



National Audit Office

Improving services and support for people with dementia

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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.

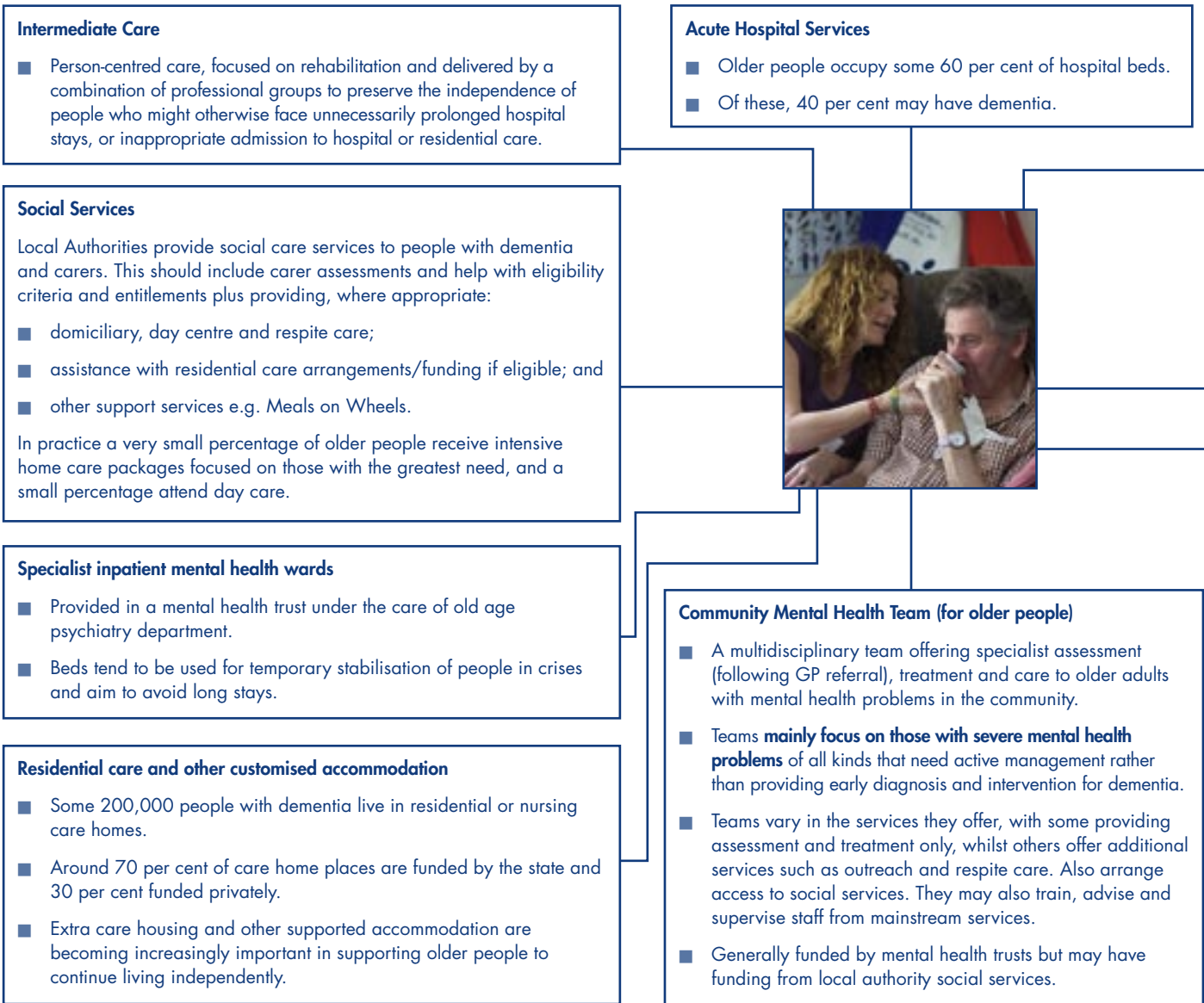
⁷ This cost is not in terms of "real" money, but is a notional or opportunity cost such as the value of a relative's time or wages forgone. It may also be interpreted as what it would cost the state to replace these carers if they were not undertaking this role.

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).