

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.

