



National Audit Office

Improving services and support for people with dementia

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 604 Session 2006-2007 | 4 July 2007

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LONDON: The Stationery Office
£18.00

Ordered by the
House of Commons
to be printed on 2 July 2007



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This report has been prepared under Section 6 of the National Audit Act 1983 for presentation to the House of Commons in accordance with Section 9 of the Act.

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28 June 2007

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SUMMARY

1 Dementia is a term for a range of progressive, terminal organic brain diseases (**Figure 1**). 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 (**Figure 2**). The emotional impact on people with dementia and their families can be enormous, with depression and high levels of stress common.

2 It is a common misconception that dementia is caused simply by old age – it can also affect younger people, though age is the main risk factor. Some 560,000 people in England are estimated to have dementia, with a steeply rising trend over the coming years. Whilst direct costs to the NHS and social care are currently at least £3.3 billion a year, the overall annual economic burden¹ is estimated at £14.3 billion² (**Figure 3 on page 6**).

¹ Economic burden includes informal costs (e.g. carer time) as well as formal costs.

² In February 2007, the Alzheimer's Society published *Dementia UK*¹, research it had commissioned from The Institute of Psychiatry, King's College London and the London School of Economics and Political Science, on the prevalence and costs of dementia, Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society*. All figures taken from Dementia UK for this report relate to England. *Dementia UK* is acknowledged as being the most comprehensive and up to date research available on dementia, derived by experts in the field. Given the expertise involved in producing the research, we have accepted this research as the best available, with agreement from the Department of Health.

Summary text continued

1 Dementia is a term for a range of progressive, terminal organic brain diseases

Types of Dementia

Alzheimer's disease accounts for 62 per cent of dementias in England. It changes the chemistry and structure of the brain, causing brain cells to die.

Vascular dementia is caused by problems with the supply of oxygen to the brain following a stroke or small blood vessel disease. Vascular dementia along with those mixed vascular with Alzheimer's dementias, make up around 30 per cent of the total. Conditions that affect the circulation of blood to the brain, such as hypertension, can contribute to vascular dementia.

Source: National Audit Office analysis

Dementia with Lewy Bodies is caused by protein deposits that develop inside nerve cells in the brain and interrupt its normal functioning. It shares symptoms with Parkinson's disease, including slowness of movement. It accounts for 4 per cent of dementias in England.

Fronto-temporal dementia is a rare form of dementia, encompassing Pick's disease, and affecting 2 per cent of people with dementia in England. It often affects the under 65s, with dramatic effects on behaviour and personality, rather than memory, in the early stages.

2 Disease progression varies considerably, but broadly falls into three phases

Early Stage symptoms, often misattributed to stress, bereavement or normal ageing include:

- loss of short-term memory;
- confusion, poor judgement, unwillingness to make decisions;
- anxiety, agitation or distress over perceived changes and inability to manage everyday tasks.

Middle Stage symptoms include:

- more support required, including reminders to eat, wash, dress and use the lavatory;
- increasingly forgetful and may fail to recognise people;
- distress, aggression and anger are not uncommon, perhaps due to frustration;

Source: National Audit Office analysis

- risks include wandering and getting lost, leaving taps running or forgetting to light the gas;
- may behave inappropriately e.g. leaving the house in night clothes;
- may experience hallucinations.

Late Stage symptoms include:

- inability to recognise familiar objects, surroundings or people – but there may be some flashes of recognition;
- increasing physical frailty, may start to shuffle or walk unsteadily, eventually becoming confined to bed or a wheelchair;
- difficulty eating and sometimes swallowing, weight loss, incontinence and gradual loss of speech.

3 Dementia has suffered historically from poor awareness and understanding, combined with the stigmas attached to both mental illness and old age. The voluntary sector has highlighted the concerns over services for people with dementia. The Audit Commission's 2002 Forget Me Not report found GPs attached a lack of urgency to diagnosing and addressing the disease^{xxxiv}. Dementia is given some coverage in the National Service Frameworks on mental healthⁱⁱⁱ, older people^{iv} and long-term conditions^v, but to date has not received a specific high priority and changes within the Department around older people's mental health mean that the Programme Board has not met for some time. The Healthcare Commission, Audit Commission and the Commission for Social Care Inspection found evidence³ of inadequacies in health and social care services for older people with mental health problems.

4 More recent attention given to dementia includes the following:

- In 2005, the Department produced a Service Development Guide^{vi} for Older People's Mental Health, and commissioned an exercise to map services across the country.
- In its 2006 report, *A new ambition for old age*^{vii}, the Department acknowledged that more still needed to be done to provide specialist mental health services for older people, improve the skills and knowledge of generalist staff and promote mental health as part of active ageing.

3 Healthcare Commission, Audit Commission and Commission for Social Care Inspection (2006) *Living well in later life – A review of progress against the National Service Framework for Older People*.

- From April 2006 the Department added a minimum requirement to record and review cases of dementia in the voluntary Quality and Outcomes Framework⁴ of the new GPs' contract.

All these initiatives attempt to provide some guidance as to what good services should look like but as yet there is no consensus on the defined care pathway that all people follow (see Figure 11). There is consensus however that dementia should be diagnosed early and appropriate interventions offered immediately.

5 In November 2006 the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) produced a comprehensive

guide, *Supporting people with dementia and their carers*^{viii} (the NICE/SCIE guideline). The guideline evaluates the role and economic aspects of different pharmacological, psychological and psychosocial interventions and services in treating and managing dementia, and sets out best practice for care of people with dementia and support for unpaid carers.⁵ The Healthcare Commission has proposed a National Clinical Audit of dementia in 2008-09; this is an important development and has the potential to help achieve a similar step change in awareness and understanding of dementia as has been done in stroke care.^{ix}

3 Key facts on dementia

- In 2007 the *Dementia UK* report¹, commissioned by the Alzheimer's Society, estimated that there are some 560,000 people with dementia in England. Dementia is estimated to account for three per cent of all deaths.² However, it is estimated that over four times as many people may die with dementia.¹
- People can live with dementia for many years – the average time from diagnosis to death³ is 11-12 years, but diagnosis is often made late so the course of the illness can be as long as 20 years.
- The main risk factor for dementia is age, with prevalence rising to 12.2 per cent of people at age 82, but cardiovascular factors are also important, and people with learning difficulties (e.g. Down's Syndrome) may be affected earlier. People with dementia over 65 are described as having "late-onset" dementia. At least a further 12,000 people in England under 65 have "young-onset" dementia in 2007¹ though these cases are known to be under-diagnosed.
- An ageing population, especially among the "oldest old" (over 80s) means numbers affected are set to rise more steeply in England than many developed and developing countries – rising to over 750,000 by 2020.¹
- There are currently no proven treatments that can prevent the development of dementia and no cures. The future may hold innovative new treatments (Appendix 7), for example based on gene therapy. In the meantime, drugs called cholinesterase inhibitors can delay the progression of symptoms in some with Alzheimer's disease.
- Most people are cared for at home in the early stages. Around one third of people with dementia (over 200,000 people) currently live in largely private sector care homes (making up over 60 per cent of all residents), and the trend is towards entering care with more severe disease. Unpaid carers (mostly female family members) provide the majority of care in the community but smaller families, divorce and changing expectations may mean a smaller supply of unpaid carers in future – currently it is estimated that they save the taxpayer £5.4 billion a year.^{1,4}
- The annual economic burden of late-onset dementia is estimated at £14.3 billion¹ (more than stroke, heart disease and cancer combined) of which the majority falls to families. Between 25 and 30 per cent of care home costs are funded privately.⁵ NHS and local authority social care services provided for people with dementia cost £1.17 billion and £2.13 billion¹ respectively.
- Most people with dementia have at least one co-morbidity. In our Lincolnshire case study, 59 per cent of patients with dementia had 2 or more co-morbidities.

Source: National Audit Office analysis and Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science*

NOTES

- 1 Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, Kings College London and London School of Economics and Political Science*.
- 2 Office of National Statistics (2005) *England and Wales – cause of death as stated on death certificates*.
- 3 This period is shorter if people are diagnosed at a late stage of their disease, or if they get the disease at a time of life when their life expectancy is not long anyway.
- 4 Knapp M, Comas-Herrera A, Somani A and Banerjee S (2007) *Dementia: International comparisons* (report for the NAO).
- 5 English Community Care Association.

4 The Quality and Outcomes Framework (QOF) is a voluntary system of payment, introduced as part of the new General Medical Services contract in April 2004, to reward GPs for good practice. Participation is around 96 per cent. Each financial year, the number of points achieved by a surgery is collated and converted into a payment which takes account of the size of the practice and the number of patients with chronic illness. Data for the 2006-07 financial year is due to be published in the autumn.

5 Following NICE protocol, this guideline incorporates recommendations from the NICE technology appraisal on the clinical and cost effectiveness of donepezil, galantamine and rivastigmine for mild-to-moderate Alzheimer's disease and memantine for moderate-to-severe Alzheimer's disease (see www.nice.org.uk/TA111). This technology appraisal has been challenged and is currently the subject of a judicial review.

6 We examined what health and social care services are available for people with dementia and their unpaid carers in England and whether they are providing effective and good quality support; and the scope for better use of resources against a background of rising demand. Our primary focus is on the diagnosis and treatment of dementia in people over 65, who account for the vast majority of people with dementia, but where relevant we highlight specific issues relevant to the 12,000 or so people who have been diagnosed with young-onset dementia. The report does not cover prevention; despite a growing body of research on actions or activities that might help prevent or delay the onset of dementia, this is still a relatively under-developed area of research and the focus of the NHS is on intervention, treatment and care once diagnosis has been made.

7 Our methodology included: focus groups and a web forum of people with dementia and unpaid carers; a census of Community Mental Health Teams (CMHTs); a health and social care system case study of provision for people with dementia in Lincolnshire; and a survey of 1,000 GPs – further details are at Appendix 1.

Key findings

On the scale of the challenge and responsibilities

8 The 2007 *Dementia UK* report by the Alzheimer's Society estimated that some 560,000 people in England (one person in 88) have dementia⁶ (just over half with Alzheimer's disease) and some 476,000 people are unpaid carers of people with dementia. Numbers of people with dementia are projected to increase by nearly 40 per cent in the next 15 years. The annual economic burden of late-onset dementia in England is £14.3 billion, or £25,391 per head.

9 Nearly two-thirds of people with dementia live in the community; a third in care homes. Specialist NHS dementia care is delivered mainly through GPs and mental health trusts, which may provide services such as Memory Services and/or Community Mental Health Team (**Figure 4 overleaf**). As the disease progresses people with dementia may need help at home (domiciliary care, received subject to meeting eligibility criteria) and, in the later stages, residential/nursing home care. Care homes are delivered largely by independent sector organisations contracting with local authorities' social services departments; around 30 per cent of people fund their own care in independent homes.

10 Annual costs to the taxpayer of direct health and social care services for people with dementia are around £3.3 billion. Informal care costs of £5.2 billion are borne by families⁷, while £5.8 billion of care home costs are shared between families (30 per cent) and public funding (70 per cent)⁸. With the increase in the population of older people in England, the overall costs are set to grow rapidly as a proportion of spending for both taxpayer and citizen.

11 The split between fully-funded healthcare and means-tested social care is similar to other countries, but differences across England and Scotland mean that it continues to be controversial. On 26 June 2007 the Department published a new national framework to bring clarity to the rules (The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care), and separately HM Treasury are considering the long-term funding of social care.

On arrangements for diagnosis and early intervention

12 Experts and the Department agree that early diagnosis and intervention in dementia is cost-effective^x, yet there is a significant diagnosis gap and only a third to a half of people ever receive a formal diagnosis. In terms of the percentage of suitable patients receiving anti-dementia drugs, UK performance is in the bottom third in Europe, below almost all northern and western European nationsⁱⁱ and the average reported time to diagnose the disease in the UK is also up to twice as long as in some countries.^{xi}

13 Fear and ignorance of the disease are barriers to people and unpaid carers approaching their GP about suspected dementia, but we also found GPs' own attitudes could hamper early diagnosis. Our web forum, focus groups and GP survey revealed that there remains a widely-held perception that little can be done, and a lack of urgency attached to diagnosing and addressing the disease. Fewer than two thirds felt it was important to look actively for early symptoms. GPs who completed our knowledge survey on dementia scored on average only 47 per cent correct answers and their confidence in diagnosing dementia had fallen since 2004. Only 31 per cent felt they had enough training to diagnose and manage the disease and seventy per cent felt they had too little time to spend on people with dementia.

⁶ Not all of these people have received a diagnosis.

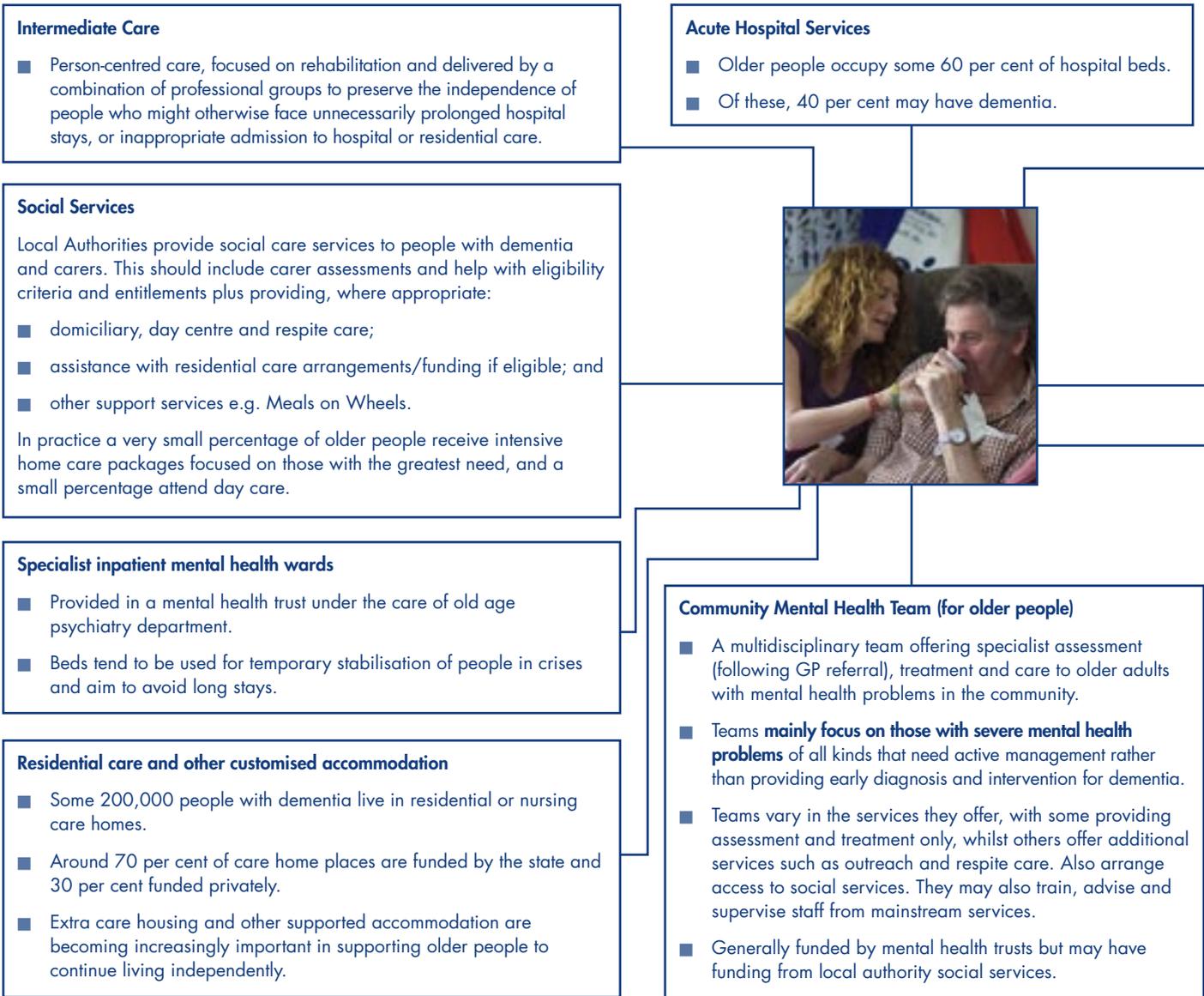
⁷ This cost is not in terms of "real" money, but is a notional or opportunity cost such as the value of a relative's time or wages forgone. It may also be interpreted as what it would cost the state to replace these carers if they were not undertaking this role.

⁸ Estimated by the English Community Care Association.

14 A wide range of screening and diagnostic tools and tests are in use by GPs, psychiatrists and others, but specialist knowledge is needed to make the best use of them, and only a very small number of GPs have dementia as a registered special interest. Brain scanning (MRI or CT) is recommended to establish a clear diagnosis but is being used regularly by only 66 per cent of CMHTs. The average wait for an MRI scan for dementia is ten weeks which is slightly longer than the national average for MRI generally, though waits for CT scans are shorter at seven weeks.

15 People with dementia and unpaid carers participating in our focus groups reported that diagnosis of dementia is often poorly communicated – it is not uncommon for this never to be set out in writing for the family. CMHTs and GPs reported that some other health and/or social care professionals lack the training and knowledge to provide advice on services and support that may help improve people’s quality of life. However, there are also examples of good practice (see Case Example 3).

4 There is a wide range of frontline services and support that people with dementia can access



Source: National Audit Office analysis

16 Often dementia is not diagnosed until a patient is admitted to hospital for an acute physical illness⁹, but it may be missed here too.^{xii} Acute hospital staff generally consider it crucial to establish any pre-existing *physical* conditions in a patient, but *mental* health screening of older patients who appear confused¹⁰ is not routine (although the Older People's NSF requires protocols that include screening). Hospital old age psychiatric liaison teams trained to do the job are not always available and vary widely in their approach and resources.^{xiii} Moreover,

Family/Informal Carers

Some 476,000 informal (i.e. unpaid) carers:

- provide a service valued at £5.4 billion;
- provide the mainstay of support to people with dementia who live in the community;
- know the person with dementia best;
- often act as coordinator between the many different services involved in the delivery of care to the person with dementia.

GP

Often the gateway to care for people experiencing symptoms of dementia, the GP should:

- Diagnose or refer the patient to specialist services for a diagnosis.
- Monitor and manage the progression of the disease.
- Signpost patients and carers to other support services; and
- Is ultimately responsible for the primary care of all 560,000 people with dementia, including 201,000 in residential care.

Memory Service

- Usually a multidisciplinary team **focusing on early detection, assessment and treatment** for people with memory problems.
- The best services provide home-based assessment, diagnosis, counselling, treatment and ongoing support for carers.
- May be incorporated within a CMHT or be a stand-alone service.
- Takes referrals from GPs/CMHTs, refers people for tests (e.g., scans at an acute hospital) and interprets the results to determine diagnosis.
- Funding is mostly through the mental health trust but may also include PCT or local authority money.

evidence from our Lincolnshire case study suggests that dementia diagnoses may not always be available in hospital, as healthcare staff fear it could be a barrier to discharging the patient to suitable rehabilitation or intermediate care.

17 Memory Services are recommended by the NICE/SCIE guideline as the single point of referral for all cases of suspected dementia, and we found 69 per cent of GPs had a local service to which they could refer patients, should they so decide. Memory Services, such as the Croydon Memory Service, can provide a cost-effective way of significantly increasing the number of people seen for early diagnosis and intervention^{xlvi} and they can also break down the stigma associated with dementia by not being labelled "mental health" or "old age psychiatry". However, their development has been piecemeal and services vary. The role of CMHTs in diagnosis and early intervention is inconsistent, with most focusing solely on people with severe mental illness. Overall, less than a third of GPs agreed that there were satisfactory specialist services locally to meet need.

18 Diagnosing more people and doing so earlier may be cost-effective by enabling more to be done to delay progression of the disease. Having a clear diagnosis, could also reduce the number/length of acute hospital episodes and delay the need for admission to more expensive long-term care. In addition, using therapies that reduce behavioural problems is known to reduce carer stress^{xiv}, which is often the trigger for unplanned entry into care homes. NICE^{xv} estimates the costs of cognitive behaviour therapy for unpaid carers at £27 million.

19 Other benefits of early intervention include the opportunity for families to plan their future medical care and finances, including putting in place Enduring Powers of Attorney where appropriate.¹¹ Many people make a positive choice to move into a care home, particularly when they do not have a family carer and security of care. It may also be more cost-effective if a high level of support is needed.

9 Holmes (1999)^{xii} found that 27 per cent of older people with dementia who had been admitted to hospital for a specific condition (hip fracture) only had their dementia diagnosed whilst in hospital.

10 Confusion in hospital patients can be due to dementia, acute confusional state (including delirium) and acute confusion. Most patients who develop acute confusion will eventually progress on to dementia.

11 The Mental Capacity Act 2005 will introduce Lasting Power of Attorney (LPA) from October 2007. These will replace Enduring Powers of Attorney and, from October, no new EPAs will be made. LPAs can cover both finance and personal welfare.

On management of services and support in the community

20 From 2006-07, GPs have been incentivised to record and monitor people with dementia and three-quarters of those in our survey said they did so. However, GP patient records are currently not accessible to other professionals outside the GP practice, making coordination of care difficult. To avoid distressing people with dementia, continuity and consistency of care arising from good coordination are important but currently are rarely available. Evidence from our focus groups shows that people with dementia and carers would prefer to have one health or social care professional as their main contact.

21 The Department recommends Community Mental Health Teams as the route into coordinated services for older people with mental health needs, but its target that these teams should be fully integrated across health and social care by 2004 has not been met – in 2006 only 56 per cent were integrated. The commissioning of CMHTs has also lacked any clear vision or strategy. Most teams responding to our survey felt they were well-coordinated with social services and the voluntary sector, but there was a low level of coordination with ambulance services and a lack of outreach arrangements with A&E and acute wards. As a result CMHTs were largely unable to prevent admission to hospital where another approach could have been better for the patient.

22 We also found significant gaps in CMHTs' ability to access specialist skills and services. A quarter had no access to a social worker and 29 per cent no clinical psychologist. Teams generally offered a range of support services but more than a fifth said funding was a barrier to providing day care and respite care. Given that family carers play a vital role, these latter services¹² may make the difference between a person with dementia being able to live at home or having to enter a care home. There is evidence that between a half and two-thirds of unpaid carers are either not receiving a carer's assessment, are not having the assessment followed up or are not having the needs met once assessed. According to our focus groups, there is also a shortage of appropriate services for people with young-onset dementia. These are vitally important, as are appropriate services for people from black and minority ethnic groups or with learning difficulties.

23 There are problems with the quality of domiciliary social care for people with dementia, including failure to train care workers in dementia care and lack of staff continuity, according to both unpaid carers and CMHTs, echoing the 2006 findings of the Commission for Social Care Inspection.^{xvi} People with dementia who have less severe needs may have difficulty getting support owing to a tightening of social care eligibility criteria by councils.

24 If a person with dementia suffers a health crisis (e.g. a fall or infection) admission to an acute general hospital is often the only option, even if the medical need is not acute. However it is known that hospital admission can worsen symptoms of dementia and reduce independence permanently. Specialist mental health beds are often not equipped to support those with frailty and physical needs. *Everybody's Business* (2005)^{vi} recommends shared care wards for such co-morbidity, but there are very few of these in England. Intermediate care services can be reluctant to admit people with dementia, making discharge from hospital difficult for these patients. The fact that so many people with dementia are previously undiagnosed and/or unknown to mental health services makes coordinating services to avoid hospital admission yet more difficult.

25 Half of CMHTs in our survey felt acute hospital nurses were inadequately trained in dementia needs, so in practice these patients, who need extra attention and supervision to stop them deteriorating, may not be receiving adequate support. Whilst there has been significant progress in recent years in reducing the number of older patients whose discharge from hospital is delayed^{xvii}, people with dementia are estimated to make up half of those that remain^{xviii}. We also found that only 58 per cent of CMHTs were working closely with acute trusts to manage these discharges.

26 A formal system of holistic "case management" of people with dementia by CMHTs would enable better coordination of their care across the whole system, involving unpaid carers and making the best use of resources. The Department has promoted case management in other long term conditions, such as diabetes, to reduce unnecessary hospital admissions.^{xix} Taking this approach in dementia (see Case Example 5), and linking it with GP registers of dementia patients and ambulance service records, would help ensure appropriate awareness of all relevant professionals.

12 A range of other services are also key to supporting carers on a day to day basis such as continence, chiropody, transport and sitting services.

27 Most CMHTs would need to gear up their range of skills to take the lead on case management, for which the funding could come from releasing unnecessary acute hospital beds¹³ and delaying admission to a care home. For example the financial model we commissioned from the London School of Economics showed that in just one condition (fractured hip), effective identification of patients with dementia as they enter hospital, and more proactive, coordinated management of their care and discharge (provided a suitable discharge destination is available) could produce savings of between £64 million and £102 million a year nationally.^{xx}

On scope for the system to respond as a whole to the challenge of dementia

28 Dementia represents a key test of how well health and social care services, along with their partners in the private and voluntary sectors, work together. However, only 29 per cent of CMHTs in our census had any joint health and social care funding arrangements in place. Following the reorganisation of primary care trusts in 2006, which resulted in most primary care trusts becoming coterminous with local authorities, there are now real opportunities for joint funding as part of Local Area Agreements.¹⁴

29 Our Lincolnshire case study demonstrates the potential of a joint local approach to improve provision for people with dementia. Following our bed usage survey which revealed that patients with dementia were found most often on acute wards and most no longer needed to be there, the community has decided to redirect funding to providing alternative bed- and home-based services and improving early diagnosis, potentially benefiting 500 people a year and reallocating at least £6.5 million more effectively¹⁵ (Appendix 6).

30 In terms of making effective use of the private and voluntary sector, there is also scope for improvement. The low number of registered specialist dementia beds in care homes (less than 28 per cent of the total) not only inhibits diagnosis but can lead to a lack of visibility of the need for dementia training in care home settings. The Commission for Social Care Inspection has underlined^{xxi} that the care homes industry is poorly developed to meet users' needs, in terms of amount and quality of care.

31 Raising the level of awareness of dementia and its care across public and professionals alike is also a priority. Professional training for medical and nursing

staff currently includes little or no coverage of the topic. In terms of public awareness, the Department is piloting a new "Life-check" programme designed to help people understand their own health risks and work with services to address them. The programme does not currently cover "life-checks" for older adults but, if piloted, these could offer an opportunity to discuss dementia in a routine way and reduce the associated stigma.

32 At present, some 95 per cent of hospice patients have cancer. Three quarters of hospice-based care is provided by the voluntary sector, who have traditionally focused on cancer patients. Provision of end of life care for people with dementia has been limited. Though dying at home does not suit every family, at present it is often not an option^{xxii}, with many people rushed to hospital to spend their last days or hours in a distressing, undignified and costly environment. A three year, £12 million End of Life Care Programme was announced at the end of 2003 to spread best practice with a specific work stream on end of life care in care homes. The Department is also developing a national Strategy for End of Life Care (due to be published at the end of 2007) which will incorporate the needs of people with dementia. We have identified concerns about end of life care for patients including, but not only, those dying with dementia, and are planning to examine these issues in a separate study which we hope to publish in late 2008.

Overall conclusions

33 Dementia presents a significant and urgent challenge to health and social care in terms of both numbers of people affected and cost. It is also a major personal challenge to anyone experiencing early symptoms and seeking diagnosis, which merits the seriousness accorded to, say, cancer. Parallels can be drawn between dementia now and cancer in the 1950s, when there were few treatments and patients were commonly not told the diagnosis for fear of distress.

34 Until 2005 the Department, and therefore local commissioners, attached little priority to dementia, partly because of the focus on other major diseases such as cancer and heart disease. At the same time, progress was hampered by a lack of good quality data, by stigma, and by the low level of political and national focus on older people's mental health. This was exacerbated by a lack of effective joint working across health and social care. As a result, people with dementia have not benefited from the developments in mental health services seen for working age adults.

¹³ Case management is effective in reducing hospital admission if it follows on from a comprehensive geriatric (also known as multi-disciplinary) assessment.

¹⁴ A Local Area Agreement 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.

¹⁵ £6.5 million is the community's total expenditure on all patients between April 2006 and January 2007 on excess bed days under Payment by Results. A significant proportion of this spend is on patients with dementia.

35 We conclude overall that services are not currently delivering value for money to taxpayers or people with dementia and their families:

- Health and social care services are spending significantly on dementia.
- Spending is late – too few people are being diagnosed or being diagnosed early enough. Early interventions that are known to be cost-effective, and which would improve quality of life, are not being made widely available. This results in spending at a later stage on necessarily more expensive services.
- Services in the community, care homes and at the end of life are not delivering consistently or cost-effectively against the objective of supporting people to live independently as long as possible in the place of their choosing.

36 The rapid ageing of the population means costs will rise and services are likely to become increasingly inconsistent and unsustainable without redesign. Given the data now available on the scale and impact of dementia, the evidence base for cost-effective intervention, and the growing consensus for action among health and social care bodies, the opportunity now exists to address these challenges.

Recommendations

37 Our specific recommendations should be considered alongside the Alzheimer's Society *Dementia UK* report, the Department's service mapping exercise and evidence from the other initiatives in paragraph 4; and may require 'spend-to-save' investment:

On improving diagnosis and early intervention

- a** Primary Care Trusts, working with GPs, should benchmark their performance in diagnosing dementia against expected prevalence and set local targets for improvement, to which end they should encourage more GPs to adopt dementia as a special interest.
- b** Primary Care Trusts, on behalf of their health and social care communities, should use the GP registers of dementia patients to feed into their local strategic needs assessments, in planning and commissioning their diagnostic, intervention and support services for people with dementia and carers.

- c** The Royal College of Psychiatrists and the Royal College of GPs should take the lead (working with the British Geriatrics Society and the Association of Directors of Social Services) in developing a multi-professional protocol for diagnosis and early intervention in suspected dementia. The evidence from our work suggests this should include: guidance on the skills needed to make formal diagnosis; a template on the type of information to give to people with dementia and their unpaid carers, including what to expect as the disease progresses and the financial and professional support available; details of the standards to apply in correspondence on referral, diagnosis and treatment, including guidance on copying this correspondence to family members/carers; and the criteria for moving patients from specialist services, such as CMHTs, back to the care of the GPs.
- d** Where local areas do not have a Memory Service they should commission one, in line with the evidence that these services can help reduce stigma. This may be done as part of a CMHT, or through a GP with special interest, or separately, for example by geriatricians or neurologists. The Memory Service should also be explicitly responsible for raising awareness among referring clinicians of young-onset (under 65 years) dementia to improve detection in this group.
- e** Memory Services and others providing diagnosis for people with dementia should ensure that all appointments where diagnosis is given, provide advice and information (as per the list of items recommended by the NICE/SCIE guideline) and offer an opportunity to access counselling by suitably qualified and experienced staff.
- f** On admission of patients aged 65 or over, where there is evidence of cognitive impairment, Acute Hospital Trusts should initially provide a medical response to identify and treat any medical problems. This should then be followed up by a mental health assessment and, where indicated, testing and diagnosis of dementia. Reduced costs resulting from better management and reductions in length of stay should help Primary Care Trusts to fund the commissioning of assessment and associated community support needed from local specialist services e.g. specialist old age psychiatric liaison services, intermediate mental health care teams and CMHTs.

On improving management of services and support in the community

- g** Based on evidence that a case management approach, when following a comprehensive multidisciplinary assessment, can cut acute and mental health hospital admissions, health and social care economies should consider adopting such an approach to dementia, ensuring that all those diagnosed have a care plan which is shared by all professionals involved (as in Case Example 5). CMHTs, working with the voluntary sector, are likely to be best placed to act as a central point/care navigator and own the care record, of which patients and carers should have a copy at home. In developing this approach, lessons learned from the Care Programme Approach should be borne in mind.
- h** The Department should work with the Royal College of Psychiatrists and others to develop guidelines on the size and composition of Older People's Community Mental Health Teams (including Memory Services) to reduce variations. As a minimum, this should include staff mix, relationships with memory services and acute trusts, their access to specialist services and their role in case management of people with dementia.
- i** Primary Care Trusts should, in consultation with local partners, establish a local care pathway based on best practice in diagnosis and therapy for dementia, for their health and social care economies, in line with the NICE/SCIE guideline.

On gearing up the system as whole to respond to the challenges of dementia in the future

- j** The Department should champion and coordinate improvements in dementia services as an explicit part of its approach to improving health and social care, including providing strong and transparent leadership for dementia management. The Department should also consider the need for a campaign to raise awareness of dementia amongst frontline staff and the general public. As part of this, the Department should consider commissioning campaigns to raise awareness of dementia amongst frontline health and social care staff and the general public.
- k** In view of the data that is now available from the *Dementia UK* report, together with the findings in this report and the older people's mental health mapping exercise, the Department should consider producing some economic modelling work with a view to developing evaluation toolkits for providers and commissioners similar to those developed by the Department for stroke services (see www.dh.gov.uk/stroke)

- l** The Department, Skills for Health and Skills for Care should work with the General Medical Council and the Royal Colleges to improve the coverage of dementia in undergraduate and postgraduate medical and nursing training, in view of the increasing number of patients a health professional is likely to come into contact with who have dementia. Similar consideration should be given to improving training for social care staff.
- m** If the Department pilots "Life-Checks" for older adults, it should include older people's mental health within its programme, making sure dementia is discussed at an appropriate life-stage for maximum impact.
- n** The Department should work with NICE and SCIE and voluntary groups to develop a generic leaflet on dementia – symptoms, causes, treatments and therapies - which can be tailored locally and would be suitable for health and social care professionals, people with dementia and friends and families to explain how to approach services and what to expect from ongoing care and support.
- o** The Department should ensure that the proposed National Clinical Audit of dementia is carried out during 2008-09. The audit will provide an opportunity to monitor implementation of our key conclusions.
- p** The new Local Government and Public Involvement in Health Bill provides an opportunity to improve older people's mental health services through enhanced local partnership working:
 - In developing their "Joint Strategic Needs Assessment" of the health and social care needs of their local population, all local authorities and Primary Care Trusts should ensure this includes identifying the mental health needs of older people; and
 - In developing priorities in their Local Area Agreements, local partners should develop a mental health strategy to improve their overall service provision.

Both of the above exercises should involve consultation with local GPs, intermediate care providers, care homes, the voluntary sector, people with dementia and their unpaid carers. Sources of data should include the feedback reports from our CMHT survey, consideration of the recommendations from our focus groups at Appendix 4, and the findings from our GP survey. The strategies should also draw on the results of the national Older People's Mental Health mapping exercise and, in due course, the National Clinical Audit. Commissioners might also consider a bed-mapping exercise similar to our Lincolnshire case study (Appendix 6).



Dementia presents a significant and urgent challenge to health and social care

1.1 Until 2006, there was no definitive information on the numbers of people affected by dementia in England, the costs to the economy, or indeed the scale of services being provided. This has now changed. The publication of independent research carried out for the Alzheimer's Societyⁱ has brought new information on numbers and costs. This followed an analysis of wider social care costs by Sir Derek Wanless for the King's Fund.^{xxiii} And the results of the Department's first ever mapping exercise of older people's mental health services^{xxiv} became available in 2006. This part reviews the new baseline information available on dementia. It also examines the roles and responsibilities for care and the Department's policy response to date.

Newly available information demonstrates the scale of dementia and its costs

1.2 The 2007 *Dementia UK* report, commissioned by the Alzheimer's Societyⁱ, estimates that in 2006-07 there were around 560,000 people with dementia in England, or 1.1 per cent of the total population. The same report predicts an 80 per cent increase in the numbers of people aged 65 and over in England, by 2051, with a shift towards the "oldest old" (150 per cent increase in those aged over 80).¹⁶ Prevalence¹⁷ increases with age and the total number of people with dementia is expected to rise to 600,000 by 2010 (**Figure 5**). The report also estimates that around 12,000 people under 65 in England have young-onset dementia. This latter figure is based on referrals to services and therefore likely to be an underestimate – the true figure may be three times as great.ⁱ Dementia affects over 11,000 people from black and minority ethnic groups and large numbers of people with learning difficulties such as Down's Syndrome.

1.3 Official statistics¹⁸ show dementia responsible for only three per cent of deaths in 2005, with death certificates very often recording other immediate causes of death such as pneumonia. However, statistics in the *Dementia UK* report suggest that up to 13 per cent of deaths may be attributed to dementia (**Figure 6 overleaf**). There are an estimated 476,000 unpaid carers for people with dementia in England. Dementia costs the health and social care economy more than cancer, heart disease and stroke combined^{xxv} – 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).ⁱ

The Department is ultimately responsible for the dementia programme

1.4 The needs of people with dementia require a complex and flexible combination of health and social care. The Department has responsibility for setting the policy and funding for health care, including care in respect of older people's mental health and for people with long term conditions. It also sets the policy framework of adult social care and, through specific grants managed centrally, provides 15 per cent of adult social care expenditure, all of which play a significant role in dementia care. The remainder of funding for adult social care is provided by the Department for Communities and Local Government, council tax and through charges incurred by people using services. Care itself is delivered through a range of directly provided and commissioned NHS, social care and independently provided services (**Figure 7 on page 17**).

16 The UK population is ageing faster than some, for example, Denmark, Ireland, the Netherlands, but not as fast as others, for example, Spain, and Germany (see Appendix 3).

17 The number of people who have dementia at a particular time point or within a particular period.

18 Office of National Statistics (2005) England and Wales.

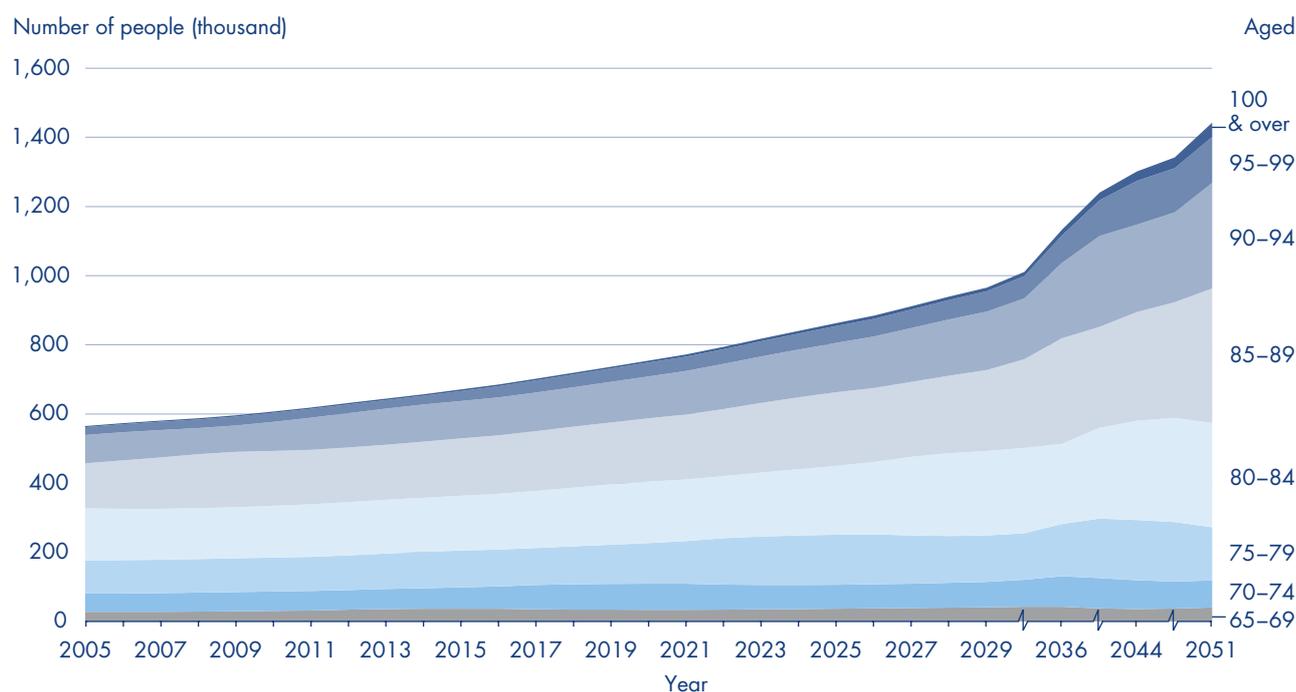
1.5 The Department of Health's high level objectives (Public Service Agreement Targets first set in the 2004 Comprehensive Spending Review) do not specifically mention dementia, but contain two line items where a focus on improving dementia care would contribute to delivery:

- Objective II: to improve health outcomes for people with long-term conditions by offering a personalised care plan for vulnerable people most at risk; and to reduce emergency bed days by 5 per cent by 2008, through improved care in primary care and community settings for people with long-term conditions.
- Objective IV: to improve quality of life and independence of vulnerable older people by supporting them to live in their own homes by:
 - Increasing the proportion of older people being supported to live in their own home by 1 per cent annually in 2007 and 2008; and

- Increasing by 2008 the proportion of those supported intensively to live at home to 34 per cent of the total of those supported at home or in residential care.

1.6 Since 1999 a series of policy initiatives have offered the opportunity to address strategically the needs of people with dementia (Appendix 2) and contribute to the delivery of these targets. However, it was not until 2005 that the Department developed policy specifically directed towards older people's mental health issues. Dementia, and older people's mental health in general, have not benefited sufficiently from advances made as a result of the National Service Frameworks (NSFs) for older people^{iv} and mental health.ⁱⁱⁱ They have therefore been excluded from the developments that have benefited working age adult services, as noted by the National Directors for older people and mental health.^{xxvi} Dementia was also not specifically considered in the National Service Framework on Long Term Conditions, which focuses mainly on other neurological conditions.

5 The number of people with dementia in England is increasing and will reach 1 million by 2031 and 1.4 million by 2051



Source: Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science*

NOTES

1 Prevalence rises rapidly from age 65, when it affects 1.3 per cent of the population, more than doubling every five years up to 32.5 per cent at age 95. Prevalence rates appear to vary little between countries, though they identify and diagnose dementia in different ways. Dementias can also affect people as young as 30. Factors including age, genetic background, medical history and lifestyle may determine onset. Dementia affects all socio-economic groups. The *Dementia UK* report used the Expert Delphi Consensus methodology to produce best estimates of prevalence of dementia for 2006-07 and onwards using currently available data.

2 The *Dementia UK* report used the Expert Delphi Consensus methodology to produce best estimates of prevalence of dementia for 2006-07 and onwards using currently available data.

6 Relative impacts of dementia and cancer in England

| | Dementia | Cancer |
|--|--------------------------------------|----------------------|
| Number of people with the disease | 560,000 | 230,000 ¹ |
| Deaths (percentage of total) | 3% (though may be as high as 13%) | 25% |
| Healthcare spend by Department of Health (2005-06) | £1.17 billion | £4.3 billion |

Source: Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science and Department of Health Cancer Policy Team*

NOTE

¹ Cancer data sourced from the Department of Health Cancer Policy Team (numbers affected relate to 2004, the most recent data available from the Department, whereas the dementia data relates to 2006).

1.7 This is in contrast to Australia where, in 2005, the national government Department of Health and Ageing launched the *Dementia – a National Health Priority* initiative, following publication of a report by the Australian Institute of Health and Welfare (2004) *The Impact of Dementia on the Health and Aged Care Systems*. As a result, new models of care now in use in mental health for younger people e.g. assertive outreach programmes, crisis resolution teams, early intervention and the Care Programme Approach, which are designed to help people manage their condition and keep them out of hospital, are not widely available to older people with mental health problems, especially dementia.

In practice most dementia care takes place in the community and most costs fall to families

1.8 Around two-thirds of people with dementia in England are currently cared for in the community. Among those aged over 65 living in nursing homes the estimated prevalence of dementia is 66 per cent and residential care homes 50 per cent.ⁱ Unpaid care (or informal care), mostly by female relatives, families and others, is the mainstay of dementia care around the world, but the future supply of unpaid carers is likely to be considerably lower than

at present because of changing demographic patterns, smaller families, divorce, labour force participation rates for women, geographical mobility and changing expectations of society.

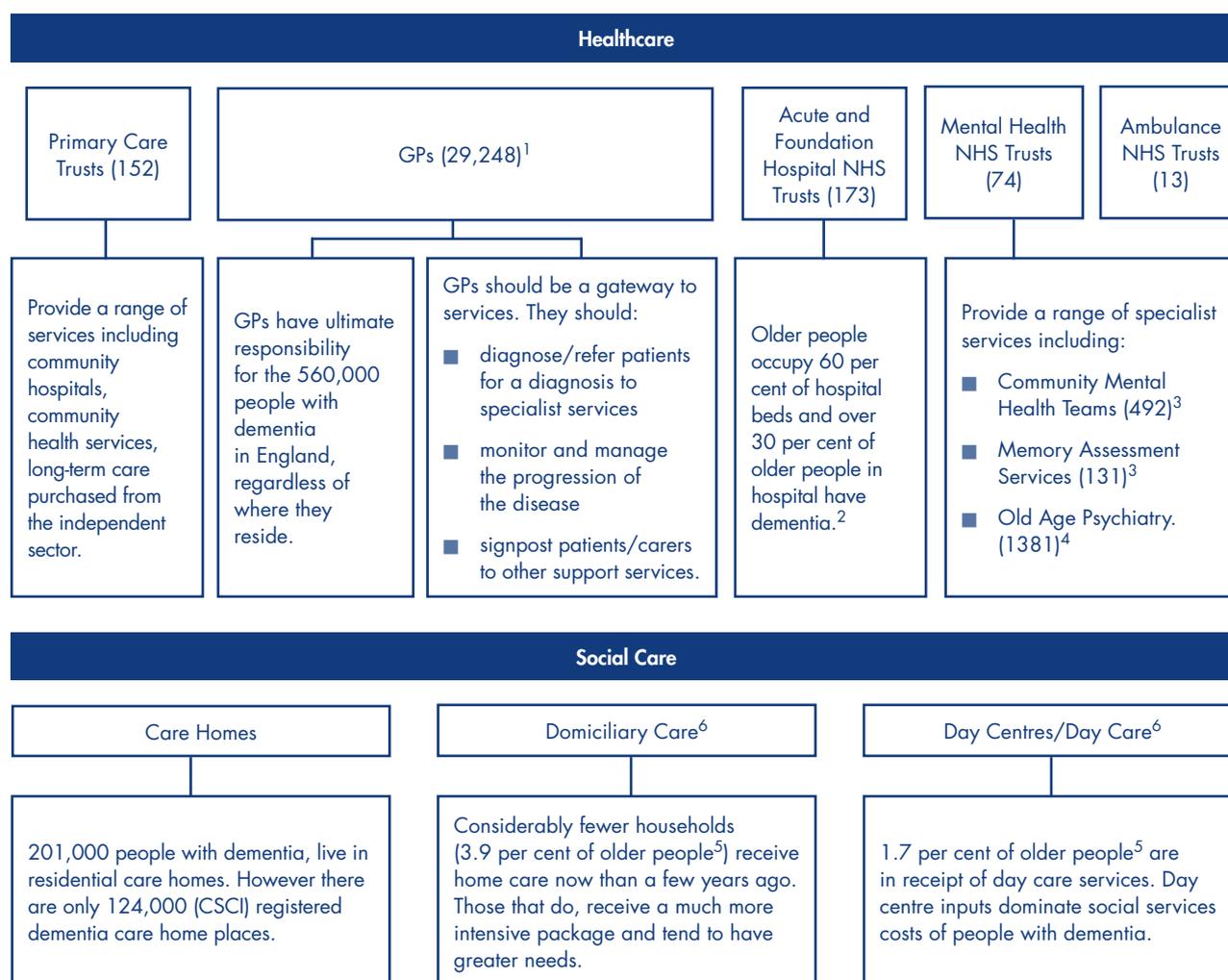
1.9 In England, statutory services for dementia care are a combination of NHS primary and secondary care (e.g. diagnosis, prescription of medication, physical, psychological and occupational therapies, mental health inpatient treatment) which are free at the point of use, and local authority social care (e.g. home help, assistance with washing and dressing, day centres, long-term residential or nursing home care), which is means-tested. Dementia officially makes up 11 per cent of the total mental health cost allocation of the NHS.^{xxvii}

1.10 The responsibilities, and the proportion of overall costs, falling to unpaid carers increase as dementia progresses (**Figure 8 overleaf**), until residential/nursing home care is required, when the direct costs relating to accommodation become large (**Figure 9 on page 19**). Unpaid carers' costs include lost employment, lower earnings and lost pension entitlementsⁱ, and they suffer health consequences of their own, particularly depression. Indeed, as our focus groups show, a key issue for unpaid carers is the loss of their own life as they knew it. The *Dementia UK* report estimated that informal carers for people with dementia in England save the taxpayer £5.4 billion a year. Our previous report on *Progress in implementing clinical governance in primary care: lessons for the new primary care trusts*^{xxviii} highlighted the importance of services recognising the role played by unpaid carers and involving and informing them. Unpaid carers are supported through legislation¹⁹ and voluntary organisations play an important role in the lives of unpaid carers by providing support and advice.

1.11 In 2006 Sir Derek Wanless carried out a major review of the costs of social care for the King's Fund^{xxix}. In view of the rapidly ageing population and the existing inequalities, the Review recommended a fundamental change of the financing arrangements, based on a citizen-state partnership model of matched funding for care, up to a benchmark level, and extra support for those on low incomes, partly financed by changes in the benefits system. Following the Wanless Review, HM Treasury announced its intention to consider this Review and the report from the Joseph Rowntree Foundation and other key documents and this work is ongoing.

¹⁹ The Carers and Disabled Children Act 2000.

7 There are a number of key players involved in the delivery of care for people with dementia⁷



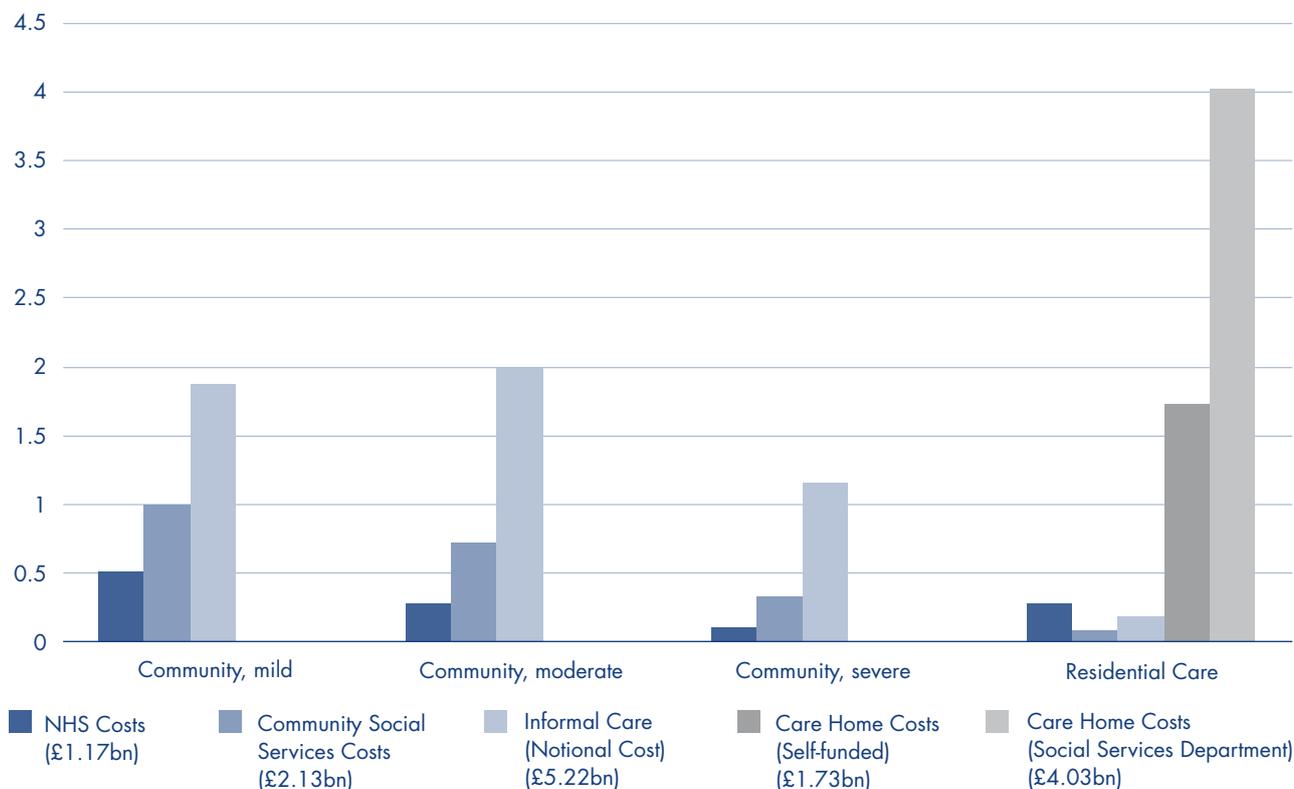
Source: National Audit Office analysis

NOTES

- 1 Royal College of General Practitioners (2006) *Information Sheet Profile of General Practitioners*.
- 2 Royal College of Psychiatrists (2005) *Who cares wins. Improving the outcome for older people admitted to the general hospital: Guidelines for the development of Liaison Mental Health Services for older people*.
- 3 Barnes D and Lombardo C (2006) *A Profile of Older People's Mental Health Services: Report of Service Mapping 2006*, Durham University.
- 4 Membership Office, *Royal College of Psychiatrists* (May 2007).
- 5 Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society*, Kings College London and London School of Economics and Political Science (Older people are people aged 65 and over.) The 2005 census data and *Dementia UK* both report that there are over 8 million older people in England.
- 6 Patients receiving domiciliary care may also be in receipt of day care and vice versa.
- 7 In addition to informal care provided by unpaid carers, at any one time people with dementia will have, or need to, access to a range of health and social care services. For example, a person with dementia may receive services from the district nurse or community matron, see their GP, attend a day centre and be in receipt of domiciliary care. As the disease progresses, the needs of most people with dementia for domiciliary and other care and support will increase. Ultimately a care home may become appropriate or the person with dementia may stay in their own home supported by various aspects of health and social care.

8 Around half of the £14.3 billion estimated economic burden of dementia in England is borne by families through informal care and self-funded care home costs¹

Dementia costs in England (Annual costs 2005-06 £billions)



Source: Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science*

NOTES

1 Informal care is costed using (i) the hourly cost of a home care worker for specific tasks and (ii) the minimum wage for time spent on general tasks and supervisory activities.

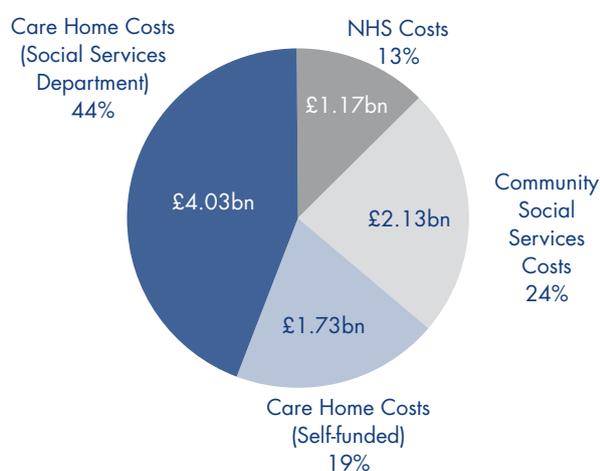
2 The estimated service cost of late onset dementia is over £14 billion per annum. Most of this is accounted for by supported accommodation (i.e. care home) costs and informal care (i.e. notional) costs. Some £6.87 billion is borne by people with dementia and their families.

1.12 Prior to 2001, nursing home residents (apart from those fully funded by the NHS, see paragraph 1.13) were means-tested for all their care home fees, including the services of a registered nurse. In England, since 2001, the NHS has funded all nursing care provided by a registered nurse, including in a care home, but the rest of the care and accommodation remains means-tested by the local authority. In Scotland, since 2002 both personal and nursing care are provided free of charge, but our international comparisons review showed that England is not alone in separating health and social care costs and most countries have some form of means-testing (Appendix 3).

1.13 The split of responsibility between families and state for older people's care, especially dementia care, remains controversial, owing to the complexity of differentiating "health care" from "personal care" needs. In England, the Department's guidance states that the NHS will fund all the care needs (including accommodation where this is part of the care) if an individual meets local eligibility criteria for a primary health need, known as NHS Continuing Health Care.²⁰ This guidance was originally issued in 1995, but updated in 2001 following the legal judgement in the case of Pamela Coughlan (1999), which found that the NHS was responsible for funding her care and accommodation because her needs were beyond those which could be met by social services. Local decision-making means that these criteria vary between Strategic Health Authorities and in some areas mental health needs have been given less attention than physical needs.

²⁰ <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/IntegratedCare/Continuingcarepolicy/index.htm>.

9 The total estimated direct cost of dementia is £9.1 billion, the bulk of which relates to the cost of care home places



Source: Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science*

NOTE

£5.76 billion, equivalent to almost two thirds of the direct costs of dementia (i.e. excluding informal care costs), borne by families, the NHS and social services, relates to the provision of care home places for people with dementia. NHS costs and social services costs account for the remaining one third of direct costs.

1.14 In 2003, an influential report from the Health Service Ombudsman, *NHS funding for long term care*, established that eligibility criteria had been wrongly applied in many cases and that people had been wrongly denied NHS care. In a number of these cases this was because psychological needs had not been properly considered as part of the person's need for health care.²¹ The Ombudsman has continued to raise this issue in subsequent reports, the most recent being *Retrospective continuing care and redress* in 2007. In 2006, the Department consulted on the development of a new national framework for NHS funded continuing health care and nursing care. The framework, which was published on 26 June 2007, introduces a single set of criteria and a single decision making process, which takes account of mental health needs, to introduce national consistency.

Understanding of effective treatments and therapies is advancing

1.15 There are currently no proven measures or treatments that can prevent dementia and the causative factors are considered too complex to make general population screening useful.^{viii} The course of disease is unpredictable and may vary considerably both by individual and from day to day in the same person. Some live with dementia for up to 20 years, and the end stage can be very long, though average life expectancy is around 11-12 years from diagnosis.

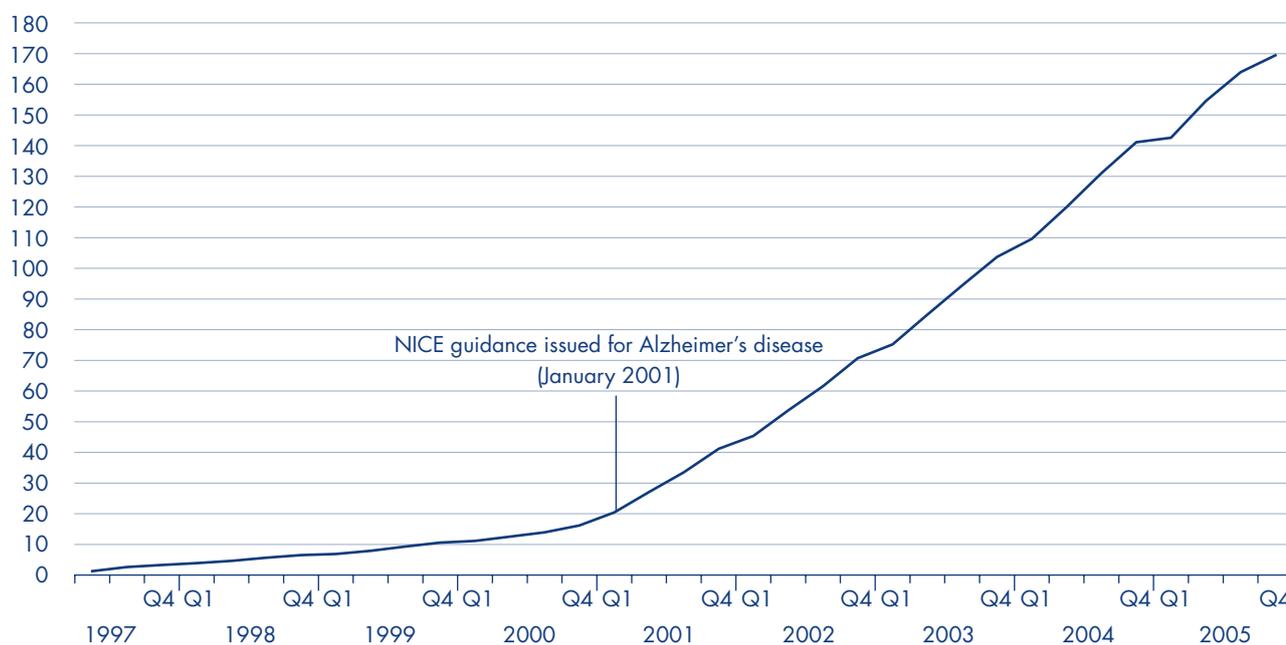
1.16 Factors affecting a person's experience of dementia and their rate of decline in independence include the type of dementia, their physical condition and emotional strength and the support available, from family and formal care services. People with dementia are often frail and suffer from other long term conditions, and often depression. Every person's experience of dementia is unique and their needs range from physical and psychological to emotional and spiritual. Therefore, experts now agree that a "whole person" approach is needed in dementia care.

1.17 While there is no cure for dementia, there is increasing evidence of therapies and treatments that can help with the symptoms. Drug treatments are one element. Drugs known as cholinesterase inhibitors help some people with dementia become less forgetful and confused, though they cannot stop the disease eventually worsening. Since the licensing of these drugs between 1997 and 2000, and approval by NICE in 2001, rates of prescription have risen dramatically (**Figure 10 overleaf**), which suggests that many more people are being helped by these medicines. During 2005 in England, the NHS spent some £60.9 million on dementia drugs, around 60 per cent in primary care, and nearly 40 per cent in secondary care.^{xxix}

²¹ In a landmark case, the Ombudsman upheld a complaint from Mrs Barbara Pointon in 2003 that psychological needs should also be deemed "healthcare" and therefore eligible for NHS funding. Ambiguous local criteria had meant that only physical needs had been taken into account.

10 Numbers of prescriptions of drugs for dementia have risen rapidly since approval by the National Institute for Health and Clinical Excellence (NICE)

Prescription Items ('000s) used in the treatment of dementia, dispensed in the community, in England



Source: Prescriptions dispensed in the community statistics, Department of Health

1.18 In 2006 the National Institute for Health and Clinical Excellence issued an update of its original 2001 advice to the NHS in England on the use of drugs for the treatment of dementia.^{xxx} This advice concluded that the cholinesterase inhibitors are cost-effective in moderate Alzheimer's disease, but not in early or late stages (they are not licensed for late stage use), and not in other types of dementia. Memantine was considered not cost-effective within its licensed indication at the time of the appraisal for moderately severe to severe Alzheimer's disease. This decision is currently the subject of a judicial review, after concern from patient and other groups over the methods used to establish whether the drugs were cost-effective.

1.19 The National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) together produced a major evidence-based good practice guideline on the health and social care of people with dementia (the NICE/SCIE guideline)^{viii}, in November 2006. This clinical guideline makes a large number of detailed recommendations for the identification, treatment and care of dementia across the whole health and social care systems with priorities for improvement, setting a standard for all health and social care communities to aspire to and demonstrating the importance of these professionals all working together.

1.20 Besides incorporating the NICE technology appraisal guidance on the use of drugs for people with Alzheimer's disease, the guideline also sets wider standards for the care of people with all types of dementia which clinicians and commissioners are expected to implement. We examine the performance of services in relation to some of these in Parts 2 and 3. The guideline recommends therapies and treatments other than the drugs described above, including:

- structured group cognitive stimulation programmes in all types of mild and moderate dementia;
- alternative therapies for people with dementia and agitation such as aromatherapy, multisensory stimulation, therapeutic use of music and/or dancing, animal-assisted therapy, or massage;
- cognitive behaviour therapy for people with dementia who have depression and/or anxiety; the therapy may include their carers; and
- various sensory stimulation therapies for anxiety e.g. reminiscence therapy, multi-sensory stimulation, animal assisted therapy and exercise for people with dementia with depression and/or anxiety.

1.21 The technology appraisal recommends research on acetylcholinesterase inhibitors and memantine.²² It also recommends research to address the relationship between disease progression of people with Alzheimer's disease and carer utility (quality of life). The future may hold radically different treatments for dementia, possibly involving gene therapy and vaccines with an increasing volume of research ongoing internationally on a range of approaches (Appendix 7).

The opportunity now exists to address the challenge effectively

1.22 There is now strong consensus that more needs to be done to improve services for people with dementia. Moreover, definitive data are now available on the scale and costs of the challenge.ⁱ All experts agree that early identification of dementia symptoms and intervention, in ways tailored to the individual, is unequivocally beneficial. This was most recently underlined in January 2007 by the Department's National Director for Older People.^x Since 2005 the Department has set out its aims for older people's mental health in a series of policy documents and a service development guide^{vi}. In 2006 the Department established a programme board for Older People's Mental Health bringing together Older People's and Mental Health leads, accountable under the Social Care, Local Government and Care Partnerships Directorate. However, this has not met for some time due to changes at the Department.

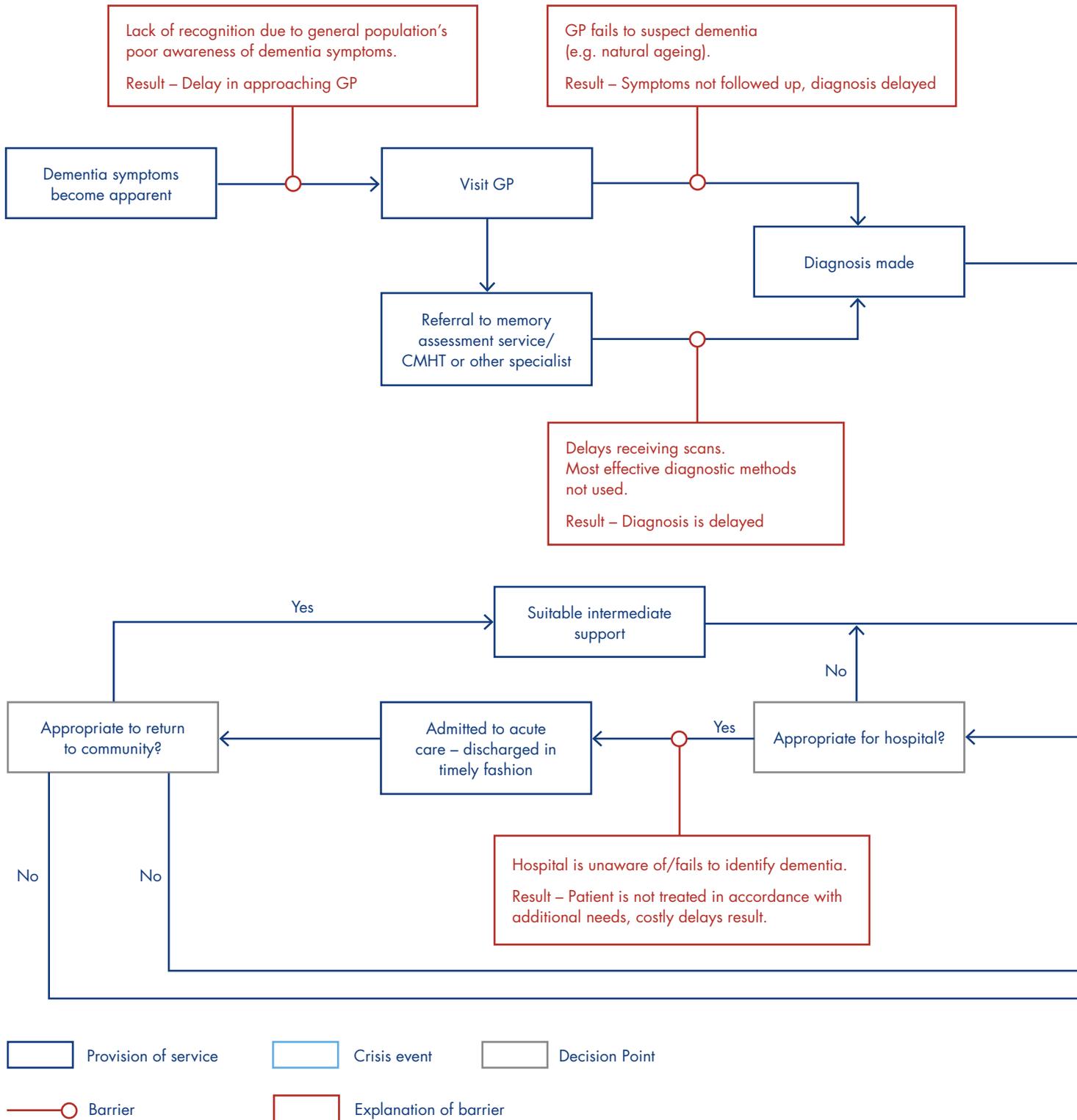
1.23 Historically there have been few effective central levers to improve local services for dementia. Some new levers now exist – dementia care is included in incentives for GPs under their new contract from 2006-07 and the Healthcare Commission will review strategic planning for Older People's Mental Health in its 2006-07 Annual Health Check of Primary Care Trusts.^{xxxi} The Healthcare Commission has also funded a project to scope the feasibility and likely scale of improvements for patients that could come from a clinical audit of dementia services. The scoping report, undertaken by the Royal College of Psychiatrists, was completed in March 2007 and the Commission now proposes to procure a full clinical audit, which it expects to start late in 2007-08, subject to overall funding. The Commission for Social Care Inspection are planning to carry out a thematic inspection on the quality of residential care for people with dementia in England in late 2007.

1.24 More importantly, the evidence is accumulating that, in line with other long-term conditions where the focus is on care closer to home and avoidance of unnecessary hospital admission, there are cost-efficiencies to be found in better management of dementia. There are already models of good practice available in specific services: the Care Services Improvement Partnership (CSIP) funded by the Department offers support and access to good practice; and there are useful lessons from the Partnerships for Older People Projects (POPPs), through which the Department is awarding up to £60 million to 29 localities.

1.25 Parts Two and Three of this report examine how services currently support and care for people with dementia through diagnosis and living with the disease, and the barriers that service users face (as illustrated in **Figure 11 overleaf**). Part 4 looks at opportunities for system improvements and better use of resources overall.

22 The technology appraisal recommends: research on the use of acetylcholinesterase inhibitors and memantine for the treatment of psychotic symptoms in dementia; research (preferably randomised controlled trials) to investigate the effect of memantine on subgroups of people with Alzheimer's disease suggested to derive enhanced benefit from memantine, such as those with behavioural disturbance; and research to generate robust and relevant data on both short- and long-term outcomes, disease progression through relevant health states, quality of life and costs of treating people with moderately severe to severe Alzheimer's disease.

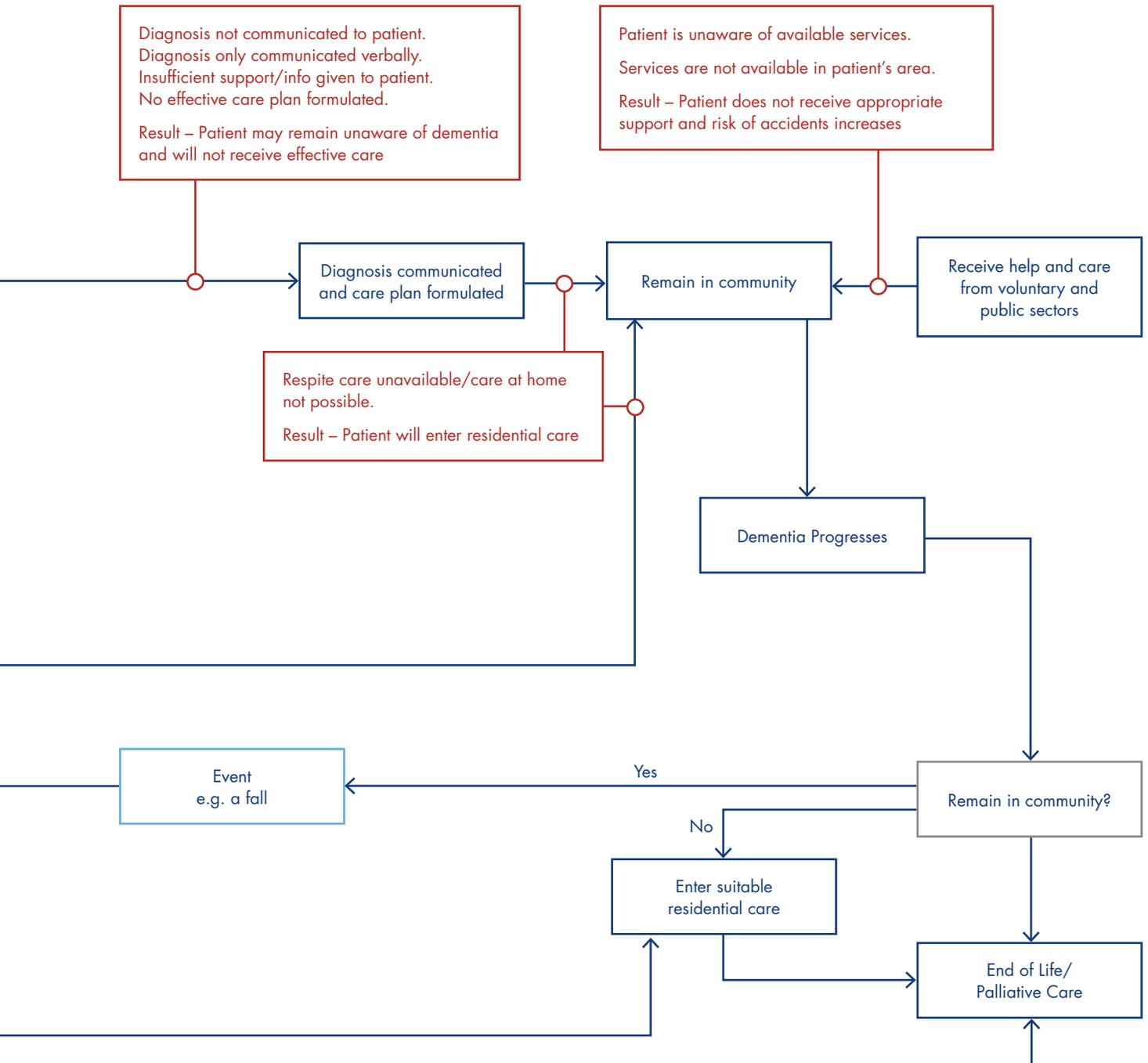
11 People with dementia and their carers can encounter numerous barriers which affect diagnosis and care



Source: National Audit Office analysis

NOTE

There is no definitive dementia care pathway. In practice people with dementia access NHS and Social Care Services through various entry points and at different stages in the progression of the disease. However many people with dementia encounter barriers which can delay or prevent diagnosis and provision of appropriate care.





Services in England could do better on early diagnosis and intervention

2.1 There is clear evidence that early diagnosis and intervention improve outcomes for service users and unpaid carers (paragraph 1.22). Without diagnosis, no interventions or services can be offered. This part examines the performance of services and support in England in detecting, diagnosing and providing early intervention on dementia, and the experiences of people with dementia and their unpaid carers in using these services.

Many people with dementia never receive a diagnosis

2.2 The UK's performance on diagnosis compares poorly with other countries. For example, using as a proxy for diagnosis the prescription rate for cholinesterase inhibitors in Alzheimer's disease, the UK was in the bottom third of EU countries (**Figure 12**), even before NICE guidance suggested restricting these drugs to a smaller group of patients. The 2004 *Facing Dementia Survey*^{xi} showed the reported time taken to diagnose Alzheimer's disease, after first noticing symptoms, is longer in the UK (32 months) than in France (24), Spain (18), Italy (14) or Germany (10).

"It took 3½ years to get my diagnosis. I was referred around in circles with a diagnosis of depression and eventually... through the Alzheimer's Society, given an appointment with a psycho-geriatrician and, after tests, diagnosed." (Focus group)

2.3 The same survey found fewer unpaid carers in the UK (51 per cent) reported that physicians recommended treatment at the time of diagnosis than in Germany (78 per cent), France (83 per cent), Italy (85 per cent) and Spain (86 per cent). This correlates with the lower expectations that UK doctors had from the available drug treatments, where only 68 per cent agreed that early treatment can delay the progression of Alzheimer's disease compared with their colleagues in Spain (86 per cent), Germany (87 per cent), Italy (91 per cent) and France (92 per cent).

2.4 We examined data in 2006 on expected and recorded prevalence of dementia which shows that, across England, many people with dementia never have their condition identified and diagnosed. Only five people per 1,000 were diagnosed at age 65-69, compared with an estimated actual prevalence of 13 per 1000, while in people over 80, only 60 of the expected 122 were diagnosed (**Figure 13 overleaf**).

Awareness and attitudes among people with dementia and family carers are a key barrier to diagnosis

2.5 Fear of the disease in the patient or the family is acknowledged to be a major barrier to seeking diagnosis, as is inability to distinguish between symptoms of dementia and normal signs of ageing. In the *Facing Dementia Survey* (2004)^{xi} unpaid carers explained the delays in consulting a doctor as:

- not being aware of the symptoms (70 per cent of respondents);
- being in denial about their relative having the illness (64 per cent);
- not appreciating the seriousness of the symptoms (61 per cent); and
- believing the symptoms to be just 'normal ageing' (58 per cent).

2.6 Eighty-six per cent of respondents to our web forum said they had basic or no awareness of dementia until being affected by it. The stigma attached to dementia may put people off seeking a diagnosis. For people from ethnic minorities, Rait and colleagues (1996)^{xxxiii} describe dementia care as having a 'triple whammy' of disadvantages, owing to discrimination and bias affecting: older people; people with mental disorder; and the greater difficulty experienced by minority ethnic groups in accessing care.

“There is a stigma attached to dementia for some [of my] family members.” (Focus group)

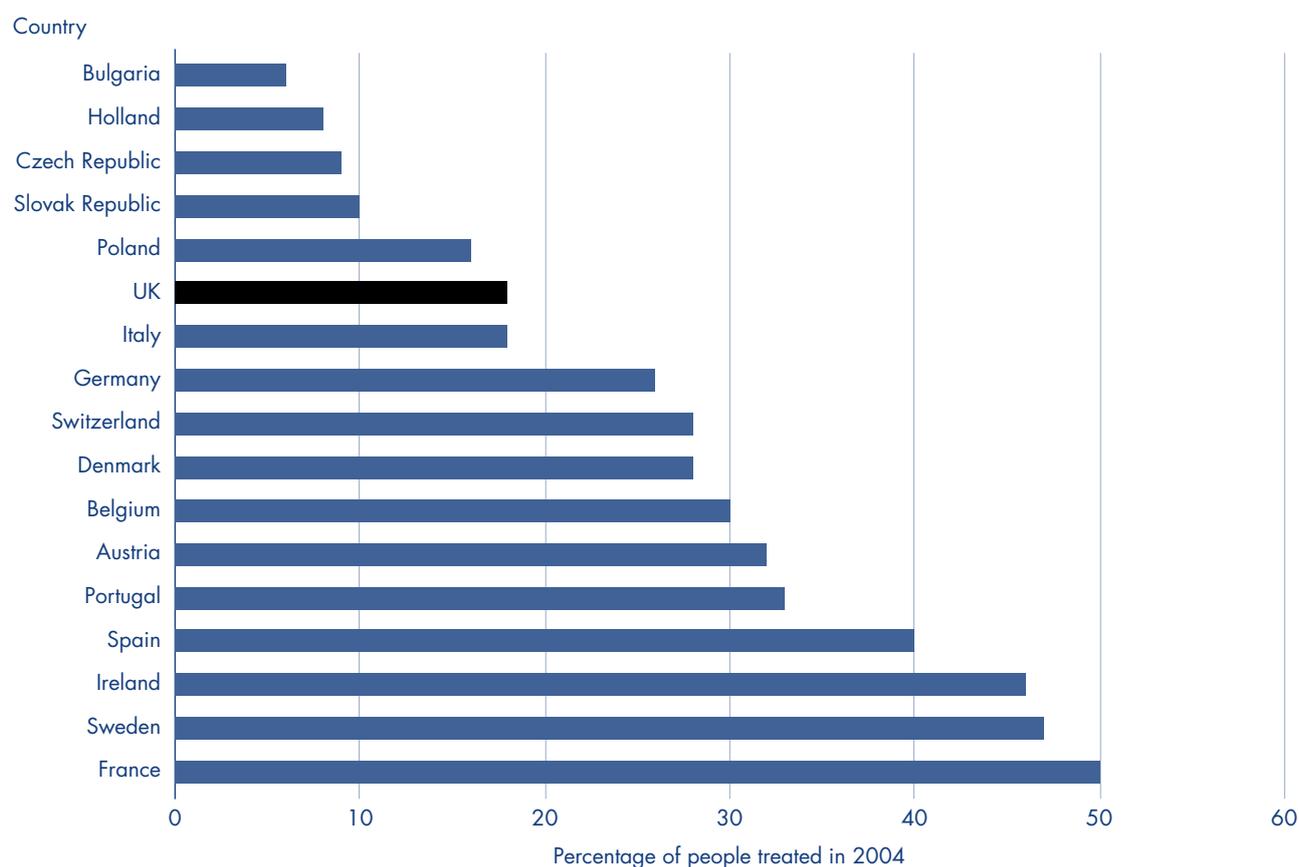
“[People should realise that] what you’ve got is not catching.” (Focus group)

2.7 Because of the nature of the disease, people with dementia may find it difficult to understand the process of diagnosis. They may also miss appointments or fail to follow treatments because they do not remember, or do not understand the value in them. The involvement of unpaid carers in the process is therefore vitally important.

“If you don’t know what’s going on, you can’t help [relatives].” (Focus group)

However, carers reported it was often difficult to speak to their relative’s GP owing to the GP’s concerns over patient confidentiality. This problem of unwillingness on the part of a range of health professionals (not just GPs)^{xlii} to involve the carer can adversely affect the delivery of care. Applying for Enduring Power of Attorney entitles relatives or unpaid carers to act on behalf of the person with dementia, for example making decisions about financial affairs, but this still does not grant legal access to medical records. This is only possible if the person with dementia is willing and able to authorise it, which is one of the reasons why early diagnosis is important.

12 The UK compares poorly with most EU countries in the percentage of people with Alzheimer’s disease treated with anti-dementia drugs



Source: Waldemar et al. (2007)¹ cited in Knapp et al. (2007)²

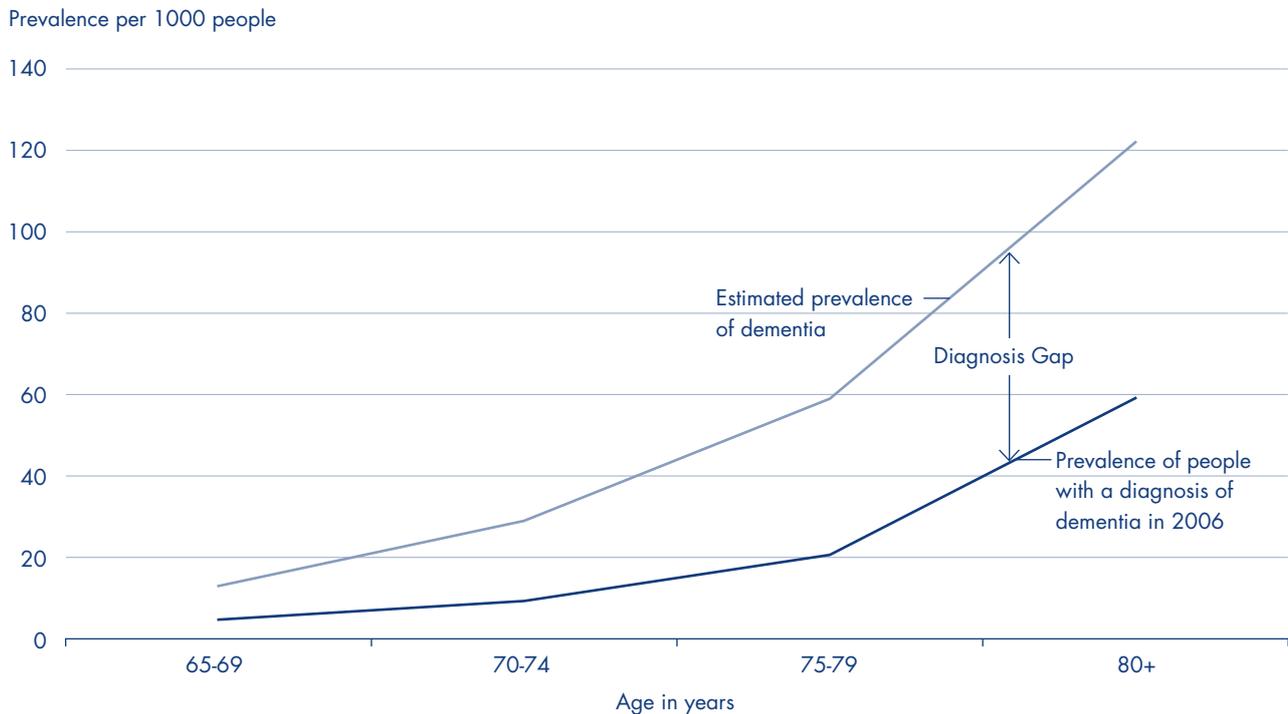
NOTES

1 Waldemar G, Phung TT, Burns A et al. (2007) Access to diagnostic evaluation and treatment for dementia in Europe. *International Journal of Geriatric Psychiatry*, 22, 47-54.

2 Knapp M, Comas-Herrera A, Somani A and Banerjee S (2007) *Dementia: International comparisons* (report for the National Audit Office).

3 These prescription rates are the best available proxy for diagnosis in the absence of better data. Treatment is not possible without diagnosis and ability to treat should not vary by country. These data therefore allow comparison of health systems at an aggregate level directly in their delivery of one element of treatment for dementia. Using this test the UK appears to be a low prescriber with the majority of peer European countries having prescription rates 1.5 to two times higher. Discussion concerning the cost-effectiveness of the available drugs notwithstanding, these data provide evidence that the UK is functioning relatively poorly in terms of the diagnosis and treatment of dementia.

13 More than half of people with dementia are not diagnosed



Source: Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society, King's College London and London School of Economics and Political Science* (estimated actual average prevalence) and *General Practice Research Database report to the NAO* (reported prevalence based on diagnoses)

NOTE

The graph above shows reported prevalence of dementia, based on levels of diagnosis within Primary Care Trusts, for ages 65 and upwards in 2006. The estimated actual average prevalence has been calculated using data from 2007 *Dementia UK* report in conjunction with population estimates from the Office for National Statistics. The latter does not take into consideration those aged 85 and above, due to restrictions on the data available, and as such forms a very prudent estimate of the true prevalence of dementia in the over 65 population.

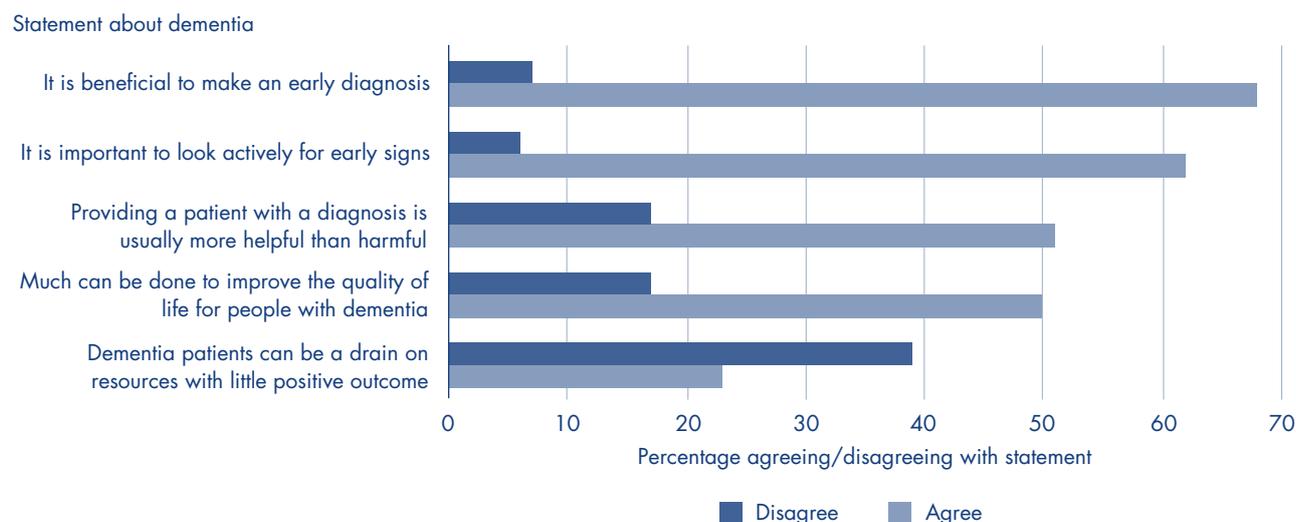
GP attitudes and skills can be a gateway or a barrier to diagnosis

2.8 People experiencing memory loss, and their family carers, often call first on their GP for help. The GP is the gatekeeper to other health services and should generally refer the patient to specialist services to perform the necessary tests and make a diagnosis. A few GPs may have undertaken additional training in dementia ("GPs with special interest" or GPwSI²³). Whilst there are no official figures, the number of GPwSI in dementia is thought to be very small. In terms of attitudes, the Audit Commission's 2002 report, *Forget Me Not*, found that GPs' attitudes affected diagnosis with GPs believing that there is little that can be done about dementia^{xxxiv}. We found little room for encouragement since 2002 in the importance that GPs place on an early diagnosis (Figure 14).

2.9 It is not uncommon for GPs to dismiss dementia symptoms as normal effects of ageing. A 2004 study^{xxxv} tested GPs' knowledge and also asked them to rate their confidence in making a diagnosis. GPs in our survey did no better against the same questions in 2006, with the proportion of correct answers falling to 47 per cent from 48 per cent (Appendix 5). The best scores in 2006 related to questions about the differences between Alzheimer's disease and vascular dementia whilst the worst scores were on how to conclusively confirm diagnosis and differentiate from other conditions. There was poor awareness of epidemiology, with 41 per cent of GPs underestimating how many patients with dementia they should expect to find in a practice list. The proportion feeling somewhat or very confident about their ability to make the diagnosis had fallen to 58 per cent in 2006, from 64 per cent in 2004. Training, tools and support were clearly still an issue (Figure 15).

²³ A GPwSI has additional training and experience in a specific clinical area and takes referrals for the assessment/treatment of patients from other GPs, or provides an enhanced service for particular conditions or patient groups. GPwSIs are appointed to meet the needs of a single PCT or group of PCTs, and typically undertake two sessions per week in their specialty.

14 GPs vary in their perceptions of what can be done for people with dementia



Source: National Audit Office survey of GPs (2006)

NOTE

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 can be a drain on resources with little positive outcome.

15 GPs' views on their ability to diagnose and manage dementia have changed over the past four years

| Statement | 2006 (%) | 2002 (%) |
|---|----------|----------|
| I have received sufficient basic and post-qualifying training to help me diagnose and manage dementia | 31 | 48 |
| I use specific tests and/or protocols to help me diagnose and manage dementia | 56 | 40 |
| I have ready access, when required, to specialist advice to help me diagnose and manage dementia | 62 | 60 |

Source: National Audit Office survey of GPs (2006) and Audit Commission (2002) *Forget Me Not: Developing mental health services for older people in England*

2.10 There can be particular problems for younger people. For some participants in our focus groups and web forum, their GPs simply did not believe they could have dementia because of their age. Diagnosis therefore took even longer with people incorrectly diagnosed with depression or other illnesses. The Alzheimer's Society was often the only recourse for help.

"My wife is 56 and is now in a nursing home. By the time the doctors diagnosed and referred her [to hospital] a lot of the damage was already done. Within months of being diagnosed she had to be sectioned." (Focus group)

"At one end you've got 'You're too young to have dementia', and at the other you've got 'you're 75, what do you expect?'" (Focus group)

Specialist services are often best placed to diagnose but these are patchy and roles are unclear

2.11 There is no international consensus on which specialty within medicine should take the lead in diagnosis and treatment of dementia or how such treatment should be delivered.ⁱⁱ In the UK the lead specialty that has evolved to diagnose and treat people with dementia is old age psychiatry. However, diagnosis and treatment might also be carried out by a geriatrician (e.g. if there is concomitant acute physical illness requiring admission to hospital, which is often the case), a neurologist (e.g. where the person is relatively young), or a GP (where the GP has a particular skill or interest in the area).

2.12 Where GPs themselves are not equipped to make a formal diagnosis, they should refer a patient to specialist services. This will most commonly be to the local old age psychiatric service if there is no local specialist Memory (Assessment) Service or Community Mental Health Team (CMHT). Where there is a Memory Service it may be run by old age psychiatric services or by other specialists in the diagnosis and care of dementia. The type and capacity of specialist services provided by mental health trusts varies: whilst practically all areas have an old age psychiatry team, if not a dedicated consultant, not all have a Memory Service or a Community Mental Health Team for older people (see Figure 7 in Part 1).

2.13 Less than two thirds of GPs we surveyed agreed they had access to specialist advice locally to help with diagnosing and managing dementia. But a quarter disagreed that specialist services are best at diagnosing dementia. Three quarters of GPs told us they were unaware of any protocol or guidance for diagnosis and management of dementia in their area, though local health communities should have had one in place by 2004, according to guidance promulgated by the Department.²⁴

2.14 One route into services and support is a CMHT for older people, a multidisciplinary team offering specialist assessment, treatment and care specifically to older adults with mental health problems in their own homes and the community. It may provide a whole range of community-based services itself, or be complemented by one or more teams providing specific functions. According to the Department's mapping exercise (2006)^{xxiv} there were 492 CMHTs in England, but their capacity and focus vary. In-reach support to general hospitals was provided by 48 per cent of CMHTs, 65 per cent offered psychological therapies and 80 per cent provided services to care homes. Our census revealed that many concentrate on those people with severe mental illnesses only and do not offer any services for those with mild or moderate dementia.

Memory services can be effective but vary in approach

2.15 Memory Services are a newer specialist approach to early diagnosis and intervention. These services have the advantage that they can see a large volume of patients more flexibly than say, CMHTs, or old age psychiatrists who have to respond to crisis situations as a priority. Memory Services can also help break down the barriers to diagnosis. For example, by calling themselves a "memory" service rather than a "mental health" or "old

age psychiatry" service (**Case Example 1**), by improving communication (**Case Example 2**) and by moving away from intimidating psychiatric or other hospital settings to a primary care environment (**Case Example 3**), they can be more approachable and reduce stigma.

2.16 The NICE SCIE guideline recommended that memory assessment services should be the single point of referral but did not define how they should be provided. According to the Department, they should provide early intervention to maximise quality of life and manage risk, offer home based assessment, give pre- and post diagnostic counselling, make use of specialist psychometric assessments and timely brain imaging for diagnosis, explain the diagnosis, give information about prognosis and options for care, provide advice and support and pharmacological treatment, follow-up and review.^{xxiv}

2.17 Memory services (often called memory clinics) vary considerably in size, approach and capacity. The service mapping exercise found 131 memory services (an increase from 58 in 2000^{vi}) of which 38 per cent were provided in a psychiatric hospital, 27 per cent in a CMHT and 16 per cent in a general hospital.

CASE EXAMPLE 1

Croydon Memory Service (CMS) has doubled the numbers of people with dementia assessed and helped overcome the stigma attached to referral for dementia

CMS is an integrated service within which ALL members of the team work generically to offer a comprehensive assessment, diagnosis and management service. This enables a high patient throughput with a doubling of the cases with dementia seen in the borough. 400 new assessments are carried out per year. Assessments are carried out with both the client and unpaid carer at their home and a plan is discussed at a multidisciplinary team meeting. Where necessary, further investigations are performed. A wide range of medical, psychological and social interventions are offered to help maintain an individual's independence and quality of life. The service runs a number of support groups and has specific initiatives focussed on people from minority ethnic groups so that 27 per cent of the service's clients are of ethnic backgrounds other than White British. The team is proactive in its relationship with GPs, it provides outreach work with various local groups and has a presence in the luncheon clubs and drop-in centres within Croydon.

When CMS was set up, it was called the Croydon Dementia Service for the first two weeks, and during this time received one referral. On changing the name to Croydon Memory Service, referrals began to flow in from all GPs in the area and there is now a very low refusal rate (4 per cent).

²⁴ The Department's Priorities and Planning Framework for 2003-06 required protocols to be in place by April 2004 across all health and social care systems for the care management of older people with mental health problems.

Nine per cent were located in a primary care centre and 14 per cent in other settings. Sixty-nine per cent of GPs in our survey said that they were able to work closely with a memory service, suggesting that coverage is improving. Variations exist because memory services have grown up locally in a piecemeal fashion, often directly in response to the licensing in 2001 of anticholinesterase drugs for Alzheimer's disease. Currently a clinic might offer a whole range of services or it might simply be a vehicle for prescription of medication. There is a need for some standardisation of these services in terms of capacity and content of assessment and care provided.

Use of different diagnostic tools can lead to inconsistency

2.18 There are many different screening and diagnosis tools in use and not all are suitable in all cases. For example, when patients are highly articulate or educated, the score on a particular cognitive screening test may under-represent their level of impairment. Therefore, these tests are not conclusive on their own; experience is needed in using them and scores should be looked at in conjunction with a person's history. Screening is only of use when capacity exists to make diagnoses in those screened positive. Our Lincolnshire case study found a wide range of screening tools in use in the acute sector. Mini Mental State Examination (MMSE) and (Abbreviated Mental Test) AMT were the most common assessments, but over ten other assessments were also in use. Ninety-seven per cent of CMHTs responding to our survey were using the MMSE regularly and 78 per cent were using physical assessments, but a significant proportion were also using other methods. GPs seemed more consistent, with 86 per cent using the MMSE. This underlines the need for specialists (e.g. old age psychiatrists or GPs with a special interest) to take the lead on diagnosing dementia.

2.19 The NICE/SCIE guideline recommended structural imaging (MRI or CT scanning) to exclude other cerebral pathologies and to help establish the type of dementia. In our census, 26 per cent of CMHTs used MRI scans regularly, while 66 per cent used CT scans regularly. Average waits were 10 weeks for MRI scans and seven weeks for CT. Half of CMHTs were waiting more than two months for an MRI scan and a quarter waited more than 2 months for CT. Some memory services pay acute trusts for scans whilst others have in-house facilities which may affect their use of scanning. NICE^{xv} estimates that the additional national cost of implementing its recommendation on structural imaging will be £20.22 million.

CASE EXAMPLE 2

Hampshire Partnership NHS Trust's use of specially trained memory nurses has improved efficiency and effectiveness

The Memory Assessment & Research Centre, Hampshire Partnership NHS Trust recruited three Memory Nurses following publication of the NICE guidance and the NSF for Older People. The role requires interpersonal and communication skills and ability to work with NHS staff at all levels.

Impact on service delivery: Capacity has been increased; waits for appointments in the Memory Clinic have reduced to 4 weeks; an additional 200 people can be seen and an additional 1,000 follow-up appointments can be undertaken each year; Memory Nurses are able to prescribe drugs and have a low average cost (£15 per contact versus £50 for a psychiatric staff member).

Impact on service users and unpaid carers: Memory nurses co-ordinate and facilitate the Memory Matters Carers' Education course and extended the service; and quantitative analysis showed that service users (78 per cent) and unpaid carers (91 per cent) are either very happy or quite happy for the memory nurse to be the main contact regarding dementia medication rather than a doctor.

Impact on staff and organisations: Increased communication and liaison with wider older people's mental health services.

CASE EXAMPLE 3

Newbury Memory Clinic offers holistic diagnosis and advice in the community and has helped improve attendance

The clinic is run in a GP Surgery by the mental health trust old age psychiatry team and includes a GP with a special interest in dementia, for one session a week.

The previous service was based at Sandleford Hospital and the number of patients not attending appointments was high. Since relocation, the numbers of missed appointments are very low. Older patients appreciate the pleasant setting in a modern GP surgery, where a baby vaccination clinic takes place at the same time as the memory clinic. Also, all appointment letters are copied to a relative or unpaid carer with the patient's permission.

A diagnosis of dementia at the clinic is immediately followed by a meeting with the memory clinic nurse who counsels the patient and unpaid carer and provides them with written information. They then meet with an adviser/counsellor from the local Alzheimer's Society, at which they receive advice, information and referral to a range of support networks and therapeutic activities.

There is scope to improve communication and support around diagnosis

2.20 Having a full awareness of one's condition provides a greater sense of control and empowerment to service users and unpaid carers.^{xxviii} However, we found a general lack of satisfaction amongst people with dementia and unpaid carers with the way diagnosis was communicated.

2.21 Sixty per cent of CMHTs said they did not always tell people with dementia the diagnosis, while 70 per cent of those who did, rarely or never set the diagnosis out in a letter. This means relatives/unpaid carers/others who may need to know about the diagnosis, cannot access all the relevant information. Neither can the person with dementia refer back to the diagnosis letter. Despite clear statements from Ministers²⁵ that 'doctor to doctor' letters about patients should be copied to them, this does not routinely happen.

2.22 Our focus groups and our earlier report, *Progress in implementing clinical governance in primary care: lessons for the new primary care trusts*^{xxviii}, both found widespread poor practice in providing copies of referral letters and proper written information for service users and unpaid carers. The Department's own 2006 Primary Care Patient Survey^{xxxvi} agreed. This is particularly important for people with dementia and unpaid carers who may find it difficult to keep track of appointments and their diagnosis and treatment plans without clear documentation.

2.23 GPs rated telling the patient the diagnosis as the third most difficult of 10 aspects of dementia care. Focus group participants were often disappointed in the manner in which GPs or specialists communicated the diagnosis.

"When we went to get the test results, the Professor at the hospital said to my husband, 'I'm afraid George,²⁶ you have lost your marbles'". (Focus group)

For a consultant psychiatrist to see all new cases would be very costly, but staff below specialist registrar are unlikely to have the experience to communicate well with older people who may have multiple communication difficulties and they should not deal with new cases unsupervised, though we are aware of this happening in practice.^{xxxvii}

2.24 Many service users and unpaid carers felt abandoned once a diagnosis was confirmed by their GP, just when they needed help and support to plan for the future. This lack of support may result in them dropping out of the

system that could help them. Unpaid carers and users want more constructive information on the disease, its likely progression and impact, and more support from the GP.

"Yes, you've got dementia. Take these tablets. There is the door." (Focus group)

"When your husband is diagnosed ... you suddenly realise that you've lost your future, you need support to come to terms with this." (Focus group)

"More information! You can't help if you don't know, and we don't have time to look for the information." (Focus group)

2.25 People with dementia and their unpaid carers told us they generally found information and support through voluntary services only. This is backed up by our survey of CMHTs, many of whom did not provide the information that might be expected (**Figure 16**). However, there is good practice (Case Example 3 on page 29) and the NICE/SCIE guideline^{viii} gives a list of the information that should be provided.

2.26 Our web forum also highlighted that people with dementia and their family carers do not feel sufficiently involved in the development of their care package. Thirty-seven per cent of respondents rated their involvement as poor whilst participants in our focus groups stated they did not feel like they were at the centre of their care, neither that they were listened to nor that they felt valued. The involvement of people with dementia and carers is very important in the delivery of good quality care.

Dementia may be diagnosed only after an acute event but there are barriers here too

2.27 A significant proportion of people with dementia may have their first contact with healthcare services when they suffer an acute health episode and present at A&E. A 1999 study found that 40 per cent of older patients who had been admitted to hospital following a hip fracture had dementia, but 27 per cent of these only had the condition diagnosed in hospital.^{xii} From our visits and interviews with professionals, it is possible that a proportion of these admissions may have been avoided, had an earlier diagnosis of dementia been made and led to appropriate care and precautions at home.

2.28 Mental disorder in the older population is an independent predictor of poor hospital outcomes, including increased mortality, increased length of stay, loss

²⁵ Most recently health minister Rosie Winterton (February 2007).

²⁶ Name changed to protect identity.

of independence and higher rates of admission to care homes. But diagnosis can often be missed in hospital too. Detection of cognitive impairment in medical units after admission, including those specifically for older patients, is very patchy – there appears to be significant under-diagnosis.^{xiii} Formal diagnosis of dementia in these wards is not seen as a priority, which denies patients access to possible drug treatment or specialist support, and would not be the case for a similarly serious physical complaint.

2.29 Our work in Lincolnshire suggested a typical picture – we identified mental health assessments on file in only 46 of the 111 patients with dementia. We found evidence of a number of cases (at least three per cent of the total beds surveyed) diagnosed only with confusion, yet who appeared to have all the characteristics of people with dementia (Appendix 6). Possible reasons for this include: a wish to avoid patients being excluded from intermediate or rehabilitative care and the incidence of vascular dementia, in which contact with specialist mental health services may be less effective as there is less possibility of specific treatment for the dementia.

2.30 The Faculty of Old Age Psychiatry^{xxxvii} and, more recently, the NICE/SCIE guideline^{viii} have recommended all inpatients suspected of dementia be assessed by a specialist old age psychiatric liaison service. Screening

would allow dementia or other illness to be identified and be incorporated into the patient's care plan.²⁷ Such old age psychiatric liaison teams are not available everywhere and they vary in resources, status in the hospital and costs. The Royal College of Psychiatrists identified at least eight different models.^{xiii} There are a number of possible reasons why the psychiatric liaison model is not more widely used. One is the lower priority that some acute trusts assign to funding mental health care. Mental health trusts may not feel funding liaison brings them any direct benefit and to date the evidence to support the approach from a cost-benefit point of view has been insufficient to change this.

2.31 The increasing prevalence of people with dementia makes it even more important that there is satisfactory evaluation, appropriate referral and treatment of cognitive impairment in acute hospitals. Dementia is core to the work of Geriatricians and they, in collaboration with colleagues in old age liaison psychiatry, need to play a key role in the diagnosis and management of dementia.^{xlix, xiii}

2.32 Older people with dementia often present to acute care with delirium and it is not unusual for this to be misdiagnosed as dementia.²⁸ Conditions such as delirium, depression and anaemia can be effectively treated and often occur with dementia, however the presence/diagnosis of dementia may lead to these conditions being overlooked.

16 Many CMHTs do not have a policy on various aspects of advice and information that NICE/SCIE guidelines suggest they should give out on dementia

Does your team have a policy to give people with dementia and their carers advice and information on the following, and if yes, is that policy always adhered to?

| Policy | Yes a policy exists and it is always adhered to % | Yes a policy exists but it is not always adhered to % | No policy exists % | A policy is currently being developed % | Don't know % |
|---|--|--|-----------------------|--|-----------------|
| Who to contact if they need help | 56.5 | 8.2 | 28.2 | 5.9 | 1.1 |
| How to get a review of a care package | 45.2 | 10.7 | 37.6 | 4.5 | 2.0 |
| Information about how to apply for continuing NHS care | 37.3 | 16.2 | 35.6 | 6.6 | 4.3 |
| Understanding what support networks are available | 33.2 | 8.5 | 47.9 | 7.6 | 2.8 |
| Understanding what financial entitlements or benefits there are | 33.1 | 11.7 | 46.6 | 4.9 | 3.7 |
| Understanding the options available for ongoing care in the community | 30.6 | 10.3 | 48.6 | 7.8 | 2.8 |
| Understanding the likely progression of the disease | 24.7 | 9.3 | 53.3 | 9.9 | 2.7 |

Source: National Audit Office census of CMHTs

27 Testing for confusion has been included in a forthcoming urgent care pathway for older people developed for the Department of Health. The report states that such testing should take place within the first three hours of an emergency response to allow sufficient time for appropriate action to be taken.

28 A new web-based BMJ Learning dementia module has been developed to help clinicians in the diagnosis of dementia and the distinction of conditions such as delirium. See www.bmjlearning.com.



Management of community care following diagnosis is disjointed and often ineffective

3.1 Some 360,000ⁱ older people with dementia in England – 65 per cent of the total – live in private households, some with relatives, others alone. They need varying levels of support from family and health and social care services to help them manage the condition and maintain the best possible physical and mental health. This Part examines how well health and social care services fulfil this role and the experience of people with dementia and unpaid carers in using them.

3.2 In the community, people with dementia face risks. For example, they may forget to switch off a cooker or turn off taps, risking fire or flood; they risk injury from wandering or falls and some may hurt themselves or be violent to others. Self-neglect is another risk – forgetting to take medication, to wash, eat or drink. Both statutory and voluntary/private sector services can help mitigate risks and keep people with dementia at home for longer, particularly if they work together. Assistive “telecare” solutions²⁹ can provide an essential component of support in enabling people with dementia to live more independently within their communities. Investment in such provision provides choices and alternatives to institutional care, however funding is means-tested and access is therefore variable.

GPs are now rewarded for monitoring patients with dementia

3.3 Under the new contract for General Medical Services³⁰, since April 2006 GPs have had a financial incentive to keep a register of dementia patients and review each case every 15 months. Seventy-six per cent of

GPs in our survey said they had a register and 79 per cent that it prompted them to review cases, though types of review varied widely. Seventy per cent of GPs said a lack of time during surgery visits prevented them doing as much as they would like for people with dementia. The registers are not accessible to others in the system such as the ambulance service, A&E or mental health trust. Clearly, registers can only benefit those who are diagnosed.

3.4 Forty-one per cent of GPs in our survey were unfamiliar with available services to support patients at home, whilst 21 per cent were unsure how to refer patients to such services. The lack of advice from the GP forces many to seek out support by themselves from voluntary organisations. Over half of our web forum respondents stated that few of the needs of the person with dementia were met by health and social care services. Thirty per cent of respondents felt this way, even when they tried to explain what they needed, while almost a quarter said they had no opportunity to explain to anyone what their needs actually were. Few respondents felt carer needs were met (37 per cent and 25 per cent respectively). Conversely, over 80 per cent of people with dementia and carers felt that support provided by charitable/voluntary services was satisfactory or better.

“There is nothing there – you have to go out and find it yourself.” (Focus group)

“It was the local Alzheimer’s [Society] branch who gave us a folder on services and benefits available.” (Focus group)

29 Telecare solutions can notify a carer if a person with dementia gets out of bed at night or leaves the house alone. Personal alarms allow a person with dementia to summon help if they fall.

30 Introduced 1 April 2004.

Support provided by CMHTs varies considerably

3.5 For ongoing care, the Department set a target for all communities to have an integrated (health and social care together) older people's CMHT by 2004. Coverage has increased since the Audit Commission reported in 2002^{xxxiv} but is not yet complete – only 56 per cent of CMHTs responding to our survey said they were integrated. The Department provided guidance on what skills ought to be available within a CMHT, but did not specify services, constitution, or funding, as had happened for community mental health services for working age adults in the Mental Health NSF. We looked at what CMHTs were doing in practice in 2006.

3.6 Many CMHTs currently focus their resources only on those people with severe mental health needs requiring intensive ongoing psychiatric care, and may not come into contact with the majority of people in the community with dementia. Our census revealed, on average, CMHTs have 275 people with dementia under their care but this varies from a range of 5 to 1500. With an average CMHT covering a population of around 22,000 over 65s, they should actually expect to find around 1,000 people with dementia in the community. The amount they spent per head of population aged over 65 ranged from £1.25 to £342. This suggests a very variable approach to targeting care but may also be indicative of variations in methods used to measure costs.

Some CMHTs lack key staff and clear care pathways

3.7 CMHTs did well on the requirement to provide a single point of access for users to contact – 98 per cent said they did give each client a named worker. However, on access to specialist skills they did less well. Good practice guidance, such as from the Faculty of Old Age Psychiatry (2004)^{xxxvii}, suggests that specialist teams should have access to community psychiatric nurses, occupational therapy, clinical psychology, social work and preferably also physiotherapy and speech therapy. **Figure 17 overleaf** shows that many teams did not have the recommended number of Whole Time Equivalent staff members in each specialism. Moreover, 25 per cent of CMHTs responding to the question had no social worker at all and 29 per cent had no access to a clinical psychologist.

3.8 Seventy-six per cent of CMHTs responding to us in 2006 had a defined care pathway for dementia and 87 per cent said they had an agreed protocol for diagnosis and treatment (against a target of 100 per cent by 2004). But in both cases, around half of CMHTs said that these were not always followed. The Single Assessment Process³¹ was to be introduced by April 2002 to bring together a coordinated approach to health and social care assessment for older people; nearly five years later it is still not in use nationwide with only 46 per cent of CMHTs who responded to our survey using it.

CMHTs cannot provide a full range of services in all areas

3.9 CMHTs could be in a good position to offer a range of effective services to meet the needs of people with dementia in the community. They may serve as a central contact for the person with dementia and liaise with all other parties on their behalf, with the named case worker ensuring records are kept up to date and accurate information passed on as appropriate. However, CMHT responses show that some cannot provide or cannot fund services such as meals on wheels, respite care, occupational therapy and day care (**Figure 18 overleaf**). Moreover, when asked specifically about structured group cognitive stimulation which is recommended by the NICE/SCIE guideline as an effective therapy for dementia, only 29 per cent of CMHTs said they were offering it regularly.

3.10 There are also particular problems for people with young-onset dementia. They often struggle to obtain a diagnosis of dementia and, once diagnosed, support services are either not available or they are not appropriate, with CMHTs highlighting this as the fifth most significant barrier to improvement.

“My wife said to me, ‘Why am I going out with very old people?’” (Focus group)

“My husband is 58 and I’m the sole carer. I had to give up work to look after him because of the lack of any facilities for younger people with dementia.” (Focus group)

31 The Single Assessment Process (SAP) was introduced in the NSF for older people, and aims to make sure older people's care needs are assessed thoroughly and accurately, but without procedures being needlessly duplicated by different agencies.

17 Many CMHTs do not have access to the recommended selection of skills

| Professional | Recommended no. of whole time equivalents (WTEs) ¹ | % of valid responses with the recommended WTEs |
|---|---|--|
| Social worker | 1.0 | 56 |
| Community psychiatric/mental health nurse | 2.5 | 55 |
| Clinical psychologist | 0.5 | 33 |
| Community support, or Support Time and Recovery (STaR) worker | 1.0 | 32 |
| Occupational therapist | 1.0 | 23 |
| Team leader/administrator/manager (if a separate team member) | 1.0 | 12 |

Source: National Audit Office census of CMHTs

NOTES

1 The Faculty of Old Age Psychiatry (2004)³ recommended the following core staffing for a CMHT per 10,000 over 65s: 2.5 wte Community Psychiatric Nurses (trained), 1.0 wte Support Workers or equivalent, 1 wte Occupational Therapist, 1 wte Social Worker, 0.5 wte Physiotherapist, 0.5 wte Clinical Psychologist, 1.0 wte Team Secretary/CMHT Manager.

2 Many community mental health teams did not have the recommended number of Whole Time Equivalent staff members in each specialism. Not all respondents provided a valid response to every question, so that the percentage of teams with at least the recommended WTEs may in fact be overstated.

3 The Royal College of Psychiatry (2004) *Raising the Standard. Specialist services for older people with mental illness*, Report of the Faculty of Old Age Psychiatry.

18 There are significant variations in the availability of community services for people with dementia

| If you saw a person with dementia today who needed one of the following interventions to support them to stay at home, would you be able to provide it at the level required? | No, service is insufficient funding to provide it | | | |
|---|---|--------------------------------|---|--------------|
| | Yes % | No, service is not available % | No, service is insufficient funding to provide it % | Don't know % |
| Community psychiatric/mental health nurse | 97.2 | 0.3 | 2.5 | 0.0 |
| Meals on Wheels | 82.5 | 11.1 | 4.2 | 2.2 |
| Occupational Therapy | 83.3 | 3.6 | 11.7 | 1.4 |
| Regular needs assessment | 78.7 | 7.8 | 5.2 | 8.4 |
| District nurse | 75.9 | 6.5 | 3.7 | 13.7 |
| Day care | 74.4 | 3.3 | 19.2 | 3.1 |
| Community support workers | 72.2 | 14.2 | 11.1 | 2.5 |
| Respite care | 66.6 | 6.2 | 23.2 | 4.0 |
| Specific home care provision from a dedicated team | 44.5 | 42.3 | 12.3 | 0.8 |
| Telecare | 34.2 | 31.6 | 10.6 | 23.6 |
| Extra Care Housing | 33.3 | 27.7 | 19.8 | 19.2 |

Source: National Audit Office census of CMHTs

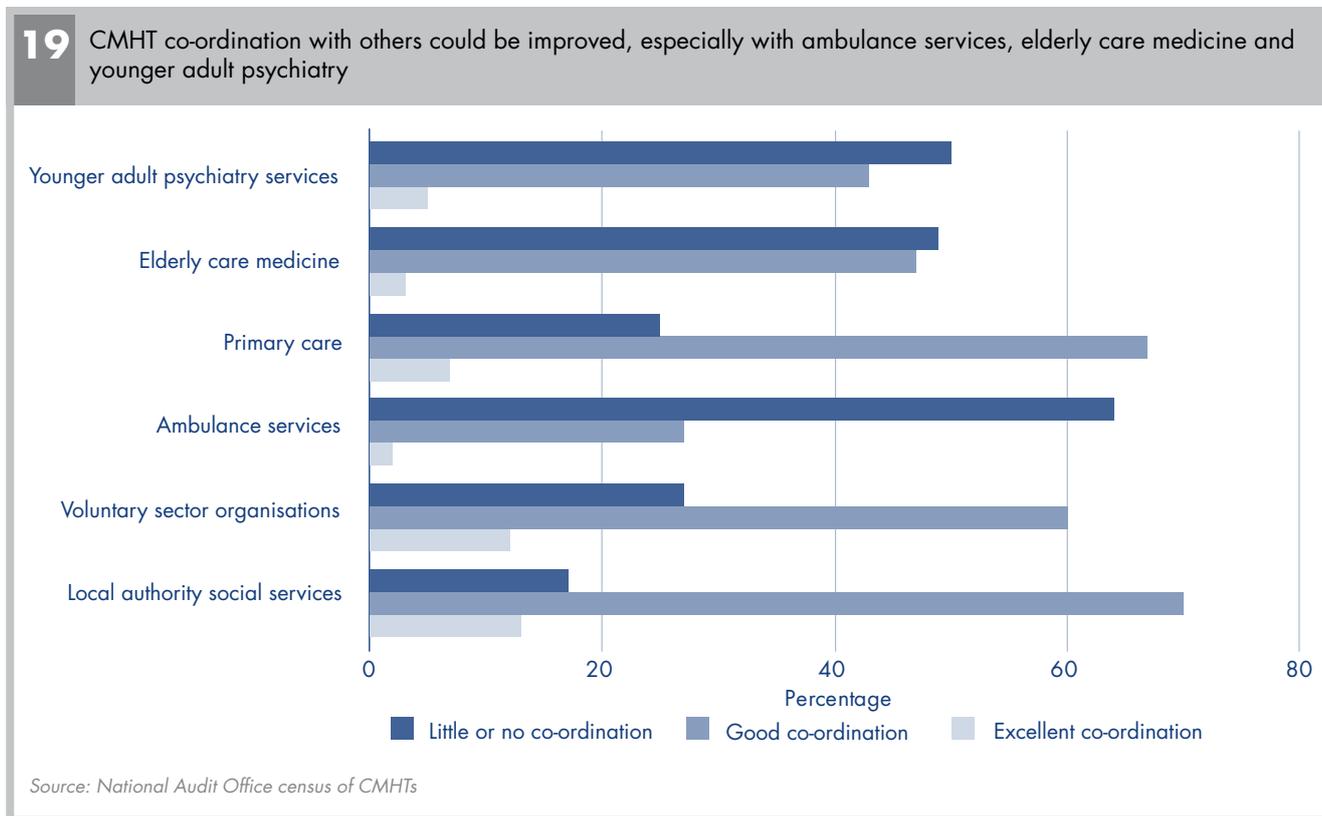
NOTE

Some community mental health teams do not provide or cannot fund important community support services such as meals on wheels, respite care, occupational therapy and day care.

Joint working by CMHTs with others could be improved

3.11 A quarter of CMHTs have little or no co-ordination with other primary care providers (Figure 19). Poor co-ordination means people with dementia, who are ill-placed to co-ordinate their own services, may not

be getting the appropriate care they need and may feel stressed and marginalised in dealing with the health and social care system.^{xxviii} The majority of teams also told us they do not have formal outreach with care homes, A&E departments or other acute specialties (Figure 20), though some have informal arrangements. The majority have informal arrangements with care homes.



20 CMHTs generally have more formal and informal outreach arrangements with nursing/residential care homes, than with acute specialties

| In providing services for people with dementia, does your team have outreach arrangements with ...? | Formal outreach arrangements % | Informal outreach arrangements % | None % | Don't know % |
|---|--------------------------------|----------------------------------|--------|--------------|
| Nursing/residential care homes | 29.1 | 58.8 | 11.2 | 0.8 |
| A&E departments | 19.0 | 25.2 | 51.6 | 4.2 |
| Other acute specialties | 23.6 | 29.9 | 37.6 | 8.8 |

Source: National Audit Office census of CMHTs

NOTE
Outreach arrangements may help with care co-ordination – these may be formal or informal arrangements and are more common with care homes than acute specialties.

3.12 Most CMHTs in our census reported using the skills of key voluntary sector groups locally (**Figure 21**). One scarce resource is the specialist dementia “Admiral nurse”. Admiral nurses are specialist mental health nurses who support people with dementia and their families, working with other health professionals to improve the experience of those affected by dementia, in a similar way to Macmillan nurses in cancer. They may also provide educational support to other professionals and promote best practice. They are part-funded by primary care trusts and social services and are also supported by the charity *fordementia*.³² Admiral nurses are employed in NHS Mental Health Trusts and/or Integrated Health and Social Care Trusts. There are only 45 Admiral nurses across the country (compared with 2,900 Macmillan nurses) and only 36 CMHTs responding to our survey (10 per cent) said they worked with one. It is important that all nurses have the skills and knowledge required to care for people with dementia, but Admiral nurses won particular praise in our focus groups and web forum as providing outstanding service and support.

“I have found the help given to us both through Admiral Nursing service to be invaluable, a real “lifeline” without which I couldn’t cope.” (Web forum)

Access to and quality of domiciliary care could be improved

3.13 Home care (domiciliary care) is a core service for many people living with dementia and their unpaid carers. The Commission for Social Care Inspection reported^{xvi} in 2006 that councils are restricting eligibility to services

as part of cost-efficiency measures. The Association of Directors of Adult Social Services³³ told us with higher numbers needing social care and an overall demographic increase in the over 85 population, the demand for resources from local government are increasing and adding to the existing pressures on services. This situation is mirrored abroad, with low level support virtually disappearing in some countries (Appendix 3). The Association also said the government has recognised that there is a need for a national debate on the future funding of adult social care services, but this will not alleviate the current pressures being experienced.

3.14 The Commission for Social Care Inspection has also been critical^{xvi} of the quality of care in terms of staff training, flexibility, consistency, time provided to each client and cost. The Commission found that, in part owing to poor relationships between councils and private providers, the domiciliary care sector was underdeveloped and ill-equipped to manage staff effectively. Thirty-six per cent of CMHTs in our census felt that domiciliary workers were inadequately trained with respect to treatment, care and support for people with dementia. Around two-fifths of CMHTs were providing informal training to local authority domiciliary care staff, agency staff and voluntary sector staff.

“It is a disgrace the way some home care workers treat people with dementia. These people should be fully trained in dealing with dementia.” (Web forum)

“Home care staff [are] always rushed – personal care [is] attended [to] as if on a conveyor belt. The person with dementia [is] not treated with respect.” (Web forum)

21 CMHTs make variable use of voluntary sector and other specialist staff

| Does your team make use of any other staff with specialist knowledge and skills, such as | Yes % | No % | Don't know % |
|--|-------|------|--------------|
| Alzheimer’s Society staff | 88.0 | 11.4 | 0.6 |
| Other voluntary bodies (such as Age Concern) | 91.9 | 8.1 | 0.0 |
| Admiral nurses | 10.2 | 86.7 | 3.1 |
| The regional Dementia Services Development Centres | 36.5 | 52.2 | 11.2 |
| Other | 43.4 | 35.5 | 21.1 |

Source: National Audit Office census of CMHTs

NOTE

The vast majority of CMHTs make use of voluntary bodies such as the Alzheimer’s Society and Age Concern. Few make use of Admiral nurses, which is likely to be due to the limited number of Admiral nurses (only 45 in total across the country) making access to their skills difficult.

³² *Fordementia* recently launched a support helpline, Admiral Nursing Direct 0845 257406, for people with dementia, their carers and professionals.
³³ Association of Directors of Adult Social Services (ADASS) is the successor organisation to the Association of Directors of Social Services (ADSS).

3.15 Skills for Care (part of the sector skills council for social care) told us they were aware of problems with:

- historically poor numbers of qualifications with a lack of incentives to gain further qualifications, for example, NVQs³⁴ (though they feel the situation is improving);
- the high number of home care staff without English as their first language, leading to communication problems. Communication skills are a requirement of the Common Induction Standards which all staff should complete, but communication problems are an issue despite this;
- poor pay and difficulties with recruitment and retention leading to high turnover; and
- a lack of continuity for people who are using the service. Unpaid carers have to explain their requirements repeatedly to new care workers and frequent changes can unsettle and distress people with dementia.

“Lack of continuity in the staff that visit my mum to give her medication causes her confusion.” (Focus group)

The General Social Care Council³⁵ will begin registration during 2007 for domiciliary and residential social care workers. The Council has recommended that on entry to the social care register, social care workers must gain a relevant qualification for their role within the first period of registration. However, this will not necessarily contain any dementia specific training which would be invaluable given the particular difficulties in communication for people with dementia.

Few people with dementia benefit from direct payments

3.16 More recent approaches such as Direct Payments³⁶ are designed to help social care users get more tailored, flexible services. Direct payments may be used, for example, to employ a live-in carer, which can be much cheaper than using an agency carer. However, take up is especially low among older people – only 9,000 people over 65 used a direct payment at some point in the year in 2005-06 compared to over 300,000 receiving state-funded home care.^{xxi} The rate is even lower in those with dementia, who find the system of direct payments confusing and onerous – complications include having to

manage on-costs such as employer’s national insurance, holiday and sick pay. However, local authorities should be able to put people in touch with organisations such as the Rowan Organisation, who provide a recruitment and payroll service and assist in the administration of direct payments and the employment of Personal Assistants. Some progress has been made in addressing the practical obstacles, for example payments can be made into an agreed third party’s bank account to be administered by a relative.^{xvi}

Services and support for unpaid carers are not always adequate

3.17 Without informal/unpaid (family) carers, the present system of care and support to people with dementia would be unsustainable, but caring can place a heavy burden on their own physical, emotional and mental health. Anyone over 16 who provides essential care for a friend or relative is entitled to a Carer’s Assessment under the Carers and Disabled Children Act 2000. The assessment, carried out by a social worker or a member of social services, enables the unpaid 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.

“I was told what was available and I grabbed it with both hands.” (Focus Group)

3.18 Social services use the assessment to decide what help to provide. They cannot refuse to meet an identified need solely on the basis of funding, but may set eligibility thresholds for their population according to the availability of resources. Our report on stroke services^{xxxviii} reported that less than half of unpaid carers had had their care needs assessed, whilst a Carers UK survey in 2003 put this figure even lower at only 32 per cent.^{xxxix} Those who do have an assessment do not always have that assessment followed up or have their needs met once assessed. The Commission for Social Care Inspection has criticised councils for having a “fragmented and limited” response to unpaid carers’ needs.^{xxi}

A social worker asked me the questions and filled it out for me but I never knew what it was for and never heard about it again. (Focus group)

34 Skills for Care have developed a “Knowledge Set” on dementia which assists employers in providing specific training on dementia. Skills for Care tell us their Dementia Knowledge Set is well used in the adult social care sector and provides a good model to improve understanding of dementia in other parts of the health and social care system. For details see [http://www.skillsforcare.org.uk/files/KS%20dementia%20main%20doc\(2\).doc](http://www.skillsforcare.org.uk/files/KS%20dementia%20main%20doc(2).doc)

35 The General Social Care Council (GSCC) is the social care workforce regulator and guardian of standards for the social care workforce in England. Established in 2001, it registers social care workers and regulates their conduct and training. (www.gsc.org.uk)

36 Direct Payments are cash payments made in lieu of social service provisions, to individuals who have been assessed as needing services. They were introduced in 2000 and councils were given a duty to offer them in 2003.

“There are no resources for the needs identified.”
(Focus group)

3.19 Good quality respite care (now referred to as short breaks), provided either by health/social services or the voluntary sector is one service of particular value to unpaid carers of people with dementia – it allows both people with dementia and unpaid 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, and can help people with dementia live at home for longer. Twenty-three per cent of CMHTs reported that whilst they had access to a respite service, funds were not available to provide it at the level required (Figure 18 on page 34). Over half of respondents to our web forum stated they did not receive enough respite care. For 17 per cent, no respite care was available at all when requested. There were also some concerns about quality. Similarly, over half (51 per cent) of web forum respondents felt the amount of day care provided to them was too little.

I would like more respite, but I can't afford it ... I would like more, so [my] health doesn't suffer. (Web forum)

You are told that there are no carers out there, there's no funding, you can't have respite care. (Web forum)

Respite shouldn't be offered to people for them to be put into an establishment with carers who have no training – it sets us back because they have had bad experiences. (Focus group)

3.20 Forty-one per cent of GPs in our survey said there was no carer support group in their area and a further 16 per cent did not know of one – hence 57 per cent were unable to offer unpaid carers anything. Since 2002 the proportion of GPs who agreed that “much can be done to improve the quality of life for carers of people with dementia” had declined from 84 per cent to less than two thirds.^{xxxiv} Over half of the carers responding to our web forum felt the support they had received from the NHS and social services was poor.

Crisis response for people with dementia could be improved

3.21 There is strong evidence that, for people with dementia, acute hospital admission can exacerbate their confusion, leading to further loss of independence and possibly precipitating entry to a care home, and should be avoided if not necessary.^{xl} Under the Department's Long Term Conditions Strategy, some patients with conditions

such as diabetes have agreed care plans that they keep at home, but this does not apply routinely in dementia even where there is a clear diagnosis. Without information on the patient's condition and a plan for dealing with such crises, it is difficult for services (e.g. ambulance service, NHS Direct) to avoid unnecessary hospital admission

CASE EXAMPLE 4

The Carers' Resource provides advice and support

The Carers' Resource (Craven, Harrogate and Airedale)¹ is an independent charitable company offering a direct point of contact for unpaid carers and professionals seeking information, advice, support, referral and advocacy. In January 2003, it was commissioned to provide a dedicated carer support officer (CSO) at the Harrogate and Rural District Memory Clinic Service, whose role is to:

Before each clinic: Obtain names and telephone numbers of patients from the psychiatrist's secretary and contact each patient/carer the day before or on the day of the appointment; explain what will happen at the appointment; and ask for a carer to accompany the patient.

At each memory clinic: Welcome the patient and carer; sit in with the psychiatrist whilst preliminary information is gathered; and take the carer into a separate room whilst the patient's assessment takes place.

In the next room: Explain what is going on next door; with the help of the carer, compile a list of skills lost and new behaviours of the patient for the psychiatrist's information; assess the carer's level of stress using a Strain Scale and highlight any areas that the carer would like the psychiatrist to know in confidence.

Joint discussion at the end: Rejoin patient and psychiatrist when they call and join in the general discussion about the psychiatrist's findings and possible treatment.

The CSO will also assess the patient for eligibility for Attendance Allowance or Disability Living Allowance; advise on accessing bursaries (such as training or hardship funds); discuss Power of Attorney; arrange home visit if wanted; provide reminiscence training, coping strategies and befriending services for the carer; and be available as a contact for future support (50 per cent of carers make contact at a later date). The set-up of the service enables longer-term follow-up by the staff, with re-referral into statutory services when appropriate. Appreciation for the service is expressed both by carers and healthcare professionals and the service believes its partnership working adds value and is cost-effective.

There are 129 carers' centres in the UK² providing carers with assistance, information, advice and advocacy as well as saving health and social care professionals' time.

NOTES

¹ See www.carersresource.org.

² For a complete list of Carers' Centres in the UK, see <http://www.princessroyaltrust.org.uk/map/>.

when presented with a patient who may not be able to communicate but who could be cared for appropriately at home if care details were available (**Case Example 5**).

3.22 Research^{xii,xli} shows that many³⁷ of the older people coming into acute hospital with pre-existing mental health problems (both dementia and depression) were previously unknown to mental health services. In our Lincolnshire case study, almost half of hospital patients with dementia had arrived at hospital following a 999 call. A fifth had sudden unexplained disorientation or unconsciousness, which may not necessarily indicate an acute health need in people with known dementia.

3.23 Once in hospital, people with dementia need special attention, for example to help them eat, which staff may not have the training or time to provide.^{xlii} A quarter of CMHTs provide formal dementia training to general hospital staff, whilst 38 per cent provide informal training. Overall, 59 per cent of CMHTs feel that dementia training amongst medical staff in acute secondary care is adequate, good or excellent, whereas half consider the training of secondary care nurses to be inadequate.

Discharge from hospital can be delayed by lack of alternatives

3.24 Our report, *Ensuring the effective discharge of older patients from NHS acute hospitals*^{xliii} in 2003, highlighted that older patients were more likely to experience delayed discharge and that lack of joint working and care home capacity were key factors. Delayed discharges overall have reduced significantly following the introduction of legislation to charge social services for delays. Where delayed discharge is still a problem, around half of those affected are people with dementia.^{xliiii} Our case study in Lincolnshire found that 68 per cent of people with dementia in acute beds had no further need to be there and that the average length of stay for orthopaedic patients with dementia was 44 per cent longer than for those without. Some 58 per cent of CMHTs said they worked with acute trusts to manage discharge and 61 per cent were aware of a discharge coordinator in each local acute trust.

CASE EXAMPLE 5

Sandwell health and social care economy has introduced “yellow folders” for some older people with dementia to improve management of crises

The primary care trust and local authority in Sandwell, West Midlands, have a joint policy unit which has developed a model for a care record that older people keep with them at home in a yellow folder. It contains care assessments and plans and was introduced as part of efforts to implement the Single Assessment Process. Some people with dementia use the system although it is not specific to dementia. It was developed in a bottom-up fashion with the involvement of older people. The ambulance service is fully briefed about the care plans and should ask to see them whenever they see an identifying sticker on the patient’s home telephone.

The community recognises that the challenge now is to increase uptake and recognition of the system across all health and social care providers, particularly acute trusts.

3.25 Intermediate care and rehabilitation beds, which could take patients who no longer need acute care, often explicitly exclude people with dementia. Over three quarters of CMHTs had five or fewer rehabilitation beds in their area for people with dementia. Over two thirds reported similar numbers of intermediate care beds.

3.26 Specialist mental health beds for older people might also be needed in a crisis for temporary stabilisation of older people who have severe behavioural issues. There is some evidence that these beds have been vulnerable to recent closures, without consideration of the wider system implications. The average number per 10,000 relevant population varies by a factor of 2.5 by strategic health authority^{xliv} and a third of CMHTs reported ten or fewer beds in their area, with three quarters having fewer than 20. We found Mental Health Trusts tend to reserve them for patients at earlier stages of their condition or with relatively few co-morbidities (Appendix 6). Whilst efforts have been made to integrate older people into mainstream mental health services, some dedicated beds are still needed – experts agree that older frail people are at risk in general mental health wards and their pattern of risk and need is different. Once again the acute general hospital is often the only option.

37 Holmes (1999)^{xii} found that 27 per cent of older people with dementia who had been admitted to hospital for a specific condition (hip fracture) only had their dementia diagnosed whilst in hospital.



There are opportunities to improve the quality and cost-effectiveness of the system's response to dementia

4.1 With a rapidly ageing population, overall expenditure on care and support for people with dementia will need to increase, regardless of future policy decisions about the way it is distributed between state and families. However, against this background there are clear opportunities to make better use of the existing and any future resources. This Part examines priorities for improvement in the management and delivery of dementia care and support, drawing on: published research; a self assessment by CMHTs of the relative importance of a number of identified barriers or bottlenecks and their achievement in addressing these barriers (**Figure 22**); and suggestions from people with dementia and unpaid carers in our focus groups (Appendix 4). It also draws together evidence on potential efficiency savings. The majority of these issues are about whole system working and therefore need to be tackled by a whole health and social care economy acting in concert.

There are now opportunities to achieve real joint working on dementia between health and social care

4.2 Because people with dementia need a complex mix of health and social care support to help them remain healthy and independent, dementia is a key test of the quality of local joint working. The need for good joint working has been underlined repeatedly in expert reports (Appendix 2), but continues to be a serious barrier for people with dementia.

"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." (Focus group)

"The carer is the coordinator – only I know what goes on each day." (Focus group)

CMHTs were particularly concerned about lack of joint funding as a barrier to improvement in dementia care and this is clearly linked to joint working (Figure 22). Sixty-four per cent of teams felt that better joint funding and 77 per cent that better joint working would result in either modest or major financial savings. Only 29 per cent of teams said they had any joint funding arrangements in place.

4.3 Initiatives to bring together health and social care locally, for example the development of joint "Care Trusts" or the use of Section 31 of the Health Act 1999 to set up joint services, have had limited success to date in integrating older people's mental health services. Negotiations on how much each party contributes can be drawn-out and difficult, especially when savings arising from expenditure by one party benefit only the other (for example, extra social care for people with dementia at home reduces crisis hospital admission), and it is relatively easy for parties to withdraw from agreements. Following reorganisation of Primary Care Trusts in 2006³⁸ there are now real opportunities to improve joint working, with many more coterminous Primary Care Trusts and local authorities in a position to make use of the framework provided by Local Area Agreements.³⁹

4.4 The Local Government and Public Involvement in Health Bill, which is currently going through Parliament, will create a new framework for Local Area Agreements from 2008. This, together with the requirement for all local authorities and Primary Care Trusts to undertake a "Joint Strategic Needs Assessment" of the health and social care needs of their population from April 2008, should provide an opportunity to increase the priority given to older people's mental health services.

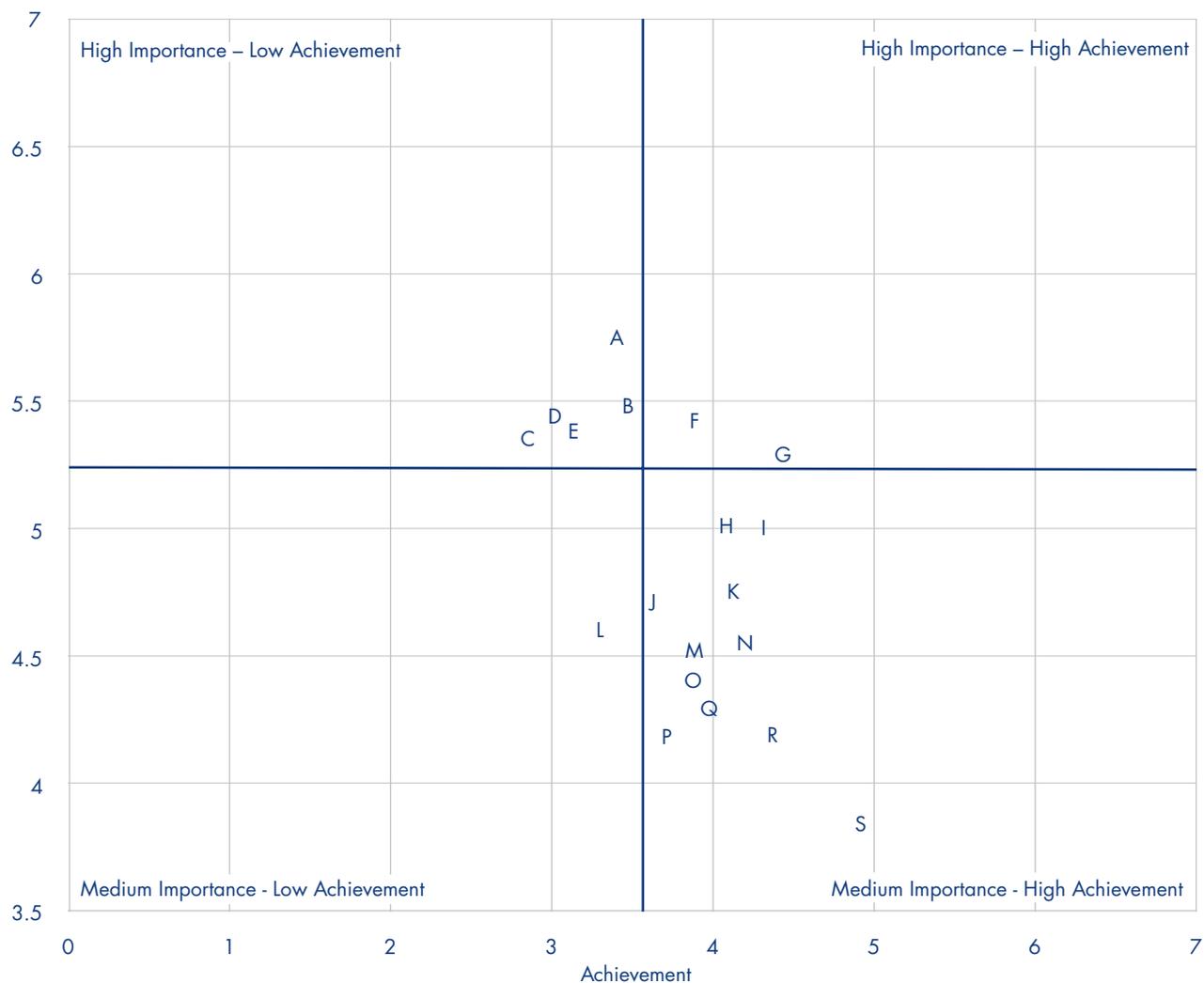
38 Through a programme of mergers, the number of Primary Care Trusts was reduced from 303 to 152 to bring them into line with local authorities and emergency services, and to release savings at the front line.

39 Local Area Agreements, introduced in 2005, set out the priorities for a local area, as agreed between local commissioners and providers of services in health, social care and local authorities.

22 Whilst CMHTs believe they are performing well in overcoming barriers of medium importance, their performance against those barriers deemed to be of higher importance is poorer

CMHTs rated all the barriers as being of medium to high importance (above 3.5 on average), hence the y axis starts at 3.5.

Importance



Potential barriers to improvement

- | | |
|--|---|
| A. Lack of care home beds/places | L. Lack of joint working between the management of acute and mental health trusts |
| B. Lack of social services respite places | M. Lack of joint working between geriatric and mental health specialities |
| C. Lack of joint funding between health and social services | N. Lack of a day hospital/outreach facilities |
| D. Lack of rehabilitation services | O. Lack of access to geriatric healthcare services |
| E. No services for young onset dementia | P. Inappropriate admissions to acute physical wards |
| F. Difficulty discharging from acute psychiatric wards | Q. Waiting time to obtain a MRI/CT scan (or other barriers to early diagnosis) |
| G. Lack of joint working between health and social care agencies | R. Inappropriate admissions to acute psychiatric wards |
| H. Poor understanding by GPs | S. No memory clinic |
| I. Poor understanding by social services | |
| J. Difficulty discharging from acute physical wards | |
| K. Lack of joint working between other organisations | |

Source: National Audit Office census of CMHTs

NOTE

Respondents were asked to rate how important they felt each factor was as a potential barrier or bottleneck to delivering effective care for people with dementia. They were then asked to indicate the current level of achievement in addressing each barrier in their area (1 being low and 7 high). Therefore the high achievement rating for S 'No memory clinic' implies that most CMHTs have access to such a function. The high importance rating given to the barrier C 'Lack of joint funding between health and social services' coupled with the low achievement rating would indicate that many CMHTs believe this to be an important barrier which is not being adequately addressed in their areas.

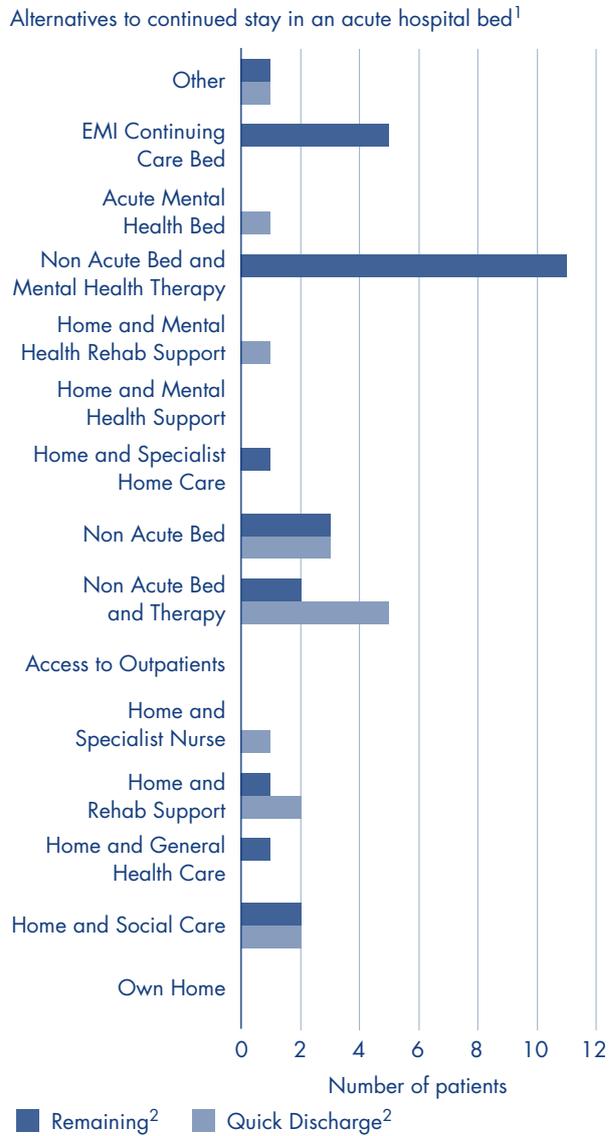
4.5 The Department has published the *Commissioning framework for health and well-being (2007)*^{xlv} for consultation. This develops the idea that bringing together partners using Local Area Agreements will help to “promote health, well-being and independence, by using contracts, pooling budgets and using the flexibilities of direct payments and practice based commissioning”. It also states that the Department of Health and the Department for Communities and Local Government will develop a single health and social care vision and outcomes framework. In addition, the Department is developing commissioning guidance for Older People’s Mental Health services.

A whole system approach at local level can provide the data to give dementia the priority it deserves

4.6 As a result of the low priority nationally, as well as poor quality information on local needs, health and social care economies in England have tended not to undertake any effective long-term planning for dementia care, in contrast to children’s services and working age adult mental health services which usually have five year strategic plans. However our whole system work on alternatives to acute care for people with dementia in Lincolnshire (Appendix 6) shows how a relatively quick information gathering exercise can provide data for health and social care commissioners to use in strategic planning. Our county-wide bed survey identified a wide range of potential alternatives to hospital admission for patients with dementia. With 68 per cent of dementia patients in the acute hospital no longer in need of acute care on the day we visited, we also identified a range of alternatives to continued stay on these wards (**Figure 23**).

4.7 The Lincolnshire community as a whole have agreed in principle new protocols and care pathways for people with dementia. Based on these they are developing plans to divert funding from unnecessary acute bed usage to new or redesigned intermediate care beds and home-based care, supported by specialist mental health services, which should provide better care for some 500 people with dementia a year and redirect a total of £6.5 million (a significant part of which will relate to dementia) to more appropriate services. This kind of exercise could be replicated relatively easily elsewhere and, in view of the importance assigned by CMHTs nationally to greater availability of care home, respite and rehabilitation beds (Figure 22), could identify significant opportunities for reconfiguration of services.

23 On the day of our Lincolnshire bed survey, many people with dementia, found in acute hospital beds, could have been cared for elsewhere



Source: Balance of Care Group case study for National Audit Office (2006)

NOTES

- 1 Health and social care staff undertaking our bed survey assessed that a range of alternative care settings would have been appropriate for people with dementia who were in acute hospital beds on the day of the survey.
- 2 ‘Quick discharge’ patients were transferred out of hospital within two weeks of the survey taking place. The remaining patients were still in hospital when we followed up after two weeks.

Earlier, effective intervention could save money and help families

4.8 Sixty-three per cent of CMHTs in our census felt that earlier diagnosis and intervention would generate financial savings for the taxpayer. One clear way of reducing costs for both families and the taxpayer is by delaying entry to care homes, which is very often precipitated by unpaid carer stress.

4.9 NICE estimates that there are 220,000 dementia carers with psychological distress^{xv}. If interventions to reduce unpaid carer stress could delay unplanned entry to residential/nursing home care of the people they care for, it could save lead to savings to the taxpayer and individuals since care home costs are the single largest component of dementia care costs. Ways of achieving this could include:

- The NICE/SCIE guideline recommended a range of interventions for people with early stage dementia^{viii}, including cognitive behaviour therapy, life review and memory improvement strategies. There is evidence that those receiving such therapies show measurable improvements in quality of life and behavioural disturbances and that addressing behavioural problems in the person with dementia is a significant factor in reducing unpaid carer stress.^{xiv} Based on data from Croydon Memory Service, the cost per head of providing these therapies in a memory assessment service would be between £150 and £380 per year, or a maximum of £190,000 for 1,000 people over six months.
- The NICE/SCIE guideline recommended that unpaid carers of people with dementia who experience psychological distress should be offered psychological therapy, including cognitive behaviour therapy, estimating that the national additional cost of this would be £27.36 million.
- Our census of CMHTs and our focus groups both supported increased spending on respite care and carers' support, with 75 per cent of CMHTs saying more home support would bring net savings. Lack of respite was the second most important barrier highlighted by CMHTs (Figure 22);

“Make the system more cost-effective by giving carers the correct levels of support and they will be able to manage at home for longer – in the long term it would save the Government money. Otherwise it’s a sticking plaster on an open wound.” (Focus Group)

4.10 There are other more intangible but no less important benefits from early diagnosis and support. Early diagnosis gives people the opportunity to make choices and plan for the future while they are still relatively well. This may include decisions about treatment and end of life care (including artificial feeding and resuscitation), the writing of wills and/or Advance Directives⁴⁰, setting up of Enduring Power of Attorney or the appointment of advocates.

Case management by Community Mental Health Teams could provide a framework for coordinated dementia care

4.11 Case management⁴¹ is an approach already in use for people with long term conditions such as diabetes.^{xlvii} There is evidence that, when it follows a comprehensive geriatric or multi-disciplinary assessment,^{xlviii} it can save money by preventing hospital admissions or enhancing hospital care and avoiding unnecessarily long stays. A written care plan is kept at the patient’s home for reference by any emergency care worker and formal care protocols are established for ambulance crew to follow. A good care plan may enable a crisis to be handled at home with appropriate care and support.

4.12 The British Geriatrics Society has proposed a dementia case register system^{xlix} with a shared care record, generated by the old age psychiatrist at diagnosis, that would be accessible to all others with whom the patient comes into contact. Currently this rarely happens, though some memory services retain and track patients after diagnosis. Our focus groups identified a “joined up approach to the delivery of care” with a “single point of contact for people with dementia and their carers” as key priorities (Appendix 4).

4.13 The wide variation in services provided by CMHTs (paragraph 3.5-3.11) suggests a need to clarify the role of CMHTs, their constitution and how they should be funded. If CMHTs shared information and clarified respective roles with their local memory assessment services, under the aegis of either Mental Health Trusts or Primary Care Trusts, they would be well placed to take on the role of case managing all those diagnosed with dementia. A named team member would act as “care navigator”, simplifying the system and reducing stress for unpaid carers and people with dementia, and ensuring that all professionals concerned are informed about the care package. The case management database could eventually be linked electronically, through new NHS IT arrangements, with dementia registers and records of physical health checks held by GPs.

40 Also known as Advanced Decisions. See Alzheimer Europe (2006) *The use of advance directives by people with dementia*.

41 Case Management is where a named coordinator, for example a Community Matron, actively manages and joins up care by offering, amongst others, continuity of care, coordination and a personalised care plan for vulnerable people most at risk.

4.14 While many patients with early stage dementia would require only minimal case management and would come through GP referral, others may be identified proactively through their interaction with health and social care services. Although all cases of dementia vary, there are some predictable risk factors associated with the condition such as falls, urine infections, challenging behaviour and wandering.ⁱ A new tool, the Combined Predictive Model⁴², has been used in other long-term conditions to help Primary Care Trusts identify which patients are most in need of case management, and could also be used in dementia.

Improved screening and management in the acute hospital can save money and improve outcomes

4.15 Even with effective case management, hospital admission will sometimes be needed, but prompt discharge is crucial to improving outcomes for patients. A range of models of psychiatric liaison within the acute hospital are in use.^{xiii} Acute trusts sometimes experience problems introducing such arrangements, owing in part to problems securing funding and in part to lack of acceptance by physicians and surgeons of the authority of non-medical staff. A whole system approach involving medical staff, such as the survey we undertook in Lincolnshire, could help with developing a shared understanding and acceptance of new measures.

4.16 As we found in our Lincolnshire case study, reducing unnecessary acute bed days for people with dementia can also release funds to provide intermediate home-based or bed-based solutions to which people could be transferred on discharge with specialist mental health support provided by the revamped CMHT. In a separate exercise we looked at just one condition common in people with dementia (hip fracture) to identify further scope for releasing funding nationally below.

As an example, better management of hip fracture with dementia could generate savings

4.17 Hip fractures (clinically known as fractured neck of femur) are common in the over-65s, accounting for more than 20 per cent of orthopaedic bed occupancy in the UK^{li}. Outcomes are poor, with mortality rates estimated at 31 to 33 per cent in the year following fracture.^{lii} The care home admission rate is estimated at 13 per cent of those previously living at home in the year following fracture.^{liii}

The Leeds hospital research^{xii, xli} suggests that length of stay and discharge destination in this situation are dependent on psychiatric status. Therefore mental health assessment and evaluation of psychiatric status is crucial to enable speedy and effective discharge, with the ultimate aim of returning as many patients to their previous dwellings as possible.

4.18 We commissioned consultants to examine the impact of psychiatric status on care experience in hospital following a fractured neck of femur and develop a model (Figure 24)⁴³. Our consultants identified two scenarios which result in shorter lengths of stay and better outcomes for people with dementia and cost savings to the NHS and social services (Figure 25). Application and actual savings achieved (Figure 26 on page 46) would depend on the availability of services in each health and social care community and will need integrated planning of intermediate and/or home based services. This sort of analysis could be extended to other acute hospital scenarios common to people with dementia.

Care homes need gearing up for the challenge of dementia through partnership with the private sector

4.19 Over 200,000 people with dementia are estimated to live in care homes, some 62 per cent on averageⁱ of all residents in such settings.⁴⁴ Around the world, rates of residential/nursing home care are falling relative to community care, because of factors including perceived quality of life in different settings, personal preference and cost.ⁱⁱ With people putting off entry into care homes until later, care homes are seeing more highly dependent people with severe dementia.

4.20 Most care home places are provided by the private sector, some by local authorities and some by the voluntary sector. In March 2007, there were 18,581 registered adult care homes offering 442,720 places of which 124,040 (less than 28 per cent)⁴⁵ were registered as specialist dementia places^{lv}, with significant geographical variations. These figures alone, when compared with the estimated prevalence of dementia, suggest under-diagnosis in care homes which may in some cases be deliberate. Providers have complained of barriers to becoming registered for specialist dementia care which can result in people having to move from one home to another when they are diagnosed, potentially very detrimental unless the care is vastly improved. The Commission for Social Care Inspection is currently addressing these issues.

42 The model integrates A&E, inpatient, outpatient and GP data to predict risk of admission to hospital across an entire patient population and identify people before their conditions deteriorate.

43 The full report is available at www.nao.org.

44 This figure will be higher in nursing homes.

45 It is possible for care homes to register one place under 'dementia' and 'dementia - 65 and over'. The number of dementia places stated here is a combined total for both these client groups and, therefore, will be an overestimate of the true number of dementia places available.

24 Experience of fractured neck of femur by psychiatric status – a macro simulation model (see Appendix 1)

| Care experience by psychiatric status for a total of 63,992 ¹ admissions for hip fracture in England in 2004-05 ² | Psychiatrically well | People with dementia |
|---|----------------------|----------------------|
| Fractured neck of femur admissions | 18,188 | 25,709 |
| Length of stay | 26 days | 43 days |
| Bed days | 480,000 | 1,110,000 |
| Expenditure on acute episode | £0.6 billion | £1 billion |
| Expenditure on post-discharge care: | | |
| Community health and social care | £37.4 million | £35.2 million |
| Residential care | £9.7 million | £15.5 million |
| Nursing home care | £5.2 million | £144.6 million |
| Outpatients | £390.8 million | £487.3 million |
| General Practitioner | £38.7 million | £48.3 million |
| Readmission | £19.8 million | £24.7 million |
| Likelihood ⁴ of dying in the six months following admission for hip fracture | 1 | 2.6 |
| Likelihood of being admitted to a care home following discharge | 1 | 17.84 |
| Likelihood of being fully discharged by the end of six months | 1 | 0.5 |

Source: Henderson et al (2007) *Maintaining good health for older people with dementia who experience a fractured neck of femur (report for the NAO)*

NOTES

- For ease of comparison only the psychiatrically well and people with dementia groups are shown here. The remaining 20,000 admissions (approximately) had either depression, delirium or another psychiatric illness on admission.
- Hospital Episode Statistics (2007) www.HESonline.nhs.uk.
- People with dementia who suffer a fractured hip spend longer in acute hospital, cost significantly more to care for (both during their stay and post discharge) and are more likely to die or be admitted to a care home following their discharge from hospital than a person who is psychiatrically well.
- Likelihood is between zero and one, where one is certain.

25 The Geriatric Hip Fracture Programme and Hospital at Home/Early Supported Discharge result in shorter lengths of stay and better outcomes for people with dementia and cost savings to the NHS and social services

Geriatric hip fracture programme

Involvement of the geriatric team begins in the orthopaedic unit, early after admission. Additional medical and nurse/therapist time is spent with the patient as well as social worker time to assess and manage needs. Frailer patients, previously living in the community, may be transferred to a rehabilitation unit, but those with less disability remain in the orthopaedic unit until able to return home. Evidence suggests this intervention can decrease the length of stay by 9 days on average per patient. Savings are also reported in the form of reductions in admissions to nursing homes of 10.5 per cent and a greater likelihood of patients returning to their previous residence.

Hospital at home/Early supported discharge

Recommended for people who were previously relatively fit and well, this approach may exist as part of a Geriatric Hip Fracture Programme. Selected patients are identified early in the orthopaedic unit and transferred home with a Hospital at Home package of care and a package of community health and social care services. No significant geriatrician input, but skills in assessment, discharge planning, community resources and coordination are required, with multidisciplinary staffing. The model draws on evidence that suggests that Hospital at Home package leads to a reduction in length of stay of 6.9 days per patient. The intervention is not always applicable for people with dementia, but assuming that only 45 per cent of the population with dementia would receive this treatment, the model still shows reductions in expenditure (4 per cent). Should all patients with dementia be suitable candidates, then savings are more significant. The saving is lower for those with dementia compared to the psychiatrically well as fewer patients with dementia (60 per cent compared to 90 per cent) will be able to be discharged home.

Source: Henderson et al (2007) *Maintaining good health for older people with dementia who experience a fractured neck of femur (report for the NAO)*

26 Estimated savings from use of the Geriatric Hip Fracture Programme and Hospital at Home/Early Supported Discharge

| | Psychiatrically well group (Annual cost estimated at £623m) | | Dementia group (Annual cost estimated at £1,037m) | |
|--|--|---|--|---|
| | £millions saved per year if applied across England | % reduction of base case expenditure ("usual practice") | £millions saved per year if applied across England | % reduction of base case expenditure ("usual practice") |
| Geriatric Hip Fracture Programme | 31–42 | 5–7 | 64–80 | 6–8 |
| Hospital at Home/Early Supported Discharge | 109 | 17 | 46–102 | 4–10 |

Source: Henderson et al (2007) *Maintaining good health for older people with dementia who experience a fractured neck of femur (report for the NAO)*

4.21 The Commission has also criticised local authorities for the quality of their commissioning of care home care, their focus on price at the expense of quality and partnership, and failure to develop a mature functioning market.^{xxi} Historically, there was no clear link between the fees charged and the quality of care. The Commission is to introduce a system to rate care homes on a four-star rating system in January 2008. They expect the new system to give care homes an incentive to improve standards and also to provide useful information for residents and relatives. The Commission is also trialling an innovative new observational approach designed to capture those personal, holistic aspects of care which have been hard to capture through traditional inspection methods.

4.22 Caring for people with severe dementia requires special skills including communication methods, pain management and stimulation. Specialist support from CMHTs, GPs or psychiatrists can help. There are some good examples (e.g. **Case Example 6**) but also evidence of poor practice. For example, the use of anti-psychotic drugs in patients with dementia who have behavioural problems is not recommended except in short-term management of high-risk situations, as they have serious side effects and may exacerbate dementia. Over a third of CMHTs in our census said anti-psychotics were used regularly in their area, even in patients with mild psychotic symptoms. A 2001 report^{lvi} found that over 40 per cent of people with dementia in care homes are prescribed neuroleptics. The Commission for Social Care Inspection has also highlighted poor practice in care homes' medicines management generally. In 2005-06, some 23 per cent (1,624) of complaint contacts made to the Commission related to care homes that were registered to care for people with dementia. Care practice, staffing and abuse (financial, physical, verbal, and sexual) were the three main causes of complaint.

CASE EXAMPLE 6

Extra care housing allows people with dementia to live as independently as possible

Methodist Homes Housing Association (part of MHA Care Group) founded the Moor Allerton Care Centre in Leeds in 2005. The Centre provides 70 one and two bedroom apartments and a dementia day care centre supporting a further 20 older people each day. Of the flats, 20 are specifically for older people living with dementia, 5 are for intermediate care in partnership with the Primary Care Trust and the remaining 45 are for older people with a range of care and support needs. This extra care scheme also includes a wide range of communal facilities including a restaurant, hair salon, craft room, lounges and meeting spaces.

MHA consulted with commissioners in the area to establish positive working relationships with local commissioners and to develop a service which fits well within broader local service strategies.

The service is committed to providing alternative care options that enable people to remain as independent as possible for as long as possible. High quality, flexible, responsive and person-centred care ensures well-being by meeting the physical, emotional, social and spiritual needs of service users. There is a range of service provision, adapted as required to meet services users' individual and changing needs, from simple social support to high levels of care and there is specialised support for people with dementia. Staff are well trained, the physical environment is designed to meet the needs of older people and people with dementia and activities are enjoyable and meaningful.

There is a supportive social community and good links with the wider community. For example the Centre has links with local faith communities to help tenants maintain their spiritual connections and there are links with local schools and voluntary organisations.

A recent evaluation of the centre by the regional dementia services development centre, Dementia North, was positive about all aspects of the service model, with service users and their family praising the facilities, staff and service.

4.23 The Department has identified new funding specifically for improving the quality of care for older people in care homes, including a £67 million grant which is being made available through the Dignity in Care campaign.⁴⁶ This offers an opportunity for commissioners and care homes to invest in lasting improvements to building fabric, staff training, links with expert support (such as from the local mental health team or voluntary sector) and systems and procedures, and to build these into the contractual framework for the future. The campaign also includes the development of a Dignity in Care Practice Guide to help support local people to improve dignity in care services and an online⁴⁷ network to help support people to work together to tackle local issues around dignity.⁴⁸

4.24 New models of housing-based care, such as extra care housing, are helping to maintain older people's independence. They can support people with dementia and provide flexible, often 24-hour, care arrangements for security and peace of mind.

There is now an opportunity to gear up end of life care for people with dementia by working with the Third Sector

4.25 The disease course of dementia is complex with many peaks and troughs. The end stage can be difficult to define, but is often deemed to begin when the patient experiences complete loss of mobility, loss of coherent verbal communication and ceases to feed. The NICE/SCIE guideline^{viii} states that dementia care should incorporate a palliative care approach (now referred to as End of Life Care) from the time of diagnosis until death. We found 16 per cent of CMHTs were providing palliative treatments regularly and 45 per cent occasionally.

4.26 There are very few bed-based services able to cater for the needs of those dying with dementia. Three quarters of hospice-based care is provided by the voluntary sector, who have traditionally focused on cancer patients. Some 95% of hospice patients have cancer. Care for people with end stage dementia is beginning to be better understood, but there is a lack of skill and understanding on the part of care home and community staff.^{xxii} Specialist expert advice on pain management, swallowing and bowel management can also help care workers avoid causing

pain and distress through unnecessary (and costly) hospital admissions – care homes may seek emergency hospital admission for residents who are dying, even though there may be little that medical intervention can offer. Advanced Directives can help by setting out the person's wishes, for example on resuscitation or artificial feeding.

4.27 A three year, £12 million End of Life Care Programme was announced at the end of 2003 to spread best practice with a specific work stream on end of life care in care homes. The Department is also developing a national Strategy for End of Life Care for all adults, regardless of condition. The needs of people with dementia will be incorporated into the strategy which is due to be published by the end of 2007. Examples already exist of supporting people with dementia to die at home with specialist support at potentially lower cost than in a care home (**Case Example 7**).

CASE EXAMPLE 7

Supporting people with dementia to die at home can be less costly than in a care home and with positive outcomes for the people and carers involved

The Hope for Home research project was undertaken between 2005 and 2006 in Greenwich and Bexley. Interviews were undertaken with 14 carers of people with dementia who were cared for at home in the months leading up to their death. The study found:

Advantages of home care at end of life stage:

- Positive outcomes for carers, who appreciated the opportunity for home care
- Financial savings: care cost £337,670 compared to £1.03 million which would have been spent on nursing home care – a saving of £697,000 shared between 14 patients
- Effectiveness of regular “key worker” input to support patients at home
- There is a need for carers to be able to request a visit from someone “for any reason or no reason” to enable support and access to the services required

Problems with home care at end of life:

- Poor GP availability and input
- Poor district nurse availability and input
- Access to the right equipment and care packages is patchy, and often happens because the family know someone on the “inside” of community health and social care provision.

46 At the request of the Department of Health, the Social Care Institute for Excellence has produced a Dignity in Care Practice Guide to support the wider initiative. See <http://www.scie.org.uk/publications/practiceguides/practiceguide09/index.asp>

47 <http://www.scie.org.uk/publications/practiceguides/practiceguide09/index.asp>

48 <http://www.dignityincare.org.uk>

Greater understanding of dementia and its care by public and professionals is a priority that can be addressed

4.28 Better general understanding of dementia and training for care staff would make a real impact on services and support, according to our focus groups (Appendix 4). The general perception of dementia may be seen as analogous to that of cancer in the 1950s, when there were few effective treatments and it was relatively common for patients not to be told the diagnosis to avoid distress. In cancer care today, the emphasis is on early diagnosis and treatment, and end of life care when appropriate. The shift came from a combination of technological advance, raised awareness and cultural change.

4.29 The stigmas surrounding mental health and older people's issues remain a significant barrier to greater awareness and openness about dementia. While the work of charities helps to highlight the suffering of people with dementia and their unpaid carers and raise funds, there is a low level of awareness about different dementias, treatment and what can be done to improve quality of life and independence for people with dementia. However, the ageing of the population has an increasingly high profile and a raft of work on older people's issues generally is ongoing. *A Sure Start to Later Life: Ending Inequalities for Older People* (2006)^{lvii} examined quality of life of older people and tackling exclusion. Age Concern and the Mental Health Foundation are jointly looking into *Mental Health and Well-being in Later Life*^{lviii} to raise awareness, create better understanding, influence policy and planning and improve services.

4.30 The Department announced in January 2006^{lix} a new "NHS Life-check" service to help people at critical points in their lives to assess their risks of ill-health and address them. This is still in development and piloting phase and does not currently include coverage of older people's mental health but, if piloted, could offer an opportunity for health workers, whether GPs or others, to discuss dementia with patients as a matter of routine, without stigma.

Reviews of generalist healthcare training offer the opportunity to reflect dementia needs in proportion to their importance

4.31 There is no compulsory undergraduate medical component on dementia or older people's mental health and very little general coverage. One leading medical school in England told us its medical course includes 12 days of psychiatry teaching in total, with none on older people at all. After qualification, GPs are required to complete a certain number of continuing professional development (CPD) hours each year, but there is no requirement to spend any of these on older people's mental health. The Royal College of Nursing told us most student nurses receive between two and five hours of teaching on mental health and older people which covers, in the main, dementia. But there is no requirement to do a minimum number of hours training on older people's mental health. Since older people with dementia are encountered in most healthcare settings this has the effect of producing a workforce that is not trained well enough for the job it has to do.

4.32 All professional, academic and voluntary sector stakeholders we spoke to agreed on the need to improve basic medical and nursing training in dementia, including young-onset dementia. Skills for Health⁴⁹, the UK sector skills council for health, is currently reviewing all National Occupational Standards, including those on mental health. It has yet to establish how to work with commissioners and workforce developers on how training and workforce development should respond to the ageing population, or develop new training on older people's mental health.

"Catch the students early who are going to deal with people with dementia and train them specifically about this." (Focus group)

49 Skills for Health aims to help the whole sector to develop solutions to deliver a skilled and flexible UK workforce in order to improve health and healthcare. It does not provide training directly but sees education and training providers as some of its key partners and seeks to influence education and training supply.

APPENDIX ONE

Main elements of our methodology

Outlined below are the main elements of the methodology used to produce this report. Whilst our surveys are focused largely on the healthcare side, the surveys included a number of questions about social services and we also consulted with the Local Government Association and the Association of Directors of Adult Social Services to gain their perspective.

Focus groups with service users and unpaid carers

We commissioned PricewaterhouseCoopers LLP to conduct three focus groups with people with dementia and unpaid carers to identify the:

- main issues affecting people with dementia and unpaid carers (in order of priority if possible);
- practical changes that could be made to bring improvements to the lives of people affected by dementia; and
- impact that such changes could have on the lives of people affected by dementia.

The focus groups were brought together with the assistance of the Alzheimer's Society and included a total of 20 people from both rural and urban areas across England, and both older people and those dealing with younger-onset dementia. Two groups involved unpaid carers and one involved people living with dementia (necessarily those with early-stage disease). The findings are used to illustrate and triangulate with other evidence, and the full report by PricewaterhouseCoopers LLP is available at www.nao.org.uk.

Web forum for service users and unpaid carers

We ran a web-based discussion forum for people with dementia and unpaid carers, asking them to tell us “what you would like Parliament to know about service for people with dementia” regarding a series of questions. The high level findings are used to triangulate with other evidence and a summary of the 174 responses is available at www.nao.org.uk

Survey of Community Mental Health Teams

Community Mental Health Teams for Older People (CMHTs) are a key mechanism for delivering services to people with dementia at local level. They are set up and managed at local level, by either Primary Care Trusts, Mental Health Trusts or possibly local authority Social Services Departments. In 2005-06, an exercise by Durham University's School of Applied Social Sciences, sponsored by the Department, identified evidence of some 492 such teams across England in the first ever attempt to map the delivery of services to older people with mental health needs. Following considerable reorganisation at Primary Care Trust level during 2006, many of these teams changed their names, merged, disappeared or were created anew. There was therefore no clear picture of how many teams remained in place in November 2006 when we sought to carry out a census using an online self-completion questionnaire, though we estimate that the number of responses we received (371) represents approximately 75 per cent of all CMHTs as at the deadline for responses of 22 December 2006.

The complete set of survey questions and a summary of responses are available at www.nao.org.uk and detailed results of the survey are to be compiled into a set of feedback reports for Community Mental Health Teams to facilitate benchmarking and improvement of services.

Whole system case study of provision for people with dementia in Lincolnshire

In designing the study we sought to examine the drivers and barriers faced by commissioners and providers of services at local level in responding as a whole health and social care system to the needs of people with dementia. To help us do this, we commissioned the Balance of Care Group to work with Lincolnshire's⁵⁰ whole health and social care community which includes Lincolnshire Partnership Trust (the mental health trust), Lincolnshire Primary Care Trust, United Lincolnshire Hospitals NHS Trust and Lincolnshire County Council's Adult Social Care Department. The focus of the project was a survey of bed utilisation covering acute medical and orthopaedic, community and intermediate, and inpatient mental health beds across the county. It created a snapshot of the ages, conditions and status of patient in these beds on a single date (29 November 2006) and, with a particular focus on those patients with dementia or suspected dementia, whether their care needs might have been met in an alternative care setting, either avoiding admission entirely, or through earlier discharge.

All the participating organisations were involved in discussion and interpretation of the results of the bed survey and a report of the conclusions was agreed. The Lincolnshire health and social care community have taken this forward into planning for older people's mental health across the county and are developing a costed action plan involving changes to the provision of bed-based and non-bed-based services. Appendix 6 gives more details of our findings; both the report of the Balance of Care Group's findings and the action plan are available at www.nao.org.uk; the results have been used to illustrate and interpret our national findings in this report.

Survey of GPs

We commissioned Doctors.net.uk (who provide internet services to some 142,400 doctors across the UK, to survey a cross-section of at least 1,000 of its English GP members with a range of questions covering their attitudes, awareness and practice regarding patients with dementia. In total 1,011 completed the survey, with at least 9 per cent of the total from each of eight English regions. As part of this survey, we drew on previous work by the Audit Commission in their reports *Forget me*

not – mental health services for older people, 2000 and 2002, and also on Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J and O'Carroll R (2004) GPs' knowledge, confidence and attitudes in the diagnosis and management of dementia, *Age and Ageing*; 33: 461-467 (which developed a knowledge quiz for GPs). We sought to compare levels of awareness and attitudes in 2006 with those measured previously. The results are used through the report, the knowledge quiz results from 2004 and 2006 are at Appendix 4.

Analysis of data on GP practice in relation to dementia

As the Quality and outcomes framework requirement on GPs to keep a register of patients with dementia and their reviews of these patients was put in place only in 2006, we had no access to data on the performance of GPs in this respect. We therefore commissioned the General Practice Research Database (GPRD)⁵¹ to extract and analyse data on the reported incidence and prevalence of dementia in GP practice populations from 1990 to 2006. The aim was to identify variations between the reported prevalence and incidence and that which would be expected according to an expert consensus of the actual numbers in the population of England. The results are used in Figure 13.

Modelling of care management for people with dementia and fractured neck of femur in acute hospital

To understand the cost implications of extended stays in acute hospital for people with dementia, as well as the possible strategies to improve their management and outcomes, we commissioned a review and costing exercise from the London School of Economics Personal Social Services Research Unit (PSSRU). We decided to examine the case of a person with dementia who has fallen and suffered a fractured neck of femur (broken hip), which is a common condition affecting older people, especially those with dementia. Some 64,000 people a year are admitted to hospital with a fractured hip and of these around 40 per cent also have dementia. PSSRU constructed a macro-simulation model⁵² to compare a base case of "usual care" with different potential good practice scenarios and identified the financial implications of each. They tested their model and scenario assumptions

50 We were looking for a health and social care community which was aware that its dementia services could be improved and which was seeking to make those improvements. Lincolnshire became aware of our work through the Care Services Improvement Partnership (CSIP) and approached the NAO to volunteer to take part in the case study exercise.

51 GPRD is a database collecting detailed anonymised longitudinal records on patients at 450 primary care practices across the UK for research purposes and is managed by the Medicines and Healthcare products Regulatory Agency.

52 A macro-simulation model builds a picture of the world using aggregate data, starting with the population of interest and separating it into groups with relevant characteristics. Relevancy is determined through analyses of the characteristics that influence, in this case, receipt of services and expenditure. Receipt of services and expenditure are simulated by attaching probabilities, for example probability of receipt of services to each group.

with the assistance of a group of experts in geriatric psychiatry, psychiatric nursing, orthopaedic surgery and ortho-geriatrics.

Interviews with key stakeholders

We met with numerous stakeholders in the field of dementia, including in the Department of Health, NHS, voluntary sector, private care home sector, patient and unpaid carer groups, clinical and social services national representative bodies.

International comparisons

We commissioned the London School of Economics and Political Science (Personal Social Services Research Unit or PSSRU) to produce a comparative report between 14 countries on: demographic patterns, attitudes towards dementia, approaches to diagnosis, funding arrangements and availability, range and balance of services, role of informal carers, role of voluntary sector and government services, programmes/services in place. The results are used in the report and at Appendix 3; the summary report is at www.nao.org.uk.

Good practice visits

We visited a number of good or notable practice sites including memory services, care homes, a carers' resource centre and a hospital liaison team.

Consultation and working with others

We brought together a Steering Group of representatives from other national bodies with an interest in the subject of dementia, to help guide our study. This included the Royal College of Psychiatrists' Research and Training Unit (Dr Tim Kendall, Deputy Director); National Collaborating Centre for Mental Health (Dr Catherine Pettinari, Centre Manager); National Institute for Health and Clinical Excellence (Julie Royce, Associate Director – Implementation Support, and Elena Terol Sabino, Implementation Adviser); Social Care Institute for Excellence (Amanda Edwards, Head of Knowledge Services); Healthcare Commission (Amanda Hutchinson, Head of Long Term Conditions and Older People Strategy, and Dr Andy Barker, Consultant in Old Age Psychiatry and Senior Clinical Adviser to the Healthcare Commission on Older People's Mental Health); Commission for Social Care Inspection (Rachel Ayling, Programme Director of Organisational Change, and Penny Banks, Head of Information and Reporting).

We also consulted at key stages of the study with the 27 expert members of the NICE/SCIE Dementia Guideline Development Group, including service user and carer representatives, who are not listed here but can be found at <http://www.nice.org.uk/page.aspx?o=guidelines.inprogress.dementia>.

We liaised with the Alzheimer's Society and London School of Economics and Political Science (Personal Social Services Research Unit) (Professor Martin Knapp) as they prepared their report *Dementia UK*, which was published in February 2007.⁵³ And we collaborated with the Royal College of Psychiatrists' Research and Training Unit team (Dr Paul Lelliott and Professor Martin Orrell) who were commissioned by the Healthcare Commission to scope a new national clinical audit of dementia care.

Additional key contributors to our work to whom we owe grateful thanks include:

Martin Orrell, Professor of Ageing and Mental Health, Department of Mental Health Sciences and London Centre for Dementia Care, and Associate Medical Director, Mental Health Services for Older People, North East London Mental Health Trust.

Dr Steve Iliffe, Reader in General Practice, Royal Free and UCL Medical School, and Principal in General Practice, Lonsdale Medical Centre, Kilburn, London.

Mrs Barbara Pointon, who cared for her husband Malcolm for 15 years and is an inspiration to others.

Sube Banerjee, Professor of Mental Health and Ageing at the Institute of Psychiatry, Clinical Director of Mental Health in Older Age, South London and Maudsley NHS Foundation Trust, and Senior Professional Adviser on Older People's Mental Health to the Department of Health.

Dr John Holmes, Senior Lecturer in Liaison Psychiatry of Old Age, University of Leeds.

Professor David Challis, Director of the Personal Social Services Research Unit, University of Manchester.

Mr Peter Ashley, who has dementia with Lewy Bodies and provided us with the valuable perspective of a person with dementia.

53 Knapp et al. (2007) *Dementia UK: A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK*, Kings College London and London School of Economics.

APPENDIX TWO

Key publications on dementia

| | | |
|-----------|---|---|
| Sep 1999 | <i>National Service Framework for Mental Health</i> , Department of Health | Set out national standards, service models and priorities for improvement. Covered only adults up to age 65. |
| Jan 2000 | <i>Forget me Not: developing mental health services for older people in England</i> , Audit Commission | Reviewed older people's mental health services across England and Wales. Found wide variation in practice and resources with specialist help patchy and uncoordinated. Recommended: more active identification by GPs and support from specialists; information and help for carers; improvements to specialist services; improvements to home-based services, day care and respite care; better support for staff in care homes; improved management of multidisciplinary community mental health teams; a shared vision and better coordination of health and social care services locally. |
| Mar 2001 | <i>National Service Framework for Older People</i> , Department of Health | Launched a ten year programme of improvement for older people's services against eight standards. Standard 7 covered mental health in older people and stated that people should have access to integrated mental health services to ensure effective diagnosis treatment and support for them and carers. Explicitly mentions dementia as an area needing early identification and treatment. |
| Feb 2002 | <i>Forget me Not 2002: developing mental health services for older people in England</i> , Audit Commission | Updated previous report that had set out the Audit Commission's analysis of mental health services for older people in England and Wales, underlining the continuing need for improvement against the 2000 recommendations. |
| Mar 2005 | <i>National Service Framework for long-term conditions</i> , Department of Health | Set 11 quality requirements for services to support people with long term conditions, including person centred care, early recognition and diagnosis, appropriate emergency management, community support, attention to special needs in hospital, palliative care, support for carers. Focused mainly on neurological conditions other than dementia. |
| July 2005 | <i>Securing better mental health for older adults</i> Professors Philp and Appleby, National Directors of Older People's Services and Mental Health | Position statement from the National Directors for Older People and Mental Health. Launched a new initiative to join forces across mental health and older people's services, recognising that separately they had not met the challenges |
| Nov 2005 | <i>Everybody's Business – Integrated mental health services for older adults: a service development guide</i> Department of Health and Care Services Improvement Partnership | A guide describing the key elements of a comprehensive older adult mental health service, designed to inform local discussions on commissioning. |
| Dec 2005 | <i>The State of Social Care in England, 2004-2005</i> Commission for Social Care Inspection | The first comprehensive overview of social care in England. While many aspects of social care continue to improve, it found many people were still not getting a good deal. Councils needed to work more closely with providers to drive up quality and avoid short-sighted cost-cutting that resulted in people unnecessarily admitted to hospital. Better support for carers should be a high priority. This was followed by the <i>State of Social Care in England 2005-2006</i> . |

| | | |
|-----------|---|--|
| Jan 2005 | <i>Who Cares Wins</i> , British Geriatric Society & The Royal College of Psychiatry | Drew attention to the neglected clinical problem of mental disorder affecting older people admitted to general hospitals. Called for the development of specialist liaison mental health services for older people, based on the best available evidence. |
| Sept 2005 | <i>Delirious about dementia: towards better services for patients with cognitive impairment by Geriatricians</i> , British Geriatrics Society and Faculty of Old Age Psychiatry, Royal College of Psychiatrists | Defines how geriatricians can play a more integral role in the recognition, diagnosis and management of patients with dementia. Presents a model for the care of patients with dementia that focuses on the role geriatricians play in the fully integrated care pathway. Demonstrates how this ideal may be achieved through small changes that can be effected locally. |
| Mar 2006 | <i>Securing Good Care for Older People: Taking a Long-Term View</i> , Derek Wanless for the King's Fund | Review of social care commissioned by the King's Fund from Sir Derek Wanless. Sought to determine how much should be spent on social care for older people in England over the next 20 years and what funding arrangements need to be in place to ensure that this money is available and will produce high-quality outcomes. On dementia specifically, it highlighted the need for better information on costs, service and numbers affected, need for increases in trained care staff and good quality care in care homes and suggested that ring-fenced funding may be helpful. |
| Mar 2006 | <i>Living Well in Later Life, a review of progress against the National Service Framework for Older People</i> , Healthcare Commission, Audit Commission and Commission for Social Care Inspection | Progress in some areas but still further work to do. Still evidence of explicit discrimination in mental health services for older people which are not as developed as those for working age. All aspects of mental health services for older people needed to improve. Committed to a joint review of older people's mental health services (which has since been de-prioritised). |
| Apr 2006 | <i>A new ambition for old age: Next steps in implementing the National Service Framework for Older People</i> Department of Health | Sets out priorities for the second half of the 10 year National Service Framework for Older People under three themes: Dignity in Care, Joined-Up Care and Healthy Ageing. Consists of ten programmes driven nationally (one of which is mental health in old age). |
| May 2006 | <i>Supporting people – promoting independence</i> , Commission for Social Care Inspection | Reviewed the impact that the Government's Supporting People programme had had on the lives of social care service users in terms of allowing more to live independently. Found that many people had benefited where high performing councils had used the programme to improve joint working with housing and health services. But older people had received the least amount of grant despite making up the largest group in the programme. Development of "extra-care" housing for older people had generally excluded those with mental health needs. Step-down support was not sufficiently developed. More information about the programme needed to be provided to users and advocacy services that assist people. |

| | | |
|----------|--|---|
| Aug 2006 | <i>Raising the Standard. Specialist services for older people with mental illness</i> , The Royal College of Psychiatry: Report of the Faculty of Old Age Psychiatry | Made a wide range of recommendations to improve services for older people's mental health including the need for a higher priority to be given to the topic by the Department. Also addressed training in older people's mental health issues, mental health liaison services in acute hospitals, community services and the development of fully comprehensive old age psychiatry services in all localities. Its recommendation on incentivisation of GPs to record and monitor patients with dementia was implemented in 2006. |
| Nov 2006 | <i>Dementia: supporting people with dementia and their carers</i> , National Institute for health and Clinical Excellence and Social Care Institute for Excellence | Guideline making recommendations to health and social care services on best practice in the identification, treatment and care of people with dementia and the support of unpaid carers, and the most cost-effective interventions. Based on a review of all relevant up to date research and advice from a range of experts. |
| Jun 2006 | <i>Inquiry into Mental Health and Well-Being in Later Life</i> , Age Concern and Mental Health Foundation | The first of several reports from an independent inquiry into mental health and well-being in later life. Recommends action to remove the barriers that prevent older people from participating in society. Encourages local authorities to take a lead role in partnership with the NHS, voluntary organisations, business representatives, community groups and individuals to develop programmes that promote positive mental health and well-being in later life. |
| Feb 2007 | <i>Dementia UK</i> , Alzheimer's society with King's College London and London School of Economics | An overview of the prevalence and cost of dementia in the UK. Establishes an estimate of the numbers of people in the UK who currently have dementia, and trends expected to 2051. Estimates Current and future costs of dementia and makes recommendations for future dementia care. |

APPENDIX THREE

International comparisons

The London School of Economics Personal Social Services Research Unit (PSSRU) report examined comparative information and data from: Australia, Canada, Denmark, Germany, France, Italy, Ireland, Japan, the Netherlands, New Zealand, Norway, Spain, Sweden, USA and the UK.

Demography and prevalence

The numbers of older people will increase substantially over the next fifty years in all countries covered by the report, although rates of ageing will vary greatly. In England, between 2002 and 2041, there will be an 80 per cent increase in the numbers of people aged 65 and over. However, such long demographic projections carry a substantial degree of uncertainty, and may underestimate numbers of very old people.

The rate of growth in the elderly population in England is expected to be noticeably higher than in Denmark, Germany, Italy and Sweden; very similar to projections for France, Netherlands, Scotland and Wales; but slightly lower than projections for Spain, Ireland and Northern Ireland.

The number of people with dementia aged 60 or above in Western Europe is estimated to grow from 4.9 million in 2001 to 6.9 million in 2020 and 9.9 million in 2040. The proportionate increase between 2001 and 2040 (102 per cent) in Western Europe is considerably lower than in all other regions of the world except eastern European countries with high adult mortality.

According to the PSSRU long-term care projection model, demand for long-term care is likely to increase substantially over the next three decades and beyond. To keep pace with demographic pressures, between 2002 and 2041, there would have to be massive increases in the number of occupied care home places; the number of home care hours and long-term care expenditure.

Approaches to diagnosis

While there are few differences between countries in the underlying prevalence of dementia, the ways in which diagnosis and care are provided by formal health and social services and the rate of diagnosis and treatment vary widely. There is no international consensus on which specialty within medicine should take the lead in diagnosis and treatment or how such treatment should be delivered. There is consensus that diagnosis should be made as early as possible.

27 The older population (65 years and older) is predicted to increase significantly across Europe

| European Country | Older (65 years and over) population | | |
|------------------|--------------------------------------|--------------------|---------------|
| | 2005 (millions) | 2050 (millions) | Change (%) |
| Ireland | 0.5 | 1.4 | 180 |
| Northern Ireland | 0.2 | 0.5 | 150 |
| Spain | 7.3 | 15.4 | 111 |
| Norway | 0.7 | 1.4 | 100 |
| Netherlands | 2.3 | 4.3 | 87 |
| England | 8 | 14.8 | 85 |
| Wales | 0.5 | 0.9 | 80 |
| France | 9.9 | 17.7 | 79 |
| Scotland | 0.8 | 1.4 | 75 |
| Denmark | 0.8 | 1.3 | 63 |
| Sweden | 1.6 | 2.5 | 56 |
| Italy | 11.6 | 17.8 | 53 |
| Germany | 15.5 | 22.4 | 45 |

Source: Knapp et al. (2007) *Dementia: International Comparisons report for the National Audit Office*

NOTE

England will see an 85 per cent increase in its older population by 2050, similar to the Netherlands, almost twice as much as Germany but just under half of that in Northern Ireland. The biggest increase will be in Ireland, where the older population will increase almost three-fold.

Financing arrangements

All countries covered by this review have increased the resources devoted to long-term care over recent years, but they are also wrestling with the challenge of how to finance long-term care services over the coming decades. There is still heavy reliance on pre-payment financing which is not related to actual or expected service use, and which redistributes in favour of less healthy, poorer and older people. Most but not all countries have some means-testing of services.

The boundary of the health and social care systems can be problematic when financing arrangements differ. Budgetary restrictions in some countries have led to long waiting lists for some services. Within the overall cost of dementia, the burden falling on families has generally been found to be substantial. Expenditure patterns generally show a move away from spending on institutional care in favour of community-based services.

Differences between England and other parts of the UK in per capita expenditure, per capita provision and unit cost for residential and nursing homes, home care and day care are quite marked.

It is difficult to identify expenditure exclusively in dementia programmes. **Figure 28** below gives OECD estimates for public and private expenditure on broad long-term care as a percentage of GDP in 2000. Total expenditure ranges from a low of 0.60 per cent of GDP in Italy and 0.61 per cent in Spain, to in excess of two per cent in Scandinavian countries.

Services

A common theme in relation to policy across all countries is the balance between institutional or care home and home-based care. Home care services in many countries are being transformed from traditional home help models to personal care. For older people in general, the OECD (1996) found movement towards convergence around a level of roughly five per cent of older people supported in institutional settings, ranging from below 1 per cent (in early 1990s or late 1980s) in Greece to above 6.5 per cent in Canada, the Netherlands, New Zealand and Norway. In contrast, the study found that countries varied much more in the provision of home-based care (home help, meals, day care, community nursing etc). For example, no more than five per cent of all older people in Austria, Germany,

28 Public and private expenditure on long-term care as a percentage of GDP (2000)

| | Total expenditure | | | Public expenditure | | | Private expenditure | | |
|--------------|-------------------|--------------|-------------|--------------------|--------------|-------------|---------------------|--------------|-------------|
| | Home care | Institutions | Total | Home care | Institutions | Total | Home care | Institutions | Total |
| Sweden | 0.82 | 2.07 | 2.89 | 0.78 | 1.96 | 2.74 | 0.04 | 0.1 | 0.14 |
| Denmark | | | 2.6 | | | | | | |
| Norway | 0.69 | 1.45 | 2.15 | 0.66 | 1.19 | 1.85 | 0.03 | 0.26 | 0.29 |
| Netherlands | 0.6 | 0.83 | 1.44 | 0.56 | 0.75 | 1.31 | 0.05 | 0.08 | 0.13 |
| UK | 0.41 | 0.96 | 1.37 | 0.32 | 0.58 | 0.89 | 0.09 | 0.38 | 0.48 |
| Germany | 0.47 | 0.88 | 1.35 | 0.43 | 0.52 | 0.95 | 0.04 | 0.36 | 0.4 |
| USA | 0.33 | 0.96 | 1.29 | 0.17 | 0.58 | 0.74 | 0.16 | 0.39 | 0.54 |
| OECD average | 0.38 | 0.88 | 1.25 | 0.35 | 0.64 | 0.99 | 0.06 | 0.19 | 0.24 |
| Canada | 0.17 | 1.06 | 1.23 | 0.17 | 0.82 | 0.99 | n/a | 0.24 | 0.24 |
| Australia | 0.38 | 0.81 | 1.19 | 0.3 | 0.56 | 0.86 | 0.08 | 0.25 | 0.33 |
| France | | | 1.1 | | | | | | |
| Japan | 0.25 | 0.58 | 0.83 | 0.25 | 0.51 | 0.76 | 0 | 0.07 | 0.07 |
| New Zealand | 0.12 | 0.56 | 0.68 | 0.11 | 0.34 | 0.45 | 0.01 | 0.22 | 0.23 |
| Ireland | 0.19 | 0.43 | 0.62 | 0.19 | 0.33 | 0.52 | n/a | 0.1 | 0.1 |
| Spain | 0.23 | 0.37 | 0.61 | 0.05 | 0.11 | 0.16 | 0.18 | 0.26 | 0.44 |
| Italy | | | 0.6 | | | | | | |

Source: Knapp et al. (2007) *Dementia: International Comparisons* (report for National Audit Office)

NOTE

With total expenditure of 1.37 per cent, the UK has the fifth highest level of total expenditure on home care and institutions as a percentage of GDP (public expenditure is seventh highest and private expenditure is second highest). Total expenditure is significantly higher in Sweden, which spends 2.89 per cent in total.

Ireland, Italy, Portugal and Spain were receiving home help at the time of the study, compared to more than 10 per cent in Denmark, Finland, Norway and Sweden. There has generally been deliberate targeting of resources on people with the greatest needs, particularly through intensive home care packages. 'Low-level support' has virtually disappeared in some countries.

The largest provider in the care of older people in all countries studied here is the 'informal sector' – families, neighbours and community groups that offer support without funding or charging. The availability of informal care heavily influences the level and type of need for formal care for which resources must be found.

Attitudes towards dementia

Comparative data on attitudes towards dementia across countries were largely unavailable. Some evidence is summarised below.

The Eurobarometer surveys of public attitudes to ageing and older people found a remarkably high level of solidarity across the European Union countries and suggested that 'the social contract⁵⁴ is in good shape' (Walker 1993). **Figure 30** summarises how people felt about older people's standards of living.

29 The Facing Dementia Survey (2004) collected data across European countries and found that the UK was the worst performer on all the following criteria

| | France | Germany | Italy | Spain | UK |
|--|--------|---------|-------|-------|----|
| Time taken (in months) to diagnosis of Alzheimer's disease after symptoms first noticed | 24 | 10 | 14 | 18 | 32 |
| Proportion of carers (%) reporting physicians recommended treatment at time of diagnosis | 83 | 78 | 85 | 86 | 51 |
| Proportion of carers (%) who believe governments do not invest enough in Alzheimer's disease | 80 | 77 | 65 | 82 | 87 |
| Proportion of doctors (%) who agreed that early treatment can delay progression of Alzheimer's disease | 92 | 87 | 91 | 86 | 68 |

Source: Knapp et al. (2007) *Dementia: International Comparisons* (report for National Audit Office)

30 Percentage of respondents in 12 European Union countries in 1992 agreeing with the statement: 'Those in employment have a duty to ensure, through contributions or taxes, that older people have a decent standard of living'

| Country | Agree strongly | Agree slightly | Disagree | Don't know |
|----------------|----------------|----------------|----------|------------|
| Denmark | 60.1 | 29.8 | 8.3 | 1.8 |
| United Kingdom | 45.9 | 37.2 | 9.3 | 7.5 |
| Spain | 45.7 | 38.1 | 7.2 | 9.1 |
| Netherlands | 42.4 | 38.2 | 13.8 | 5.6 |
| Portugal | 41.2 | 32.3 | 17.8 | 8.7 |
| Ireland | 40.7 | 40.9 | 7.5 | 10.9 |
| Greece | 39.4 | 35.0 | 12.5 | 13.1 |
| Italy | 38.4 | 40.1 | 9.6 | 11.1 |
| Luxembourg | 34.2 | 44.8 | 14.0 | 7.0 |
| Belgium | 32.5 | 42.7 | 17.9 | 6.9 |
| Germany | 30.4 | 48.4 | 15.0 | 6.2 |
| France | 25.9 | 51.2 | 17.6 | 5.3 |

Source: Knapp et al. (2007) *Dementia: International Comparisons* (report for National Audit Office)

54 The social contract is interpreted as being a social policy contract based on intergenerational transfer of resources through taxation and social expenditure.

APPENDIX FOUR

Focus group recommendations and priorities

Our focus groups identified a number of areas where people with dementia and their unpaid carers would like to see changes, summarised below.

| Area for change | Detailed recommendation which participants believe would have an impact on their lives |
|---|--|
| Programme to increase awareness and understanding of dementia amongst the general public | Introduction of a programme to inform and improve the general public's understanding of the impact and effects of dementia |
| Improvement in the length of time for a correct diagnosis | Promotion of a timely diagnosis process with specific training to assist GPs in achieving a correct diagnosis as early as possible |
| Provision of a relevant information pamphlet on the day of diagnosis | Information should be easily accessible through most health and social care professionals and available as soon as diagnosis has occurred. In particular, clear information should be provided in relation to the following areas as soon as possible after diagnosis: <ul data-bbox="799 1167 1366 1429" style="list-style-type: none">■ Managing finances;■ Preparation of wills;■ Practical advice about finances and entitlements;■ Information on how the disease will progress;■ Information about local services; and■ Information about services which are free and those that require a fee. |
| Improved promotion and awareness of existing services | Provide tailored and flexible care services, in particular, to suit the needs of those aged 50 to 60 years who have dementia |
| Development of tailored care provision for service users aged between late forties and late fifties | Improve co-ordination and integration between service providers and the promotion of increased interaction between such providers and unpaid carers for individuals with dementia |
| Provision of a smaller and more consistent team of care home staff | Consider providing each individual with dementia with a single point of contact (this person would provide support and information to both the person with dementia and their unpaid carer) |
| A joined-up approach to the delivery of care | |
| Identification of a single point of contact for all people with dementia and their unpaid carers | |

| Area for change | Detailed recommendation which participants believe would have an impact on their lives |
|--|---|
| Provision of more flexible services to meet the needs of users and their unpaid carers | |
| Provision of carer support groups | Consider implementing local networks to enable unpaid carers to share their experiences; this could be through formalised carer support groups being in place |
| Greater provision of respite care facilities | Improved focus and support for the carer assessment process including the actual implementation of identified support to meet carer needs, for example phone support, respite care, talking therapies etc |
| Increased carer allowance | Specific dementia care training for health and social care staff in line with their roles and responsibilities; |
| Providing dementia care training consistent with roles and responsibilities | At Governmental level, maintain an ongoing review of funding and latest research into the provision of dementia services |
| Increasing Government funding towards staffing and development of further services | Review existing documentation and forms to apply for services and benefits to determine if simplification and further assistance in their completion can be provided |
| Simplification of forms for benefits and services | Continuation of Alzheimer's drugs to newly diagnosed individuals |

APPENDIX FIVE

GP knowledge quiz results

| Question (correct answer in bold) | Correct responses | |
|---|-------------------|-------------------|
| | 2004 ¹ | 2006 ² |
| A general practitioner with a list of 1,500–2,000 people can expect to have the following number of people with dementia on their list: | 38% | 38% |
| A. 1–6 | | |
| B. 7–11 | | |
| C. 12–20 | | |
| D. 21 or more | | |
| By 2021, the prevalence of dementia in the general population in the UK is expected to: | 11% | 30% |
| A. Decrease slightly | | |
| B. Remain approximately the same | | |
| C. Increase slightly | | |
| D. Nearly double | | |
| One of the risk factors for the development of Alzheimer’s disease is: | 58% | 59% |
| A. Hardening of arteries | | |
| B. Age | | |
| C. Nutritional deficiencies | | |
| D. Exposure to aluminium | | |
| Which of the following procedures is required to definitely confirm that symptoms are due to dementia? | 21% | 20% |
| A. Mini-Mental State Exam | | |
| B. Post mortem | | |
| C. CAT scan of the brain | | |
| D. Blood test | | |
| Which of the following sometimes resembles dementia? | 69% | 25% |
| A. Depression | | |
| B. Acute confusional state | | |
| C. Stroke | | |
| D. All of the above | | |

| Question (correct answer in bold) | Correct responses | |
|--|-------------------|-------------------|
| | 2004 ¹ | 2006 ² |
| Which of the following clinical findings best differentiates vascular dementia from Alzheimer's? | 71% | 82% |
| A. Word-finding problems | | |
| B. Short-term (2-minute span) visual memory loss | | |
| C. Stepwise disease course | | |
| D. Presence of depression | | |
| Which statement is true concerning the treatment of dementia patients who are depressed? | 72% | 53% |
| A. It is usually useless to treat them for depression because feelings of sadness and inadequacy are part of the disease | | |
| B. Treatments for depression may be effective in alleviating depressive symptoms | | |
| C. Anti-depressant medication should not be prescribed | | |
| D. Proper medication may alleviate symptoms of depression and prevent further intellectual decline | | |
| Which of the following best describes the functions of the Alzheimer's disease Society? | 55% | 69% |
| A. Central research, information and campaigning role | | |
| B. Provision of local support and education to carers | | |
| C. Providing day and home care for dementia patients | | |
| D. All of the above | | |
| Overall average scores | 49% | 47% |

NOTES

1 Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J and O'Carroll R, (2004) General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia *Age and Ageing*; 33: 461–467.

2 NAO survey of GPs (2006).

APPENDIX SIX

Whole system case study in Lincolnshire: identifying alternatives to hospital for people with dementia

The aim of the project, led by consultants the Balance of Care Group, was to explore the potential for changes in care pathways for people with dementia, and identify potential changes to service provision across health and social care services. We are grateful to the four participating health and social care organisations in the county (Lincolnshire Primary Care Trust, United Lincolnshire Hospitals NHS Trust, Lincolnshire Partnership Trust and Lincolnshire Adult Social Care) for volunteering to provide the setting for the case study, which was intended to be illustrative of the issues faced across England. The full report of findings and the county's action plan are at www.nao.org.uk.

The central focus of the project was a survey of a total of 863 adult inpatient case notes which was carried out with the help of health and social care professionals across Lincolnshire on 29 November 2006. The patients surveyed were in a range of places but included all those in:

- medical and orthopaedic beds in acute hospitals (667 patients);
- intermediate care placements in community hospital and care homes (121);
- specialist inpatient beds for older people with mental health problems (75); and
- any 'outlier' patients of these specialties were also included.

The surveyors used a recognised clinical benchmark tool, the Appropriateness Evaluation Protocol (AEP) to identify patients whose care might not require an acute hospital setting – these are referred to as being “outside AEP criteria”. The AEP is an instrument which provides criteria for evaluation of current care practice. Originally

developed in the USA, it has been adapted and validated for use in the UK and Europe.⁵⁵ A similar approach to identifying alternatives was also used in looking at patients in the specialist mental health and intermediate care settings but the protocol was different in these cases.

Key overall findings were:

1. Age of patients

The average age of patients included in the survey was 76. Of the 863 patients surveyed, 715 (83 per cent) were aged 65 or over; 63 per cent were over 75.

2. Location of patients with dementia

Thirteen per cent (111) of all patients had a documented diagnosis of dementia. Most were on acute hospital wards (**Figure 31**).

31 Most patients with dementia in our survey were located on acute hospital wards

| Location of patients with dementia | Percentage (number) |
|---|---------------------------|
| Acute hospital wards | 59 per cent (65) |
| Specialist older people's mental health units | 36 per cent (40) |
| Intermediate care (community hospitals, care homes) | 5 per cent (6) |
| Total | 100 per cent (111) |

Source: Balance of Care Group analysis for the National Audit Office

⁵⁵ Lang T, Liberati A, Tampieri A, Fellin G, Gosalves M, Lorenzo S, Pearson M, Beech R, Santos-Eggiman B (1999) A European version of the Appropriateness Evaluation Protocol, *International Journal Technology Assessment in Health Care*, 15 185-197; Goddard M, McDonagh M, Smith D (2000) *Annex E: Avoidable use of beds and cost-effectiveness of care in alternative locations* cited in Department of Health (2000) *Shaping the Future NHS: Long Term Planning for Hospitals and Related Services: Consultation Document on the Findings of the National Bed Inquiry – Supporting Analysis*. (London, Department of Health).

Overall 59 per cent of dementia patients had two or more comorbidities, indicating the presence of long term conditions and possible issues of frailty. Patients with dementia in specialist mental health units tended to be younger than those in acute hospital or intermediate care, and have few other medical problems, indicative of the focus on treating mental rather than physical conditions. Less than 10 per cent of these patients had mobility problems. Moreover, although there is no formal bar to people with dementia accessing intermediate care, in practice the emphasis on relatively rapid access to rehabilitation services, or a period of recuperation, militates against accepting more complex dementia patients with multiple comorbidities. So, overall, the frailest and sickest patients with dementia were on the acute wards.

3. Diagnosis of dementia

We found evidence of substantial under diagnosis or under-recording of dementia. Possible reasons include a wish to avoid patients being restricted from accessing some care settings, and the incidence of vascular dementia, which may not result in previous contact with specialist OPMH services.

We found evidence of a mental health assessment for only 46 of the 111 patients with dementia. It is likely that some assessments were not available because either a standard proforma was not used (the key findings being incorporated in other medical notes) or the proforma was not held with the main notes. Despite the low numbers, the Balance of Care Group's experience suggested that the use of assessments was higher than in hospital populations surveyed in the past.

The incomplete nature of the mental assessment documentation, coupled with some of the data regarding behavioural characteristics of patients, indicated that there might be substantial numbers of patients with dementia in all settings that had not been diagnosed, or the diagnosis omitted from the notes. Some 23 of 105 (21 per cent) intermediate care patients were assessed as "confused", indicating that some might have undiagnosed dementia, or the diagnosis had been withheld to avoid prejudicing access to rehabilitation. (There was some anecdotal evidence for the latter.) The Balance of Care Group's clinical advisers therefore reviewed all 119 patients

with mention in their notes of confusion, and classified them into groups at high, medium and low risk of having dementia. This was based on:

- Age.
- Mental health Assessment scores.
- Potentially linked comorbidities e.g. vascular disease.
- Confusion on admission that was still present on the day of care.
- Whether the confusion could have a toxic cause e.g. urinary tract infection.

Thirty (25 per cent) of those reviewed were at "high risk" of dementia – most of these would normally be given a dementia diagnosis on the basis of the information in the notes alone. It is probable that some of the 38 "medium risk of dementia" patients would also have been diagnosed with at least moderate dementia. Of the high risk group, eleven were intermediate care and all but one had only a single comorbidity. This suggests that patients with clear but not formally diagnosed dementia may be cleared for an intermediate care bed despite their mental health problems if it is felt that wider frailty issues are not too unmanageable.

4. Potential for avoiding admissions

On the day they were admitted to the acute hospital, 16 per cent of patients were outside AEP criteria – in other words, the evidence suggested they could have been cared for in a non-acute setting.⁵⁶ For those patients with diagnosed dementia, the proportion was similar (17 per cent).

One feature that differentiates the dementia admissions from others is the extent of admissions that relate to a single AEP criterion, 'sudden onset of unconsciousness or disorientation'. This reason for admission particularly applied for patients with no or few comorbidities, and in these cases it may be that some of these admissions could have been avoided if it was known patients had dementia but not other conditions. Altogether 14 acute admissions with dementia (21 per cent) fell into this category. For the 17 acute patients with confusion identified as being 'high risk' for dementia a similar pattern could be observed. Only 2 of the 17 'high risk' patients (12 per cent) were outside AEP criteria, but a further 7 (41 per cent) were admitted with sudden onset of unconsciousness or disorientation.

⁵⁶ Note that this does not imply that 16% of all admissions would be outside AEP criteria: within a point prevalence study the patients surveyed will be disproportionately those with longer stays, and as shown above they will tend to be frailer older people with complex health and social care needs, and more likely to be admitted outside AEP criteria.

The application of acute care criteria to the patients in specialist mental health beds was to establish the level of medical needs over and above any needs associated with the patient's mental condition. The figures, not surprisingly, indicate much smaller proportions of patients requiring acute medical care, suggesting that very few patients had 'mainstream' medical conditions.

Surveyors identified those for whom alternative care locations might, in retrospect, have been possible if relevant services had been available and suggested a wide range of services, not all of which are currently available locally (**Figure 32**). For acute patients only, we did not look for alternatives if the patient was within AEP admission criteria.

5. Potential for earlier discharge of patients

Analysing the care patients were receiving on the day of the survey (as opposed to the day on which they were admitted), those in the acute hospitals with dementia were more likely to be outside AEP criteria than other patients without dementia (68 per cent against an average of 49 per cent). In other words, having dementia made these patients much more likely to remain in acute hospital when they no longer needed to be there, compared with other patients. One specific indicator was the experience on orthopaedic wards, where the average length of stay of dementia patients surveyed (all of them non-elective) was over 24 days, compared to under 17 days for other non-elective orthopaedic inpatients.

Surveyors identified a wide range of potential alternative care settings for these patients (**Figure 33 on page 66**). In most cases the need appeared to be for some intervention to ensure these patients are able to access the same care and treatment services outside hospital as people without dementia.

6. Alternatives to hospital care

The needs of those patients with dementia who could have been cared for in non-acute settings were disparate, covering a range of home-based and bed-based services. The wide range of alternatives identified, mostly involving access to mainstream services, suggests that one of the major issues for dementia patients is arranging access to services that may only have limited experience of caring for people with dementia. The key is ensuring that these

patients do not get 'left behind', since it is always more straightforward for generalist services to deliver care needs for the mainstream: there is therefore potential for support from in-reach specialist mental health teams to ensure the generic services are available as required. Over half of those with dementia in the acute hospital also required either some, or constant, supervision, which is not the case for other acute patients. This means that any alternatives provided needed to be designed to work with people with dementia.

There were two specialist services for which substantial demand appeared to be completely unmet locally: non-acute, bed-based therapy delivered by staff with relevant training in care of dementia patients; and "Elderly Mentally Infirm" (EMI) continuing care (i.e. a care home with specialist registration). Follow-up work to the survey showed that not one of the 16 acute hospital patients outside AEP criteria on the day of care, and identified as suitable for one of these two options, had left hospital two weeks later.

The provision of the first of these specialist services – therapy based beds, concerned with the rehabilitation and return home of the patient – is not straightforward, as it requires a mix of medical, therapeutic and mental health skills: in principle the location could be in any of the settings included in this survey, and to identify the most appropriate approach requires further consideration by the Lincolnshire agencies of potential models of care that can best meet these needs. The shortage of the second – continuing care placements for people with dementia – is already well-recognised in Lincolnshire.

Conclusion

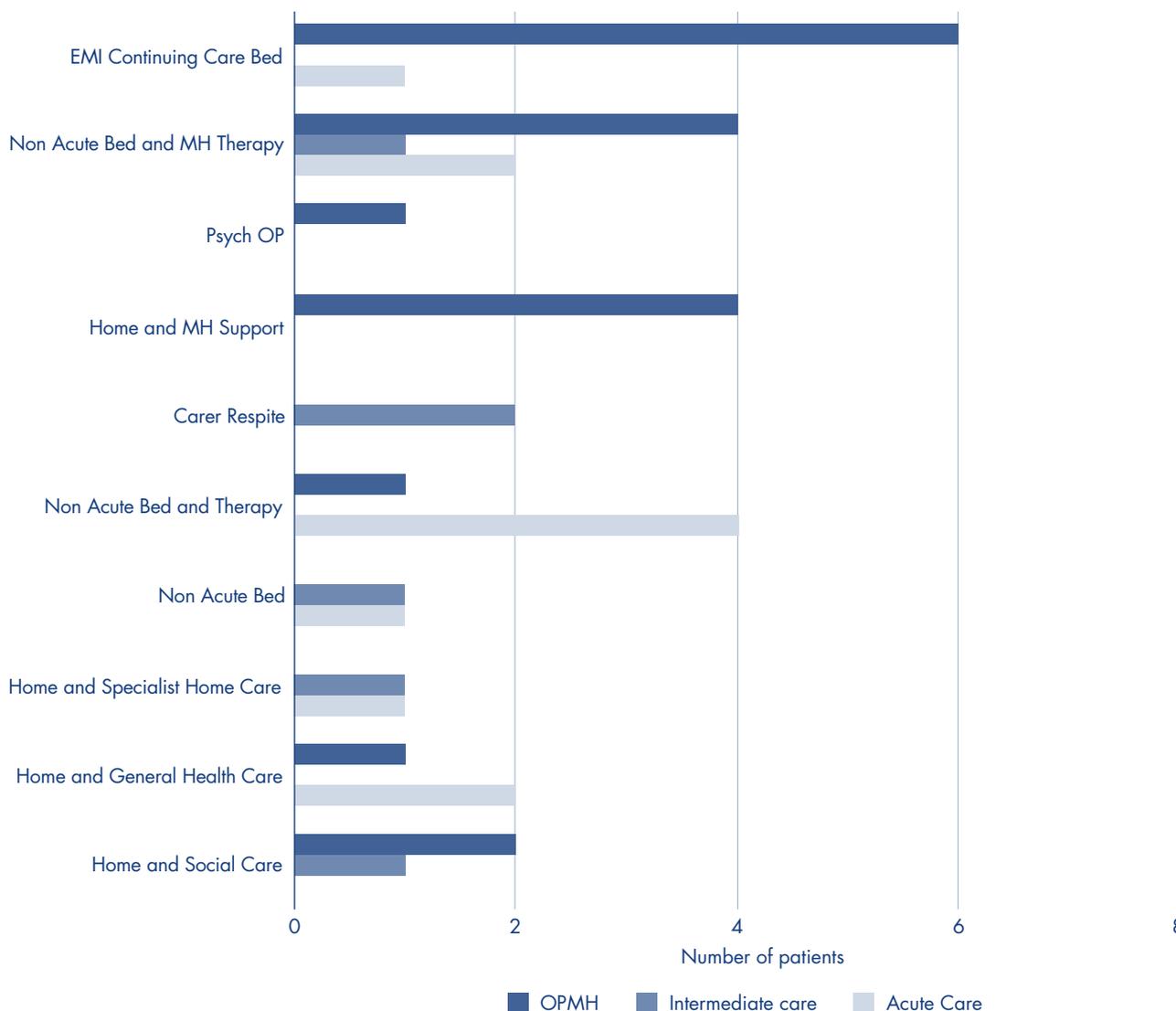
These findings were compared with those from four previous Balance of Care Group surveys in 2003 and 2004 and found to reflect a common theme in which a high proportion of dementia patients in acute hospital beds did not appear to require acute care at the time of admission (between 17 and 55 per cent), but more particularly on the day of survey (between 67 and 89 per cent). This suggests strongly that the issues raised in this case study about the need to explore alternatives to acute care for people with dementia are mirrored across England, and that the conclusions may be equally applicable elsewhere.

The findings of this survey were presented to Lincolnshire Primary Care Trust, United Lincolnshire Hospitals NHS Trust, Lincolnshire Partnership Trust and Lincolnshire Adult Social Care. They have taken the findings forward by:

- working together on a revised care pathway for both planned and unplanned care of people with dementia;
- identifying the costs of the unnecessary acute hospital bed usage identified by the survey (a total of £6.5 million over some 500 people a year, not all of whom had dementia) in order to redirect this funding to more appropriate alternatives;
- developing a revised commissioning plan for dementia services, based on the conclusions about capacity requirements in acute, intermediate, care home and specialist mental health services that came from the survey;
- trialling a multi-disciplinary rapid access clinic as a way of addressing delays in consultant appointments for suspected dementia; and
- piloting a joint panel to address delays in social care assessments and continuing NHS care assessments.

32 On the day of our survey, there were a number of potential alternatives to admission to acute care that would have been appropriate for patients with dementia

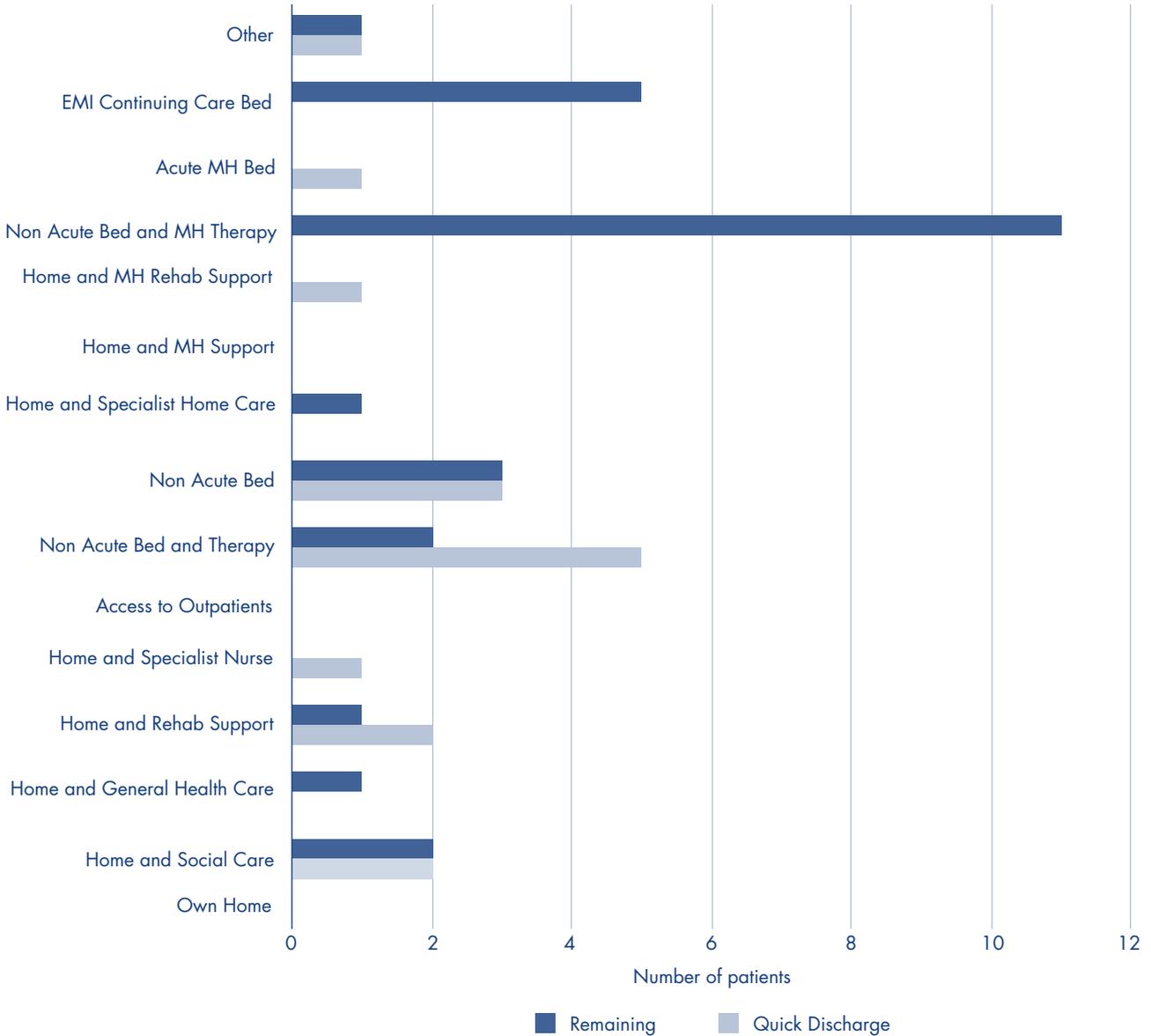
Alternatives to admission to an acute care bed



Source: Balance of Care Group analysis for the National Audit Office

33 On the day of our survey, there were a number of potential alternatives to acute hospital that would have been appropriate for patients with dementia

Alternatives to continued stay in an acute care bed



Source: Balance of Care Group analysis for the National Audit Office

APPENDIX SEVEN

Scientific research

There have been major scientific advances in dementia research in the past 25 years. Some of these breakthroughs⁵⁷ include:

- Identification of cholinergic⁵⁸ deficits (1977), leading to the development of cholinesterase inhibitors (licensed in 1997 for Alzheimer's disease and 2006 for Parkinson's disease dementia);
- Identification of the Tau protein which channels chemical messages inside nerve cells and of Amyloid protein⁵⁹ as the content of brain plaques (clusters of dead and dying nerve cells) in Alzheimer's disease. These led to the Amyloid cascade hypothesis, identification of autosomal dominant genes for familial Alzheimer's disease and a-secretase. Numerous treatments now being investigated;
- Identification of a-synuclein as the major protein in dementia with Lewy bodies;
- Identification of APO E4 – a genetic risk factor for late onset Alzheimer's disease;
- Recognition of the importance of vascular risk factors and lifestyle in Alzheimer's disease;
- Description of Fronto-temporal dementias and identification of major genetic causes;
- Recognition of the importance of Person Centred Care; and
- An evidence base for best care practice providing the opportunity to improve quality of care.

There are two large publicly funded clinical trials in dementia in the UK:

- The DOMINO Study, an MRC multi-centre £2.6 million study looking at the use of cholinesterase inhibitors and memantine in severe dementia; and
- The SAD study, an HTA £1.5 million randomised study looking at depression in dementia.

In 2006 the Department of Health announced the launch of seven new Local Research Networks in England (Dementias and Neurodegenerative Diseases Research Network – DeNDRoN) with £3 million per annum to coordinate and deliver research studies which focus on the prevention, diagnosis and treatment of Alzheimer's Disease, Huntingdon's disease, Parkinson's disease and motor neurone disease. The New Local Research Networks, part of the UK Clinical Research Network, are made up of regionally based, collaborative groups in NHS Trusts, Primary Care Trusts, Hospital and Universities and managed within each host organisation.

The NHS Health Technology Assessment programme has recently funded randomised controlled trials of the effectiveness of antidepressant treatment for depression in dementia (£1.5 million), befriending by trained lay workers of dementia caregivers (£638,000), a systematic review of non-pharmacological interventions for wandering (£125,000) and the development of a quality of life in dementia scale – DEMQOL (£323,000).

57 Adapted from a presentation by Professor Clive Ballard, Director of Research at the Alzheimer's Society http://www.alzheimers.org.uk/News_and_Campaigns/Forthcoming_events/dementia_uk_conference_material.htm

58 Having physiological effects similar to those of acetylcholine, which is released at the end of nerve fibres and is involved in the transmission of nerve impulses in the body.

59 Amyloid is a waxy translucent substance consisting of protein in combination with polysaccharides that is deposited in some animal organs and tissues under abnormal conditions (as Alzheimer's disease).

34 Research is poorly funded in the UK compared to the USA

| Research funding | USA | UK |
|---|-------|-------|
| Total research funding (£ per person with Alzheimer's disease) | 121 | 13 |
| Annual research funding by Alzheimer's charities (£ per head of population) | 0.037 | 0.058 |
| Annual public research funding (£ per head of population) | 0.66 | 0.15 |

Source: Access Economics Pty Limited (2003) *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia* and Knapp et al. (2007) *Dementia UK: Report to the Alzheimer's Society*, King's College London and London School of Economics and Political Science¹

However, although these initiatives give some cause for optimism, they amount to only another £0.09 per UK citizen, leaving UK public funding of research at £0.24 per UK citizen, almost three times lower than in the US.

The NICE-SCIE guideline makes a number of recommendations for research, including:

- Acetylcholinesterase inhibitors and memantine for the treatment of psychotic symptoms in dementia;
- Cognitive stimulation and/or acetylcholinesterase inhibitors in Alzheimer's disease;
- Psychological interventions for unpaid carers of people with dementia; and
- The effect of staff training on behaviour that challenges.

Drug companies are currently funding a range of trials including anti-inflammatory drugs, such as aspirin, to help prevent or reduce progression of the disease. Researchers are also testing antioxidants such as Vitamin E, aimed at inhibiting free radicals which can destroy healthy brain cells. Work is also ongoing on the possibility of a vaccine to treat or even prevent early stages of dementia developing. Other possibilities in the future include development of gene therapy and stem cell research. Translating this research into practical solutions will depend on an increase in clinical trials.

GLOSSARY

| | |
|---|--|
| Advance Statement/ Directive | These can be statements of an individual's wishes in certain circumstances, for example instructions to refuse some or all medical treatment or requests for certain types of treatment. They can also state someone to be consulted at the time a decision needs to be made. The individual should seek advice about the legal status of these statements/directives. They might be called Living Wills. |
| Assistive Devices/Telecare | Term used to cover a multitude of aids for the older person for use in and around a house and for extra mobility outside the house. |
| Care Programme Approach (CPA) | A standardised way of planning a person's care. It is a multidisciplinary approach that includes the service user and, where appropriate, their carer to develop an appropriate package of care that is acceptable to health professionals, social services and the service user. The care plan and care coordinator play important role in this. |
| Commission for Social Care Inspection (CSCI) | The body that inspects and reports on care services and councils to improve social care and eliminate bad practice. |
| Crisis Resolution Team | A service aimed at treating adults with severe mental health difficulties in the least restrictive environment and with the minimum disruption to their lives. It acts as a "gatekeeper" for admission to acute mental health services, and where appropriate provides intensive multi-disciplinary treatment at the service user's home. Where hospitalisation is necessary, the team also assists in planning and facilitating early discharge |
| Delirium | A condition including severe confusion, disorganised thinking, disorientation and restlessness. Delirium may be caused by physical agents such as infections, toxic substances, metabolic disorders or strokes. |
| Enduring Power of Attorney (EPA) | A legal document that enables someone to appoint one or more persons to manage their financial affairs and property, either now or in the future. |
| Nursing Home | A care home with qualified nurses permanently on site registered to provide nursing care |
| Residential Home | A care home providing 24 hour general care but with no registration to provide nursing care |
| Social Care Institute for Excellence (SCIE) | An organisation that aims to improve the experience of people who use social care by developing and promoting knowledge about good practice in the sector |
| Skills for Care | The strategic body for workforce development for adult social care workforces in England, led by care employer networks and other sector interests. It is the adult social care for England part of the UK-wide Sector Skills Council, Skills for Care and Development. |

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