term decline and increase in dependency, want to feel that there is continuing support available to them when they need it.
15. In the course of consultation it has become clear that this support needs to be provided without removing health and social care professionals from front-line care, and needs to be complementary to the other elements of the care pathway described here. There are interesting models of provision of support and signposting that are emerging, mostly from the third sector. However there is a lack of good-quality definitive studies available at present from which to choose models with the greatest likelihood of success. This is clearly an area where there is a need to invest in service model development, piloting and evaluation to generate data upon which to make commissioning decisions. A development, demonstration and evaluation phase is therefore proposed.
16. In order to stimulate debate, one possibility for testing would be a ‘dementia adviser’ who can provide a point of contact, advice, and signposting and enabling contact with other services if needed. These posts might best be commissioned from the third sector, but could be located within the early diagnosis and intervention service described above to enable professional support and advice and seamlessness of service. The volume of cases diagnosed with dementia makes this a challenging role that requires a clear remit. Contact details for the dementia adviser could be given to the person with dementia and carers at diagnosis. At the end of an episode of care, individuals with dementia and their carers would therefore not just be discharged from services, but instead continue to have access to the dementia adviser who could contact people pro-actively perhaps once or twice a year to check how things are.
17. The role of a dementia adviser would not be that of intensive case management, as carried out by members of community mental health teams or outreach workers who go into people’s homes, or Admiral Nurses. Rather they would provide a single identifiable point of contact with knowledge of and direct access to the whole range of

local services available. Their actions would therefore be to identify what the problems might be, and then to signpost and facilitate engagement with the specialist services that can best provide the person with dementia and their carers with the help, care and support they need simply and quickly. This remit would allow dementia advisers to work with the high numbers of people diagnosed with dementia in each area. They could work with both social care and health care services and be jointly commissioned by local authorities and PCTs.

Peer support and learning networks for people with dementia and their carers

Objective 5: Development of structured peer support and learning networks.

The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

How this can be delivered

- Demonstrator sites and evaluation to determine current activity and models of good practice to inform commissioning decisions.
- Development of local peer support and learning networks for people with dementia and their carers that provide practical and emotional support, reduce social isolation and promote self-care, while also providing a source of information about local needs to inform commissioning decisions.
- Support to third sector services commissioned by health and social care.

The case for change

18. One clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and their carers, to exchange practical advice and emotional support. Structured models of peer support already exist in some parts of the country, with examples such as carer support groups and dementia cafés. However, they often cater for only a very small proportion of those who might benefit from them. In structured models of support it is possible to incorporate advice and support from health and social care professionals in an effective and efficient manner. Health and social care commissioners need to consider how to support the development of local peer support networks for people with dementia and their carers.

19. This element of the strategy is complementary to the previous one. People with dementia and their carers can obtain continuity of care and support not only from statutory services, but also in the form of peer support. If the strategy is successful in ensuring that early diagnosis of dementia becomes the norm, then this opens up the possibility for much greater levels of peer support and interaction.
20. There is much good practice in this area already, but activity is often at a relatively low level. The challenge here is first to determine which models of peer working to adopt, and then how to make them available for all who want to access them locally. What is proposed therefore is a programme incorporating investigation and analysis of current practice and the development and evaluation of new models.
21. The value of such an approach is that this can empower people to make choices about what they want, and enable them to care for themselves. Providing people with dementia and their carers with peer support can assist enormously in helping them plan their own lives. On an aggregate level, this can generate advice for commissioners and providers on the local needs of people with dementia and their carers to inform the development of services.



Public Health Overview and Scrutiny Committee

Alzheimer's Society Services in Buckinghamshire.

Background

The original Buckinghamshire branch was started in 1987 and from that three branches evolved: Milton Keynes, South Bucks and Aylesbury & Buckingham. The South Bucks office is based in Beaconsfield, the Aylesbury & Buckingham office is in Aylesbury which is also the Locality office for Bucks, Berks and Oxon and the Milton Keynes office is in Stony Stratford.

The Alzheimer's Society in Buckinghamshire is part of the Berks, Bucks, Oxon Locality. The Society has six part time staff (Dementia Support Workers) in Bucks (excluding Milton Keynes) and eighty volunteers, supported by the Locality management staff. A group facilitator is being recruited to take a lead on Singing for the brain services and Dementia Café.

Prevalence of Dementia

People with dementia (2005 figures)					
30-64	65-74	75+	Total	% of people 65+ with dementia	% of all people with dementia
127	697	4051	4875	6.43	1.01
52	234	1271	1558	6.55	0.71

People with dementia (2021 figures)					
30-64	65-74	75+	Total	% of people 65+ with dementia	% of all people with dementia
135	862	6107	7103	7.07	1.44
66	430	2059	2555	6.28	1.02

Buckinghamshire

Milton Keynes

Source dementia UK report

Alzheimer's Society Services in Bucks

Existing Services

Bucks, Berks & Oxon Locality - Summary Of Services

North Bucks		South Bucks
Alzheimer's Cafe		Newsletter
Bee-Friending Scheme		Bee Friending Scheme
Carers Coffee Morning		Carer Support Group Amersham
Drop in		Carer Support group Stoke Poges
Former Carer social group		Carer Support Group Wycombe Day
Helpline		Carer Support Group Wycombe Evening
Lunch Club		Carers Grant
Memory cafe		Helpline
Memory Support Group		Information Provision
Newsletter		One to one
Singing for the Brain		Singing for the Brain
Social Events and outings		Social events and outings
One to One		Tea & Talk
Information Provision		Former Carers
Helpline		Training Courses

Service attendance in
Buckinghamshire *Apr 09-Mar 10*

Count of Attendances

Support Groups	1370
Singing for the Brain	1384
Social events	841
Outings & Day Trips	103
Dementia Cafes	628
Helplines	2730
Information Provision	538
Bee-friending	46
Dementia Support Services	225
Provision of grants for holidays	11
Other services	85

Source : service database

Peer support services (Singing for the Brain and Cafés) provide an opportunity for Carers and People with Dementia an opportunity to enjoy time together in a safe environment.

The Bucks wide befriending scheme has been running for around 18 months and there are now 30 trained volunteers providing 100 hours of client contact per month, the service also allows respite for the carer.

Service Development

It is proposed to develop new Dementia Café's in the county, especially where no services exist in the proximity. An expansion of the Befriending scheme is also planned.

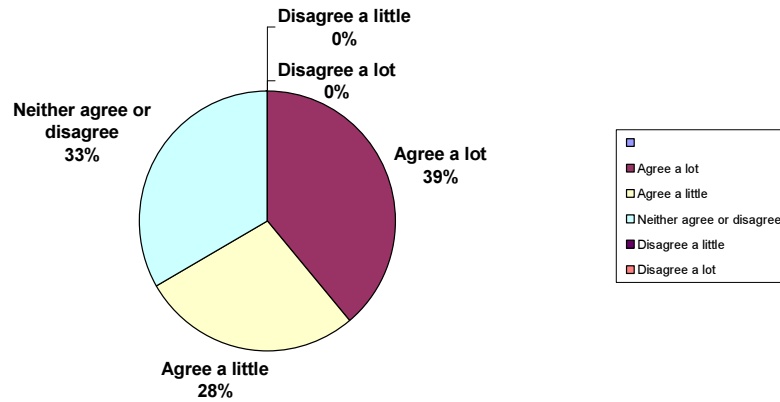
Should resources be made available the Alzheimer's Society would seek to assign a Dementia Support Worker to each consortia of GP Practices in the County.

The Service Strategy for the Society is to have a stronger focus on People with dementia.

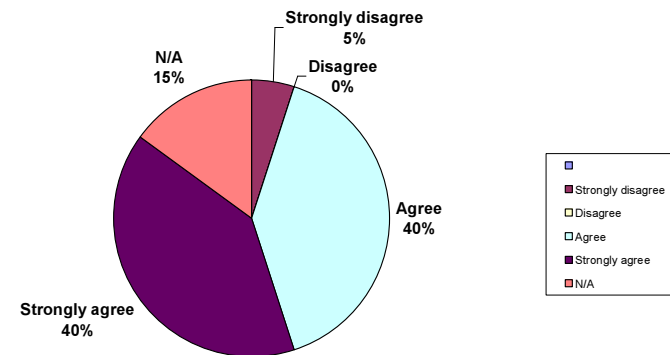
Service Outcomes

A sample of outcomes based upon a Bucks County Council questionnaire:

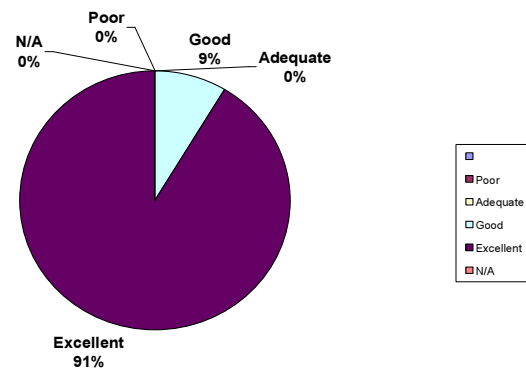
I feel my health has improved - ALZHEIMER'S SOCIETY



This service has helped me to be independent - ALZHEIMER'S SOCIETY



Overall satisfaction of the service - ALZHEIMER'S SOCIETY



Finance

The current cost of service provision in Bucks is approximately **£136,000 pa.** which does not include any estimate of time donated by volunteers. Grant funding is currently **£43,000pa** , derived from the Carers Grant and Prevention Grant.

The funding gap is bridged by donations and fundraising.

Awareness Raising

The Society has trained volunteers and staff in the county who give talks to various stakeholder groups and third sector organisations.

National campaigns also help to raise awareness in Buckinghamshire.

Further detail can be provided if requested.

Ken Dorling

Locality Manager

Berks, Bucks & Oxfordshire



H | D | R | C



THE NATIONAL COUNCIL FOR PALLIATIVE CARE



nhsalliance



JEWISH CARE



All-Party Parliamentary Group on DEMENTIA



Mental Health Foundation



PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



Leading the fight against dementia



social care institute for excellence



Alzheimer's Society



National Dementia Declaration for England

DAA Dementia Action Alliance

www.dementiaaction.org.uk

National Dementia Declaration for England

A call to action

Dementia is one of the greatest challenges facing our ageing society. There has been major progress in recent years in securing public and political commitment to responding more effectively to dementia. We now need to ensure that this commitment is turned into concerted action. With the publication of this National Dementia Declaration we announce the launch of a Dementia Action Alliance and a major plan of action to change the experience of living with dementia in England for good. The organisations signed up to this Declaration call on all families, communities and organisations to work with us to transform quality of life for the millions of people affected by dementia.

The scale of the challenge

There are 750,000 people living with dementia in the UK now and by 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain which over time seriously impairs the ability of someone with dementia to live independently. Symptoms can include severe memory loss, mood and personality changes and behaviour that challenges others such as serious confusion, agitation and aggression. Many people with dementia also have other medical conditions or develop them during the course of their illness.

Families currently provide the majority of care and support for people with dementia and this can be both tiring and stressful – physically, emotionally and financially. A large number of people with dementia also live alone and can be at particular risk of isolation or abuse. However, if people with dementia are diagnosed early, and they and their families receive help, they can continue to live a good quality of life.

The financial cost of dementia in the UK is £20 billion a year and rising. Two thirds of people with dementia live in their own homes and one

third live in care homes. One in four people in hospital have dementia and two thirds of people in care homes have dementia.

This National Dementia Declaration has been created by people with dementia, carers of people with dementia and a large number of organisations who seek radical change in the way that our society responds to dementia. We seek a similar level of change as has been seen in our society's response to cancer over recent decades.

All organisations that are signatories to this National Dementia Declaration are setting out publicly what they intend to do by 2014 to transform quality of life for people with dementia and their family carers.

In 2011 the Dementia Action Alliance will seek support from partners in civic organisations, businesses and professions to deliver dementia supportive communities. For more information visit www.dementiaaction.org.uk

Why is there a need for a National Dementia Declaration?

- Public awareness of dementia is high but understanding about it is still very poor: Fear of dementia also remains high; there is a reluctance to seek help and few people understand that it is possible to live well with dementia. In addition there is limited understanding of the fact that dementia can affect people in many different age groups.
- NHS and social care systems have not historically developed to reflect the fact that people with dementia are now a key group using many services.
- Only one third of people with dementia receive a specialist diagnosis and many are receiving that diagnosis late. GPs often report being reluctant to diagnose dementia either because they lack the knowledge to do so, do not see the benefits of early diagnosis or because they are aware of the lack of specialist support and services available for people after a diagnosis.
- Following diagnosis many people with dementia and carers report receiving no information about their condition or about what support might be available.
- Reports from regulator the Care Quality Commission (CQC) and its predecessor the Commission for Social Care Inspection (CSCI) show that although there are examples of excellent dementia care in care homes, many providers are struggling to deliver quality of life for people in the later stages of the condition.
- Equally, some people with dementia struggle for too long in their own homes without the help they need when better person-centred care or a good care home could provide a more stimulating and supportive environment.
- The All-Party Parliamentary Group on Dementia and Professor Banerjee have both produced reports revealing people with dementia are being inappropriately prescribed or over-prescribed antipsychotic drugs which increase risk of death and reduce quality of life.
- Health and social care staff routinely report that they have not received training in how to treat or care for people with dementia, despite the fact that they are now increasingly in contact with people with dementia.
- The National Audit Office and Parliamentary Public Accounts Committee have found that there is very ineffective use of current resources to deliver quality of life for people with dementia. For example the NAO has highlighted the potential for the NHS to identify savings of at least £284 million per year through improving dementia care. In addition to the costs borne by public services people with dementia and carers face high costs for care.
- UK spending from all sources on dementia research is low compared to other disease groups and by international standards.

Government action on dementia

In 2009 the then government in England published a five-year National Dementia Strategy. As part of this work, strategies on end of life care and carers are also in place. NICE/SCIE guideline 2006 and Dementia Quality Standards describe what good dementia care should look like.

The coalition government has stated its commitment to implement the National Dementia Strategy; however, it can only do so much. The Department of Health, as a signatory to the Declaration, will set out what it intends to do to help improve the lives of people with dementia. However, radical and sustainable change will only come about through the action of individuals and organisations working together locally and nationally to challenge what is wrong and to do things better.

Desired outcomes for people with dementia and their carers

People with dementia and their family carers have described seven outcomes they would like to see in their lives.

There is overlap between these outcomes and the draft outcomes in the Department of Health's National Dementia Strategy Implementation Plan. Both the Department of Health's draft outcomes and those described below will need to be developed further. In addition work will need to be done to better understand how to measure these outcomes.

1 I have personal choice and control or influence over decisions about me

I have control over my life and support to do the things that matter to me.

I have received an early diagnosis which was sensitively communicated.

I have access to adequate resources (private and public) that enable me to choose where and how I live.

I can make decisions now about the care I want in my later life.

I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

2 I know that services are designed around me and my needs

I feel supported and understood by my GP and get a physical checkup regularly without asking for it.

There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.

I am treated with dignity and respect whenever I need support from services.

I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.

My carer can access respite care if and when they want it, along with other services that can help support them in their role.

3 I have support that helps me live my life

I can choose what support suits me best, so that I don't feel a burden.

I can access a wide range of options and opportunities for support that suits me and my needs.

I know how to get this support and I am confident it will help me.

I have information and support and I can have fun with a network of others, including people in a similar position to me.

My carer also has their own support network that suits their own needs.

4 I have the knowledge and know-how to get what I need

It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.

I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.

I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.

My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

5 I live in an enabling and supportive environment where I feel valued and understood

I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.

I am making a contribution which makes me feel valued and valuable.

My neighbours, friends, family and GP keep in touch and are pleased to see me.

I am listened to and have my views considered, from the point I was first worried about my memory.

The importance of helping me to sustain relationships with others is well recognised.

If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.

My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

6 I have a sense of belonging and of being a valued part of family, community and civic life

I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.

Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.

My carer and I continue to have the opportunity to develop new interests and new social networks.

It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

7 I know there is research going on which delivers a better life for me now and hope for the future

I regularly read and hear about new developments in research.

I am confident that there is an increasing investment in dementia research in the UK. I understand the growing evidence about prevention and risk reduction of dementia.

As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.

I believe that research is key to improving the care I'm receiving now.

I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.

What do organisations signing up to the National Dementia Declaration commit to?

Separate to this Declaration, each signatory organisation will be setting out what it intends to do by 2014 (the date when the current National Dementia Strategy comes to an end) in order to deliver better quality of life for people living with dementia and their carers. These plans are being published separately. Each organisation is committed to the following principles:

- Ensuring that the work they do is planned and informed by the views of people with dementia and their carers and showing evidence for this
- Being an ambassador for the National Dementia Declaration and securing commitment from partners for the second phase of the Declaration
- Reporting publicly on their progress against the plan they have set out to support delivery of the National Dementia Declaration
- Working in partnership with other organisations to share knowledge about best practice in dementia
- Improving understanding about dementia.

How will the Declaration be tracked and monitored?

Organisations signed up to the National Dementia Declaration commit to making public the information about what they are doing to deliver better quality of life for people with dementia. They will be expected to publicise their contribution to the Declaration widely, especially to people with dementia, carers and the organisations representing them. In that way organisations can be held to account, particularly by their local population, to ensure they deliver what they have signed up to. There will be quarterly reporting on the outcomes and an annual report so it is possible to see what progress there has been.

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Dementia Action Alliance



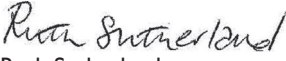
Tom Wright
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Baroness Sally Greengross
Chairman, All-Party Parliamentary Group on Dementia



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Chief Executive, Alzheimer's Research Trust



Ruth Sutherland
Interim Chief Executive, Alzheimer's Society



Jane Ashcroft
Chief Executive, Anchor



Jenny Owen
Association of Directors of Adult Social Services



Mike Parsons
Chief Executive, Barchester Healthcare



Julia Scott
Chief Executive, British Association of OTs and COT



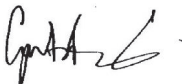
Alex Mair
Chief Executive, British Geriatrics Society



Nancy Rowland
Director of Research, Policy and Professional Practice, British Association for Counselling and Psychotherapy



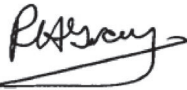
Mark Ellerby
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Cynthia Bower
Chief Executive, Care Quality Commission



Helen Owens
Managing Director, Care UK



Phil Gray
Chief Executive, Chartered Society of Physiotherapy



Caroline Bernard
Acting Chief Executive, Counsel and Care



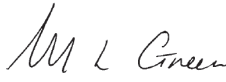
Ted Smith
Chief Executive, Craegmoor



Barbara Stephens
Chief Executive, Dementia UK



Paul Burstow MP
Minister of State for Care Services, Department of Health



Martin Green
Chief Executive, ECCA



Pete Calveley
Chief Executive, Four Seasons Healthcare



David Williams
Chair, Housing and Dementia Research Consortium



Simon Morris
Chief Executive, Jewish Care



Cllr David Rogers OBE
Chair, Community Wellbeing Board, Local Government Group



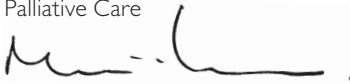
Dr Andrew McCulloch
Chief Executive, Mental Health Foundation




Roger Davies
Chief Executive, MHA



Eve Richardson
Chief Executive, National Council of Palliative Care



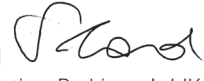
Dr Michael Dixon
Chairman, NHS Alliance



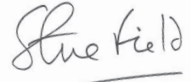
Nigel Edwards
Acting Chief Executive, NHS Confederation



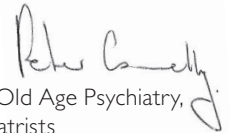
Sir Andrew Dillon
Chief Executive, National Institute for Health and Clinical Excellence



Steve Ford
Chief Executive, Parkinson's UK



Professor Steve Field
Chair, Royal College of GPs



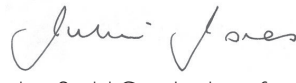
Dr Peter Connolly
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Professor Croisedale-Appleby
Chair, Skills for Care



John Rogers
Chief Executive, Skills for Health



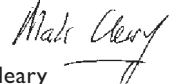
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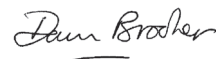
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