



House of Commons

Committee of Public Accounts

Improving Services and Support for People with Dementia

Sixth Report of Session 2007–08

*Report, together with formal minutes, oral and
written evidence*

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The Committee of Public Accounts

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Committee staff

The current staff of the Committee is Mark Etherton (Clerk), Philip Jones (Committee Assistant), Emma Sawyer (Committee Assistant), Pam Morris (Committee Secretary) and Alex Paterson (Media Officer).

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Summary

Dementia is a term for a range of progressive, terminal organic brain diseases. Dementia affects over 560,000 people in England and costs some £14 billion a year. Parallels can be drawn between attitudes towards dementia now and cancer in the 1950s, when there were few treatments and patients were commonly not told the diagnosis for fear of distress. There are also stigmas associated with mental health and older people's issues, which present barriers to improving awareness, understanding and openness about dementia.

Despite its significant human and financial impact, the Department has not given dementia the same priority status as cancer and coronary heart disease. As a result the NHS has not afforded dementia the same focus for improvement. Large numbers of people do not receive a formal diagnosis for a variety of reasons including GPs' lack of knowledge and/or confidence to make a diagnosis, fear of dementia, and a perception amongst the public and professionals that little can be done to help people with dementia.

Where a diagnosis is made, it is often not communicated sensitively or appropriately, with patients and their families left without adequate advice or support. People with late-onset dementia have all the additional health problems that accompany old age, and they require support from multiple health and social care service providers. But the task of managing and co-ordinating this care usually falls to their carers.

Carers bear a heavy burden, saving the taxpayer millions of pounds by caring for relatives with dementia at home. Carers are often poorly supported however, with few receiving their entitlement to a carer's assessment and many unable to access good quality respite care or domiciliary care. As a result people with dementia may be admitted to a hospital where they experience longer lengths of stay and poorer outcomes than people who are psychiatrically well; or to a care home, earlier than might otherwise be the case. Both of these outcomes are more costly than domiciliary care. Once in a care home, a lack of dementia beds and staff with appropriate training in dementia care can lead to poor medicines management and other examples of inadequate care.

On the basis of a report by the Comptroller and Auditor General (C&AG),¹ we examined the prevalence and costs of dementia, diagnosis and early intervention, access to and quality of support services, and experiences of people with dementia in hospital and care homes. We took evidence from witnesses from the Department of Health and the NHS.

1 C&AG's Report, *Improving Services and Support for People with Dementia*, HC (Session 2006–07) 604

Conclusions and Recommendations

- 1. There are over 560,000 people in the UK with dementia, costing the economy some £14 billion a year, yet dementia has not been a NHS priority.** In response to the C&AG's report the Department is now developing a National Dementia Strategy. The Strategy should have a clear timetable for implementation, and should include criteria for evaluation and reporting progress and addressing areas of underperformance such as poor diagnosis or availability of interventions recommended by NICE. It will also require an effective communication strategy to engage patient groups, health and social care professionals, the Royal Colleges, health and social care inspectorates, and the voluntary sector, all of whom are essential to improving care for people with dementia.
- 2. Unlike cancer and coronary heart disease there is no single individual with responsibility or accountability for improving dementia services.** Without clear leadership there is a risk that dementia care will continue to lack priority. The Department should appoint a Senior Responsible Officer to drive through the dementia strategy, learning from the model used for cancer services.
- 3. Between a half and two-thirds of people with dementia never receive a formal diagnosis.** Diagnosis should always be made, regardless of whether interventions are available. The rate of diagnosis could be significantly improved by GP practices receiving greater support from mental health services; by the Royal College of Psychiatrists and the Royal College of GPs developing a dementia care pathway including guidance on the importance of early diagnosis; and by the Institute of Innovation and Improvement promulgating good diagnostic practice.
- 4. There is poor awareness amongst the public and some professionals of dementia and what can be done to help people with the disease.** The Department should commission a dementia awareness campaign to increase understanding of the symptoms of dementia, emphasising that there are interventions and treatments which can slow the progress of the disease and help people with dementia and their carers lead independent lives for longer.
- 5. People with dementia require support from multiple health and social care providers but this is often difficult to manage.** On diagnosis, people with dementia and their carers should be given a single health or social care professional contact point to improve the co-ordination of care between the various services and professionals. This contact point could be a social worker or a community psychiatric nurse, for example.
- 6. Between a half and two thirds of all carers do not receive the carer's assessment to which they are entitled.** Carers often struggle to cope with caring for a relative with dementia at home, particularly if the person with dementia has challenging behaviour, leading to costly admission to a care home or hospital. The Department should emphasise to local health organisations and their social care partners that they need to develop an action plan which gives priority to assessing and meeting the needs of carers. The Department should develop a commissioning toolkit to help

demonstrate the cost benefits of the different options for providing support, including respite and domiciliary care.

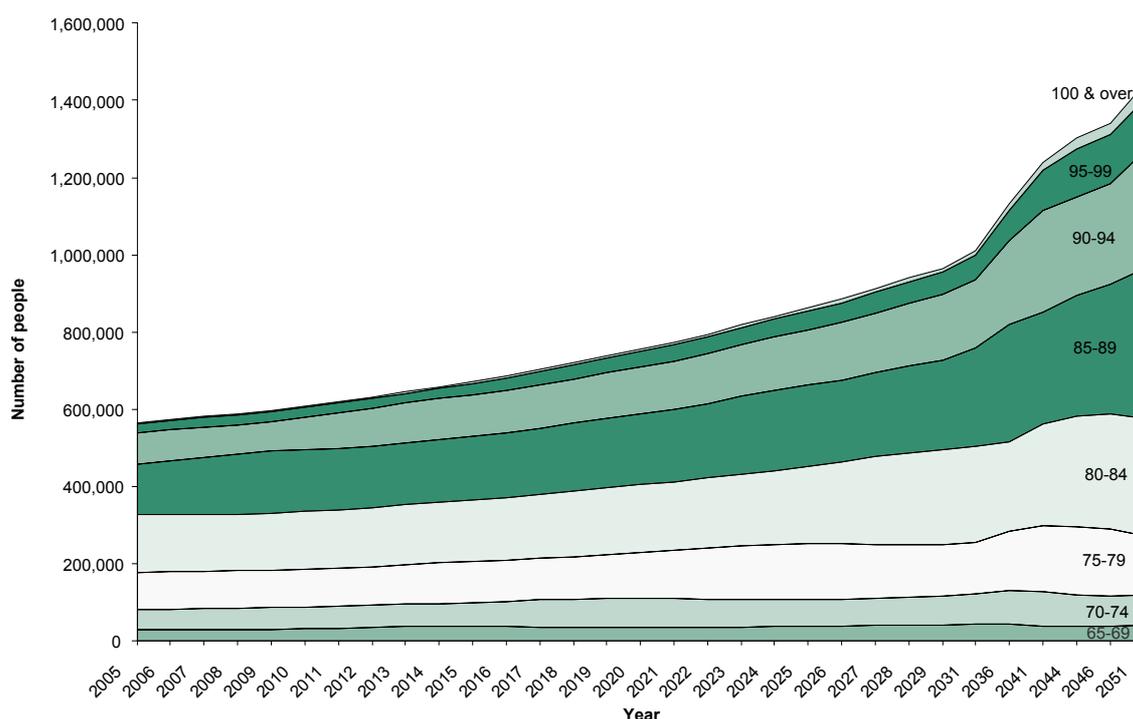
- 7. 62% of care home residents are currently estimated to have dementia but less than 28% of care home places are registered to provide specialist dementia care.** Few care home staff have specialist nursing qualifications or have been trained in dementia care. There is high turnover in staff and high vacancy levels and some staff do not have English as a first language. Poor standards of care have resulted in instances of inappropriate medicines management and complaints that people are not afforded sufficient dignity and respect. The Commission for Social Care Inspection should assess staff qualifications and training as part of its review of the quality of care for people with dementia, and local mental health services should use the findings when allocating resources to community psychiatric teams so they can provide adequate out-reach services to support care homes.
- 8. Hospital care for people with dementia is often not well managed, increasing the risk of longer stays, admission to a care home and deterioration in the patient's health.** Hospital staff generally focus on the physical reason for admission and can fail to identify or deal with dementia as a disease, resulting in longer stays and poorer outcomes than for people who are psychiatrically well. To improve the cost effectiveness of acute care, families or carers of people with dementia should hold a copy of the care record so that paramedics will be able to make an informed decision whether the person needs to be taken into hospital or can be treated at home. For older patients admitted and known or suspected to have cognitive impairment, hospitals should routinely undertake a mental health assessment.

1 The prevalence and cost of dementia and the development of a Departmental strategy diagnosis and early intervention

1. Dementia is a term for a range of progressive, terminal organic brain diseases. Symptoms include decline in memory, reasoning and communication skills, and ability to carry out daily activities, and loss of control of basic bodily functions caused by structural and chemical changes in the brain. Alzheimer's disease is the most common form of dementia. Age is the main risk factor in dementia. Official statistics show dementia was the cause of 3% of all deaths in 2005, and may have contributed to up to 13% of all deaths.²

2. In 2006–07 there were around 560,000 people with dementia in England. Prevalence increases with age and the number of people with dementia is set to increase by over 30% over the next 15 years. Figure 1 shows the expected rise in prevalence over the coming 50 years.³

Figure 1: The number of people with dementia in England is increasing and is estimated to reach 1 million by 2031 and 1.4 million by 2051⁴



Source: C&AG's Report Figure 5 (adapted from *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science, 2007*)

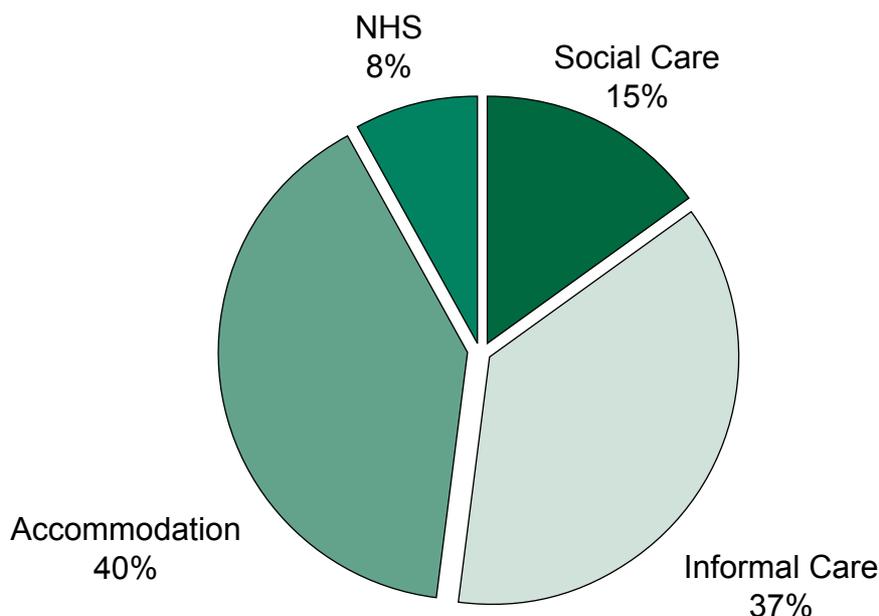
2 Q 68; C&AG's Report, paras 1, 1.3

3 Qq 2, 39, 68–71; C&AG's Report, para 1.2;

4 C&AG's Report, Figure 5

3. Dementia costs the health and social care economy more than cancer, heart disease and stroke combined.⁵ In total the estimated economic burden of late-onset dementia in England is £14.3 billion a year (on average £25,000 per year for each affected person).⁶ The contribution made by informal carers is estimated to save the taxpayer over £5 billion per year. The biggest component of cost relates to care home accommodation, which totals almost £6 billion per year. Costs of NHS services and social services total £3.3 billion a year. Figure 2 provides a breakdown of the different cost components relating to dementia.⁷

Figure 2: Breakdown of economic burden of dementia in England (2006–07)⁸



Source: C&AG's Report, Figure 8

4. Despite the significant human and financial costs of dementia, the disease has not been a priority for the Department or the NHS. It was not until 2005 that the Department developed policy specifically directed towards older people's mental health issues. Dementia services, and older people's mental health services, have not benefited from the National Service Frameworks for older people, mental health or long-term conditions.⁹ Following publication of the C&AG's report on dementia services, the Government identified dementia as a national priority and the Department has since established a Working Group to develop and deliver a national dementia strategy within the next year.¹⁰

5. By October 2007, the Working Group had met three times and identified three key themes to focus on in developing its strategy: improving public and professional attitudes and understanding; enabling early identification and early treatment for people with

5 Lowin et al (2007) Alzheimer's disease in the UK. Comparative evidence on costs and illness and volume of health services research funding, *International Journal of Geriatric Psychiatry*, Vol 16, 1143–1148

6 *Dementia UK: Report to the Alzheimer's Society*, King's College London and London School of Economics and Political Science, 2007

7 Qq 41–42, 46; C&AG's Report, paras 1.3, 1.10

8 C&AG's Report, Figures 8 and 9

9 Q 2; C&AG's Report, para 1.6;

10 Qq 2–7, 84–87, 114–123

dementia; and improving the quality of care for people once they are diagnosed (from diagnosis to end-of-life). Following development of a national dementia strategy, the working group intends to generate an implementation plan.¹¹

6. Whilst the Chief Executive of the NHS has overall responsibility for dementia care, there is no-one with the specific responsibility for improvements in dementia service, as there is for cancer. The Department confirmed that the strategy will consider whether there might be merit in appointing a Senior Responsible Officer to drive through the development and implementation of the dementia strategy and take overall responsibility for dementia care in England.¹²

11 Qq 2, 5, 84

12 Qq 89–98, 114

2 Diagnosis and early intervention

7. There is clear evidence that early diagnosis and intervention improve outcomes for people with dementia and their carers. Between a half and two-thirds of people with dementia, however, never receive a diagnosis: only 5 people per 1,000 were diagnosed at age 65–69 in 2006, compared with an estimated actual prevalence of 13 per 1,000, while in people over 80 years only 60 of the expected 122 were diagnosed. Many people with dementia are not diagnosed until they go to hospital after an acute event, but even in such cases an accurate diagnosis might not be made. If the prescription rate of anti-dementia drugs (cholinesterase inhibitors) in Alzheimer’s disease is used as a proxy for diagnosis, the UK compares very poorly with other EU countries, and indeed is ranked in the bottom third of countries.¹³

8. There are a number of reasons for this poor diagnosis rate. Lack of awareness amongst the public and fear of, or stigma attached to, the disease means that people with the disease do not seek a diagnosis. GPs may consider that they lack the skills and/or confidence to make a diagnosis. Only 31% of GPs surveyed by the National Audit Office agreed that they had received sufficient basic and post-qualifying training to help them diagnose and manage dementia. Although there is no known cure for the condition, there is considerable scope for helping people with dementia which is not well understood amongst professionals and the public. Whilst the majority of GPs surveyed agree it is beneficial to make an early diagnosis of dementia and look actively for early signs, only half agree that providing a diagnosis is more helpful than harmful or that much can be done to improve the quality of life for people with dementia. Almost a quarter of GPs think dementia patients are a drain on resources with little positive outcome, an attitude which the Department acknowledges must change.¹⁴

9. Where GPs are not equipped to make a formal diagnosis they should refer a patient to specialist mental health services. Specialist services may be a multidisciplinary team offering specialist assessment, treatment and care to older people with mental health problems in their own homes and the community (Community Mental Health Team (CMHT)); or a newer and more flexible specialist approach to early diagnosis and intervention known as a memory service, recommended by the NICE-SCIE guidelines as the single point of referral.¹⁵ There is no international consensus however on which speciality within medicine should take the lead in diagnosis and treatment of dementia. The Department’s dementia working group aims to address who should make the diagnosis of dementia. Regardless of who this might be, the Department agrees there should be greater involvement of mental health services with GP practices to deal with all mental health issues such as dementia, depressions, psychosis and anxiety.¹⁶

13 Qq 8, 9, 36–38, 49–50, 64, 68–71; C&AG’s Report, paras 2.1, 2.2, 2.4, 2.27

14 Qq 8, 33, 54; C&AG’s Report, paras 2.5, 2.8–2.9; Figures 14 and 15

15 Qq 34, 99; National Institute for Health and Clinical Excellence and Social Care Institute for Excellence, *Dementia: Supporting People with Dementia and their Carers*, 2006

16 Q 34; C&AG’s Report, paras 2.11–2.12, 2.16

10. Diagnosis should always be made as early as possible, regardless of whether interventions are available, to enable interventions (as recommended by the NICE-SCIE guideline) to be offered to the person with dementia and their carers and to allow them to make plans for the future whilst they are still able to do so.¹⁷ Early diagnosis also enables people with dementia and carers the opportunity to have some involvement in their care planning, which our web forum found is currently poor. The Department recently published a toolkit to help practitioners encourage proactive involvement of people with dementia and their carers in care planning.

11. A diagnosis is often not communicated well. GPs surveyed rated telling the patient the diagnosis as the third most difficult of 10 aspects of dementia care. Focus group participants consulted by the National Audit Office were often disappointed in the manner in which GPs or specialists communicated the diagnosis.¹⁸

12. Many families report feeling abandoned following diagnosis. The moment of diagnosis can and should be used to give information and instil hope for the life that people with dementia have afterwards. Despite NICE-SCIE guidelines which set out the types of support and information needed to support someone with dementia, the Department agreed that many families are left floundering following diagnosis of dementia.¹⁹

17 Qq 63–64; C&AG’s Report, paras 4.9–4.10

18 Q 99; C&AG’s Report, paras 2.20–2.23

19 Qq 11, 99; C&AG’s Report, paras 2.23–2.25

3 Access to and quality of support services

13. People with dementia need a complex mix of support from carers and health and social care to remain healthy and independent and they rely on multiple service providers. Dementia therefore presents a key test of the quality of local joint working, which continues to be a barrier for people with dementia. The Department acknowledges that poor integration is a common criticism of services, particularly for long-term conditions where a whole series of agencies are involved.²⁰

14. The process of care management and co-ordination for dementia is complicated and usually falls to carers to deal with. People with dementia and carers should have a single point of contact they can turn to from diagnosis right through their disease progression. Successfully co-ordinating care in dementia requires good collaboration between primary and secondary care. A care co-ordinator need not be the GP, but could be any member of health or social care services or a member of a multidisciplinary team. A member of a Community Mental Health Team would, for example, be well-placed to act as a case manager.²¹

15. Informal carers supporting people with dementia save the NHS and social care over £5 billion per year. Without them, the present system of care and support to people with dementia would be unsustainable. But caring can place a heavy burden on the carer's physical, emotional and mental health, and can lead to depression. Unpaid carers incur personal financial costs, including lost employment, lower earning and lost pension entitlements.²² All carers over 16 years are entitled to a Carer's Assessment under the Carers and Disabled Children Act 2000, which enables the carer to discuss with social services the help they need to care, to maintain their own health and to balance caring with their life, work and family commitments. Between a half to two-thirds of unpaid carers, including those caring for people with dementia, are not receiving such an assessment, and those who do receive one often do not have it followed up. The Department is taking some steps to help carers through, for example, expanding the telephone helpline for carers and increasing the level of emergency care cover available.²³

16. A key form of support in the community is domiciliary or home care, such as an assistant coming into the home to help. While this is a core service for many people with dementia and their carers, it is becoming increasingly difficult to access as councils restrict eligibility to services as part of cost-efficiency measures. As well as problems with access, there are also issues around quality of domiciliary care. Domiciliary care workers generally lack any qualifications and there are no incentives for them to gain qualifications. 70% of the social care work force is without qualification. They are poorly trained and poorly paid, leading to difficulties with recruitment and retention and consequently a high turnover of staff. Lack of continuity for service users results, which can be unsettling and distressing for people with dementia. Many home care staff do not have English as their first language,

20 Qq 61, 73; C&AG's Report, paras 4.3–4.7

21 Qq 35, 62, 74; C&AG's Report, para 4.13

22 Q18; C&AG's Report, paras 1.10, 3.17

23 Qq 18–26, 46–48; C&AG's Report, para 3.17

which leads to communication problems, despite communication skills being a requirement of the Common Induction Standards which all staff should achieve. The Department believes the situation is improving with many staff now paid above the minimum wage and training courses provided in areas such as lifting, handling and appropriate bathing. Its five-point plan to raise the status of social care will help to address this issue and make social care a more attractive career option, and help raise the standards amongst its workforce.²⁴

17. Good quality respite care is invaluable for carers of people with dementia, allowing both people with dementia and carers a short break, either in their own home, at a care home or at a community hospital facility, at a time to suit the carer. With this support, people with dementia can usually live at home for longer. Significant numbers of carers either have no access to respite care, or they have less access than they need or when and where they need it. The Department believes that improvements can be achieved through working with organisations such as the Princess Royal Trust for Carers and Crossroads, to enable assistance to be provided in people's own homes which many people prefer to care in an institution. Its Carers' Strategy is also designed to equip both the workforce and carers with the skills to care.²⁵

18. Whilst caring for a relative with dementia is often a positive choice for the carer, it carries a large personal cost. Given the savings achieved by delaying or avoiding people with dementia being admitted to hospital or care homes, carers represent a cost-effective way of providing care. The Department accepts that it needs to provide commissioners, both Primary Care Trusts and Local Authorities, with the necessary information so as to convince them to prioritise good domiciliary and respite care and this might be factored into Local Area Agreements.²⁶ As recommended in the C&AG's report, the Department is developing a business case to identify the savings and benefits.²⁷

24 Qq 58, 79–83; C&AG's Report, para 3.15

25 Qq 28–32; C&AG's Report, para 3.19

26 A Local Area Agreements is a three-year agreement that sets out the priorities for a local area in certain policy fields as agreed between central government, represented by the Government Office, and a local area, represented by the Local Authority and Local Strategic Partnership (LSP) and other partners at local level. The agreement is made up of outcomes, indicators and targets aimed at delivering a better quality of life for people through improving performance on a range of national and local priorities.

27 Qq 64, 107

4 Acute hospital admission and care home experiences

19. Over 200,000 people with dementia are estimated to live in care homes, some 62% on average of all residents in such settings. However, only 28% of care homes places are registered as specialist dementia places, meaning a significant proportion of people with dementia live in homes where staff are not appropriately trained to care for them and meet their specific needs. Whilst the Commission for Social Care Inspection²⁸ (CSCI) has recorded an increase in the number of homes meeting these standards, the proportion of residents with dementia is also increasing.²⁹

20. Many of the concerns about skills, training and turnover of domiciliary care staff are also relevant to care home staff. The challenge remains to ensure that staff recognise and acknowledge dementia and are equipped to provide appropriate care to meet the needs of people with dementia.³⁰

21. Two out of ten care homes are not meeting the medicines management standards and there is evidence of people with dementia being administered anti-psychotics to manage behavioural problems. The latter is not recommended except in short term management of high risk situations, since the drugs have serious side-effects and may exacerbate dementia. Care homes require more effective specialist input from mental health services to ensure their input and advice in the care of people with dementia and other mental health problems, especially in the area of medicines management.³¹

22. The NAO's Lincolnshire whole system case study of health and social care and acute bed survey demonstrates that admission and readmission to acute hospital care can often be avoided for people with dementia, and their lengths of stay can be reduced by finding alternative non-acute care settings for these patients. Ambulance staff should have access to appropriate information to make an informed decision as to whether the person needs to be taken to hospital or can be better treated at home.³²

23. On admission of older patients known—or suspected—to have cognitive impairment, acute hospital trusts do not routinely undertake a mental health assessment. Acute trusts usually only treat the physical symptoms which led to the admission, so the treatment and rehabilitation of people with dementia is not tailored to their needs to enable them to leave hospital earlier. Preventing unnecessary admissions and reducing lengths of stay would release resources for better care further upstream in the dementia care pathway. The Department is undertaking work similar to the NAO's whole system case study to identify the benefits of early intervention and management for people with dementia in terms of fewer admissions to acute hospital and shorter lengths of stay. The National Audit Office's

28 The Commission for Social Care Inspection registers, inspects and reports in adult social care services, and councils who arrange these services in England.

29 Q 57; C&AG's Report, paras 4.19–4.20

30 Q 76–83; C&AG's Report, paras 3.13–3.14

31 Qq 59–60, 100–104, 108–113; C&AG's Report, para 4.22

32 Q 27; C&AG's Report, para 4.6–4.7

analysis of acute admissions for fractured neck of femur also demonstrated there is a clear financial benefit from improving the treatment of people with dementia, as well as a quality of life improvement for the patients concerned. At present, a person with dementia who suffers a fractured neck of femur is over 2.5 times more likely to die in the six months following admission and almost 18 times more likely to be admitted in a care home following discharge than a person who is psychiatrically well and is only half as likely to be discharged at the end of six months.³³

33 Qq 27, 64, 135; C&AG's Report, paras 2.27–2.32, 4.7, 4.17–4.18; Figure 24

Formal Minutes

Monday 14 January 2008

Members present:

Mr Edward Leigh, in the Chair

Mr Richard Bacon

Mr Austin Mitchell

Mr Philip Dunne

Dr John Pugh

Mr Keith Hill

Mr Alan Williams

Draft Report (*Department of Health: Improving Services and Support for People with Dementia*), proposed by the Chairman, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 23 read and agreed to.

Conclusions and recommendations read and agreed to.

Summary read and agreed to.

Resolved, That the Report be the Sixth Report of the Committee to the House.

Ordered, That the Chairman make the Report to the House.

Written evidence was ordered to be reported to the House for printing with the Report

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned until Wednesday 16 January 2008 at 3.30 pm.]

Witnesses

Monday 15 October 2007

Page

David Nicholson CBE, Chief Executive, **David Behan**, Director General of Social Care, Local Government and Care Partnerships, and **Mark Britnell**, Director General of Commissioning and System Management, National Health Service, and **Professor Sube Bannerjee**, Clinical Director of Old Age Psychiatry and Professor of Mental Health and Ageing, King's College London

Ev 1

List of written evidence

The Alzheimer's Society

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Sixth Report	Department of Health: Improving Services and Support for People with Dementia	HC 228

Oral Evidence

Taken before the Committee of Public Accounts

on Monday 15 October 2007

Members present:

Mr Edward Leigh, in the Chair

Mr Richard Bacon
Angela Browning
Mr Ian Davidson

Dr John Pugh
Mr Don Touhig
Mr Alan Williams

Sir John Bourn KCB, Comptroller and Auditor General, **Tim Burr**, Deputy Comptroller and Auditor General and **Karen Taylor**, Director for Health, National Audit Office, were in attendance and gave oral evidence.

Marius Gallaher, Alternative Treasury Officer of Accounts, was in attendance.

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL

Improving Services and Support for People with Dementia (HC 604)

Witnesses: **David Nicholson CBE**, Chief Executive, **David Behan**, Director General of Social Care, Local Government and Care Partnerships, **Mark Britnell**, Director General of Commissioning and System Management, National Health Service, and **Professor Sube Banerjee**, Clinical Director of Old Age Psychiatry & Professor of Mental Health and Ageing, King's College London, gave evidence.

Q1 Chairman: Good afternoon, and welcome to the Public Accounts Committee, where today we are looking at the Comptroller and Auditor General's Report, *Improving services and support for people with dementia*, which, from what we read in the Report, appears to be the Cinderella of all Cinderella services. Mr Nicholson, would you like to introduce your team?

David Nicholson: I am the Chief Executive of the NHS, and with me are Professor Sube Banerjee, who is leading some of the work on the strategy for dementia, Mark Britnell, who is Director General of the Department for commissioning and system management, and David Behan, who is a Director General with particular responsibility for local government and social care.

Q2 Chairman: We asked the National Audit Office to take a particular interest in the matter before us. This could be a very important hearing and I hope that we raise the issue of dementia up the political agenda, as we did for those of stroke, hospital-acquired infections and now, most topically, obesity. I think that the work of this Committee was instrumental in raising the importance of the latter.

We are now dealing with dementia, which affects nearly 500,000 people and costs £14 billion a year—in some estimates. Obviously, it is a hugely important issue, and to some of us it seems that it is rather like cancer in the 1950s. A stigma is attached to it, people are not necessarily told about it early enough and there is a feeling perhaps that the cures are not very effective. I think, therefore, that this hearing could be very important in raising the issue.

In response to this Report, Mr Nicholson, you set up a working group in order to develop a strategy for dealing with dementia. Given the huge personal and financial impact of dementia, why did you not do it before? Why did you wait for the National Audit Office to jog you into setting up the working group?

David Nicholson: You are absolutely right. This is a very important issue for us to tackle, from the Department's point of view, and from that of the NHS and social care. However, the idea that we have done nothing in the past is not completely true. A lot of work has been done on dementia—for example, the older people's national service framework, the Let's Respect project carried out by CSIP (Care Services Improvement Partnership), the Everybody's Business service and the Quality and Outcomes Framework. A whole series of things have been done over the last few years to try and improve services for this group of patients.

Having said all that, the issue has not been identified as a national priority, which is reflected in the work and the emphasis that we have put on it over the last few years, during which time coronary heart disease, cancer, waiting times and other such issues have been regarded as priorities, as opposed to dementia. The great thing about the NAO's Report and the Government's response is that the Minister, Ivan Lewis identified dementia as a Government priority and hopefully, in today's conversation, we will be able to reinforce the fact that that will be the case. We are going to put things into place to make that happen. That is why we have set up the working group to put together a strategy for dementia.

A whole series of individual interventions will not necessarily make the changes that we need for these patients and their carers. An overarching strategy

National Health Service

that sets out everything from the epidemiology of dementia, through research and development and staffing to the way in which patients are identified and treated is the right approach.

Q3 Chairman: Has the working group met yet?

David Behan: We have put the programme board together. The programme board is chaired by me, and Mark Britnell is on the board, to get the health and social care—

Q4 Chairman: So it has not met?

David Behan: The project group, which sits under the programme board, has met.

Professor Banerjee: We have met on four occasions. I chair the group.

Q5 Chairman: It has met?

Professor Banerjee: The working group to develop the strategy has met on four occasions, and we have worked to identify the three main themes that we will be working on. The membership of the external reference group, which is chaired by the Alzheimer's Society, has been agreed, and that group is due to meet very soon, so the work has started in earnest. We have identified the three main themes that need to be addressed, which are early identification, public attitudes and understanding—

Q6 Chairman: But the main group has not actually got down to work?

Professor Banerjee: No, the main group *has* got down to work.

Q7 Chairman: What are its time scales? How urgent is this? Are we talking about six months or a year? What is it?

Professor Banerjee: We have been set a year to deliver the strategy.

Chairman: Okay.

David Nicholson: Having said that, an important document for the NHS is the operating framework, which comes out at the end of November, the beginning of December. It is the main communication between the Department and the NHS as to the planning priorities for the next year. We have said that emerging things that have come out of work so far can go into that operating framework.

Q8 Chairman: If we look at figure 13 on page 26—this is also mentioned in paragraph 2.4—we see that between half and two-thirds of people with dementia are not receiving a diagnosis. Why is that?

David Nicholson: There is a whole range of issues here; some of them are societal, some are about professions and some are about the system that we operate. There are societal fears about dementia, and while the Department of Health is an important organisation, it is not entirely responsible for the whole of society's views about these issues, and we would not kid anyone by any stretch of the imagination if we said that we can control them all. So fear of dementia is a major issue.

There are also misconceptions about what can and cannot be done. On the one hand, in society as a whole, dementia is often seen as something that there is no treatment for and that you can do nothing about. Among some professionals, too, there is the view that there is very little that can be done. There is a lack of confidence among professionals about dealing with these issues, which is identified very well in the NAO Report. And we have not had a systematic approach to dealing with this issue.

Q9 Chairman: So you are now going to set a time frame on this issue and deal with the issues raised in the paragraph that says, "Only five people per 1,000 were diagnosed at age 65–69, compared with an estimated actual prevalence of 13 per 1,000"?

David Nicholson: Yes, it will undoubtedly be one of the things that come into this—

Q10 Chairman: So if you are summoned back in two or three years' time, we will see a completely different story, will we?

David Nicholson: I think you will see a completely different story.

Q11 Chairman: As regards those who are diagnosed, why are so many families left floundering without any adequate support?

David Nicholson: There undoubtedly are people who are left floundering after the diagnosis, but that is not true for everyone. There are some fantastic services around the NHS and social care system—indeed, I have visited some in the last few weeks—but this is a complex care pathway. Dementia is, on the one hand, a long-term condition, but it is, on the other hand, an issue in relation to end-of-life care. What we have not done yet is put together a set of pathways that would be applicable in most circumstances. That is one of the things that the strategy will have as a priority; indeed, it is one of the issues dealt with in the work that Ara Darzi and his team are doing at the moment in relation to the review.

Q12 Chairman: All this is very complex, but there is a very easy thing that you can do. There are drugs available at the early stages; they are available in Scotland, and they clearly do some good by delaying the onset of this disease, but they are not available in England. It is outrageous, is it not, as far as our English constituents are concerned, that there are people being treated in Scotland?

David Nicholson: Judgments about the use of such drugs are taken by NICE, and we are guided by that.

Q13 Chairman: But you do not necessarily need to accept NICE's decision. You did accept it, perhaps gratefully. Perhaps it resulted in large savings. How much money is involved? If you had not accepted NICE's recommendations, and if we were to provide in England the same drugs at the early and middle stages as are available in Scotland, what would have been the cost?

David Nicholson: I am sorry, I do not have that figure.

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Q14 Chairman: Was it a factor in your decision?

David Nicholson: No. We accepted NICE's recommendation.

Q15 Chairman: What would you say to the Alzheimer's Society, which has produced evidence to suggest that you, or NICE, did not take account of the cost to carers? If that had been taken into account, the mathematics might have been very different.

David Nicholson: This is obviously subject to appeal.

Q16 Chairman: So did you take account of the cost to carers or not?

David Nicholson: Well, we didn't; it was NICE that did it.

Q17 Chairman: Did NICE take account of it?

David Nicholson: I think that that will be the subject of the appeal.

Q18 Chairman: Paragraph 1.10 states that informal carers save the NHS and social care some £5.4 billion a year. Do you accept that? Presumably you do, because you have accepted the Report.

David Nicholson: Yes, we accept the Report.

Q19 Chairman: So why do between half and two thirds of unpaid carers not receive a carer's assessment, as they are entitled to under the Carers and Disabled Children Act 2000?

David Nicholson: That is a figure for all carers, not just carers for people with dementia.

Q20 Chairman: So why are between half and two thirds not receiving a carer's assessment, as they are entitled to?

David Nicholson: We believe that the position on dementia is better than that, based on—

Q21 Chairman: That comes from paragraph 3.18, which again you have accepted by accepting the Report.

David Nicholson: That is about carers in general, rather than—

Q22 Chairman: So you are now going to deal with this problem, are you?

David Behan: If I may help, Mr Chairman, I should like to say five things on the work that we are doing with carers. We have spent more than £1 billion on carers since the Act was passed, and this year we shall spend £185 million on extending the work that we have been doing on the carer's grant to local authorities. The five things that we are doing at the minute are: first, reviewing the Prime Minister's strategy on carers, which we shall publish in the new year; secondly, expanding the telephone helpline that is there to signpost carers to the appropriate help; thirdly, carers have often told us that they need help with access to emergency care at very short notice, and we are making resources available to local government to expand emergency care; fourthly, preparing carers so that they have the skills to secure their support through the development of an expert

carers programme; and, lastly, developing proposals for a standing commission on carers, which will be made up of people outside Government, designed to challenge us.

Q23 Chairman: Excellent answers. Will you now please answer the question that I asked, Mr Nicholson?

David Behan: If I could help again, Mr Chairman—

Q24 Chairman: Why are between half and two thirds of unpaid carers not receiving a carer's assessment, as they are entitled to under the Carers and Disabled Children Act 2000?

David Behan: All the evidence is that there has been an increase year on year since 2000 in the number of assessments carried out. The number of assessments offered to people is about 380,000—

Q25 Chairman: That does not answer the question. You are saying that there is an increase; you have not answered the question that I put to you. Why are between half and two thirds of unpaid carers not receiving a carer's assessment, as they are entitled to under the 2000 Act? You just have to say, "They are not, and I am going to deal with it." That is all that you have to say.

David Behan: We acknowledge that people are not receiving the assessments—

Q26 Chairman: Good. And you are going to deal with that.

David Behan: And the work that I have just described is part of the package to increase that.

Q27 Chairman: Right. Thank you very much. One last question from me. The Lincolnshire study was obviously very successful, as shown in appendix six. Are you going to make that best practice now throughout the country?

Professor Banerjee: The Lincolnshire case study is an interesting and useful whole-systems approach to locating people with dementia in a particular health system, attaching costs to those individuals and working out whether they would be best placed in other places. The data from the case study are similar to those from other studies that have been carried out in general hospitals, from which we know that people with dementia spend longer on wards and have higher re-admission rates. We know that focused work with those individuals, to ascertain their diagnoses and tailor both their treatment and rehabilitation to the needs determined by their dementia, will enable them to leave hospital earlier. The value of the Lincolnshire case study is that it quantifies that for a particular area, and it is encouraging that local health commissioners are interested in taking the potential savings from that and reinvesting them in community services. Certainly, the whole thrust of the work that we will do with the dementia strategy is to identify areas where care can be better provided. A lot of evidence suggests that a greater focus on diagnosis would help people at all stages, including when they are in acute hospitals.

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Q28 Angela Browning: I should first declare an interest as a vice-president of the Alzheimer's Society.

Returning to Mr Behan and the question of carers, I want to pick up on something. Whatever extra money is being spent, it is patently obvious at local level that placements in community hospitals—they are often managed by the local GP service—which are one of the resources that are available for respite care if carers have an emergency or are simply worn out, are rapidly drying up and are no longer available for dementia cases. We know that there is a shortage of spaces in nursing homes. In fact, there is not just a shortage of spaces; there are very few spaces with the closure of nursing and residential homes. You have identified extra money and said that will be spent on supporting carers in this area, but where will the beds come from?

David Behan: The work that we will do at local level will be for health and social care to come together to identify the needs of people with dementia and Alzheimer's and the needs of their carers. One of our expectations is that that assessment will enable plans to be made for how best to put services together. You have already referred to the work in Lincolnshire, and Professor Banerjee has referred to the work that is being done in other places. It is from that analysis that we expect local services to be designed and developed to meet those needs.

We know from speaking to people—I guess that you know this from your work with the Alzheimer's Society—that some people are looking for emergency respite and support not just in institutions, but in their own homes. An awful lot can be achieved through organisations such as the Princess Royal Trust for Carers, and Crossroads, when practical assistance, often by friends, neighbours and relatives, can be provided to people in their own homes. That will obviate the crisis, and allow carers some respite and the individuals with Alzheimer's or dementia some support by people they already know. We are looking not just at institutional care as the basis for respite and emergency care; we are also looking laterally at support that can be provided within the community.

Q29 Angela Browning: One of the wards in one of my local community hospitals that deal just with dementia patients has closed this year, and one of the reasons given for that closure was the hospital's inability to recruit suitably qualified staff to man that ward. If we transfer most of that work to the community and the people you have just identified, and if the health service could not supply suitably qualified people to meet the necessary standards of care that patient group, how will neighbours and other volunteers provide that standard?

David Behan: Clearly, people's level of dependency is different, and I am sure that Professor Banerjee would share the differences with you. Some of our work this year has been on prevention pilots, and five of the 29 pilots focused on working with people with dementia. A number of those schemes have been successful in maintaining people in their own homes. We acknowledge in our work over the past few months that equipping the work force with the necessary skills to provide appropriate care is an

important part of the work. I referred earlier to the expert carers' strategy, which was designed exactly to equip not just the work force, but carers with the skills to care. We are optimistic that by rolling that out we can provide a range of provision for different circumstances and needs. We acknowledge that development of the work force is an important part of what we need to do, and part of our work on improving the quality of the strategy's service will take forward our thinking on that. We will ask the expert reference group that we have set up as part of our arrangements to contribute their views on how we can take that forward.

Q30 Angela Browning: It seems a bit topsy-turvy to me to close a facility before you have the alternative in place. Will that be the nationwide experience?

David Behan: We are determined, in announcing the strategy, to give a clear sense of direction. We are doing that in an inclusive way. People from the Alzheimer's Society and carers' groups are involved in the work, and we are pretty determined to ensure that the strategy captures the elements that people who have Alzheimer's and their carers feel are important to support them.

David Nicholson: It is worth saying that we are learning some quite hard lessons in relation to all this. You are absolutely right. Certainly in my conversations with carers and people interested in this sort of issue, they say, "We like the look of your exciting, interesting community service, but don't you dare take away our existing service until we are satisfied." That is reflected in the Darzi Report and what Ian Carruthers said in his work. It is increasingly what the expectation of particularly the NHS will be—to be able to demonstrate that before we close other services.

Q31 Angela Browning: That may be the expectation, Mr Nicholson, but it is not what is happening out there.

David Nicholson: I am saying that it is one of the lessons that we are learning from what is happening at the moment, and that is why we have said what we have in the Darzi Report.

Q32 Angela Browning: In terms of playing catch-up as far as the NHS is concerned, is it NHS policy that there will be no more respite in, for example, community hospitals?

David Nicholson: No.

Q33 Angela Browning: Moving on from that, I am very concerned about the situation with GPs, because we see some very interesting figures in the NAO Report. For example, on page 7 at paragraph 13, we see that GPs' confidence in carrying out a diagnosis has fallen since 2004. I wonder what you think the explanation for that is.

David Nicholson: In a sense, this reflects what I said in the initial answer about the confidence of professionals to deal with these kinds of issues. There is no doubt that there is the same amount of training and support for GPs in these areas, but they are becoming more complex and GPs do not feel as

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confident. I do not think that anything has happened to the system to enable that to be the case, because GPs, for example, are now supposed to have a register of people with dementia. I think that they are having to address these issues directly for the first time and that that is what is leading to a reduction in their confidence in dealing with them.

Q34 Angela Browning: I found rather strange the fact that they were losing confidence in carrying out a diagnosis, because of course GPs see people who present sometimes with quite complex symptoms and one of the things I would have hoped of our primary care system is that GPs would be the gatekeepers to the service. In other words, we do not always expect GPs to be the person who gives the diagnosis, but we do expect them to make an appropriate referral. I see on page 9, in relation to memory services recommended by NICE, that 69% of GPs were aware that they could refer a patient to a memory service. If their own confidence in carrying out a diagnosis is reducing, why are not more of them referring to somebody who can say, "Yes, it is dementia"? Why is there a conflict in those two sets of stats?

Professor Banerjee: Perhaps I could start off on that, because I think it is a very striking finding from the Report that GPs' confidence has decreased over that period. I think that it is quite possible for people's confidence to decrease as their knowledge about dementia increases. I think that GPs' knowledge about dementia has increased in the last five years. It used to be the case that people thought of dementia, and thought of making a diagnosis of dementia, only in terms of the most severe state of dementia, so right at the end of it when people have very little in the way of memory, have very clear impairments of their function and maybe have all sorts of other behavioural problems in dementia as well. At that point, it is relatively easy to make a diagnosis of dementia, because of the severity of it.

One of the things that has become clear is the need to make those diagnoses earlier and the fact that it is possible to make diagnoses quite early in dementia now. However, it is more difficult to make those diagnoses earlier in dementia. The earlier it is, the more there is the need for specialist input into making the diagnosis of dementia, so I think that those GP results are explicable in terms of the field developing and an acknowledgement that diagnoses need to be made earlier, which is a more complicated thing.

The important point that comes from that is the second point that you were making, which is about who should make the diagnoses. It is a terrifically important point, which has not been directly addressed by much of the work in the area, including the excellent NICE/SCIE clinical guidelines. One thing that our strategy will explicitly address is who should make the diagnoses of dementia. Should it be a primary care diagnosis, or should it be a diagnosis that is made by a specialist, which could be GPs with a specialist interest or neurologists or geriatricians—whatever, but a diagnosis that is made by a specialist service—with care then carried on it the rest of the community? That question is yet unanswered. There is tremendous variation in activity, but there are good

examples in the country of systems that have been set up to deliver diagnoses early, accurately and effectively, communicating it in such a way that individuals feel supported through the process and walk with good-quality information into living the best life that they can with their dementia. The Alzheimer's Society has been part of putting those processes in place.

Q35 Angela Browning: Chairman, I should like to pursue one or two questions with Professor Banerjee, but I might ask you if I can dip back in after others have had their chance to talk.

I take a particular interest in mental health, having served on the Mental Health Bill Committee and the scrutiny committee. One thing that we know really works is when a GP practice has a community psychiatric nurse or someone from the mental health services attached to the practice so that there are not long waits for referrals. Would you, Professor Banerjee, envisage that if, as the Government have promised, there is more involvement of mental health services attached to GP practices, they would deal not only with depression, but with dementia patients? Would that be a help?

Professor Banerjee: You really hope that they would, absolutely, because the case management of dementia, following on from diagnosis, must be a collaboration between primary care and secondary care. One thing that old age psychiatry services throughout the country have done very well is learn to work with primary care. It is an entirely community-based service, and there are very good links. The focus of the strategy will be to ensure that there is sufficient capacity within the system to work with people not only at the most severe and complicated end of the spectrum, which is where mental health services have often rationed their care, but at the earlier end of the spectrum, whereby good-quality support there may prevent harm further down the line. I am agreeing with you—in a long-winded way.

Angela Browning: I have about a dozen other questions, but I shall try to distil them, Chairman, for later. Thank you.

Q36 Mr Touhig: Mr Nicholson, the Chairman referred to figure 13 on page 26, where we see that as few as one in three people with dementia receive a formal diagnosis, and that at best it is 50%. Do you not find that totally unacceptable?

David Nicholson: Absolutely. It is one of the main reasons why the Government decided to identify dementia as a priority.

Q37 Mr Touhig: We agree that it is unacceptable, we agree that it is a priority, and we spend more on dementia care than we spend on cancer, heart and stroke combined, yet under a ranking we are in the bottom three EU countries for dementia care.

David Nicholson: Absolutely. We spend most of our money at the most complex end rather than upstream.

Q38 Mr Touhig: Why are we so far behind then? We are behind Italy, France, Spain, Germany.

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David Nicholson: There are a series of reasons. The first and most obvious is that our services often reflect a history of services in this country, where, historically, mental health services were focused in large institutions dotted around the country, and there was relatively little development of community services for that group of patients. Most of the focus on improving mental health services over the last few years has been focused on adults. But under the age of 65—

Q39 Mr Touhig: There are 560,000 people in England with dementia, and that will rise by 30% in the next 15 years. The Alzheimer's Society says that it will rise by 40%. It is not something that has arrived on the horizon; it has been there for some time.

David Nicholson: It is—

Q40 Mr Touhig: You are not on top of this issue, are you?

David Nicholson: We have been doing things: the older people's national service framework, the mental health national service framework—a series of activities to take services forward. But it is not enough, and it is not giving to the service the radical change that is required.

Mr Touhig: You are really not on top of it.

David Nicholson: What is really—

Mr Touhig: You are not on top of it, are you?

David Nicholson: We are absolutely on—

Q41 Mr Touhig: We are spending £14.3 billion on this, and we are still in the bottom three in the European Union on care for people with dementia.

David Nicholson: We acknowledge that we have something to do, and that is why we—

Q42 Mr Touhig: That is a staggering amount that, is it not—£14.3 billion? You could get a few operations done for that, could you not?

David Nicholson: It is a huge amount of money, but the reason for tackling it is not to save money but to improve services for patients, and particularly to improve services for patients who do not get a service at the moment.

Q43 Mr Touhig: What are the top three improvements that you would say that you are getting for spending £14.3 billion? What are the three top improvements that we are getting for spending such a vast amount of money in dementia care?

David Nicholson: The problem we have with dementia care is that the improvements are scattered around the system in various parts of the country. I can take you to lots of places where there are significant improvements: in Croydon, with memory services; in Leeds, with services for people with complex needs; and in Cambridge—there are lots of good examples around the country where people are improving services. What we have not got is a systematic approach, and it is not good everywhere. That is the focus of our attention.

Q44 Mr Touhig: Page 24 of the Report states that someone who gave comments to the focus group had to wait three and a half years for a diagnosis.

David Nicholson: I have come across people who have waited a long time for diagnosis, but I think that I have to take you back to what we said in part of the original conversations. What can often happen is that someone presents themselves to a GP and the GP will say, "Yes, you have got a memory problem but you are getting old." I have had cases where people have been moved around the system for two or three years because of that, because when they hit the service people do not have the expertise, understanding or knowledge—

Q45 Mr Touhig: It is a prejudice against age, is it not, that is endemic in the National Health Service?

David Nicholson: It is an issue in society in general, not just in the NHS, when it comes to memory issues. I am sure that Sube sees this every day in the way that he operates.

Q46 Mr Touhig: We have 476,000 carers. These are unpaid people who look after their loved ones and so on. It costs about £25,000 to look after a person per year. These people give up their jobs, their careers, to look after a loved one. Are you not ashamed that you have let those people down?

David Nicholson: I do not think that we have let them down. Again—I am sure that many people around this room will meet and talk to carers—they are relatively modest in what they require. They regard what they do as an important part of their lives and those of their loved ones.

Q47 Mr Touhig: They are filling a gap that you should be filling.

David Nicholson: I do not accept that, but we have a responsibility to support them and to help them to do it and to make it as easy as possible. What they want is a system that works for them, not against them, and that is what our responsibility is.

Q48 Mr Touhig: So, we have £14 billion, over 500,000 people with dementia in England, and nearly 500,000 carers, and you do not think that there is some great responsibility on the National Health Service to make some improvement here?

David Nicholson: Of course there is. That is why we have put together the team that we put together to develop the strategy. That is why we have said that if there are emerging findings from the strategy that we can put in place earlier we will do that through the operating framework this November and that we will work with Sube and his team to make sure that we have a dementia service that puts us in the top three rather than the bottom three.

Q49 Mr Touhig: Page 24, paragraph 2.1, tells us that early diagnosis and intervention are cost-effective, and that despite the fact that it improves the quality of life of people with dementia, early diagnosis is being prevented because GPs have poor knowledge of dementia and lack training. You know this as a fact; why are you tolerating it?

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Professor Banerjee: The figures and findings speak for themselves; the system is not working properly. What we need to do is to understand how the system is not working properly, and the reports that we have had in the past two or three years make it clear where the problems are. Then, most importantly, we need to set in place a different system that will ensure that individuals get a diagnosis and that services work for family carers as well as the people with dementia. The fundamental change that our strategy will focus on making is to enable those with dementia to get a diagnosis early in their illness and for that diagnosis to be factored into all the care that they and their family carers receive.

Q50 Mr Touhig: But you know from this Report, and surely from your own experience, that many people are not diagnosed unless they go into hospital for some other injury.

Professor Banerjee: Absolutely. Certainly the National Audit Office Report makes it very clear that the current system is problematic in many areas. It does not take all of the opportunities that are there to make diagnoses. We have examples of services that can do such things across the country; the challenge is to make those happen in other places. With respect to your point about carers earlier, I spend a lot of time working with carers, who want to be helped to continue to care. There are things that services can do that will support carers in their caring role. Carers do not necessarily want all the caring to be done by someone else. There are positive things that come from caring and the quality of life experience—

Q51 Mr Touhig: Have you had any personal experience of caring for someone with dementia?

Professor Banerjee: I have professionally, and also my grandfather had dementia. I run a dementia service.

Q52 Mr Touhig: My wife has, and it is not easy, I can tell you. Page 48 of the Report says that GPs can go through their entire career without learning about mental health at all. What are you doing about that? There have been some improvements and GPs are now keeping the register that you referred to because there is a financial incentive under the GPs' pay scheme. The NHS invented a pay scheme that gave GPs a licence to print money. Is it not somewhat mercenary that now there is a financial incentive they are gathering the stats together in order that we can better assess the needs of people with dementia?

David Nicholson: It is perfectly reasonable if you have a payment system for GPs that you try and reflect your clinical priorities and that is what we have tried to do with dementia, albeit in a relatively modest and limited way. I was talking to a group of GPs last week who were saying that you can run a register opportunistically—when people come to you and present, you can register them as having dementia.

Q53 Mr Touhig: Now there is an incentive, they are responding.

David Nicholson: That is absolutely right, but you can take a very proactive role and go and seek people out. That is absolutely what they should be doing.

Q54 Mr Touhig: I entirely agree with you, but, coming back to the point I made earlier about age discrimination, we see from the Report that almost one in four GPs believe dementia patients are a drain on resources, with little positive outcome.

David Nicholson: Yes, absolutely.

Mr Touhig: That is terrible. It is unbelievable.

David Nicholson: It is absolutely right. It is a really important issue for us to tackle because it is part of the societal view about dementia. It is exactly part of that that we have to tackle inside the system and outside.

Q55 Mr Touhig: But you are responsible for training GPs, setting down the guidelines by which they work, and you are prepared to tolerate—

David Nicholson: No, we are not prepared to tolerate it.

Q56 Mr Touhig: I hope you will be doing something more about it.

David Nicholson: Absolutely right.

Q57 Mr Touhig: We have very little time, and I appreciate the briefness of your answers. I have one further question about the care within care homes. The Report states that only 28% of care places are registered specialist dementia places, yet 62% of people in care homes have dementia. If you had an elderly relative with dementia, would you put them in a care home? I certainly would not.

David Behan: Clearly, one of the facts that the Report identifies is the population in care homes who are suffering from dementia. There are some estimates that would say that in some places up to 80% of people in care homes are suffering from dementia. The regulator, the Commission for Social Care Inspection, noted a year-on-year increase in the number of homes meeting the standards by which they have registered, so there has been some general improvement. Angela Browning's question was about the training of the work force and there are key issues in relation to the training.

Q58 Mr Touhig: There is a constant turnover of staff.

David Behan: There is a challenge in that respect and a challenge to commission services in an appropriate way.

Q59 Mr Touhig: One final point as I am running out of time, more than 40% of people with dementia in care homes are prescribed neuroleptic drugs such as haloperidol and risperidone, which actually worsen their condition. Why do you tolerate this?

Professor Banerjee: It is very clear that people with dementia in care homes can have quite severe and difficult behaviour at times.

Q60 Mr Touhig: They are being sedated, aren't they?

Professor Banerjee: When managing people with dementia, drugs are part of the management. They should be only part of the management. The

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guidelines that we have very clearly state that it is very important that individuals should try psychological and social methods of managing behavioural problems before resorting to medication. I have concerns about the findings you are talking about. There needs to be better coherent input from mental health services into care homes wherever they are, so that we can ensure that those people with dementia who have behavioural problems, in those care homes, receive these sorts of medications only when they really need to. I think there is every possibility that much of this medication use could be decreased by effective liaison with community mental health services for older people going into care homes. The third part of our strategy is all about delivering good quality care, and that has to include care homes and the right management of behavioural problems.

Mr Touhig: That is a very helpful answer but I still do not know why you tolerate what happens in care homes.

Q61 Dr Pugh: In terms of the population of people with dementia, they are going to be known to a number of different agencies, are not they? They are possibly going to be known to their GP, the mental health trust, the acute trust and social services. Are there any sort of general stats or profiling that you have done, that show exactly how many agencies a person may be known to, once they show signs of dementia, or how many agencies they are in contact with?

If I can follow that through: if they are in touch with multiple agencies—because they may be in the local hospital from time to time, they may also connect with the mental health trust and they may also have contacts with social services—is there a concern about there not being somebody who is primarily responsible, and if there is, should that primary person responsible for their care and health be their GP, or someone else?

Professor Banerjee: People with dementia have all the problems that older people have, so they will be in touch with multiple services, just as older people are. Everybody has a GP. People have episodes of acute illness; they will need to go into hospitals; they have accidents. But they also have the problems that come with dementia; and the inevitable progressive decline of dementia, which means that individuals lose functional ability and need support, means that they are much higher users of social care—both community-based social care and social care in care homes. What this means is that there is this complex web, and, essentially, the more complex the case of dementia, either because of severity or because of comorbidities—either physical problems that they have, or psychological problems—the more individuals will be involved.

The process of care management for dementia—of helping the carers to juggle that complex web of care—is a really complicated task, and many carers find being presented with that very difficult. What they need is help to do that. The GP is the default setting for managing these sorts of care. Obviously, it is wider than the GP; there is a primary care team that can help with that. I think, in dementia—and this is

one of the things that comes out of the National Audit Office Report—that in some cases it may be that a more specialist approach to case management and care management might be more effective in the longer term.

The one thing that clearly comes out from talking with carers and people with dementia is the desire to have a single point of contact to help with care. One of the challenges that we will face in formulating the strategy is how to ensure that there is such an individual who can go from the time someone is diagnosed—which may be quite early, when they are in touch with no services, or only very simple services—right through their 12 or 14-year career with dementia. So I think there is a case for those specialist services that are engaged at the beginning in making the diagnosis, continuing to have a role as the dementia progresses; but that clearly has to be one that works very closely with the whole primary care team, in order to be able to deliver care, because the physical needs of the individual need to be met, as well as their mental health needs and dementia needs.

David Nicholson: There are different models that work in relation to this, if you look across the country. Some are very well rooted in primary care and some are rooted in secondary care, but I think Sube is absolutely right: wherever you go, what carers say is that they want one point of contact. People will say in the service that one of the issues about dementia and our progress with it is that nobody owns the issue in the system. So it is vital that we get this right.

Q62 Dr Pugh: That person need not be the GP. Could it be for example someone attached to the GP's surgery?

David Nicholson: I have seen it operate where it is a community psychiatric nurse; I have seen it operate where it is a health visitor; I have seen it operate where it is a GP; and we have seen it operate where there is a multi-disciplinary team from a secondary care perspective. It can work in all those areas, and Sube and his team are going to look at these, and see which is the most effective for the patients, but also what is most effective for the carers, and come up with a set of recommendations in his strategy.

Q63 Dr Pugh: May I go to the issue of diagnosis which has been dealt with by a couple of my colleagues? GPs are less confident, people are severely undiagnosed in care homes and when they are admitted to acute hospitals mental health problems often go unnoticed. Is there not a limited motivation to come up with a diagnosis, because if the diagnosis is arrived at there is little in the way of efficacious treatment? Is one of the reasons why GPs are slower to make the diagnosis because even if they do so they have little to offer?

David Nicholson: I can only offer this as a general point. I went into this issue with a similar question: what incentives are there in the system to identify these people because you would have to provide lots of services for them if you did? In actual fact that is not the case. Higher levels of identification do not necessarily mean that more services are required, but rather people require relatively small amounts of

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service when they need it. I do not believe that the service is operating in that regard. Historically, if you look across the country, investment is more likely where a small band of enthusiasts have worked really hard and fought for it.

Q64 Dr Pugh: If you get an earlier diagnosis, will the effect simply be that the case is better managed and the person's needs will be better seen to, or will it genuinely be the case, and is there empirical data to support this, that the onset and development of dementia can be retarded or slowed down?

Professor Banerjee: No, we have no treatments at the moment that can either arrest or reverse the dementia process or even slow it down. But to focus on the need to do that as the only thing that might be positive for people with dementia is to miss a whole world of positive interventions. You talked about just meeting the people's needs better. There is no "just" there. That is a gigantic thing to do.

Dr Pugh: I am sorry. That was poor phrasing.

Professor Banerjee: There is a widespread misconception that there is no value or there is only little value in the social and psychological elements of intervention that can be deployed. It is simply not true. One of the things that is really good about the NAO Report is that it makes that clear. This is one of the public misconceptions that we need to nail in the strategy because there are good things that can be done. People need to understand that there is value in making the diagnosis so that individuals can avail themselves of those positive interventions.

David Nicholson: That is absolutely true. Speaking more recently to people who have used the memory clinic services that Sube operates, all patients said that it improved their confidence. That is a massive thing for people generally and for that group especially.

On the wider issue about the system, there are two points. There are talks in the NAO about a business case for investment in dementia. One of the things that the working group is working on is a business case which sets out investment early and the benefits to society, the public sector as a whole and the NHS, of making that investment early. There is some useful work showing that it is beneficial, but some years down the line. A second piece of work has already started which is reflected in the Lincolnshire work. It sets out to the NHS in the short term that there are benefits if you intervene and manage dementia earlier for patients: you get less admissions to acute hospital and less intervention at that level.

Q65 Dr Pugh: Thank you. I have only two minutes left and I want to put two relatively quick but quite different questions. The GP gets QOF (Quality and Outcomes Framework) points for managing the condition a little bit better. Are you convinced that the system of awarding those points, and so the remuneration that comes with it, is effectively assessed and measured? We have all acknowledged that the decline of the patient will carry on as it will in terms of their physical condition. How can one

legitimately encourage those GPs who intervene successfully to ameliorate the general background conditions of the patient and those who do not?

Mark Britnell: The original statement from the Chair was that the analogy was cancer in the 1950s, and the question was whether people will continue to place their heads in the sand because this simply means more cost and more hassle. The first thing to say is that there is obviously an emerging evidence base now, from both the NAO and the "Dementia UK" Reports, which makes it easier for clinicians and other professionals to present a clearer evidence base for investment to local commissioners be they in health or social care. As Mr Nicholson said, we are this year guaranteeing that there will be a specific commitment for PCTs to produce a commissioning framework for dementia in the operating framework for 2008–09.

On GPs, QOF points at the moment stand at only 20 out of 1,000. Clearly, because that is set to double or treble in size over the next 20 or 30 years, as Ara Darzi will announce in the next stage review, we will look at the clinical evidence base for QOF points.

Q66 Dr Pugh: You are convinced that the money is being well spent. My final question is simply that comorbidity associated with mental health often occurs alongside dementia, but is often masked by it. What percentage of mental health patients are known by the NHS to have co-morbidity—in other words, some other psychological malaise apart from dementia? Do we know?

Professor Banerjee: In those people with whom we are in contact, we do know, and we have good epidemiological data as well. Probably about 20% of people with dementia of all sorts have depression at any one time in their illness. That depression can be treated with anti-depressants, and other psychological treatments if it is early in the illness. In terms of psychosis, it is probably more like 6% to 10% of people who have that at some point in their illness.

Q67 Dr Pugh: Is the answer about 30%?

Professor Banerjee: Overall, yes, if we are talking about all co-morbidity including psychosis and anxiety.

Q68 Mr Davidson: May I ask about the pattern of dementia? Is there anything in that that would be helpful to our understanding of this? Is it predominantly urban rather than rural, or north rather than south? Are there any discernible differences?

Professor Banerjee: What is striking about dementia is that it is only really associated with age. If we know the age structure of the population, we know what the relative levels of dementia will be. That is made clear in the "Dementia UK" Report. Dementia occurs in men and women and across the class divide, so it happens to rich and poor people, and it happens in the developed and the developing world.

There are suggestions that higher levels of educational attainment might be slightly protective, but many people with extremely high levels of attainment go on to develop dementia. In

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epidemiological terms, it is important that a proportion of dementia, perhaps between 20% and 30%, has vascular causes. What is good for your cardiovascular health is generally good for your mental health, because there are vascular risk factors for Alzheimer's, which is in turn a risk factor for vascular disease. Apart from the longevity of the population and its cardiovascular health, there is little to determine whether people develop dementia.

Q69 Mr Davidson: May I clarify or query one of those points? You said that there was no correlation with social class, but longevity is associated with social class, so presumably lots of poor people in my area will die before they get Alzheimer's.

Professor Banerjee: You are absolutely right. My point was essentially about what has an independent effect when we create a model that controls for all of the factors. The effect of class seems to be mediated through, for example, smoking behaviour and cardiovascular health, and your life expectancy is lower, so you have less time in the stage of life when you are most likely to develop dementia. You are right, but taken as a whole, if you are poorer, you are more likely to develop dementia if you live to a particular age.

Q70 Mr Davidson: For poor areas such as mine, where more people die earlier, dementia would not be as much of a priority as it would be in prosperous areas, where people tend to live longer.

Professor Banerjee: You are talking about minute differences. The difference in life expectancy between poor and rich areas is between the 70s and 80s.

Q71 Mr Davidson: No, it is not. Life expectancy in my constituency is lower than the expected age to which the pension age will rise by the end of the decade.

Professor Banerjee: The exponential increase in dementia happens around age 60 to 65, so it is the years lived afterwards that count.

Q72 Mr Davidson: May I ask about the extent to which dementia can be cured, particularly by contact with lawyers? I am thinking in particular of Ernest Saunders and General Pinochet. There was a lot of discussion at the time about those miracle cures. Was it misdiagnosis in the first place and a sharp lawyer, or was there anything medical about those cases that might be of interest to us?

Professor Banerjee: I was not personally involved in those cases, but I can tell you—

Mr Davidson: I was not suggesting that you were General Pinochet's surgeon.

Professor Banerjee: No, but what I can tell you is that dementia does not get better. In some forms of dementia, month on month, one might get a little bit better and then a little bit worse, but the definition of dementia is a progressive decline. Sometimes it is a bit stepwise, sometimes a bit wiggly and sometimes a straight line, but dementia is decline, and there is nothing that makes it go away.

Q73 Mr Davidson: Paragraphs 4.1 and 4.2 refer to whole-system working, and the point is that whole-system working should be apparent in this area. Paragraph 4.2 has a quote from somebody in a focus group who said: "I receive different phone calls from different professionals about the same issues, and no one knows anything about the others. It's just a continual round of questions." That seems to sum up so much of the health service. Is this area any worse or better, in terms of people not talking to each other, than others? In health and social care services, it has always struck me how much people operate in silos and are precious about their own element of the situation. They do not want to communicate, or are unable to. Is it any worse here than anywhere else?

David Nicholson: While that is a quote, I could take you to places where the exact opposite happens and people are very satisfied with the way that services are integrated. But it is true that it is a common criticism of health services, particularly for long-term conditions, where a whole series of agencies are involved.

I do not know whether it is any worse for dementia. My guess, having studied it more recently, is that it probably is, largely because there are interfaces between primary and secondary care; social care, the voluntary sector and health care; and mental health and generic services. Where all those link is where I think you get the problem. That is why, to me, it makes an overwhelming case that a care management approach—where an individual or a small group of people co-ordinate the care for patients—is absolutely central to getting the strategy operating.

Q74 Mr Davidson: I understand the point that it is a particularly complex area with a number of participants, but there must be many areas in the health service where the same applies. Is it worse here because the matter has been less of a priority for the centre to focus on? Have people therefore been able to get away with bad professional practice that they did not get away with in areas of the service that get a greater degree of attention and priority?

David Nicholson: There is no doubt that there has certainly been less attention to making it happen. As for whether it has turned out in practice to be worse, I would guess that it has, but I do not know directly. Do you have anything to say on that, Sube?

Professor Banerjee: It is more complicated in dementia cases. Co-ordinating care is complicated in dementia, but it is not impossible. One thing that one does have in cases of dementia is time, if it is an individual's job to help bring together the elements of care, and if people have the most important element of information, which is that the individual has dementia. One cannot expect a person with dementia to respond in a way that a person with dementia would not respond—you send an invitation saying: "Come to this place at this time," and if the person with dementia is living alone, there is no chance, or very little chance, that they will do so. You need the information that somebody has dementia and to factor that into how the systems work, and then you can get good quality care out of the system.

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Q75 Mr Davidson: You made the point that this was not necessarily universally true, and that there are examples of good practice and so on. Is there a mechanism by which good practice is disseminated, or does it just grow and blossom on its own?

David Nicholson: There are all sorts of levers around for good practice. The most obvious one for mental health is CSIP—I hope that someone will remind me what it stands for.

David Behan: Care services improvement partnership.

David Nicholson: Yes, that organisation is responsible for doing that very thing in relation to mental health services. The issue is that it has been predominantly focused on 16 to 65-year-olds, rather than over-65s, with the activities that it has got. This strategy gives us an enormous opportunity to take that forward for dementia.

Q76 Mr Davidson: The final area that I want to touch on—this relates to the service being a Cinderella service—is the section dealing with the access to and quality of domiciliary care, which could be improved. To what extent is the fairly damning indictment of staffing provision in the service, in paragraph 3.15, an indication that it really is seen as a Cinderella, low-priority service that nobody really pays much attention to? Does it not indicate that staff in this section are considered almost as the lowest of the low?

David Behan: Certainly, 70% of the social care work force is without qualification, and many of them are without training. In my earlier comments, I addressed the importance of equipping the work force with skills. The sector skills council for the social care sector is Skills for Care—

Q77 Mr Davidson: How did we get into the situation in which 70% are on the lowest wages and have the least training? Presumably that did not happen out of the blue one day.

David Behan: The evidence is that they are not now on the lowest wages. A lot of the staff will be paid above the minimum wage.

Q78 Mr Davidson: I was asking how we got into that position. I understand your point that it may be getting better, but it was not right then. I am trying to clarify why it was in such a mess when the Report was written.

David Behan: The history of the home help service, to go right back, was that it started as a nursing service for Jewish women during the first world war. As it went on through the '40s, '50s and '60s, it delivered practical help to people in their homes, such as lighting fires in coal-mining areas for coal miners who could not light fires. In the '70s, and particularly in the '80s and going into the '90s, that kind of provision was not required.

Figures show that the home care services focus increasingly on maintaining people in their homes, so we provide support to a smaller number of households, but those households are getting an increased number of hours. The task is no longer giving practical assistance such as lighting fires, but assisting with personal care—bathing, toileting and

feeding, *et cetera*. So, we in the social care sector have been faced with equipping those social care staff, or domiciliary care workers, with the skills to provide that intimate and personal care. So you will find, for instance, training courses through all employers on things like lifting and handling, appropriate bathing and appropriate control. The challenge around the dementia figures is to begin to ensure that those staff are able to recognise and acknowledge dementia and provide that service.

Q79 Mr Davidson: I understand all that, but I wanted to clarify whether you thought that it was simply because the work was seen as women's work that it was given a low value and was low paid, or whether other issues were at play that might have implications for other parts of the public service. Clearly, I am not going to get much out of that.

Will you clarify how it is that we are being told in the second section that: "the high number of home care staff without English as their first language" have communication problems, notwithstanding that communication skills are: "a requirement of the Common Induction Standards"? If the common induction standards are adequate and people are meeting them, why are there still communication difficulties? Are people cheating the tests? Are the test standards too low?

Nothing could be more distressing for an elderly person than to be unable to communicate with the person who is attempting to care for them. I can understand that not having English as a first language might not always be a difficulty—for example, it would be ideal to have Gaelic speakers with someone from the West Highlands whose first language is Gaelic, or to have Punjabi speakers, as appropriate. But it seems to be adding distress to distress if the elderly person's first language is English but the people who are involved with them cannot speak English, or cannot speak it adequately. Why is that allowed to happen?

David Behan: I completely agree with you. The Report, the Department and the Regulator have been very clear that it is not acceptable. If someone cannot communicate in the person's first language, they will not be able to help.

Q80 Mr Davidson: If it is not acceptable, why is it accepted? You are saying that it is not acceptable, so why does it happen?

David Behan: The induction standard has probably not been applied properly by employers.

Q81 Mr Davidson: So who is responsible for policing that?

David Behan: The Regulator is responsible for policing that.

Q82 Mr Davidson: Why has the Regulator not policed it, then?

David Behan: If those issues are found by inspectors when they visit, the role of the regulator is to raise them with the owners and managers of the establishments.

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Q83 Mr Davidson: That clearly has not worked. Otherwise, the National Audit Office would not have written this. If the system were self-correcting in the way that you indicate, circumstances where somebody did not have the language would be picked up by an inspector and corrective action would be taken. No problem—we would move on. But the way the Report was written leads me to believe that the problem is more systemic than that.

David Behan: The key strategic challenge is how we can begin to recruit people to work in social care. How can we get young people who are leaving school to come into social care, and then allow them to develop a career? We need to build that up.

The Minister launched a five-point plan to raise the status of social care so that we can actually “grow our own”, as opposed to what some people in the care sector have been doing over the past four or five years, which is recruiting from abroad. A key issue is whether we can develop social care as a career that people see as attractive, so that they can see themselves coming in, perhaps straight from school, and developing a career over the years. The strategic move that we need to make is about creating a career in care services that people see as attractive. Then we will be able to get out of some of the short-termism that has created pressure for people to recruit from abroad.

Q84 Mr Bacon: Professor Banerjee, you started your discussion of the working group by referring to three key themes that you have already found during your first four meetings. You said that the first was early identification, but you did not have a chance to finish with the others. What are the themes, apart from early identification?

Professor Banerjee: To put them in order, the first is about public attitudes and understanding, but it also covers professional attitudes and understanding. We have already rehearsed some of the issues. It is terrifically important to help in ridding the public, and some professionals as well, of some of the misconceptions that exist about the lack of treatability of dementia, for example. That is the first: improving public attitudes and understanding.

The second theme is about enabling early identification and early treatment for people with dementia. Again, we have spoken about some of the reasons why that might be of help. The sooner individuals get a diagnosis, the more likely they are to be able to use it to make plans about their future and to receive the care and support that will help them to live the best life that they possibly can with their dementia.

The third thing is improving the quality of care for people once they are diagnosed. The work covers diagnosis to end-of-life care. It necessarily includes care for people in the community, which involves case management, which we spoke about; care for people in acute hospitals, which involves good quality liaison services and good working in general hospitals; care for people in care homes, which we spoke about as well, and improving the quality of input that individuals in care homes receive; and, finally, end-of-life care. Things that work for people

without dementia do not work for people with dementia, especially at the end of their life, so we need to have specific provision for those individuals to ensure that their end of life is managed as well as possible.

Q85 Mr Bacon: That is very clear. Your working group has one year. When did it start? The Report was published on 4 July. Was your working group set up the following day, so to speak, or did it take a while?

Professor Banerjee: It took a little while, but as I said, we have met on four occasions. At the moment, our plan is to deliver the report a year after the announcement.

Q86 Mr Bacon: So by next July.

Professor Banerjee: A bit earlier than that, actually. It is more likely that we will need to get a final draft of our report sorted out by May so that we can consult on it and then publish a report.

Q87 Mr Bacon: And then what?

Professor Banerjee: The important thing about the strategy—the thing that we have been asked to do—is not just to develop a national dementia strategy, but to generate a strategy and implementation plan, which will look at levers available and the ways in which provision is funded in the NHS and social care. Over the next year, we will focus on that very closely.

Q88 Mr Bacon: Are you chairing this working group?

Professor Banerjee: I am chairing it with Jenny Owen, who is the social service director for Essex, and who brings a social care perspective to it.

Q89 Mr Bacon: Who is responsible for improving dementia care in England?

David Nicholson: I am responsible overall. I am responsible for setting the direction and vision and for identifying levers within the system to make it happen.

Q90 Mr Bacon: If I were to ask you who was responsible for improving cancer care in England, you would say the national cancer director.

David Nicholson: No, I would say me.

Q91 Mr Bacon: Oh, would you?

David Nicholson: He helps, supports and advises, but he does not run the cancer service or design the system and the levers that are necessary to make things happen.

Q92 Mr Bacon: Is it still Mike Richards?

David Nicholson: Yes, it is Mike Richards.

Mr Bacon: We had him here as a witness.

David Nicholson: He has made a fantastic impact on cancer services generally.

Q93 Mr Bacon: Yes, but do you have, or are you going to have a national dementia care services director, in the same way that he is national cancer director?

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David Nicholson: That is one of the matters that the strategy will consider.

Q94 Mr Bacon: So, do you think that Professor Banerjee will end up recommending himself for the job? Or is that what you would like him to do?

David Nicholson: I think that you should make your own judgment. We have found that having a national clinical director is an enormously powerful way in which to focus.

Q95 Mr Bacon: But you do not have one at the moment?

David Nicholson: Not at the moment, no.

Q96 Mr Bacon: But it is a thought?

David Nicholson: It is a possibility.

Q97 Mr Bacon: And if you do, how far off is it likely to be?

David Nicholson: We will think about the emerging findings at the end of November and the beginning of December, as part of the operating framework. So theoretically, we could consider it then.

Q98 Mr Bacon: And you do not necessarily have to wait for the publication of the green and white versions of his report before going ahead?

David Nicholson: No, and if we are not careful we will lose a whole year if we do not get something moving forward.

Q99 Mr Bacon: That is what I was concerned about. Okay, that is interesting.

I would like to ask about the care for people—who have got dementia. On page 30 of the Report, there are some shocking quotes about the service from focus groups that the National Audit Office held, such as: “Yes, you’ve got dementia. Take these tablets. There is the door” and: “When your husband is diagnosed . . . you suddenly realise that you’ve lost your future, you need support to come to terms with this.” Those are just illustrative examples. It sounds as though there is a huge gap between what ought to happen when people are diagnosed with dementia—not only for those diagnosed, but for those around them—and what actually happens. Is that fair?

Professor Banerjee: Diagnosis, and the breaking of that diagnosis to the person with dementia and their family, is a gigantically important episode in the life of that person and the family carer. It is not to be taken lightly. I think that the focus-group points that you brought out, and other experiences that people have had, suggest that in some cases it is treated lightly. That is perhaps through a lack of understanding on the part of individuals at that point. I know that diagnoses can be made well and that information can be given at any time to people in a sensitive and coherent way that is understandable to people with dementia. That information is also available to family carers.

That moment can be used to give information and instil hope for the life that people with dementia have afterwards. What we have here are examples of it

being done badly, but we also have the NICE guidelines, which are very helpful and set out clearly what good information and support would be. You cannot abandon the individual after making the diagnosis. There is a need to follow it up. There are good quality services all over the country that are doing that with people with dementia. The problem is that not everybody is getting that. There is a lot of good practice, but also poor practice. We need to ensure that good practice happens invariably.

Q100 Mr Bacon: I would like to move on to neuroleptic drugs, which were mentioned before. Do you agree with Professor Clive Ballard, the Alzheimer’s Society’s Director of Research, when he says that in most cases the prescription of these drugs is inappropriate?

Professor Banerjee: Sorry, is that in the Report?

Q101 Mr Bacon: No, it is not in the Report. I am reading an article in which Professor Clive Ballard is quoted as saying that, in most cases, although not necessarily all, the prescription of neuroleptic drugs is inappropriate.

Professor Banerjee: That is absolutely the point. Yes, I would agree with Clive. The prescription of neuroleptic drugs for people with psychosis maybe entirely appropriate. People with dementia develop psychosis, and it is important that they have their psychosis treated, because psychoses can be terribly distressing for individuals—that is a recognised comorbidity in dementia. The problem is with the management of behavioural disturbance, such as agitation in dementia, which is not caused by psychosis. I would agree with Clive entirely that it is important to work out what the antecedent of the behavioural disorder is. If it is depression, we can treat the depression; if it is psychosis, we can treat the psychosis with anti-psychotic medications; if it is caused by the person being in pain, we can treat the pain; if it is caused by a urinary tract infection, we can treat that, and so on. If the individual continues to suffer severe agitation, which is causing them distress in their dementia, that is the point at which it is important to try psychological and social ways of managing them—to see whether there are different ways of feeding or being that can help them. But there is a group of people who, after all that, remain intensely distressed by the problems that they have and who may be a risk to themselves—

Q102 Mr Bacon: And for whom neuroleptic drugs are then appropriate?

Professor Banerjee: And for whom neuroleptic drugs would be appropriate, and I think that Professor Ballard would agree with that.

Q103 Mr Bacon: I am sure he would. Do you agree that there is a group of people for whom neuroleptic drugs are prescribed far too soon, effectively, in Mr Touhig’s words, as a way of sedating those who might be a bit difficult? Indeed, that might even be done covertly through food. Is it correct that that happens?

Professor Banerjee: The covert administration of medication?

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Q104 Mr Bacon: Is that something you have heard about?

Professor Banerjee: There is a literature on the covert administration of drugs, absolutely. It happens in NHS facilities, as well as in other places. The important issue is that the places where it is most likely to happen are in the community, with individuals living in their own homes, or in care homes. Clive Ballard's work focuses largely on care homes, and there are particular issues in care homes. The solution to this—there needs to be a solution, because it is an important problem in the health system, and we are becoming increasingly aware of it and of the fact that there are non-pharmacological answers to it—is for specialist mental health services to have time and capacity, because these drugs are generally not initiated by specialist mental health services, unless you have met all the criteria we have gone through. We need to have specialist mental health services that are able to go into care homes and advise on non-pharmacological treatments and, when and if those treatments are instigated, to make sure that they are initiated at a low dose, reviewed regularly and stopped as soon as possible. That needs to be done, and it is specialist mental health care liaison going into care homes that can help us to tackle this. By themselves, GPs find such behaviours and issues very difficult to deal with, so there may be recourse to such drugs when other things might be helpful. Having good quality liaison going into homes would enable those other treatment options to be tried before drugs are.

Q105 Mr Bacon: Thank you for that. I have just two more questions. Is it correct that patients with dementia are three times more likely to have a stroke if they are medicated and twice as likely to have an early death?

Professor Banerjee: People with dementia are more likely than the general population to have strokes anyway—

Q106 Mr Bacon: But if they are medicated and on drugs?

Professor Banerjee: Sorry. There is a set of warnings about neuroleptic medication, which came out through analyses of data sets. It is by no means certain that the increased risk is associated with any particular sort of neuroleptic drugs, although there is an inherent risk in taking medications of all sorts. These drugs should be used only when their benefits outweigh the risks of their use. The people prescribing such drugs need to be aware of those benefits and risks. Speaking as a specialist mental health practitioner, I can say that those involved in old-age psychiatry and the services that we provide are aware of those risks.

Q107 Mr Bacon: Finally, Mr Nicholson, in the helpful DVD that the NAO sent us, which described some of the people who had been carers and some of the people who have been suffering from dementia, one of the points that was made strongly was that respite breaks are absolutely fundamental for people who are caring at home. Such caring is, of

course, a huge cost to people's lives individually, but it is not a cost to the taxpayer. It is a huge cost that you are not having to pay for, because all this work is being done at home by families.

Never mind the fact that there is also a big care issue here for those people; in the most accounting-like ways of looking at this issue, if one looks at it purely with financial spectacles, surely it would be very cost-effective to have more respite available, because there are all those people out there who are caring who you do not have to pay. What are you going to do to increase the amount of respite care?

David Nicholson: One of the things that we have to do is to persuade commissioners, primary care trusts and local authorities to invest in this area, to enable such respite care to happen. One of the important pieces of work is this business case, which sets out exactly the situation that you have described; how much you save by investing upstream. We will certainly be driving that message through. Also, our experience shows us that in different places different types of respite care are required. Some carers will tell you that they do not want their relative to go away to a particular unit for a period; they would rather have some help in the home. So we do not have to be dogmatic about this issue, but we would certainly see PCTs and social care organisations responding to this need for more respite care as part of this strategy.

Q108 Mr Williams: Following on from what Mr Bacon has just said, is the suggestion just apocryphal that some nursing homes use these drugs more as a management tool in some cases than to meet a medical need, or is that just a popular misconception?

Professor Banerjee: A management tool? Do you mean a tool for the management of behaviour?

Q109 Mr Williams: Yes, to tranquillise patients and to make them convenient and malleable.

Professor Banerjee: That is absolutely the concern that people have.

Q110 Mr Williams: It is a concern that they have, but is it a concern that you have? Have you seen instances of such treatment?

Professor Banerjee: I find it very difficult to understand the motivations of individuals in particular homes at particular times. If you look at the evidence as a whole—again, Clive Ballard's work is very clear on this—you will see that there are many more of these medications being prescribed than one would expect, given the level of disturbance and given the level of psychosis.

Q111 Mr Williams: Why do you think that is?

Professor Banerjee: I think that it is to control behavioural disturbances.

Q112 Mr Williams: That is right. So, the answer to my question was just a simple yes, was it not? They are used as a management tool and people are just robbed of their dignity and their human rights, propped in a chair, tranquilised and left where they are least inconvenient. Is that a completely false portrayal of what happens in many cases?

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Professor Banerjee: I know some excellent care homes where that really is not the case. I also have worked with people who have benefited tremendously from treatment. I just think that treatment needs to be given only to those people who really need it.

Q113 Mr Williams: That cannot be so, because you said that you cannot understand the amount of these medicines that are being dispensed, because the amount seems to be more than would be needed. You cannot have it both ways.

David Behan: There is an important distinction to make between the prescription of medication, which is done outside the care home, and the management of that medication, which is done within the care home. Certainly, there are no staff who work in or are responsible for care homes where they prescribe the medication.

To go back to the regulator, the CSCI (Commission for Social Care Inspectorate), what we are aware of is that compliance with medicines management as a standard is an issue that needs constant attention. Approximately six out of 10 care homes are meeting the medicines management standard; in other words, four out of 10 are not. So that is a cause for concern—whether the management is of the drugs that you are referring to or of other forms of medication. But I think that it is quite important to distinguish between where the prescription takes place and where the management and administration of that medication takes place.

Q114 Mr Williams: I come to the question that I was originally going to ask until I listened to Mr Bacon. You referred to the fact that there is a director who is responsible, or who is the prime mover, in relation to cancer. We have a high priority for heart problems and for strokes, but dementia costs more than all three put together. Yet, according to the briefing that we were given for this meeting in addition to the Report, the NAO tells us, “Dementia is not specifically considered in any of the Department’s key policy initiatives”. That is pretty damning, isn’t it? Why not?

David Nicholson: I think that it reflects the relative priority of improving dementia services over the past—

Q115 Mr Williams: It reflects the Department’s priority. “Dementia is not specifically considered in any of the Department’s key policy initiatives”, so when you say that it is not considered a priority, that means that you do not consider it a priority.

David Nicholson: I did not consider it a priority until August, when our Minister—

Q116 Mr Williams: When you found that you were coming to this Committee to answer to it.

David Nicholson: Sorry, it was not me who identified it as a priority, it was the Government. It was the Minister.

Q117 Mr Williams: It was a coincidence that it was in August, was it? When did you first get a copy of the Report to read?

David Nicholson: When it came out. No, I saw a draft, probably. The Report makes a compelling case, and we are responding to that and saying, “Yes, we need to do something about this particular compelling case.”

Mr Williams: Well, goody, goody!

David Nicholson: But there were compelling cases for cancer, coronary heart disease, waiting times—

Q118 Mr Williams: Yes, and you did something about them.

David Nicholson: Yes, we did, because the whole point of having priorities—

Q119 Mr Williams: This is bigger than the lot of them put together in the use of your resources, and you are still only thinking about doing something about it.

David Nicholson: Just because you spend a lot of money on it does not necessarily mean that it is a priority. There is a whole series of issues: what is the clinical evidence? What can improve the services? What is the state of the services at the time? What are the priorities of the Government? That is what we have been reflecting on. Coronary heart disease, cancer and waiting times were identified by the Government as priorities and were reflected in the general population.

Q120 Mr Williams: Your reply was full of questions and no answers. It says here in our briefing, “There is a lack of clarity over who is responsible/accountable for improving dementia care”. At the moment, we get the impression that no one is—in a meaningful, operative sense. If they are, they are just becoming aware of the need to be.

David Nicholson: We have identified dementia services as a priority.

Q121 Mr Williams: When?

David Nicholson: The Minister announced it in August.

Q122 Mr Williams: In August?

David Nicholson: Yes.

Q123 Mr Williams: By gosh. Then what happened—for example, in 2002? The single assessment process was to be introduced by April 2002. Five years later, it is still not in use. Only 46% of community health trusts are using it. There is a big difference between deciding that something needs to be done and actually getting around to doing it. Nothing has been done, or virtually nothing, in that case.

David Nicholson: David can say something about the single assessment process, but I have said that dementia services were not a priority. They are now.

Q124 Mr Williams: From August?

David Nicholson: The Minister identified it as a priority in August, absolutely.

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Q125 Mr Williams: Sir John, when did you provide the Department with a copy of the Report for it to clear the facts with you? When did it first see what the Report was going to look like?

Karen Taylor: About three months before publication.

Q126 Mr Williams: That would have been about July, would it not?

Sir John Bourn: It was published on 4 July, so three weeks before that.¹

Q127 Mr Williams: Just before August—in my calendar, anyhow.

David Nicholson: I am sorry, but I am being a bit dense here. Just spell out what you are trying to tell me.

Q128 Mr Williams: I am suggesting to you that it became a priority just before you came to this Committee and that, if you are not called to this Committee again soon afterwards, it will cease to be a priority.

David Nicholson: That is completely not the case.

Q129 Mr Williams: Well, what happened to the 2002 scheme?

David Nicholson: David can say something about the single assessment process, but what we are saying here is that the important thing about improving services for people with dementia is that you have to have a systematic approach to doing it across the whole range of services. It is no good doing one bit in isolation from the rest of it.

When we have looked at our clinical priorities as a whole across the NHS, we have seen that we are clearly making significant progress in cancer, coronary heart disease, waiting times, and, after the publication of the stroke strategy, stroke services. Dementia now has its place in the sun and we have the opportunity to put the focused attention of the system on improving services. That seems to me a good thing, not a bad thing.

Q130 Mr Williams: What machinery does it have, again, for its place in the sun?

David Nicholson: I am sure that Mark can tell you about that, but it is about saying that it is a priority, and about me and Ministers taking every opportunity to say that dementia services—

Q131 Mr Williams: I asked what machinery it has.

David Nicholson: I am just saying that the second part of that machinery is the allocation of resources. We have just had the Comprehensive Spending Review, and we are now working through the issue of resource allocation to the NHS. The third issue is the operating framework, which is the planning document that we set out for the NHS in December, and from which the NHS must implement the plans

that we approved in March. It will have to set out how it will make dementia a priority in real terms in communities.

You asked me about the machinery.

Q132 Mr Williams: That is what I am coming back to. Who is responsible for that machinery, and accountable for it?

David Nicholson: I have overall responsibility.

Q133 Mr Williams: But who has responsibility for the whole lot?

David Nicholson: Mark in the Department is responsible for delivering that element of the machinery.

Mark Britnell: May I just take a second of your time to explain that the operating framework basically signals a handful of priorities? An analogy has been made with cancer and stroke, and what Mr Nicholson and I are saying is that the operating framework is signalling the production of specific guidance next year to those who invest locally? They are called primary care trusts. Because of the machinery through the joint strategic needs assessment with local authorities and social care through local area agreements, the simple answer to your question is that Mr Nicholson has overall responsibility, but those chief executives and boards that run primary care trusts obviously have the local responsibility to invest in local health needs. What we are saying in the operating framework is that it is one of a handful of things that we are directing PCTs to address next year. It is assuming greater responsibility to complement announcements that Ivan Lewis and others have made on a national strategy.

In response to Mr Bacon's question about moving quickly, we know some things to be true already. We know that the evidence base from Dementia UK and the National Audit Office is making it much more compelling, straightforward and clear for commissioners—local PCTs—to invest in early diagnosis and, potentially, memory services. The operating framework will draw commissioners' attention to early investment, which will improve life and ultimately, over a period, save money for the public exchequer and for health and social care. That is why we are confident this time that our thinking is joined up.

Q134 Mr Williams: With your permission, Chairman, may I ask Sir John if one year from now, he will provide a snapshot of what progress has been made, what machinery is in existence, who is accountable, and what progress has been made, and will he give us an interim report so that we can call people back next autumn or early winter?

Sir John Bourn: Yes, I will do that.

Mr Williams: Thank you.

Chairman: I think Mrs Browning has a couple of supplementaries.

Q135 Angela Browning: Yes, thank you. I have very little time, so I hope that we shall both be short.

¹ *Correction by witness:* The Comptroller and Auditor General's Report, which was published on 4 July, was sent to the Department for working level clearance on 9 May and was submitted formally by the C&AG for Accounting Officer clearance on 19 June.

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It would be wrong of me not to say, particularly while you are here, Mr Nicholson, that Mr Touhig said in his presentation to you at the beginning that he felt that in the NHS there is an overall attitude of prejudice to older people in terms of them receiving the services and support that they need. The Report refers to acute hospital admissions. One example is the financial benefits in terms of people who are admitted for fractured neck of femur, and the difference between those who have no dementia and those who do. There is a clear financial benefit for improving the throughput of that group of people.

May I suggest, in the light of what Mr Touhig said to you, that one of the big problems with elderly people, whether or not they have dementia, is the fact that when they present with fractured neck of femur, they are constantly shuffled down the operating list and their chances of recovery are reduced dramatically by the way in which they are treated compared with other trauma patients?

David Nicholson: We have a lot to do, but there has been significant progress over the past three or four years in the way in which patients generally are treated for fractured neck of femur, and that reflects the fact that the vast majority of them are older people. I do not accept that there is evidence to suggest that older people are shuffled down the trauma waiting list.

Angela Browning: They are.

David Nicholson: If you have evidence of that, I would be happy—

Angela Browning: I have raised the matter on the Floor of the House, and I continue to read about it.

David Nicholson: I would be happy to deal with that.

Q136 Angela Browning: You will appreciate that for someone with dementia to be subject to nil by mouth for two, three or sometimes four days in a row before they get to theatre when they have a fractured hip does not improve their chances of recovery.

David Nicholson: I agree.

Q137 Angela Browning: May I move on quickly to Professor Banerjee? So much of the NAO Report and so much of what we have heard now seems to be predicated on a massive increase in the resources to GPs, for training and other things, and to community mental health teams. The Report shows that at the moment, the average community mental health team deals with 275 people with dementia when, on average, the number should be 1,000. Where are the

resources going to come from? I cannot help but feel whatever your committee concludes, the resource implications—if they are really going to deliver—are going to be massive.

Professor Banerjee: That is a very good question. It may have been why people have been reluctant to consider some of these issues. I do not agree that there needs to be the massive, gigantic expansion in services that you suggest in order to deliver, for example, early identification and treatment of dementia. Models have been developed that show that you can have a relatively high throughput of cases, that the quality of that care can be assured and that the outcomes of those services are good. They are mentioned in the NAO Report.

One reason I think this is possible is because relatively modest investments can be made that are complementary to our current services and which will work with them but deliver much more early identification and intervention and continued support. It is undoubtedly true that if you put in an early identification team, there will be knock-on effects for the community mental health teams. Part of the modelling that has been discussed is modelling the relative effects of those things. I have every confidence that a relatively modest investment in a community-based memory service, along with some enhancement of community mental health teams to deal with the increased work that comes from that further down the line, and of adult social care when that comes down the line, can form a package that makes a step change in the way that we provide dementia care in the community—at a cost that is not unaffordable by the NHS.

Q138 Chairman: Thank you very much, gentlemen. That concludes our inquiry. It has been a very important day in dealing with this issue. Don Touhig put his finger on it when he showed how the UK compares so poorly with other EU countries. On the percentage of people with Alzheimer's disease treated with anti-dementia drugs, we are behind Italy, Germany, Switzerland, Denmark, Belgium, Austria, Portugal, Spain, Ireland, Sweden and France. So, when you do come back in a year's time—I think this is a very good idea—we really want to see more progress.

David Nicholson: We are absolutely committed to improving dementia services, and I hope we will see that in the near future.

Chairman: Well, we will leave it on that note, then. Thank you very much, Mr Nicholson.

Memorandum submitted by the Alzheimer's Society

Please find enclosed a list of questions that we believe need to be answered at the PAC hearing on Monday. We hope that it will be possible to put some of these to the Department of Health officials who will be attending. The questions are drafted in two groups titled "Looking back" and "Looking forward". Within those groups the questions are in priority order from the Alzheimer's Society perspective.

The Alzheimer's Society fully supports the findings of the National Audit Office Report. In particular we support the view of the NAO that dementia services have failed up to now to provide the quality of care which people with dementia and their carers need and deserve.

Dementia is estimated to cost the UK over £17 billion a year, yet our health and social care services continue to provide inefficient care, wasting money and failing to deliver a better quality of life to people with dementia and their carers.

The Government has recently announced the development of a National Dementia Strategy and will be working closely with the Alzheimer's Society to achieve what the Department of Health has described as a "transformation plan" for dementia services by the summer of 2008. This is most welcome. But it must deliver solid commitments to change.

KEY QUESTIONS FOR THE PUBLIC ACCOUNTS COMMITTEE HEARING INTO THE NAO REPORT ON DEMENTIA SERVICES

A. *Looking back*

1. The NAO Report states that dementia care is similar to cancer care in the 1950s¹ and the Care Services Minister Ivan Lewis has said that services have failed people with dementia in the past.² How can this have been allowed to happen for so long?

2. Dementia is a large and growing problem.³ Why has dementia not been recognised as a significant health and social care challenge before? Why has there been no national plan as with cancer?

3. The report shows that public funding of dementia research is incredibly low compared to other countries.⁴ Current commitments are to a small number of clinical trials and the Dendron clinical research network which is infrastructure rather than research funding. Why is UK public funding of dementia research funding so poor compared to other countries? Has the Department had discussions about how to improve research funding in the UK for dementia?

4. Community Mental Health Teams are accepted as a good service model.⁵ Why are there not well developed CMHTs everywhere?

5. If early diagnosis is a stated policy priority for dementia why haven't memory clinics or memory assessment services been developed everywhere?

6. How can we expect better support in the community for people in the early stages of dementia as the NAO Report argues needs to happen when local authorities are all being forced to support only people judged to have critical or substantial needs?⁶

7. The NAO Report highlights the significant sums being spent on poor care which is producing poor outcomes. The Lincolnshire case study shows what can be achieved to change care.⁷ Can't this be done everywhere?

B. *Looking forward*

8. How are you going to make sure that this dementia strategy isn't just another piece of guidance that has no impact?

9. We may be a year away from launch of a full national dementia strategy. People with dementia and carers are struggling to cope now. What is the Department looking to do in the short term to improve public and professional awareness about dementia before the national strategy is published late next year?

10. The projections in the NAO Report show that the number of people with dementia in England will increase by over 40% in the next 15 years. This is going to require significant development of services and health and social care funding isn't it? Where will this money come from?

11. How will you make sure that local commissioners factor dementia into their planning?

12. Isn't the fundamental point that the NAO Report makes that dementia is not owned by any single part of the system, partly because it impacts on all parts of the system. As a result, isn't dementia a classic case where, even in an era of no top down targets there needs to be some clear central direction? If so, how far do you think that direction can go?

13. The NAO Report recognises the major burden for families which dementia causes and lack of support that family carers have to carry out their crucial role.⁸ Do you think that the NHS and social care have failed to recognise the interdependency of people with dementia and their carers? What do you propose to do to improve access to planned respite care and peer support networks?

¹ NAO Report, p11, para 33

² Speaking during a visit to a mental health centre for older people in North Kensington, Care Services Minister Ivan Lewis said: "The scale of our ambition must now meet the scale of the challenge as demographic realities mean dementia will impact on an increasing number of families in our society. The current system is failing too many dementia sufferers and their carers."

³ 560,000 people with dementia today in England, projected to increase by over 40% in under 15 years, NAO Report, p7, para 8, from the Alzheimer's Society Dementia UK report

⁴ NAO, pp 67-68

⁵ NAO, p33

⁶ The State of Social Care in England, CSCI, 2007

⁷ NAO, pp 60-66

⁸ NAO, pp 19, 37-38

14. The NAO Report identifies that the financial burden of dementia on families who have to pay large sums towards dementia care is significant.⁹ Do you agree?

Supplementary—will the green paper on the funding of social care next year look at proposals which seek to reduce the disproportionate impact of charging on people with dementia and their families?

15. The NAO Report states that only between a third and a half of people with dementia receive a formal diagnosis. There is currently a commitment in the GP contract to developing a dementia register.¹⁰ How do you think this might be developed further?

16. Nurses often don't have the skills to support people with dementia¹¹ meaning that people get bad and inefficient care. Shouldn't dementia care training be a core part of both the core nurse training curriculum and continuing professional development?

17. One of the major issues identified by the NAO is that people with dementia are rushed out of hospitals into inappropriate care homes.¹² Shouldn't local authorities take more responsibility for stimulating the provision of long-term specialist dementia care?

18. There is a lot of money being spent here. What are you going to do to improve the information available about what is spent on dementia services and what the most effective interventions are?

⁹ NAO, pp16-19

¹⁰ NAO, p32

¹¹ NAO, p10, para 35

¹² pp45-46