

OCTOBER 2011



Spotlight on
DEMENTIA CARE

A Health Foundation improvement report

Identify Innovate Demonstrate Encourage

The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK.

We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable.

We believe that in order to achieve this, health services need to continually improve the way they work. We are here to inspire and create the space for people to make lasting improvements to health services.

Working at every level of the system, we aim to develop the technical skills, leadership, capacity and knowledge, and build the will for change, to secure lasting improvements to healthcare.

This research was commissioned and funded by the Health Foundation to help identify where and how improvements in healthcare quality can be made. The views expressed in this report do not necessarily represent the views of the Health Foundation.

This research was managed by:
Helen Crisp
Assistant Director of Research and Development
The Health Foundation
020 7257 8000

Authors

Matrix evidence

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Foreword

This report brings together some of the best available knowledge on dementia. With information from national guidance, academic research and third sector reports, it tells a story that we at Alzheimer's Society, and everyone with dementia and their carers, are very familiar with.

It's a story of people who are worried about their memory who do not get the diagnosis of dementia which would enable them to get the early help that can prevent crisis. It's also about people with dementia who often struggle with a complex network of unconnected professionals without the good quality information and support which could help them. We know that people with dementia stay in hospital longer than they should. They receive care that is not appropriate and would be better off at home.

The cost of often poor dementia care and support to the UK economy is estimated to be £20 billion a year.

The positive news is that there is now a clear understanding about what we should do to significantly improve quality of life for the thousands of people living with dementia and their carers.

Along with explaining the costs of dementia, this report outlines key areas for improvement, pulling into one place guidance about what quality care should be like. Implementing this guidance would make a big difference. Not only might this save millions of pounds, but more importantly, it would significantly improve the lives of people with dementia.

Jeremy Hughes
Chief Executive
Alzheimer's Society

A call to action

IMPROVING CARE FOR PEOPLE WITH DEMENTIA

The Health Foundation has commissioned this improvement report because of the importance and urgency of the need to improve services for people with dementia and their carers. The statistics speak for themselves: there are 750,000 people with dementia in the UK and this is forecast to increase to over a million by 2021. The burden and costs of care are enormous: around £8bn in direct care costs, rising to an estimated £20bn costs to the economy as a whole. The costs of care could triple within 20 years if we don't take action to provide better care at lower cost.

We have brought together the key recommendations from major policy documents, demonstrating that these broadly align – there is a 'road map' for the components of quality care. However, current care is falling far short of what it needs to be. In order to help services address this gap between current provision and a standard of high quality care we have summarised the research evidence on ways to improve care in the most cost-effective way. While there are areas where more research would usefully add to our knowledge of better care for people with dementia, it is clear that we already have examples of evidence-based guidelines and good practice exemplars to draw upon – but these are not consistently implemented.

Current levels and the style of care provision are not meeting people's needs and in addition to the poor experience of care, they actually lead to higher costs. The rising numbers of people with dementia could either be a crushing burden for the NHS in the years to come – or, if we can get it right, high-quality and cost-effective dementia care represents one way to tackle the financial constraints in the NHS by enabling providers to reduce the unnecessary use of expensive hospital and residential care – when this is not the best way to meet the person's needs.

ACTION ON SUPPORT IN THE COMMUNITY

Late diagnosis and lack of community support mean that people with dementia and carers are not helped and advised in the crucial early stages when, with that support, they would be able to start to adapt and develop ways to live well with dementia. Providing early diagnosis support through memory clinics is a relatively inexpensive intervention but could save thousands of pounds in care costs, by supporting informal carers to cope for longer in their own homes. The lack of support for carers as the disease becomes more severe means that many dementia sufferers are left with no alternative but residential care, as family members are not able to cope on their own. Residential care represents the largest segment of the dementia care budget. Better provision of community support groups, both for people with dementia and carer support groups, respite care and 'sitting services' to give carers a weekly break, are all cost-effective ways to enable people to live at home for longer, thus reducing the huge costs of residential care.

ACTION FOR HOSPITAL CARE

The area that we highlight for most immediate action is better care for people with dementia when they are admitted to general hospital for an unrelated condition. We know that up to 70% of acute hospital beds are filled by older people and that, as the incidence of dementia increases with increased age, a large proportion of inpatients will have dementia, many of them undiagnosed. People suffering from dementia are more likely to find the hospital environment confusing and disorientating, increasing risks of a fall, or acquiring an infection while in hospital. The lack of basic training for general hospital nurses and care assistants in the behaviours and care needs of people with dementia means that they are unable to cope with these patients, often resulting in a longer than average length of hospital stay and the additional cost of this. Hospitals need to implement systematic dementia assessment for elderly patients, have liaison psychiatry arrangements in place and ensure that all care staff have training to recognise and respond to the needs of people with dementia. Appropriate care in hospital has the potential to dramatically reduce length of stay, releasing acute bed capacity, saving costs and also enabling more patients to return to their own home – not have to move to residential care from hospital, because their hospital stay has resulted in such a deterioration in their condition that home care is no longer an option.

ACTION TO REDUCE INAPPROPRIATE PRESCRIBING

The continued inappropriate use of anti psychotic drugs, as a way of chemically modifying behaviour, is not acceptable. Research has shown that within current prescribing patterns less than a quarter of those prescribed anti-psychotic medication gain any benefit and these drugs can have serious adverse effects ranging from death, to strokes, to problems with walking, which need to be weighed up against possible benefits in every instance. Too often these drugs are still used, in general hospitals particularly and in some instances in care homes, as a way to control people whose condition may make them aggressive. Every prescription of anti psychotics needs to be backed up with a rigorous needs assessment.

ACTION ON RESEARCH

The most pressing area for research on dementia is to increase the scale of bio-medical research to identify causes, treatments and a cure for dementia. The statistics show that while dementia care costs are three times that of cancer care, the investment in medical research for dementia is less than one-sixth of the total for research into cancer. New treatments which could reduce the burden and costs of care both for the NHS and for individual carers would provide a huge return on the research investment that would be felt across society.

USING THIS REPORT

The aim of this report is to collate the evidence and present a snapshot of the current state of dementia care. We hope to contribute to raising that quality of practice in dementia care, signposting people to sources of research and good practice evidence which will be used to improve the lives of people with dementia and their carers.

Helen Crisp
Assistant Director of Research and Development
The Health Foundation

Contents

EXECUTIVE SUMMARY	10
1. INTRODUCTION	12
2. BACKGROUND	18
3. NATIONAL GUIDANCE AND QUALITY STANDARDS	26
4. COSTS OF DEMENTIA CARE	32
5. SERVICES FOR PEOPLE WITH DEMENTIA	44
6. IMPROVING QUALITY OF CARE	72
7. BRIDGING THE QUALITY GAP: A SUMMARY OF THE EVIDENCE	92
8. COMMISSIONING COST-EFFECTIVE AND HIGH-QUALITY SERVICES	96
APPENDIX 1	100
REFERENCES	102

Executive summary

An estimated 750,000 people in the UK have dementia in 2011. Over the next 10 years this figure is forecast to increase to over a million. The number of people with dementia will continue to increase as the population ages. The care and support provided to people with dementia and their carers is often inadequate because the disease goes undiagnosed.

Dementia has acquired national strategic importance with the publication of the National Service Framework for older people, the National Dementia Strategy, and the National Institute for Health and Clinical Excellence (NICE) quality standard. To improve the quality of care for people with dementia, NHS and social care organisations have to deliver a range of outcomes at a time when financial restrictions mean resources are limited.

The costs of providing dementia care are largely those required to provide support and care for activities of daily life, rather than expensive medical technology. Much of the social cost of care is borne by unpaid, informal carers, who, evidence suggests, rarely receive enough support. However, elderly people with dementia often have other health needs, and having dementia substantially increases the amount of time spent in hospitals, so the healthcare costs directly or indirectly associated with the disease are significant, currently estimated as costing the UK economy approximately £20bn a year. The potential for improving the quality of care for people with dementia, and delivering cost savings, is considerable. The most promising approaches include:

- improving the quality of primary health and social care to keep people with dementia living safely at home and avoiding the need for residential care
- managing their health and social care needs more effectively to minimise the need for acute hospital admission
- managing acute admissions effectively to minimise the length of stay and risk of subsequent institutionalisation.

Primary care teams, led by GPs, play a crucial and central role in the care of people with dementia, from diagnosis to the end of life. For most patients, the GP is the central healthcare provider who coordinates care for their health and social problems. Estimates suggest that the costs of improving care earlier in the disease (for example, using memory clinics to diagnose dementia early), could deliver overall savings if early intervention resulted in a 20% or more reduction in the use of residential care later in the disease. Similarly, an estimated £700m could be saved annually if the duration of hospital stays were reduced by two days for every elderly person with dementia admitted with an acute problem.

Evidence on how to improve the quality of dementia care with reduced resources is limited, but existing evidence suggests there are benefits to providing the following:

- Adequate training for health and social care staff as well as for carers on how best to manage a person with dementia, with particular support for the primary care teams who provide most of the day-to-day care for people with dementia.
- Support for informal carers so they can continue to care without the need for residential care, and can recognise health problems early so they can be sorted before crisis point is reached.
- A multidisciplinary team of health and social care professionals to coordinate early diagnosis and care in the community.
- A specialist multidisciplinary team input to assess and coordinate appropriate in-patient care when an elderly person is admitted to hospital, so that all health needs can be addressed, efficiently minimising the length of stay.
- Psychiatric liaison services for elderly people in residential care to prevent inappropriate use of medication and improve the quality of residential care.

1. Introduction

More than one in every 100 people in the UK has dementia, and for up to one in 10 people aged 65 and over it will be the main or significant underlying cause of death. With an ageing population these numbers will increase in the coming years. The health and social care costs directly or indirectly associated with the condition are significant, and will continue to rise. Finding ways to improve the quality of life for those with dementia, while reducing costs to the NHS, is therefore a priority for health services and policy makers.

Dementia care already places a significant burden on the NHS and on social services. Improving the quality of care for people with dementia has moved up the healthcare agenda in recent years with the publication of a series of reports and policy documents that have highlighted the gap between current levels of care and what research evidence indicates high-quality care is.

There is a significant amount of evidence about how care can be improved, how costs can be reduced and what best practice looks like. However, implementation of improvements has been slow and inconsistent.

In this report we bring together the existing evidence and recommendations for improving the quality and cost effectiveness of care for people with dementia.

WHAT SHOULD WE BE DOING?

Although supportive care can maintain independence and quality of life for people with dementia for some time, there is still no effective treatment that can prevent, cure or reverse the effects of most cases of dementia. **Section 2** of this report sets out the context of caring for people with dementia. It provides details of: the features of the different types of dementia; the number of people who currently have dementia and what the geographical spread is; the behavioural and psychological challenges associated with the condition; and risk factors and prevention strategies.

A series of reports, guidelines and recommendations have been published between 2006 and 2011 on improving care for people with dementia. However, this proliferation of advice and guidance can be confusing for health and social care workers, and commissioners, as it can appear that they require different, if not contradictory, actions.

Section 3 of this report brings together the key recommendations from five major policy documents, highlighting where they align across different themes:

- National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (SCIE), *Dementia: Supporting people with dementia and their carers in health and social care*. Clinical guideline 42, 2006¹
- Alzheimer's Society, *Dementia UK*, 2007²
- Department of Health, *Living well with dementia: A National Dementia Strategy*, 2009³
- NICE dementia quality standards, 2010⁴
- Skills for Care, Skills for Health and Department of Health, *Common core principles for supporting people with dementia*, 2011⁵

These key documents highlight where current performance is lacking, and where there are concerns about quality of care. These concerns include the high number of people who are never diagnosed with the condition, the lack of coordinated care, and inadequate training of staff and carers. **Section 3.2** contains a list of the concerns relating to current performance against standards.

WHAT ARE WE DOING?

Estimates of the costs of dementia vary markedly as the majority of the costs are for social care in the community, rather than healthcare, which can be difficult to quantify. However, it is estimated that dementia accounts for over 50% of the total health and social care costs of dementia, cancer, stroke and heart disease.

Implementation of the recommendations in the key policy documents detailed in **section 3** can produce significant cost savings over a number of years. **Section 4** sets out the costs of care for people with dementia, alongside the potential savings that could be seen by implementing good practice recommendations. This section also details how the costs of dementia care compare with other long-term conditions, and compares the costs of personal social services, community care, residential care, and hospital care in relation to dementia.

Together, the key policy documents provide an overall vision of what high-quality dementia care looks like. The overarching elements of the best-practice framework are: information; early diagnosis; coordinated care; treatment of symptoms and challenging behaviour; carer support; hospital care; end-of-life care; staff training and funding and commissioning.

Section 5 provides data and details of what support and services are currently being provided in the UK for people with dementia and their carers, setting out current performance against each part of this best-practice framework.

Informal carers provide the majority of care for people with dementia and these carers often struggle to get the support, information or training they need to help them. Primary care has an important part to play in coordinating health and social care for people with dementia. GPs in the UK can currently expect to have between 12 and 20 people with dementia to care for at any one time. However, GPs are often not adequately trained in diagnosing and managing people with the condition.

Early diagnosis of dementia can help both the patient and the family and carers, and can potentially reduce costs. However, data suggest that dementia is frequently under-diagnosed in the UK. **Section 5.6** sets out the impact of failing to diagnose early, and details models used to promote early intervention.

High-quality care for people with dementia greatly depends on how well health and social care services work together. However, evidence shows that the majority of community mental health teams do not have any joint arrangements in place. **Section 5.8** focuses on the recommended composition of community mental health teams.

People with dementia who are admitted to hospital for treatment for another condition can become confused, distressed and at risk of falls or infection. This can lead to lengthy hospital stays and further costs to the NHS. An audit, detailed in **section 5.9**, has found that hospitals are often failing to recognise the needs of people with dementia and are not safeguarding people from longer hospital stays. There is also a concern that antipsychotic drugs are being prescribed to people who don't need them, leading to longer hospital admissions. **Section 5.10** provides details of this.

HOW CAN WE DO IT BETTER?

There are a number of evidence-based guidelines and good practice examples to draw upon when looking to improve the quality of care for people with dementia. If these are used effectively, it could lead to significant savings for the NHS, particularly in light of the rising number of people with dementia. This threatens to become an increasing burden to the health service unless the quality and effectiveness of care is improved.

Current health policy places greater emphasis on localised, integrated provision of services, with an expanded role for society in caring for people. This direction of travel is particularly suited to caring for people with dementia, as much of the care provided is already done so within the community. Dementia care is one of the key areas identified by Health Secretary, Rt Hon Andrew Lansley, for NHS organisations to improve. Clear guidance is needed for new clinical commissioning groups on how local services can best deliver cost-effective, high-quality care.

Section 6 summarises the best evidence available on how to improve the quality of care for people with dementia according to the recommendations set out in the key policy documents detailed in **section 3**. It also includes case studies of good practice from across the UK.

The evidence suggests that to increase the quality of care for people with dementia, steps should be taken to improve:

- awareness of the symptoms of dementia amongst carers, patients, and health and social care workers (section 6.2)
- diagnosis of dementia and encouraging staff to use standard memory tests (section 6.3)
- collaborative and integrated care in the community, including involving the voluntary sector (section 6.4)
- symptoms and behavioural problems (section 6.5)
- support for carers so they can continue to care without the need for residential care (section 6.6)
- hospital care through effective identification of patients with dementia and more proactive management of their care and discharge (section 6.7)
- intermediate care which can reduce the length of hospital stays (section 6.8)
- residential care through increasing social activity (section 6.9)
- end-of-life care (section 6.10)
- staff knowledge and awareness through training of all health, social and voluntary care staff (section 6.11)
- research through funding the collation of high-quality evidence on the most cost-effective ways of delivering care for people with dementia (section 6.12)

Section 7 summarises the evidence and the conclusions that can be drawn to guide dementia services provision and redesign. These conclusions are arranged around the Health Foundation's six quality domains: effectiveness, access, capacity, safety, patient-centredness and equity.

Finally, **section 8** draws out key considerations that commissioners of services might usefully address when contracting for dementia services. It summarises the evidence on what care strategies have been shown to offer more cost-effective care for people with dementia and their carers.

Spotlight on dementia care is a practical, evidence-based report. It sets out what the current picture of dementia care is and what the key guidance says high-quality care should look like. This 'road map' for quality care will be invaluable to those caring for people with dementia, helping them raise the level of care and quality of life for patients.

The report was commissioned by the Health Foundation to help commissioners, policy makers and clinicians meet the challenges of caring for people with dementia in 2011 and the years to come, particularly when faced with the current restraints on NHS budgets and the need for cost-effective care.

2. Background

2.1 WHAT IS DEMENTIA?

Dementia is a progressive loss of a person's mental functions necessary to live independently and safely. People with dementia lose the ability to remember, think logically, communicate effectively and care for themselves.

Dementia is caused by structural and chemical changes eventually leading to the death of brain cells. Its causes are largely unknown, making it very difficult to prevent or cure the disease. The most common form of dementia is Alzheimer's disease, with vascular dementia second most common. Vascular dementia is caused by the narrowing of arteries to the brain leading to a series of mini strokes. Many people have more than one cause of their dementia, and half of all people with dementia have some vascular damage.³ Table 1 summarises the main features and differences between the four main types of dementia.

Table 1: Features of the four main types of dementia^{1, 2, 6}

	Alzheimer's disease	Vascular dementia	Lewy body dementia	Fronto-temporal dementia
How common?	60%	15 - 30%	4 - 20%	2%
Who gets it?	Older people, especially women; people with ApoE gene or Down's Syndrome.	People with diabetes, high blood pressure, smokers, heart disease or stroke, especially men.	Older people.	Under 65s, especially men.
Main problems	Poor memory, confusion, anxiety and distress, increasingly unable to look after themselves, depression, apathy, aggression, wandering, incontinence, difficulties with eating.	Poor planning or decision-making ability, clumsy walking and movements, poor concentration, apathy, depression, aggression.	Slow and jerky movement, tremors, falls, hallucinations, fluctuating levels of awareness or confusion.	Altered behaviour and personality, problems with communication and speech.
Outlook	Progressive worsening of problems and loss of independence.	Variable – can be stable for some time then sudden worsening.	Progressive worsening of problems, loss of independence largely because of physical problems.	Progressive worsening of problems, loss of independence largely because of physical problems.

2.2 HOW MANY PEOPLE HAVE DEMENTIA?

Because many people have not received a formal diagnosis, we can only estimate the actual number of people with dementia. However, it is known that the number of people with dementia is increasing as the proportion of elderly people in the population increases. In 2007, the Alzheimer's Society estimated that there were 685,000 people with dementia in the UK. Their current estimate suggests this number rose to 750,000 by 2011.

Figure 1 shows how the number of affected people varies regionally, from approximately 30,000 in the north east region in 2007 to 80,000 in the north west. By 2021, it is estimated that these numbers will have increased by approximately 25%, but the regional variation is expected to continue.² Figure 2 shows that over time the proportion of people aged 65 and over with dementia remains consistent across regions, suggesting that regional variations in the numbers of people with dementia reflect differences in the age of local populations.

While an increase in the number of affected people may be inevitable, it is possible that the increase may not be as high as currently feared. Improved treatments for cardiovascular disease, such as statins to reduce cholesterol levels, aspirin to prevent mini strokes, and lower rates of smoking, should reduce the number of cases of vascular dementia, which are caused by mini strokes. Better prevention and treatment of cardiovascular disease may mean that fewer of the middle-aged people currently receiving these treatments will develop dementia as they age.

Figure 1: The number of people with dementia is predicted to increase over time¹

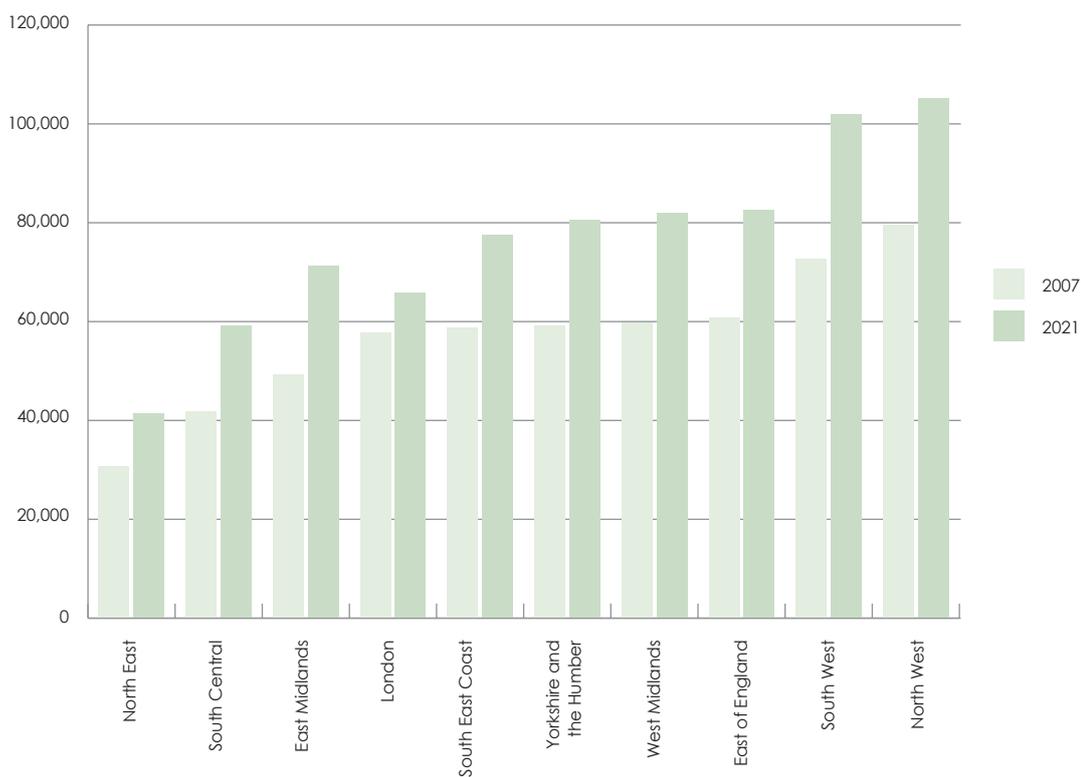


Figure 2: The proportion of people aged 65+ with dementia remains similar across regions and over time¹

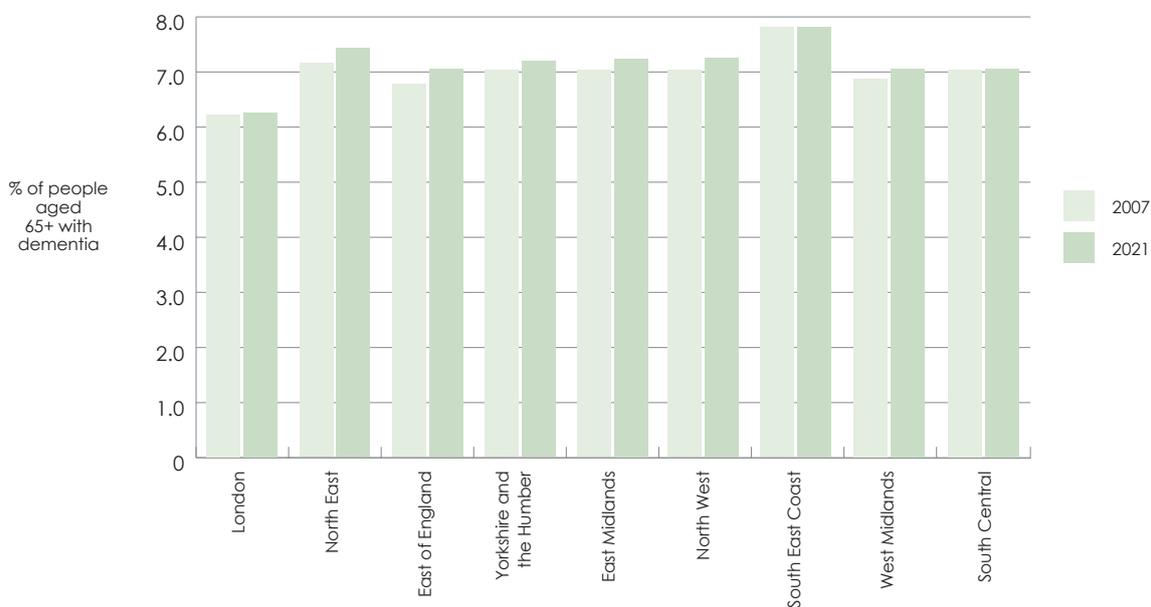


Figure 3: Proportion of people aged 65+ with dementia by PCT in England, 2007-2021²

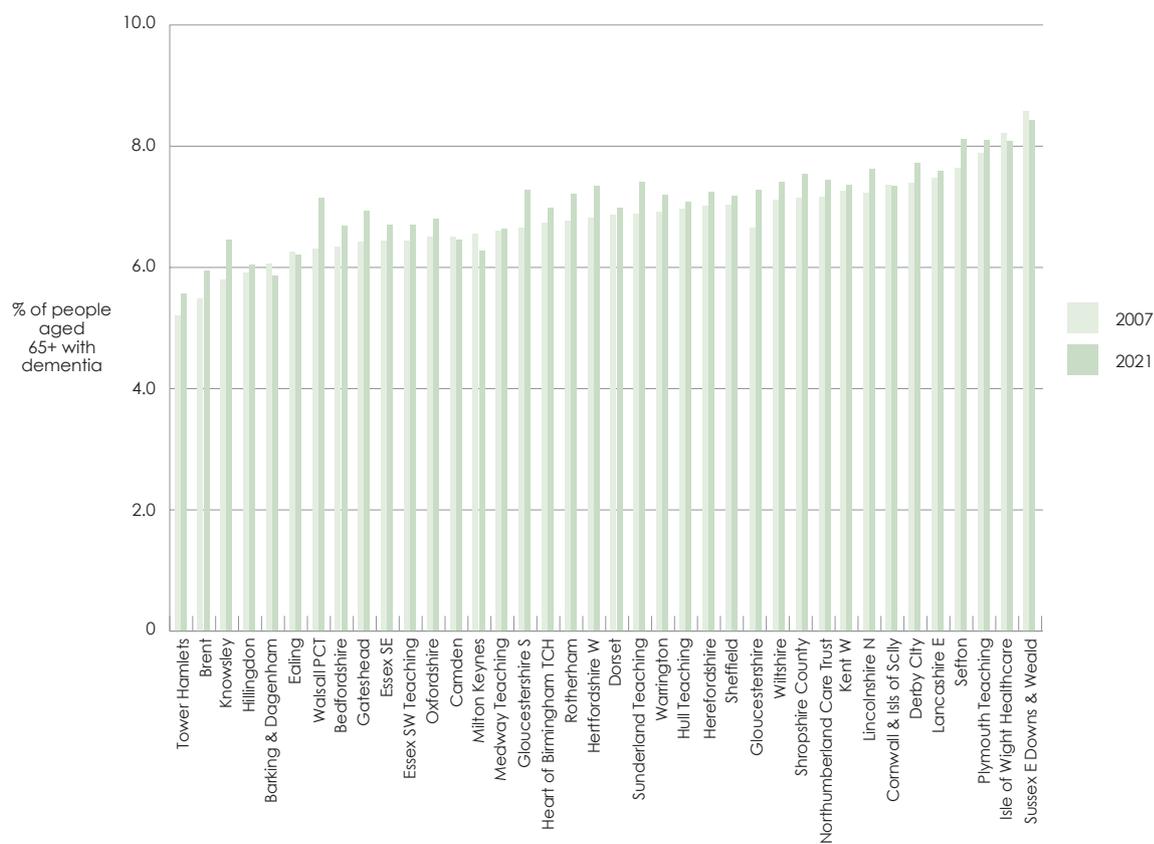
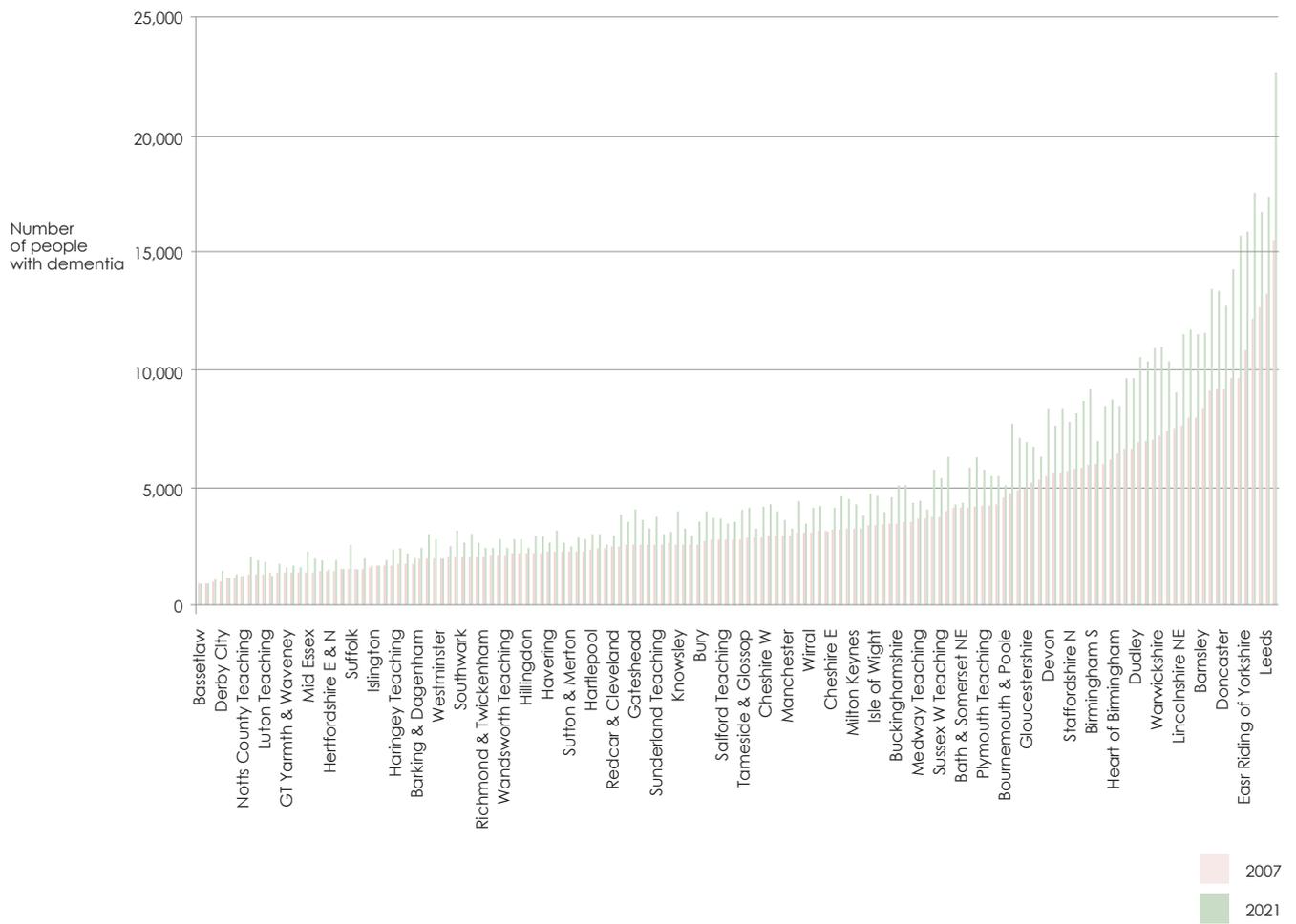


Figure 4: Number of people with dementia by PCT in England, 2007-2021²



2.3 BEHAVIOURAL AND PSYCHOLOGICAL CHALLENGES

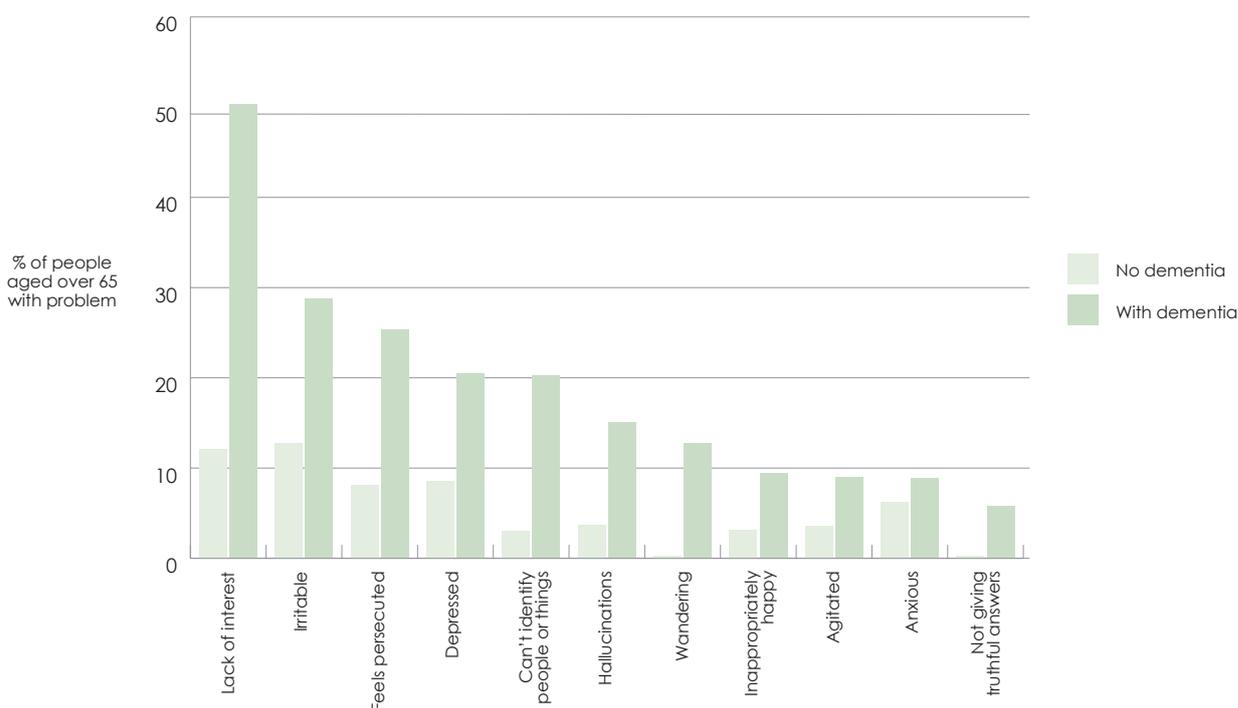
Figure 5 shows that most people with dementia do not just have problems with their memory. They also are more likely to suffer from depression, anxiety or irritability, and may feel that others are trying to harm them. They lose interest in people and events, sleep poorly, and may experience hallucinations. They often become agitated and may wander within or outside the home because of the hallucinations and distorted thinking.⁷

One study estimated that 58% of older adults in long-term care homes had dementia, and 78% of these people had behavioural and psychological symptoms of dementia.⁸ Caring for a person with dementia is challenging. Communication is difficult, and there is a need for constant vigilance to make sure they are always safe and comfortable. In one UK study, more than one-third of carers reported having been abused by the person with dementia in the past three months, 36% psychologically and 6% physically.⁹ Similarly, in a UK survey, one-third of carers reported they had shouted at or threatened the person with dementia at least once in the past three months.¹⁰

Increased risk of delirium

People with dementia are also at risk of developing delirium, with increased confusion, anxiety, hallucinations and disorientation. Between 22% and 89% of people aged 65 and older with dementia in hospital or in the community will develop delirium.¹¹ People can become delirious when they are ill, but people with dementia develop delirium when they are comparatively less ill than those without the disease.¹²

Figure 5: Proportion of people aged over 65 with and without dementia who experience behavioural or psychological problems¹³



2.4 RISK FACTORS AND PREVENTION

The causes of dementia are largely unknown, making it very difficult to prevent or cure.

Certain risk factors have been associated with the development of dementia. Dementia can be caused by mini strokes and factors that increase the risk of stroke can also increase the risk of dementia – such as smoking and diabetes. This means that treatments that reduce the risk of heart disease and stroke also have the potential to reduce the risk of vascular dementia. These include statins to reduce cholesterol levels, aspirin to prevent mini strokes, and antihypertensive to reduce blood pressure.

Having a healthy lifestyle can prevent heart disease and stroke. However, a study concluded there is still only low-quality evidence that changing one's lifestyle can prevent or delay the onset of dementia. The lifestyle changes investigated in the study included increasing physical exercise or eating a Mediterranean-style diet rich in vegetables or omega-3 fatty acids.¹⁴

Adults with a higher IQ seem to be at lower risk of developing dementia. The systematic review found high-quality evidence that brain training reduces the risk of developing dementia.¹⁴ Other risk factors include a genetic predisposition in families where several people have developed dementia relatively young.

Figure 6 shows advice from Alzheimer Europe on how to reduce the risks of developing dementia, based on an evidence review.¹⁵

Figure 6: Alzheimer Europe's strategies to prevent dementia¹⁵

- Have good social ties with a number of close friends
- Have many different physical, mental and social leisure activities.
- Have physical activity (three times a week or more, like walking, gardening, sports)
- Eat a Mediterranean diet
- Eat fruit and vegetables regularly
- Eat fatty fish at least once a week
- Do cognitive (brain) training while still healthy
- Have challenging work
- Avoid heavy drinking and binge drinking
- Avoid being overweight or obese
- Avoid high blood cholesterol and reduce the amount of saturated fat in the diet
- Avoid getting type 2 diabetes
- Avoid high blood pressure in mid life
- Avoid smoking
- Prevent depression
- Avoid working with pesticides

3. National guidance and quality standards

3.1 GUIDANCE FOR ENGLAND AND THE UK

A report by the National Audit Office in 2007¹⁶ concluded that dementia services in England cost £8.2bn per year, and were not providing value for money for the taxpayer, patients or carers. This report helped to trigger the development of the National Dementia Strategy in 2009³. Other key guidance on how to deliver high-quality care for people with dementia and their carers include the NICE-SCIE clinical guideline (2006)¹, the Alzheimer's Association report *Dementia UK* (2007)², the 10 quality standards for dementia produced by NICE in 2010⁴ and the Common core principles for supporting people with dementia, a guide to training the social care and health workforce, produced by Skills for Care, Skills for Health and the Department of Health in June 2011⁵.

Table 2 summarises the recommendations and objectives of these key guidance documents, which have considerable overlap, and shows how they apply to the quality standards.

Table 2: Guidance and standards for dementia care in England

Theme	NICE dementia quality standard, 2010	National Dementia Strategy, 2009	NICE-SCIE clinical guideline, 2006	Dementia UK (Alzheimer's Society, 2007)	Common core principles for Supporting people with Dementia, Skills for Care, Skills for Health, 2011
Information	People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.	Improving public and professional awareness and understanding of dementia. Good-quality information for those with diagnosed dementia and their carers. Development of structured peer support and learning networks.	Patients and carers should be offered information about: <ul style="list-style-type: none"> • the signs and symptoms of dementia • the course and prognosis of the condition • treatments • local care and support services • support groups • sources of financial and legal advice, and advocacy • medico-legal issues, including driving • local information sources, including libraries and voluntary organisations. 		Know the early signs of dementia.
Early diagnosis	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.	<i>Key objective:</i> Good-quality early diagnosis by a specialist and appropriate treatment, care and support.	Memory assessment services to be the single point of referral for all people who may have dementia, with access to MRI and CT scans as necessary to help make the diagnosis.	Poor understanding of dementia and its consequences is currently leading to underdiagnosis and late diagnosis.	Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.
Coordinated care	People with dementia have an assessment and an on-going personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.	<i>Key objective:</i> Improved community personal support services. Enabling easy access to care, support and advice following diagnosis. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.	Non-discrimination in access to services for ethnic groups, younger people with dementia and people with learning disabilities and dementia. Coordination of health and social care, with joint planning and development of combined care plans.	Develop community support to keep people living independently and with dignity. Develop comprehensive dementia care models to integrate the public, private and voluntary sectors.	Work as part of a multi-agency team to support the person with dementia.

Theme	NICE dementia quality standard, 2010	National Dementia Strategy, 2009	NICE-SCIE clinical guideline, 2006	Dementia UK (Alzheimer's Society, 2007)	Common core principles for Supporting people with Dementia, Skills for Care, Skills for Health, 2011
Managing symptoms and challenging behaviour	People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.	<i>Key objective:</i> Living well with dementia in care homes, through clinical leadership, appropriate care pathways, in-reach specialist services, and inspection.	Early assessment of people with challenging behaviour or other distressing symptoms to develop tailored care plans.		Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.
Carer support	Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.	<i>Key objective:</i> Implemented Carers' Strategy.	Carers to have an assessment of needs, and to be offered appropriate psychological therapy.	Guarantee carer support packages, in particular training and support groups and respite care.	Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia advice.
Hospital care	People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.	<i>Key objective:</i> Improved quality of care in general hospitals. Improved intermediate care for people with dementia.	Adequate mental health services for people with dementia during hospital admissions.	Lack of training in dementia care as part of the core curriculum for nurses contributes to hospital stays that can be twice as long for people with dementia going into hospital for similar procedures.	

Theme	NICE dementia quality standard, 2010	National Dementia Strategy, 2009	NICE-SCIE clinical guideline, 2006	Dementia UK (Alzheimer's Society, 2007)	Common core principles for Supporting people with Dementia, Skills for Care, Skills for Health, 2011
End-of-life care	<p>People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:</p> <ul style="list-style-type: none"> • advance statements • advance decisions to refuse treatment • lasting power of attorney • preferred priorities of care. <p>People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.</p>	<p><i>Key objective:</i> Improved end-of-life care for people with dementia.</p>	<p>Valid consent to be sought from people with dementia, with advanced decision-making.</p>		<p>Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.</p>
Staff Training	<p>People with dementia receive care from staff appropriately trained in dementia care.</p>	<p><i>Key objective:</i> An informed and effective workforce.</p>	<p>Adequate training of all staff working with older people in health, social care and voluntary sectors.</p>	<p>Dementia care training should be a core component of the training curriculum for nurses and social care staff.</p>	<p>Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.</p>

Theme	NICE dementia quality standard, 2010	National Dementia Strategy, 2009	NICE-SCIE clinical guideline, 2006	Dementia UK (Alzheimer's Society, 2007)	Common core principles for Supporting people with Dementia, Skills for Care, Skills for Health, 2011
Funding and commissioning	<p>People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:</p> <ul style="list-style-type: none"> • advance statements • advance decisions to refuse treatment • lasting power of attorney • preferred priorities of care. <p>People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.</p>	<p><i>Key objective:</i> A joint commissioning strategy for dementia.</p> <p>Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.</p> <p>A clear picture of research evidence and needs.</p> <p>Effective national and regional support for implementation of the Strategy.</p> <p>World class commissioning requirements:</p> <p>Local leadership to ensure a well-defined, fully integrated, locally- agreed care pathway for dementia is commissioned.</p> <p>Work with community partners including voluntary bodies such as the Alzheimer's Society as well as health and social care professionals and the public and patients.</p> <p>Manage knowledge, assess needs of the population, and prioritise investment to deliver high-quality services from a robust, flexible and diverse market.</p> <p>Promote improvement and innovation to improve outcomes, and make sound financial investments.</p>		<p>Make dementia a national health and social care priority.</p> <p>Increase funding for dementia research.</p> <p>Hold a national debate on who pays for care, and the balance between state and individual funding.</p>	

3.2 PERFORMANCE TOWARDS STANDARDS

The data presented in this report show that, despite multiple sources of policy guidance, there is still a substantial gap between the aim of high-quality care for people with dementia and their carers, and what is actually provided. Some of the main concerns are:

- the lack of reliable audit data on what is actually happening in health and social care for people with dementia and their carers
- the high number of people who are never diagnosed, or are diagnosed late so they don't benefit from early support
- the lack of coordinated care
- the lack of resources to keep people safe at home and to support carers adequately
- inappropriate care in hospitals and care homes, in particular the use of medication to sedate patients
- inadequate training of staff and carers
- poor quality end-of-life care.

By summer 2009, only 21% of acute trusts had appointed a clinical dementia lead, which negatively affected staff training and implementing high-quality care pathways. The National Audit Office review of dementia services in 2010 concluded that joint commissioning of services was improving but still very patchy. It set the target of April 2010 for all acute trusts to appoint a clinical lead for dementia services, and for every PCT to have a commissioning lead for dementia services.⁷

4. Costs of dementia care

4.1 SUMMARY

In this section we summarise the limited published cost data we have identified. The cost of health and social care for dementia is considerable. Estimates vary markedly, partly because many costs are hidden. For example, most care is provided by informal carers, who have reduced earnings and make smaller tax payments, and estimating the true cost of this is difficult. Cost data also tends to be under-reported in comparison with other data on the effectiveness of treatments and services for many health problems.

There is little published data on costs of care for people with dementia. Identifying up-to-date and comprehensive cost data should be a priority, so that commissioners of local services can benchmark costs and service provision.

The National Audit Office reports of 2007 and 2010 concluded that dementia services are still providing poor value for money. This is largely because of persistently patchy implementation of services and poor coordination of health and social care, leading to avoidable hospital admissions, prolonged length of stay as a hospital inpatient and increased need for residential care. Table 3 summarises data on costs of dementia care and offers some suggestions for where costs might be saved by improving the quality of care.

The cost for dementia care is probably underestimated, since healthcare inflation and an ageing population mean that current costs are likely to be higher than the latest published values. With increased diagnosis rates and improved quality of care, as the national Dementia Strategy, NICE/SCIE guidelines and Common core principles⁵ are implemented, cost savings may be possible within several years.¹⁷ In the meantime, implementation is likely to add to the total cost of care.

Table 3: Estimated costs of care for people with dementia and potential savings

	Estimated costs	Potential for savings
Healthcare costs	Direct healthcare costs £8bn a year in UK. Memory clinic service for early diagnosis: £220m a year in England (see section 6.2).	Cost saving after six years if use of memory clinics for early diagnosis leads to 20% or more reduction in need for residential care (see section 6.2).
	Anti-Alzheimer drugs: £720 per patient per year (assume £60 per month). ¹⁸ Excess bed-days in acute hospital : £1,400 per week. Clinical leader to implement dementia care pathway in every acute trust: £3m a year in UK (see section 5.8.2).	12% reduction in need for residential care in people with mild to moderate dementia treated for six months or longer (see section 6.4). £117m if length of stay is reduced by seven days for every inpatient with dementia admitted for fractured hip, chest infection, urinary tract infection or mini stroke (see section 4.5). £700m if length of stay reduced by two days for every inpatient with dementia by providing psychiatrist-led multidisciplinary assessment, or intermediate care. Assuming 25% of people aged 60+ admitted have dementia, and excess bed cost is £200 per day (see sections 4.1, 5.8.2, 5.9). £38m from seven day reduction in hospital admissions from use of hospital at home scheme (see section 6.7). £400 per patient whose length of stay is reduced by two days from use of psychiatrist-led assessment of all elderly patients admitted to hospital (see section 5.8.2).
	Inappropriate use of medication: £84m a year for 140,000 people in England given antipsychotic drugs who are unlikely to benefit and may be harmed by them (see section 6.4).	£84m a year from stopping inappropriate use of antipsychotic drugs (assume £600 for one year's treatment per patient ¹⁹) (see section 6.4).
Social care (local authority) costs	Long-term residential care: £9bn a year in UK. Community social service costs: £2.4bn. Home care: £150 per week. Day care: £90 per week. Residential care: £500 per week, £26,000 per year (see section 4.3).	18% fewer people needing residential care after two years with care management to coordinate health and social care (see section 6.3). £14,000 reduction in costs of residential care from psychosocial care given to carers (200 day delay in need for residential care) (see section 6.5).
Costs to the patient, family and other informal carers	Costs of informal care: £12bn a year for UK. £270 per patient per week if carer time estimated at minimum wage (see section 4.4).	£1,280 saved per patient over three months from an occupational therapy training service for carers (see section 6.4).

4.2 COSTS OF DEMENTIA CARE COMPARED WITH CANCER OR HEART DISEASE

Dementia costs the UK economy more each year than the combined costs of cancer and heart disease (figure 7). The annual cost of care for each person with dementia is higher than the median salary in the UK, and is higher than the annual cost of care for a person with cancer, heart disease or stroke (figure 8).

Concerns and issues about current dementia care

The estimated cost of implementing the National Dementia Strategy over 10 years is £1.9bn, excluding the costs of staff training. It is ultimately expected to lead to savings of £533m over the 10 years. This means a £1.35bn deficiency that would have to be found from efficiency savings, largely from long-term care and acute hospital services.²⁰

Figure 7: Total cost to UK economy, 2008²¹

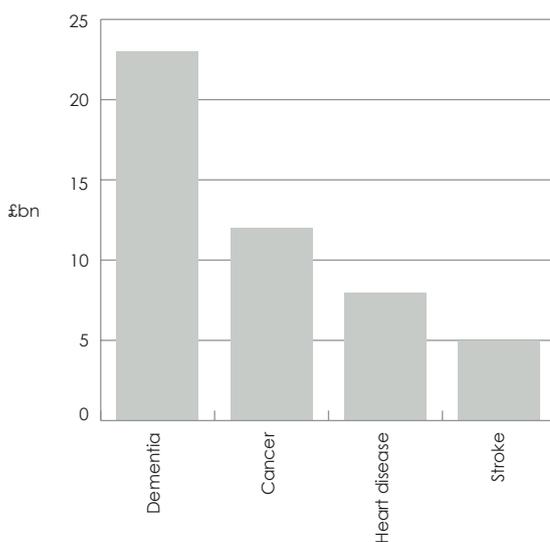
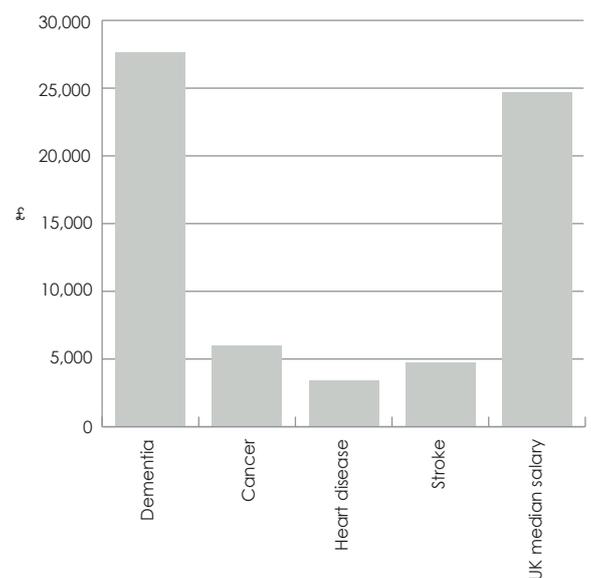


Figure 8: Annual costs per patient compared with median UK salary, 2008²¹



4.3 DIRECT HEALTH AND SOCIAL CARE COSTS

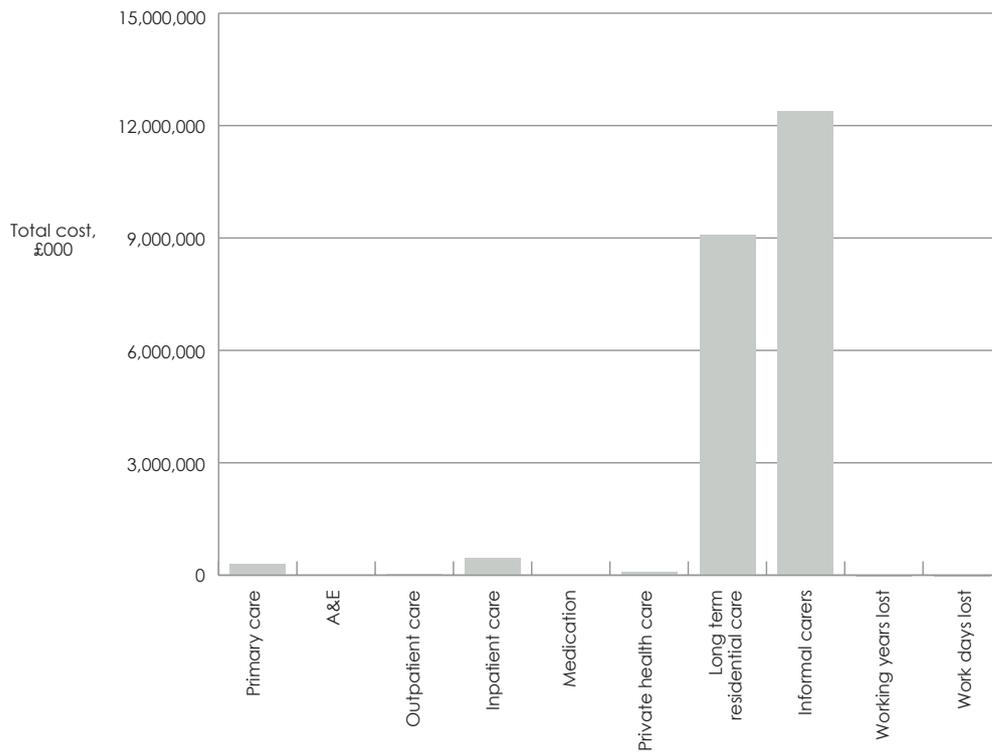
Costs of care for people with dementia in the UK were calculated to be almost £23bn in 2008.²¹

Dementia is mainly a disease of people aged over 65 years, with little in the way of specific medical treatments so the costs associated with it are predominantly for social care. Negligible amounts of money are lost through patients having to stop work or dying before reaching retirement age. Many people with dementia are cared for by younger family members, who are often unable to work full-time because of their roles as carers.

Figure 9 shows that 40% of the total costs are for long-term residential social care and 55% for informal care. Only 5% are for primary or secondary healthcare or medication costs for dementia.

Elderly people with dementia frequently have other diseases and medical problems that require treatment. In 2008, there were 7m GP consultations for people with dementia, half of which were home visits. Almost 300,000 were visits to emergency departments and 490,000 were outpatient consultations for people with dementia. An estimated 1.5m inpatient bed-days were for dementia itself. An additional 4.2m bed-days were for other problems of people with dementia (as a secondary diagnosis), at a total healthcare cost of £1.2bn.²¹

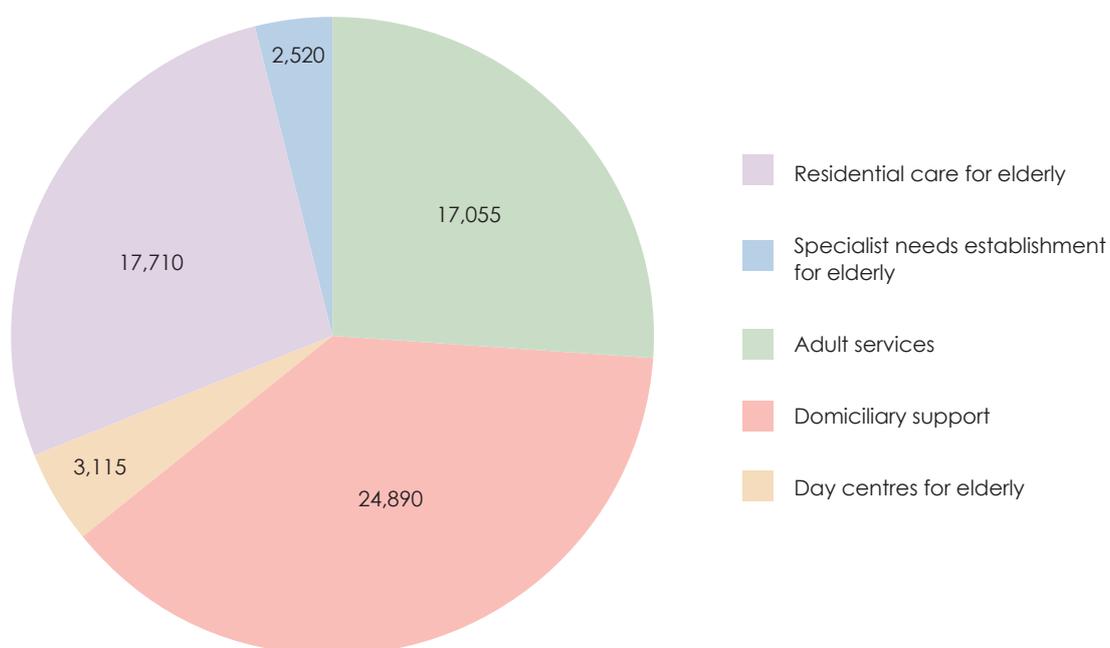
Figure 9: Costs of care for people with dementia, UK, 2008²¹



4.4 PERSONAL SOCIAL SERVICES

Most of the local authority staff working in services for the elderly in England are providing domiciliary support (figure 10). Many of these will be caring for people with dementia.

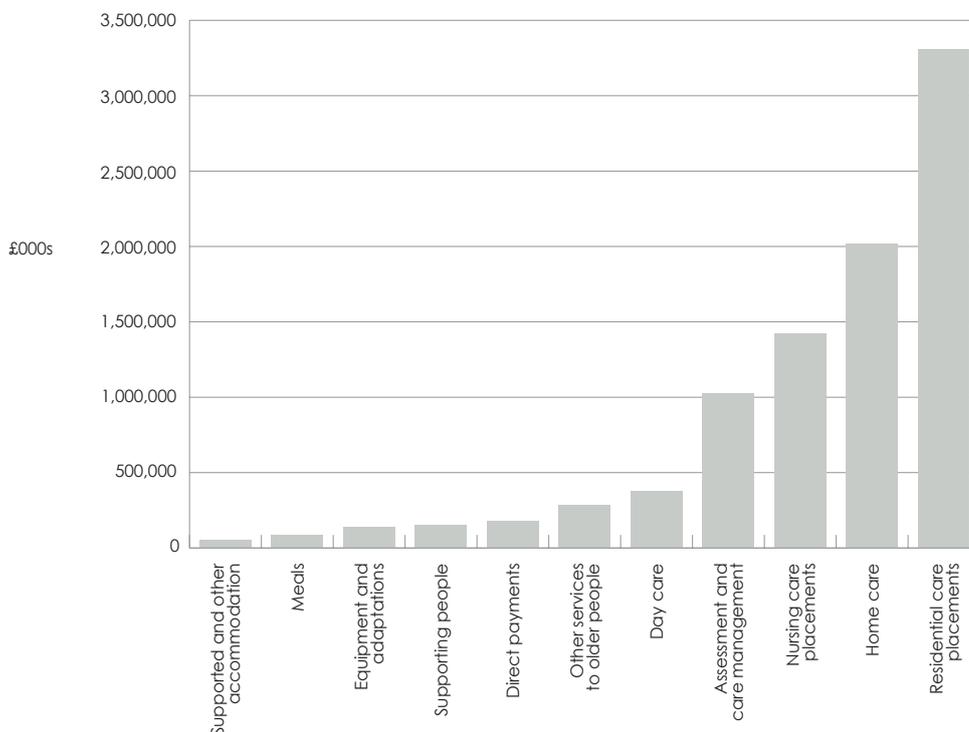
Figure 10: Type of care for the elderly given by local authority staff, 2009²²



Most personal social services costs for people with dementia in England are for residential care, home care or nursing care placements. Relatively little is spent on other services such as equipment and adaptations or day care. Figure 11 shows the total spent on personal social services for people aged 65 and over in 2008-09.

Personal social services expenditure on older people increased to £9.1bn in 2008-09 from £7.4bn in 2003-04. Expenditure on day/domiciliary (non-residential) has increased from £6.0bn in 2007-08 to £6.5bn in 2008-09.²³

Figure 11: Annual cost of personal social services for people aged 65 and over, 2008-09²⁴



4.5 COMPARATIVE COSTS FOR COMMUNITY CARE

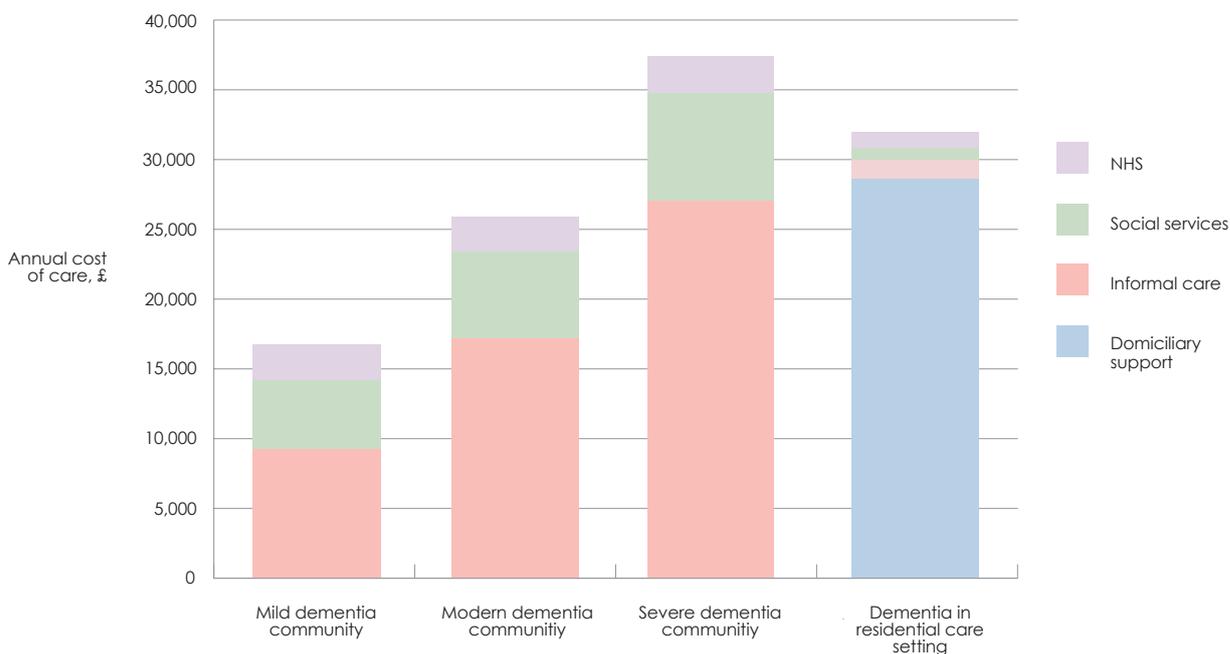
The annual costs of care increase with more severe forms of dementia. Although social care is often delivered by relatively low-paid staff, the number of hours of care needed means that total costs are high.

Table 4: Costs of social care for older people²³

Social care service	Unit cost (2008-09) ²³
Home care	£145 per week
Meals on wheels	£24 per week (£4.90 per meal)
Residential care	£498 per week (range £445 to £824)
Nursing care	£493 per week
Day care	£91 per week
Night sitter	£50 per night (2005 cost) ²⁵

Residential care is superficially expensive compared with care for people living in their own home. Supporting people with day care services is relatively cheap, estimated at £91 per week in 2008-09, compared with almost £500 per week for residential care. However, for a person with severe dementia, data suggest that a week in a standard care home is cheaper than seven nights of a sitter, at £350 or more per week, plus day care and other health and social care input. Figure 12 shows that the annual cost of residential care can be cheaper than community care for severe dementia.

Figure 12: Annual costs of care for dementia in the community compared with residential care²⁶



It is unclear from this data whether the reduced health and social care costs in residential care are because of reduced need once the elderly person is being looked after, or if it is because of difficulty in accessing appropriate levels of NHS or social services care once the patient is no longer living at home. Cheaper care is not necessarily the same as more cost-effective care. There may be a conflict between affordability and each person's preferences for high-quality care.

4.6 COST OF CARERS

Carers carry the majority of the costs for dementia care. Informal care is estimated to involve 1.5bn hours of unpaid care provided to dementia patients living in the community, valued at £12bn. The estimated cost of this informal care is more than the combined cost of social care and healthcare for dementia.

It has been estimated that a total of 512m hours are given to care for people with dementia by economically active carers, at a total cost of £6.7bn, plus another 997m hours from non-economically active carers, at an estimated cost of £5.7bn.²¹

Each person with severe dementia living in the community requires an estimated 46 hours of carer support per week.²⁷ The data on unpaid carers' time and opportunity costs in figure 12 are based on a study of community-dwelling US adults aged 70 years and over in 2001, assuming a minimum wage value of £5.80 per hour. 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. 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 their needs met once assessed.²¹

Figure 13: Burden of costs of care for people with dementia²¹

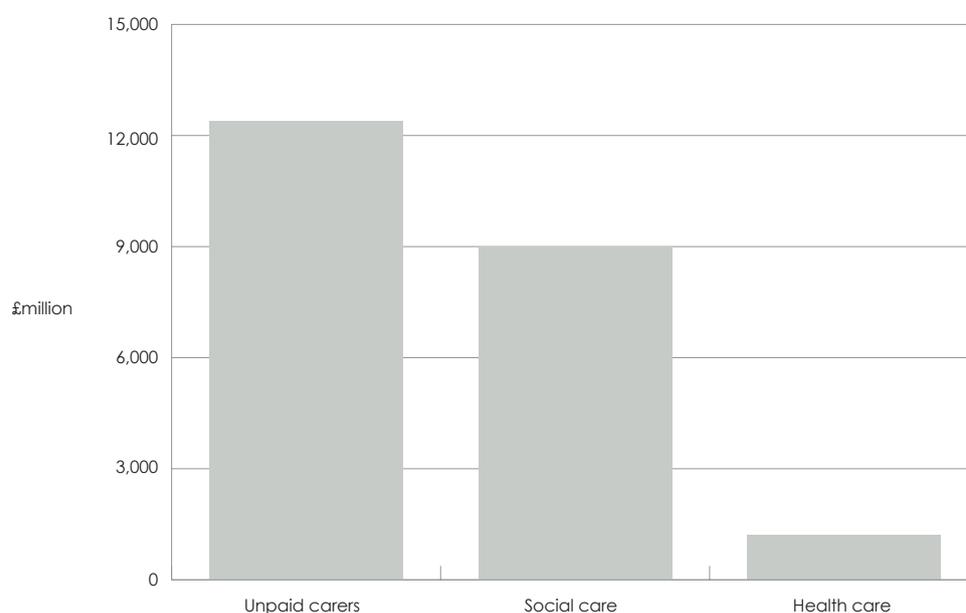


Table 5: Opportunity cost of unpaid carer time²⁷

Unpaid carers: time and opportunity cost		
	Hours of informal care per week	Annual cost at minimum wage
No dementia	4.6	£1,387
Mild dementia	13.1	£3,950
Moderate dementia	39.4	£11,883
Severe dementia	46.1	£13,904

4.7 ACUTE HOSPITAL COSTS

Although hospital care can offer little in the way of treatment for dementia itself, patients with dementia often have additional health problems that increase their risks of requiring admission to hospital.

People with dementia who are admitted to hospital often become more confused and distressed, and are at risk of falling, acquiring an infection, or becoming institutionalised and less able to care for themselves at home.

The main reasons for admission to hospital for people with dementia are because of a fall (14%) or fracture (12%), urinary tract infection (9%), chest infection (7%) and transient ischaemic attacks (7%).²⁸

A recent report found that for people with dementia, the average duration of stay after a hip fracture was 43 days, compared with 26 days in patients who were psychiatrically well.²⁹ In *Counting the cost* (2009)²⁸, the Alzheimer's Society reported DEMHOS study data that 25-35% of patients with dementia admitted with these problems remained in hospital for over one month. Table 6 shows that, if this duration were to be reduced by seven days per patient, the total savings would be almost £117m per year for these problems alone.

Table 6: Potential cost savings from reducing the duration of admissions by seven days for people with dementia admitted with acute health problems²⁹

Diagnosis	% reasons for admission to hospital for people with dementia	HES total number of admitted cases in 2008/09	Estimated number with dementia (assuming 25% have dementia)	% in hospital for one month or more	Excess day tariff (2008/09)	Estimated annual savings for seven days' shorter admission per patient with dementia
Fracture of the hip	12%	65,081	16,270	34%	£216	£24,600,240
Urinary tract infection	9%	134,743	33,686	30%	£176	£41,501,152
Chest infection (pneumonia)	7%	126,966	31,742	25%	£200	£44,438,100
Transient ischaemic attack	7%	20,562	5,140	35%	£178	£6,404,440
Total		248,284	86,838			£116,943,932

In 2008-09, over 7m hospital admissions in England were people aged 60 or over. Extrapolating the assumptions of the Alzheimer's Society that 25% of these admissions were people with dementia, if each had an average seven excess days' admission at £200 per day, £2.4bn of acute hospital costs might be saved each year by preventing these excess bed-days.

5. Services for people with dementia

5.1 WHAT DEFINES HIGH-QUALITY DEMENTIA SERVICES?

Based on the strategic documents, the overall vision of high-quality dementia care is as follows:

Information

- Public awareness of the disease and a positive attitude to it, with access to good-quality information on the illness and services available.

Early diagnosis

- High awareness among care staff of early signs of dementia.
- Good-quality local services to diagnose dementia and coordinate early interventions.

Coordinated care

- A dementia adviser to facilitate access to services.
- Multi-agency coordinated team to support people with dementia.
- An adequate and flexible range of services, support and technology that are personalised for people with dementia who are living at home, and their carers, including adequate housing support and services.
- Intermediate care, such as community hospitals and rehabilitation, for people with dementia, to help avoid the need for hospital admission and a pathway out of hospital, including appropriate use of telecare and other technology.

Treatment of symptoms and challenging behaviour

- Recognition of signs of distress and appropriate responses to diffuse anxiety and support the person's understanding of what they are experiencing.
- Minimal use of inappropriate medication such as antipsychotic drugs to sedate people.

Carer support

- Social networks offering peer support for people with dementia and their carers and input into designing services.
- Support to encourage independence and continued involvement in social and community activity.
- Support and good-quality planned breaks for carers of people with dementia, and strengthened support for carers who are children.

Hospital care

- Specialist liaison older people's mental health teams and clinical leadership for dementia care in hospitals, with defined care pathways.

End-of-life care

- Care homes that have planned care for residents with dementia including defined care pathways and specialist in-reach services from community mental health teams, primary care and dentistry.
- End-of-life care planning that begins early after diagnosis and based on the Gold Standard framework for palliative care, with good pain relief and nursing support for people with dementia at the end of their life.

Staff training

- All staff involved in the care of the patient has appropriate training, awareness of the disease and a positive attitude to it.

Funding and commissioning

- Services that are jointly commissioned by health and local authorities, which are planned to cater for the needs of the local population.
- Support at national and regional levels to ensure appropriate services are implemented.
- Improved assessment and inspection of healthcare, social care and residential services by the Care Quality Commission.

Sections 5.2–5.13 provide data on what support and services are being provided for people with dementia and their carers in England.

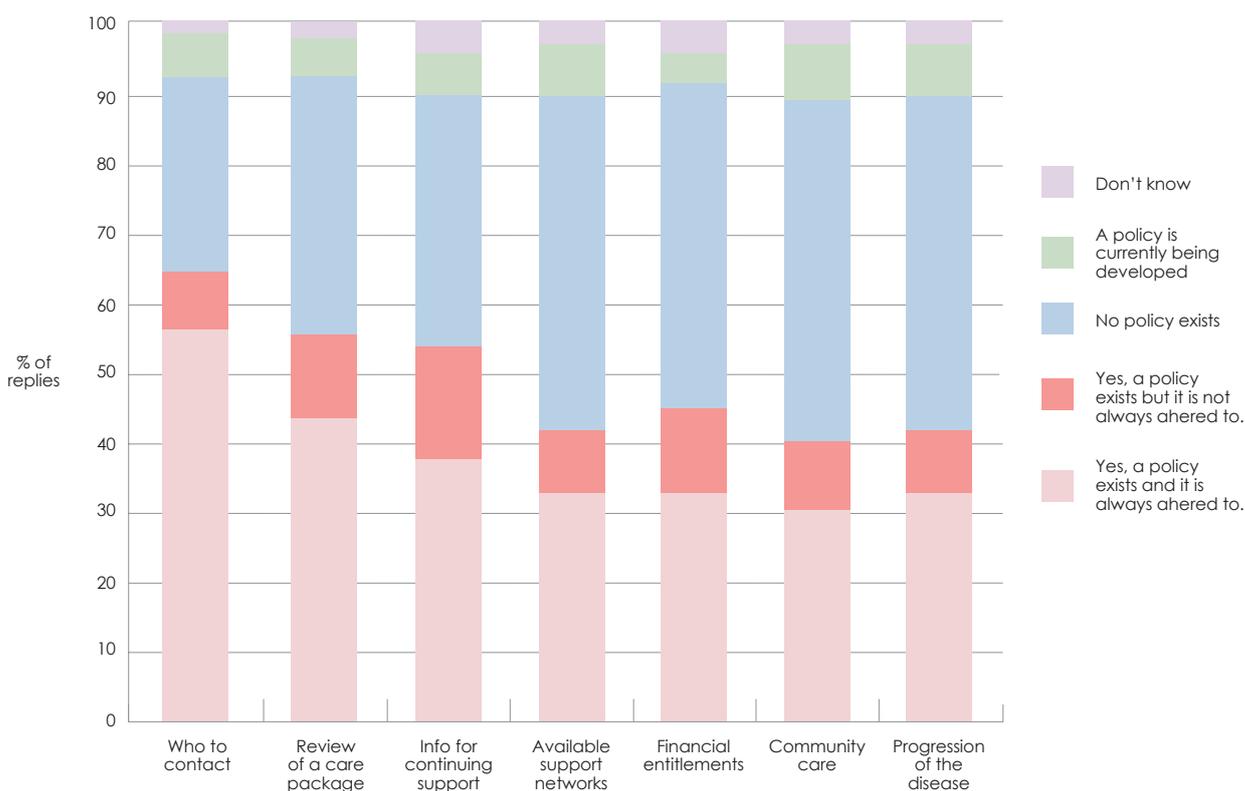
5.2 INFORMATION AND SUPPORT

Most people with dementia go to their GP for help within a year of noticing their symptoms, but some wait longer. There are several reasons for this delay, including people not recognising that their problems could be because of dementia, or thinking that nothing can be done to help or concerns about the stigma associated with a diagnosis of dementia.^{31, 32}

Carers often struggle to get enough support, including accessing the information they need to help them care for a person with dementia. Members of community mental health teams report that policies on giving information to people with dementia and their carers are often not in place or not followed.

The National Dementia Strategy Impact Assessment calculated that the cost of providing information about dementia for patients and carers, relevant for different subgroups of people, would cost £1.5m in the first two years.²⁰ The cost of producing one leaflet was £15,000 to £30,000, and designing and pre-testing the content cost between £12,000 and £67,000.

Figure 14: Variability in information provision for patients and carers¹⁶

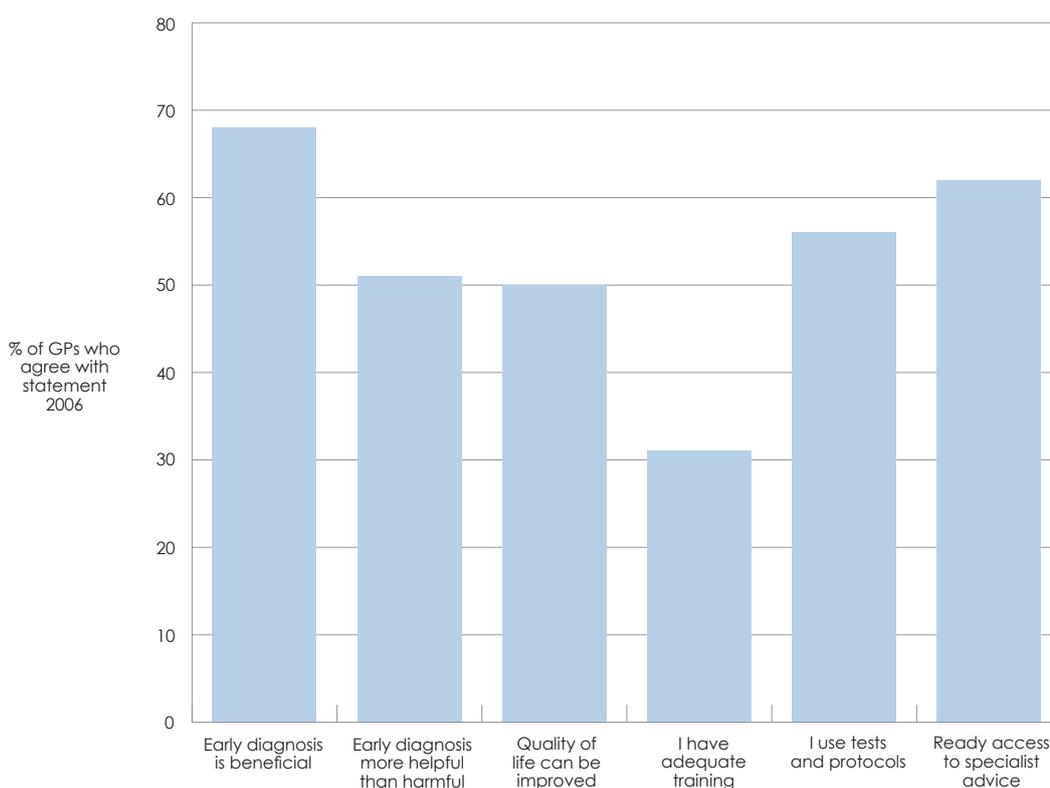


5.3 TRAINING OF HEALTH AND SOCIAL CARE STAFF

The NICE/SCIE (2006) clinical guideline for dementia¹ states that all health and social care managers should ensure all staff working with older people in the health, social care and voluntary sectors have access to dementia care training and skill development. This has been reinforced by the publication of ‘the common core principles for supporting people with dementia.’⁵ The aim is for the principles to provide a common framework as the basis for training programmes for the care workforce.

A survey of UK GPs in 2006 asked them about their attitudes to early diagnosis of dementia and how well equipped they felt they were to contribute to the diagnostic process. The survey found that two-thirds agreed that making an early diagnosis was important, but less than one-third felt they were adequately trained in diagnosing and managing dementia.⁶ These findings are summarised in figure 15.

Figure 15: Attitudes of GPs to caring for patients with dementia, 2006³³



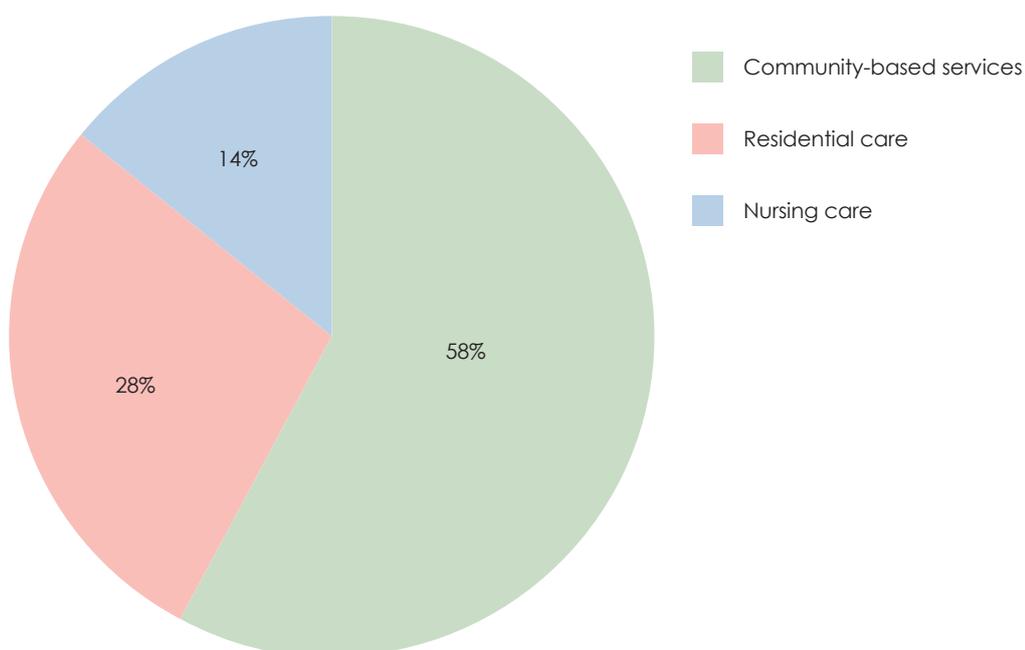
A key recommendation of the national policy and guidance, summarised in section 3 of this report, is that staff in acute hospitals need training in how to recognise dementia and how to care for people with dementia when they are admitted to hospital for other conditions. The preliminary findings from the National Audit of Dementia state that very few hospitals reported that training in awareness of dementia was mandatory for all staff. In addition, in the majority of hospitals, the training and knowledge framework or strategy (or both) did not identify necessary skill development in caring for people with dementia.³⁴

The quality of educational material on dementia is often poor. One study in Florida found that over 90% of training programmes for all health and social care staff who looked after people with dementia were poorly designed and often contained inaccurate information, language that was not person-centred, and were missing required training components.³⁵ Linking training to the national occupation standards, as set out in the core competencies,⁵ should ensure that training covers the eight principles identified, with particular emphasis on meaningful communication for people with dementia and respect and support for carers.

5.4 SERVICES FOR PEOPLE WITH DEMENTIA IN ENGLAND

People with dementia have complex needs that require coordination between health and social care services. A particularly vulnerable group are those under the age of 65 years with complex needs who may not be eligible for elderly care services.

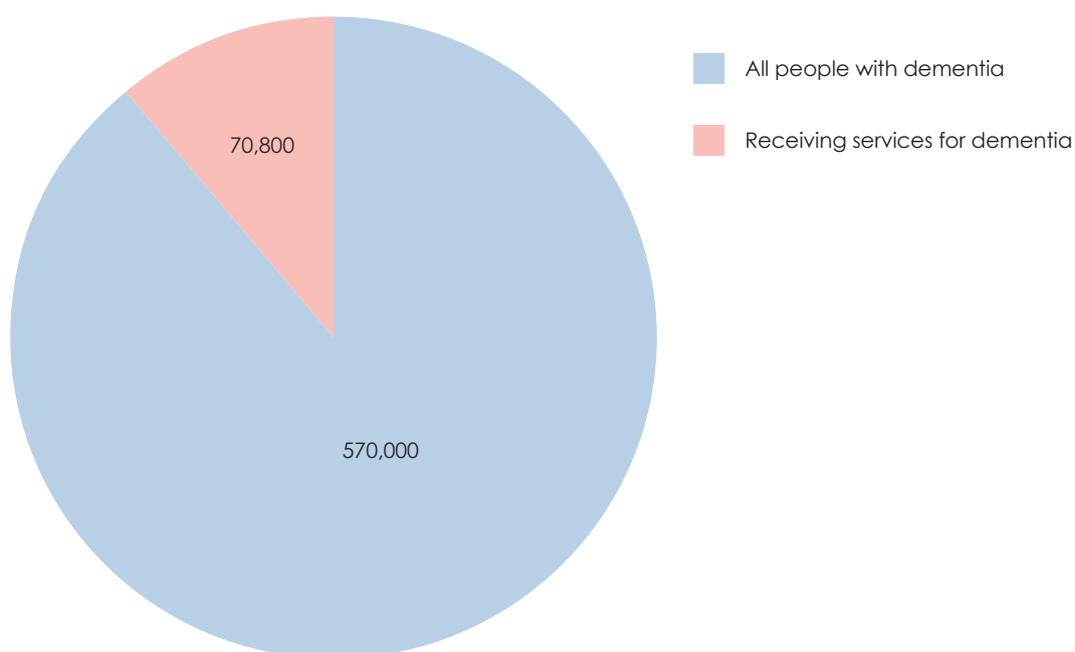
Figure 16: Type of social care services received, 2008-09²³



Of the 570,000 people living with dementia in England, just over 70,000 receive relevant social care services. Improved early diagnosis of dementia should increase the number of people who receive these services, but then the costs for care of people with dementia are likely to increase substantially.

Of those people receiving social care services in 2008-09, more than half were community-based, with 28% in residential care and 14% receiving nursing care.

Figure 17: Proportion of people with dementia who are receiving dementia services, England 2008-09³⁶



5.5 CARE PATHWAYS

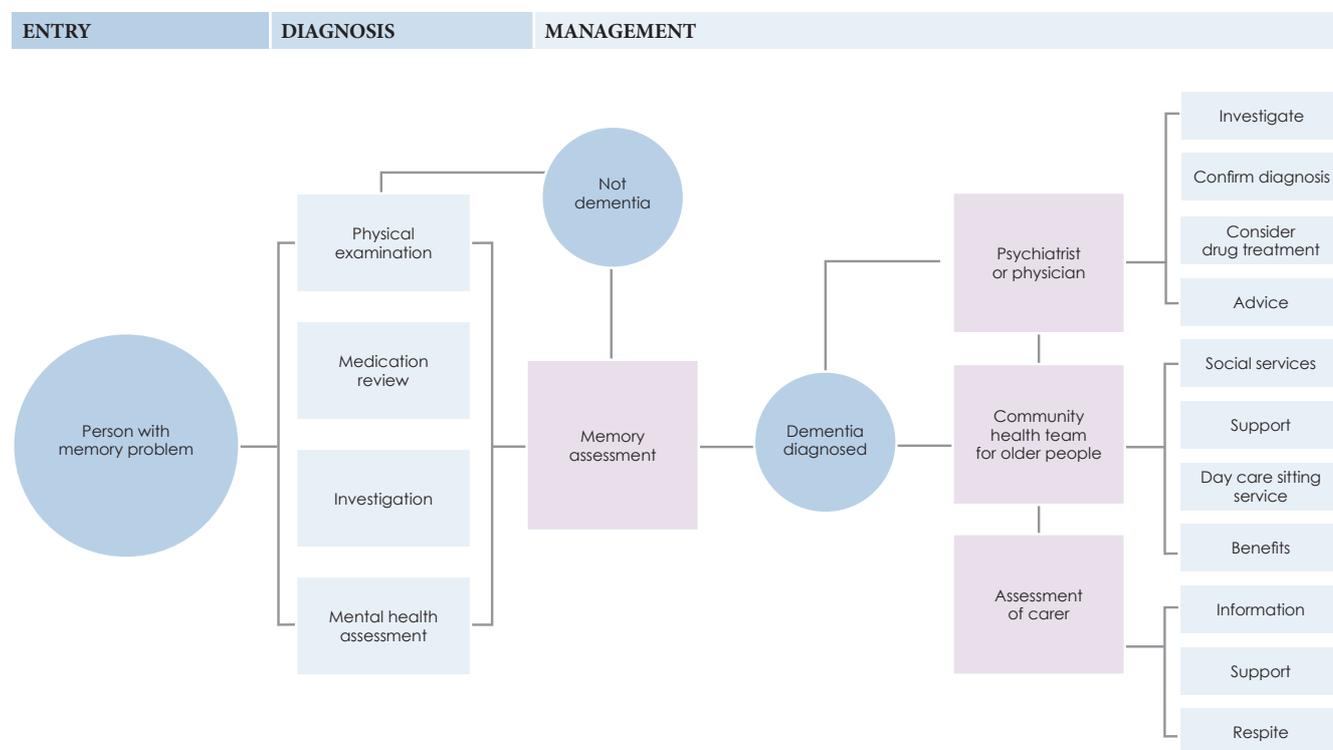
People with memory problems and dementia usually follow a complex care pathway and have difficulty accessing the limited available services. Not every elderly person with memory problems has dementia or is suitable for dementia services. Diagnosis can be made by a range of experts including the GP, community mental health team, psychiatrist or elderly medicine physician, but liaison between service providers can be challenging. Investigations such as CT scans can be used to exclude treatable problems, but the main needs are for social care services, because relatively little can be offered to treat dementia.

The care pathway for a person who has been diagnosed with dementia needs to be an iterative one, with repeated assessment and prescribing reviews as the patient's condition changes over time.

Care pathways should involve health and social care professionals from the initial diagnosis to end-of-life care. For most patients, the GP is the central healthcare provider who coordinates care for their health and social problems.

Figure 18: Typical dementia care pathway³⁷

A more detailed pathway is available from the Map of Medicine.³⁸



5.6 DIAGNOSIS

The diagnosis of dementia is essentially clinical, based on low or deteriorating scores on tests such as the mini mental state examination (MMSE).

Diagnosis may involve two types of assessment – a comprehensive geriatric assessment to identify all physical and mental health and social problems, and specific screening for dementia.

As with many long-term problems, dementia can be difficult to diagnose early, when the person's symptoms may be very similar to the increased forgetfulness of getting older. Data suggest that dementia is under-diagnosed in the UK population, even in more severe cases.

There is likely to be an ideal clinical 'window' for diagnosing dementia, when the symptoms are sufficiently advanced to make the diagnosis reasonably certain, but still mild enough that the person and their family can benefit from treatments and support. Effective care early in dementia includes the identification and treatment of associated health problems, such as poor sight or hearing, that could be contributing to the person's confusion or worsening their quality of life. Support from a multidisciplinary team of social services, primary care and specialist psychiatry or psychogeriatric services at an early stage might prevent crises when the person becomes unable to cope, and can help maintain the person's independence for as long as possible. In this way, it might be possible to reduce the need for emergency admission to hospital or to delay a move into long-term residential care.

Equitable access to dementia services is an issue particularly for ethnic minority groups, who may find it difficult to access information in a language they can understand, and for younger age groups, as many services are targeted at people aged over 65 years. The Alzheimer's Society report on dementia in the UK in 2007 estimated there were more than 11,000 people from black and minority ethnic groups with dementia, 6% of whom have early onset dementia, compared with 2% of the rest of the UK population.² Early onset dementia affects more men than women, and is often caused by frontotemporal dementia. The Alzheimer's Society report estimated that there were at least 15,000 people under 65 years known to have dementia in the UK, although the true figure could be three times as high, compared with almost 669,000 aged over 65.²

One measure widely used to assess the severity of dementia is MMSE:

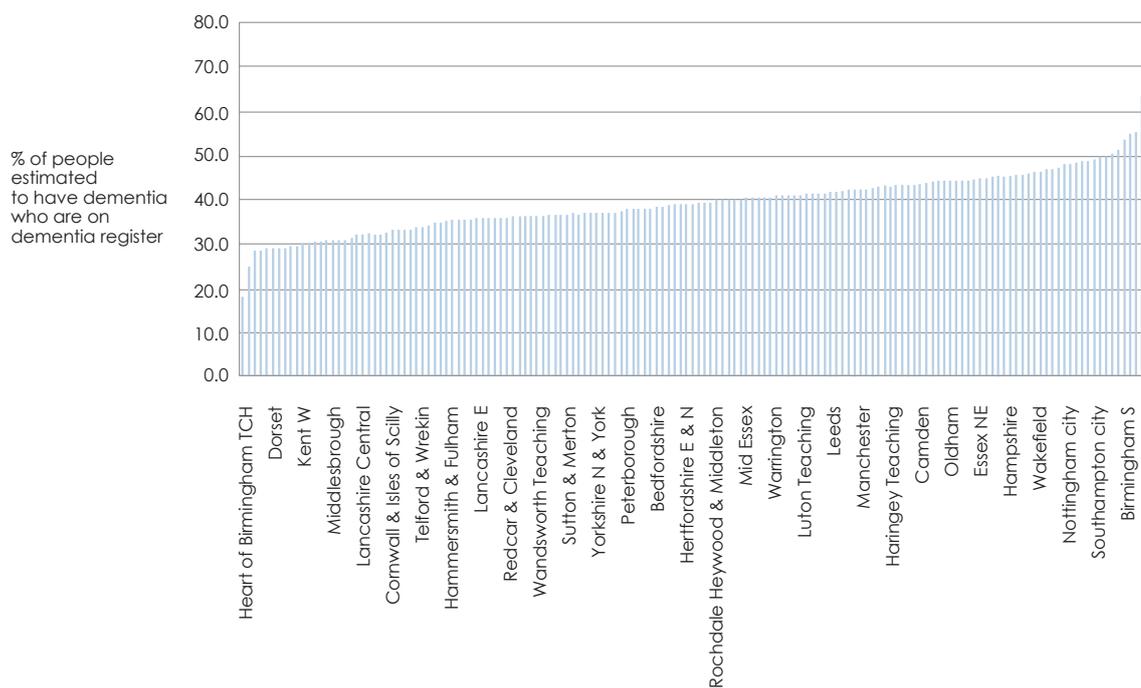
- mild dementia: MMSE 21-26
- moderate dementia: MMSE 10-20
- moderately severe dementia: MMSE 10-14
- severe dementia: MMSE less than 10.

5.6.1 Failed diagnoses

A major problem is the continuing failure to correctly diagnose people with dementia.⁶

Between a half and two-thirds of the number of people estimated to have dementia in each PCT area will not be on a dementia register, and therefore will not be identified as being in need of support.

Figure 19: Proportion of people who are estimated to have dementia who are actually on their GP’s dementia register (broken down by PCT area)^{2,39}



5.6.2 Potential cost savings from early diagnosis

Failure to diagnose dementia early leads to patients and carers missing out on important care and support. Not only does this impact negatively on their quality of life, it also means that interventions that might prevent or delay the need for residential care are not available in time for them to make a difference.

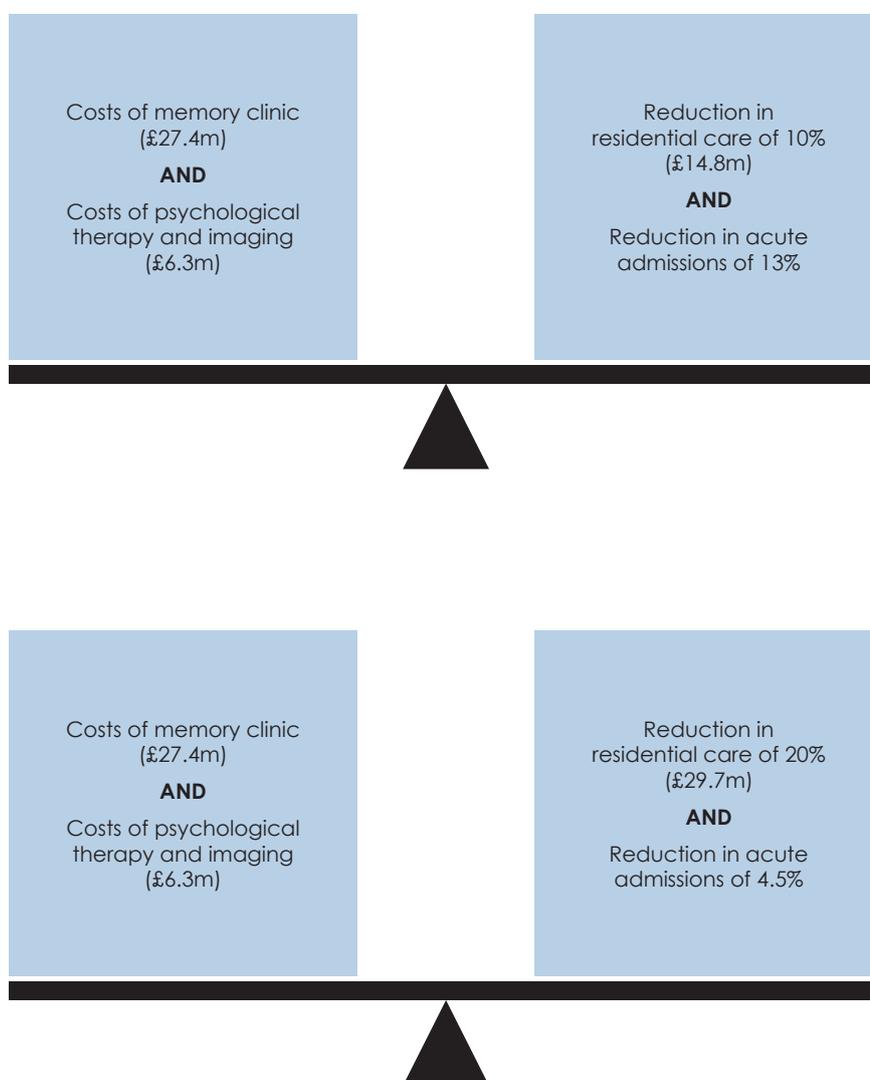
Banerjee and Wittenberg (2009)¹⁷ evaluated one particular approach to early intervention: the Croydon Memory Service Model. This model uses a multidisciplinary and multiagency team to provide early diagnosis, followed by information and medical, social and psychological help to people diagnosed with dementia and their carers. Banerjee and Wittenberg modelled the impact of such a service on dementia care throughout England, and concluded that it would be:

- (a) cost-effective after 10 years if it led to a 10% or more reduction in residential care admissions
- (b) cost saving if it led to a 20% or more reduction in residential care.

These estimates for reduction in the number of residential places required for people with dementia are likely to be achievable. One UK study found that 18% fewer people needed residential care if they had access to a care manager to coordinate their health and social care needs, with 33% of patients receiving current types of care still able to live at home after two years, compared with 51% of the case management group.⁴⁰

A Healthcare for London report used these calculations to determine the effect of establishing such a memory service for the 862,000 people aged 65 and over in London, as well as implementing the NICE/SCIE guideline recommendation of psychological therapy for carers of people with dementia, reduced use of electroencephalograms and increased use of structural imaging of the brain.⁴¹ This evaluation concluded that the set-up and running costs of the new service would be likely to delay entry to residential care and reduce emergency admissions to secondary care by improving management of the condition and preventing crises that would normally lead to an acute admission. The enhanced service would be cost saving in London if the need for residential care fell by 10% and emergency admissions fell by 13%, or if residential care fell by 20% and emergency admissions by 4.5% (figure 20).

Figure 20: Balancing the costs of a memory clinic service in London: two scenarios⁴²



5.7 PRIMARY CARE

As noted in the previous section, most people with suspected dementia are diagnosed by their GP and most of the care they receive is coordinated by primary care teams.²⁶ The primary care team, led by the GP, therefore plays a crucial role in the care of people with dementia from diagnosis to the end of life.

A report by the King's Fund,²⁶ based on a literature review, guidelines and expert opinion, concluded that GPs could deliver high-quality care for people with dementia and their carers in the following ways:

- Being aware of the risk factors and symptoms of dementia and knowing what action to take when a patient presents with symptoms that could be caused by dementia.
- Being proactive in finding patients with suspected dementia.
- Carrying out baseline assessment of patients with suspected dementia.
- Referring patients promptly and appropriately to specialist units such as memory clinics.
- Participating in shared care with specialist services and providing continuity of care so that patients can be cared for in the community for as long as they wish.
- Providing information for patients and carers to support self-care.
- Devising care plans for patients and their carers that are tailored to the on-going needs of the individual.
- Providing holistic ongoing care for the patient and their carer, referring to other services as appropriate, and with thorough reviews of the patient every six to 12 months.

All staff in the primary care team should have appropriate training and knowledge to be able to provide appropriate holistic care for people with dementia and their carers. Where specialist services are not available in an area, the report recommends that GPs should be proactive in making sure that they are commissioned.²⁶

The report found evidence that in some cases, GPs failed to recognise early signs of dementia, were unwilling to take action when dementia was diagnosed, and tended not to want to take ownership of dementia care by undertaking case management or shared care. However, it also found examples where general practices had been proactive in reducing late diagnoses and providing multidisciplinary care.²⁶

5.8 COMMUNITY CARE

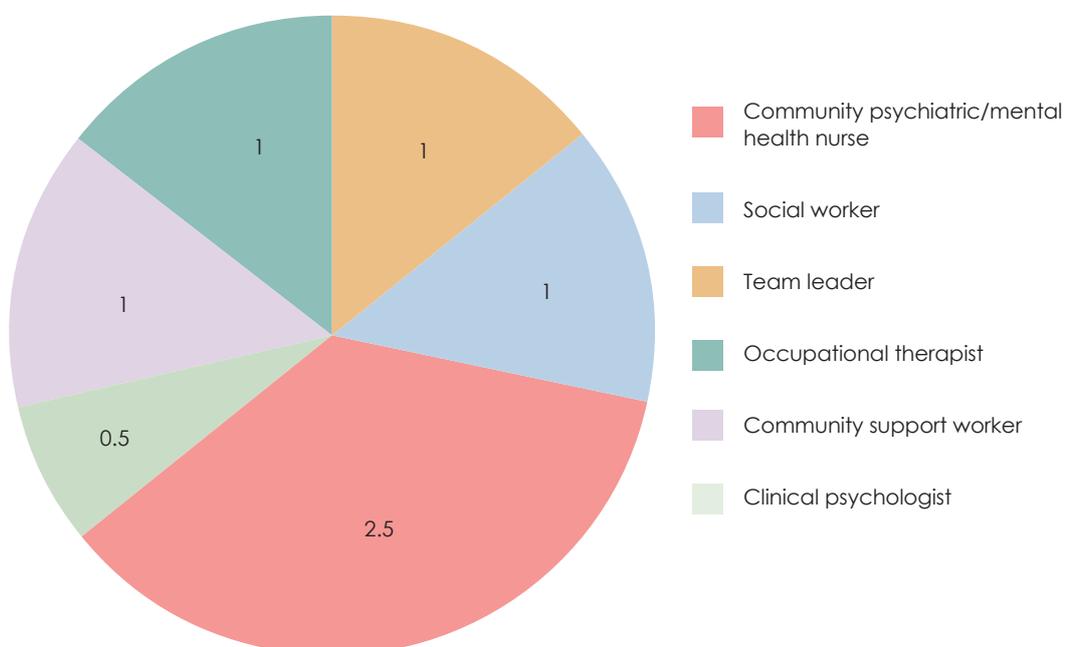
5.8.1 Recommended composition of community mental health team

The previous sections showed that a team of health and social care professionals could improve the quality of care for people with dementia.

The Royal College of Psychiatry, London (2004)⁴³ recommended the composition of the community mental health team (CMHT), for an average PCT population (figure 21).

A survey of CMHTs conducted in 2006 found fewer than half had the recommended number of staff, and at least one-quarter had no social worker or clinical psychologist.¹⁶

Figure 21: Recommended composition of community mental health team⁴³

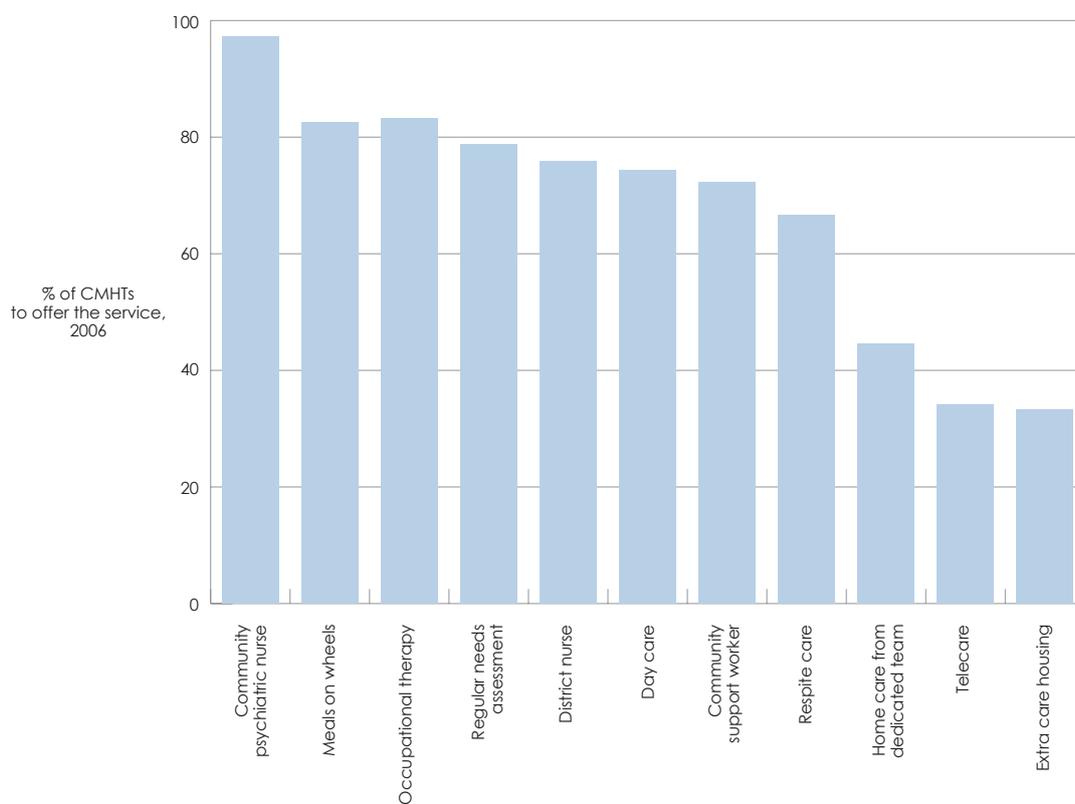


5.8.2 Availability of community care services

A survey of CMHTs in 2006 found significant variations in the availability of community services for patients with dementia.

Almost one in five CMHTs reported that either meals on wheels or occupational therapy were not available to their community. One-third could not provide respite care and one-quarter had no day care.¹⁶

Figure 22: Proportion of community care services available for CMHTs, 2006¹⁶

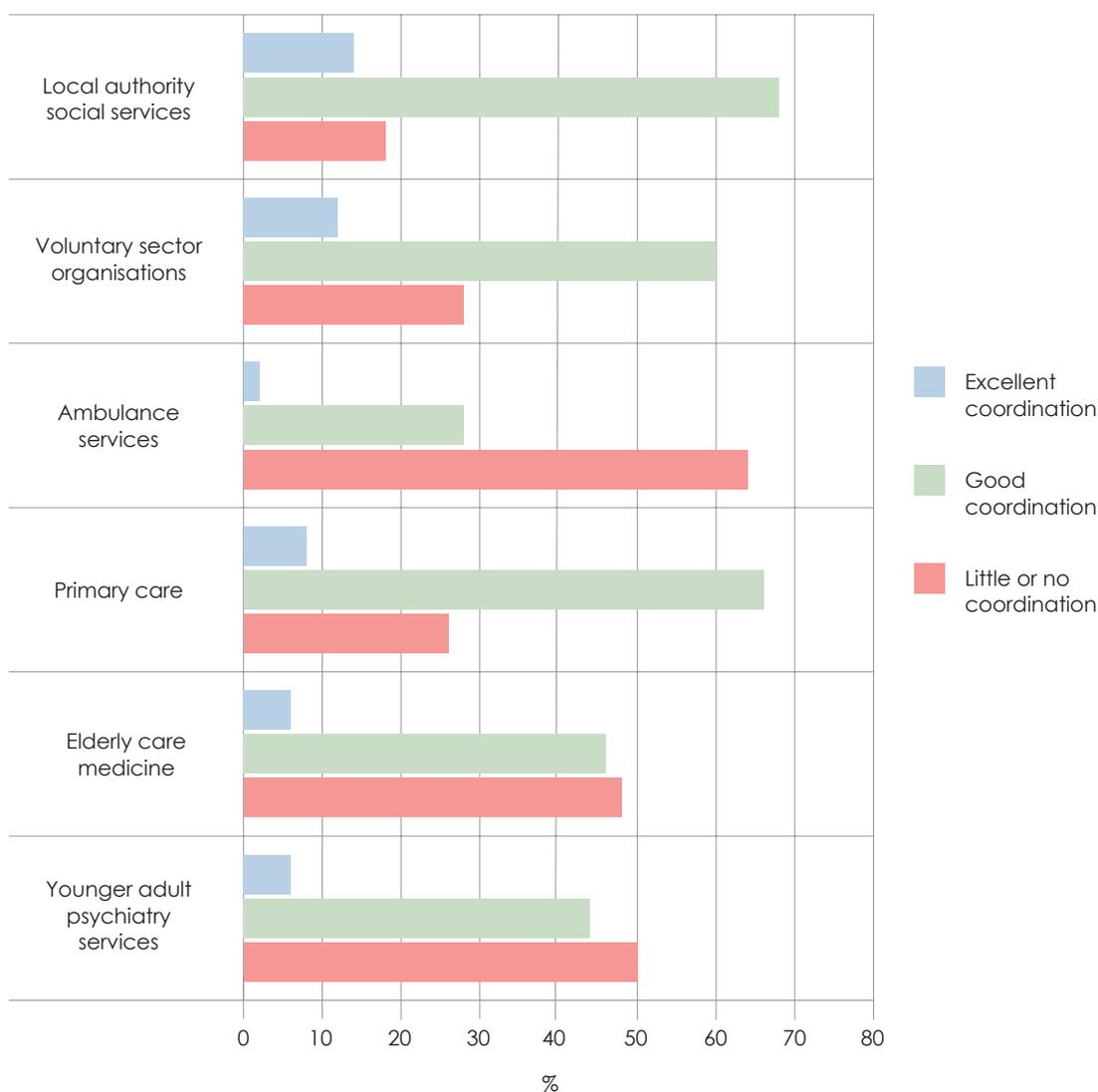


5.8.3 Inconsistent coordination of health and social care services

High-quality care for people with dementia depends greatly on how well health and social care services work together, along with their partners in the private and voluntary sectors.

Collaboration depends on several factors, such as communication and streamlined access to resources. Despite this, only 29% of community mental health teams, in one survey, had any joint health and social care funding arrangements in place (figure 23).

Figure 23: Opinion of CMHTs on coordination of services in their area: Percentage of respondents agreeing with the statement¹⁶



5.8.4 Variability in person-centred care

Person-centred care, recognised as an important component of high-quality care for people with dementia, encompasses four major elements:⁴⁴

- A value base that asserts the absolute value of human life regardless of age or cognitive ability.
- An individualised approach that recognises uniqueness.
- Understanding the world from the perspective of the service user.
- Providing a social environment that supports psychological needs.

The proportion of people aged 65 years and over receiving person-centred care, varies across local authorities, ranging from none in the Isles of Scilly and Southend-on-Sea, to over 10%, in Richmond-upon-Thames, Suffolk, and Westminster.

5.8.5 Support for carers to enable home care

A 2011 survey of people with Alzheimer's and those caring for them in their own home found that 83% responded that being able to continue to live in their own home was very important for the person with dementia.⁴⁵ The same survey found that a majority of people with dementia would want to be active in the community for as long as possible and that maintaining their independence was one of the key ways they look to primary and community health services helping them. The expansion of personal health budgets is one way in which this may be achieved.

5.9 HOSPITAL CARE

5.9.1 Adverse impact of hospital admission on people with dementia

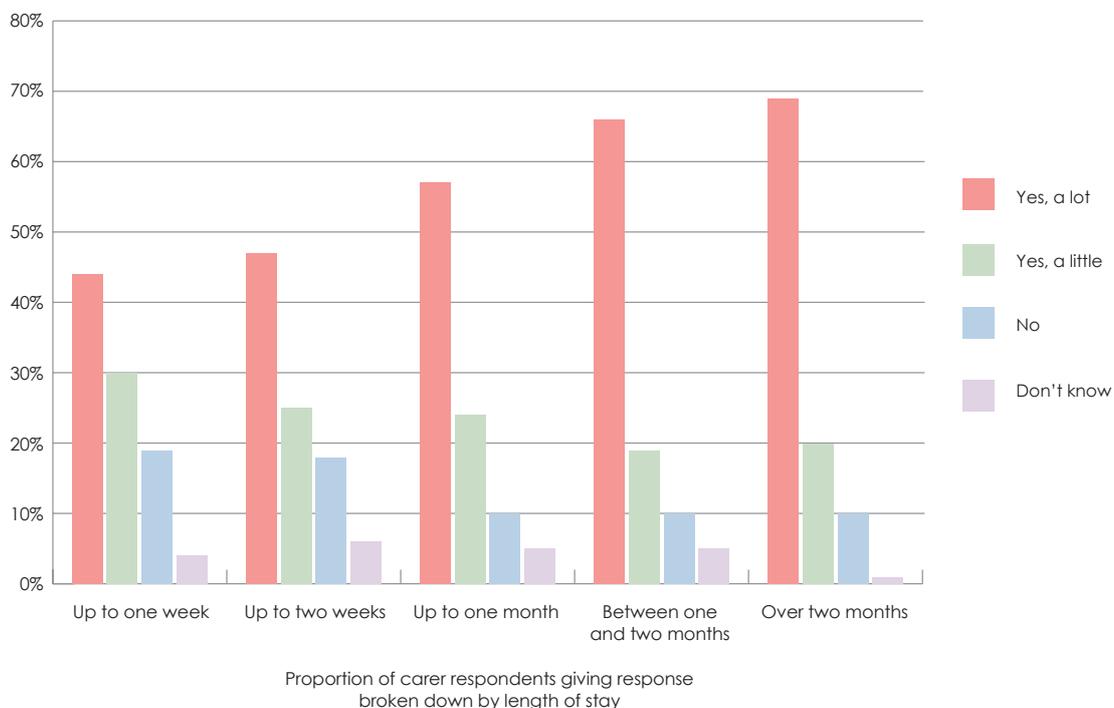
As dementia is primarily a condition that affects older people, many people with the disease also suffer from other conditions common to old age that may require hospital admission. When a person with dementia is admitted to hospital they risk developing delirium (acute confusion) arising from infection, post-anaesthetic effects and side effects of some medications. The key policy documents and guidelines for good practice, summarised earlier in this report, all highlight the need for improved care for people with dementia when they are admitted to a general hospital for another condition. This has also been highlighted in guidance from the NHS Confederation and in guidance produced by the RCN.^{46, 47}

To ensure appropriate care is given, it is essential that an older person's mental state is assessed when they are admitted to hospital. The preliminary findings reported in December 2010 from the National Audit of Dementia (Care in General Hospitals) found that the majority of hospitals say it is their policy that an assessment of people with dementia includes a mental state assessment. However, an audit of case notes showed that fewer than half the sample of patients had received a standard mental state test and very few had been assessed for delirium, or been formally tested for the presence of depression.³⁴

People with dementia may have difficulty communicating with hospital staff and a carer or relative can provide vital information to help hospital staff detect signs of deterioration in the person's mental state. The same audit found that a minority of hospitals have a formal system for gathering information pertinent to caring for a person with dementia and a minority of case notes had a section dedicated to collecting information from the carer, next of kin, or person who knows the patient well.

Overall the audit found that hospitals are failing to recognise the needs of people with dementia and they are not safeguarding people with the disease from longer hospital stays. Few hospitals said they had a system to ensure that staff on the ward are made aware if a patient has dementia and therefore the staff lack information on how the disease may affect the patients and how to adequately care for them. Only a minority of hospital boards review delayed discharge or readmissions of people with dementia. Carers often report that being in hospital had a negative effect on the person’s dementia and the symptoms of dementia, especially for those with greater lengths of stay. Figure 24 shows how carers responded to the question: ‘Do you think that being in hospital had a negative effect on the person’s dementia and the symptoms of dementia?’ The longer the patient is in hospital, the more they deteriorate.

Figure 24: Response of carers to the question: ‘Do you think that being in hospital had a negative effect on the person’s dementia and symptoms of dementia?’²⁸



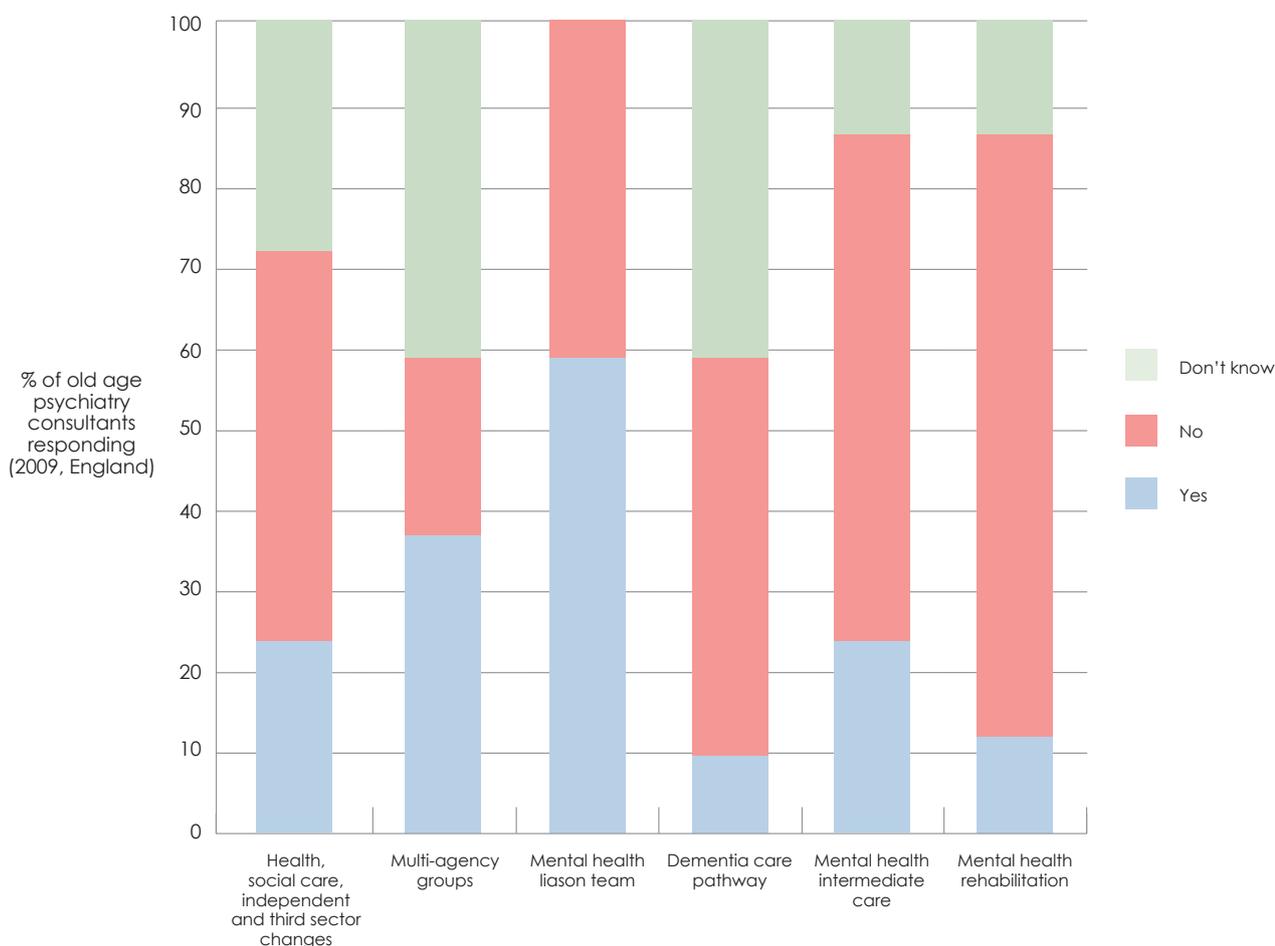
5.9.2 Clinical leadership

A survey of 218 psychiatrists for elderly people, working in England in 2009 found that one quarter were not sure what changes had been implemented locally as a result of the National Dementia Strategy.⁷

More than half of district general hospitals had mental health liaison teams, but dementia care pathways, intermediate care or rehabilitation services were available in no more than one-quarter of hospitals.

The National Dementia Strategy Impact Assessment reported that providing 2.4 hours of a psychiatrist’s time per patient could reduce the duration of their admission by over two days. The cost of appointing a clinical leader for one session per week per acute trust to develop and oversee the implementation of care pathways for dementia would cost £3m a year in total across England.

Figure 25: Dementia services available in hospitals, England, 2009⁷



5.10 DRUG THERAPY

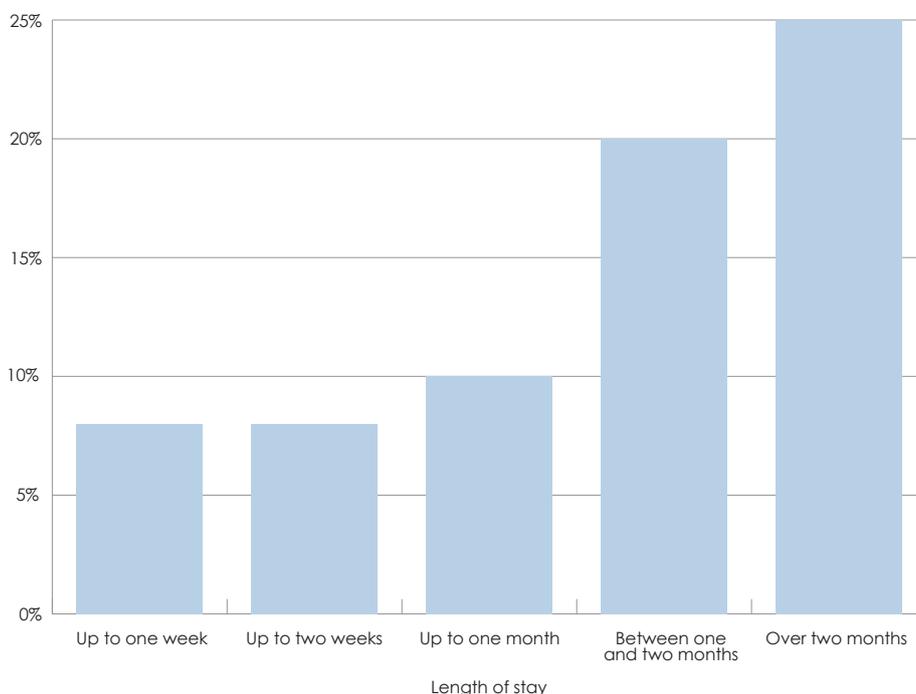
5.10.1 Use of antipsychotic drugs

People with dementia often become more confused and agitated when they are in unfamiliar surroundings, such as when they are admitted to hospital or residential care. Confusion and distress could be reduced through better staff training and more patient-centred care (see sections 6.6 and 6.8).

Antipsychotic drugs, such as risperidone, olanzapine, quetiapine, aripirazole, and haloperidol, are used to treat people with disturbed thinking and behaviour because of problems such as schizophrenia. Some patients with dementia may need antipsychotic drug treatment, but there is a concern that they are prescribed to people who don't need them, for 'behavioural control' as the drugs can also sedate a distressed patient.

The level of prescribing which is inappropriate is such that four-fifths of those prescribed antipsychotic medication receive no benefit from it but are instead exposed to increased risk of a cerebrovascular adverse event. Research has shown that inappropriate prescribing is more likely with longer hospital admissions, and may therefore be a contributory factor in the worsening of dementia symptoms in people who have longer admissions.¹⁹

Figure 26: Proportion of people with dementia on antipsychotics according to length of stay²⁸



The Department of Health is committed to reducing the use of antipsychotics prescribed to people with dementia by two-thirds by November 2011. Preliminary findings from the National Audit of Dementia (Care in General Hospitals)³⁴ suggest there is some way to go to achieve this because the majority of hospitals in the survey did not have policy to govern interventions for patients displaying challenging behaviour, aggression and extreme agitation, suitable for people with dementia. However, those hospitals that did have a protocol reported that restraint and sedation were only used as final options and for the best interests of the person with dementia.

The analysis of case notes undertaken as part of the national dementia audit of care in general hospitals showed a minority of people with dementia (20 - 44%) were prescribed an antipsychotic drug. For less than a third of these patients, the drug was newly prescribed during their admission to hospital (most of these prescriptions had therefore been made in the community).³⁴

In response to these reports, the Dementia Action Alliance, together with the NHS Institute for Innovation and Improvement initiated a campaign for 'The Right Prescription' – a call to action on the use of antipsychotic drugs for people with dementia, in June 2011. The campaign commits to involving and working with pharmacists, psychiatrists, nurses, GPs, people with dementia and their family members to ensure that every person with dementia on antipsychotic medication receives a clinical review to ensure an evidence-based, personalised care plan, by March 2012.

5.10.2 Use of anti-dementia drugs

Several drugs have been licensed for use in people with dementia in the UK. Guidance from NICE on four of these drugs, donepezil, galantamine, rivastigmine and memantine, in their 2011 review, is as follows:⁴⁸

- Donepezil, galantamine and rivastigmine are recommended as options for people with mild to moderate severity of Alzheimer's disease.
- Memantine is recommended for patients with moderate Alzheimer's disease, who are intolerant of or have a contraindication to AChE inhibitors, or people with severe Alzheimer's disease.
- Only specialists should initiate treatment. Carers' views of the patient's condition at baseline should be sought.
- Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional or behavioural symptoms.
- Patients who continue on treatment should be reviewed regularly using cognitive, global, functional and behavioural assessment. Carers' views of the patient's condition at follow-up should be sought.

The effects of the four drugs on different types of symptoms of dementia are summarised in table 7.

Table 7: Estimates of clinical effectiveness of anti-dementia drugs⁴⁹

Symptom type	Donepezil	Galantamine (higher doses, 16 mg/day or more)	Rivastigmine (higher doses, 6-12 mg/day)	Memantine
Cognitive (thinking)	✓	✓	✓	?
Functioning	✓ Short-term benefits only	✓	✓	?
Behaviour	X	?	?	X
Overall (global) scores	✓	✓	✓	✓

✓ = significant benefit X = no significant benefit ? = mixed results, benefit uncertain

The table shows the outcomes for which the drugs have been shown to have a statistically significant benefit. However, the clinical significance of the benefits, especially in the long term, is less certain.

A cost-effectiveness analysis by NICE concluded that the use of these drugs could reduce the length of time spent in full-time residential care by 1.41 to 1.54 months.

5.11 INTERMEDIATE CARE

The National Service Framework for older people set out the requirements for the NHS and local authorities to provide enhanced intermediate care services at home or in designated care settings. These services aim to prevent unnecessary admission to hospital and long-term residential care, and to provide effective rehabilitation to facilitate early discharge from hospital.

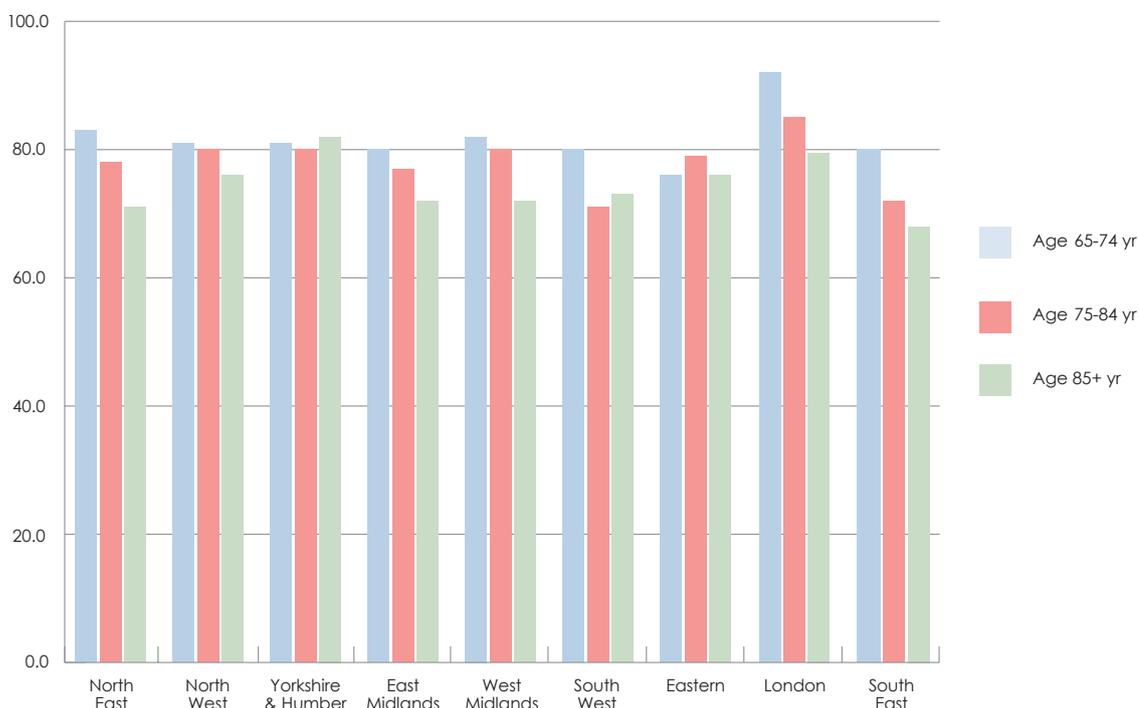
One study of hospitals in the UK in 2006-07 found that 1.6% of all 50m bed-days were caused by delayed discharges.⁵⁰ In contrast, a survey of 158 elderly patients in one UK district general hospital in 2007, with median age of 82 years, found that 58 experienced a delayed discharge of almost five days on average. Of the delayed discharges, 26% were people awaiting residential or nursing home places, 29% were waiting for assessment of needs, and 28% were waiting for domiciliary care to be implemented. During the delay, seven out of the 58 people developed new medical problems including hospital-acquired chest and *Clostridium difficile* infections, and three deaths occurred as a result of pulmonary embolism, bronchopneumonia and *C. difficile* infection.

Although the study did not state how many patients had dementia, delayed discharge was more likely in older patients and those with confusion at the time of admission.⁵¹

Intermediate care services should be multidisciplinary, involve short-term interventions lasting one to six weeks, and be designed to maximise independence and facilitate the elderly person being able to live safely at home.

Figure 27 demonstrates regional variability in the proportion of older people who are still living at home three months after being discharged from hospital, from 67% of people aged 85 and over in the South East to 82% in Yorkshire and the Humber.

Figure 27: Proportion of older people still at home 91 days after hospital discharge⁵²



5.12 RESIDENTIAL CARE

Up to 75% of residents in general care homes have dementia.⁵³ The Alzheimer’s Society (2008)⁵⁴ reported that more than half of carers think people with dementia don’t have enough to do in care homes, and studies have shown that residents interact with others for only two minutes in every six hours. Patients and staff enjoy having more activities to do, and this can improve quality of life, reduce mortality and improve mental and physical function.

The National Dementia Strategy Impact Assessment recommended that community psychiatric nurses (CPN) should be used to improve the quality of care for patients in residential homes, by assessing them for mental health problems such as depression, which is found in at least 40% of residents with dementia.^{20, 55} The level of input required was estimated to be four CPNs per PCT area, and the annual cost nationally would be £35m a year.²⁰

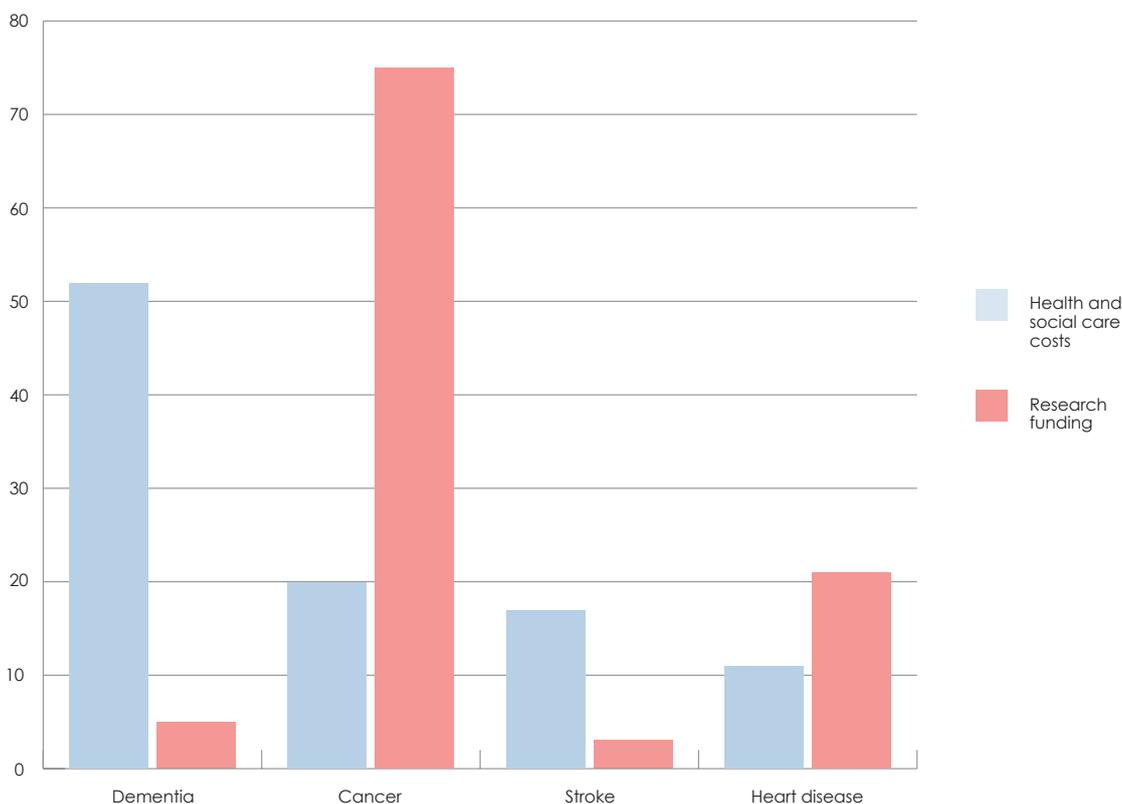
5.13 RESEARCH INTO DEMENTIA

Figure 28 shows that, although dementia accounts for over 50% of the combined health and social care costs of cancer, stroke and heart disease, dementia only receives 6% of the combined research funding that is available for these conditions. In contrast, cancer accounts for just over 20% of health and social care costs but receives nearly three-quarters of the total medical research funding for these four diseases.

Funding for research on dementia in the UK has been estimated as follows:²¹

- £14m from charitable sources.
- £36m per year from government sources.

Figure 28: Proportion of total health and social care costs and research funding spent on dementia, cancer, stroke and heart disease²¹



This report has identified that the evidence base on how to make the most cost-effective use of resources for dementia care is weak. Although a number of strategies are suggested for delivering high-quality care which are able in theory to lead to savings, these are based largely on extrapolated data and assumptions on effectiveness from small pilot studies. Future research into dementia should be focused on testing these assumptions and prioritising strategies that will have the greatest impact on overall quality of care in the most cost-effective way.

6. Improving quality of care

6.1 KEY CONCLUSIONS

This section summarises the best evidence available on how to improve the quality of care for people with dementia and their carers according to the recommendations and objectives of important policy guidance.

The key conclusions from the data and evidence are as follows:

- The main costs of dementia care are for residential care, so the greatest opportunity to save overall resources is to reduce the need for residential care.
- Informal carers carry the brunt of care for patients in the community. Providing training and support for carers is the most cost-effective way of delaying the time when patients need residential care.
- Multi-disciplinary coordinated care in the community, including the voluntary sector, can improve the diagnosis of dementia, quality of care and reduce the need for residential care.
- Clinical directors can help ensure that trusts develop and implement a coordinated multidisciplinary care pathway for people with dementia during and after a hospital admission, that reflects and provides for local needs.
- Specialist multidisciplinary input, based on these care pathways, can reduce hospital stays and prevent complications and institutionalisation.
- Psychiatric liaison services in residential care can improve the quality of care and reduce unnecessary use of antipsychotic drugs.
- Training residential care staff on behaviour management and providing more activities and stimulation for people with dementia in residential care can improve quality of life for patients and staff.
- Proactive end-of-life planning while the patient is still able to contribute to decision making reduces the burden on carers at the end of life and reduces healthcare costs.
- Future research projects should focus on testing the assumptions about likely cost savings from promising strategies to improve the quality of care, in particular examining whether scaling up innovative ways of delivering care and support would be successful when implemented nationally in the long term.

6.2 IMPROVING AWARENESS

Seventy per cent of carers say they were unaware of the symptoms of dementia before their relative was diagnosed with the disease. More than half of carers thought that the problems with memory and confusion were just part of getting old.³¹

Patients and carers need to know that dementia is not an inevitable part of growing old, and that it is worth seeking help as soon as they think there might be a problem, so that a diagnosis can be made and the patient and their family can plan for the future. The earlier a diagnosis is made, the better the opportunity to prevent or slow down deterioration and to improve quality of life. Early diagnosis will also help patients and family members make informed choices about what happens to them.³²

Patients will only get this care and support if health and social care workers also understand the benefits of early diagnosis and management, and are in a financial position to be able to offer care.

National Dementia Strategy, key messages for the public awareness campaign:

Dementia is a common disease and most people will experience it directly or by seeing it in a loved one. It is not an inevitable part of ageing, and lots can be done to help people with dementia and their carers.

Life with dementia can be good quality and people with dementia can continue to make a positive contribution to their communities.

The social environment is important in enriching life with dementia, and everyone can help to protect and support people with dementia and their carers.

Our risk of dementia may be reduced if we eat a healthy diet, don't smoke, exercise regularly and drink alcohol in moderation.

National Dementia Strategy Objective 1:

Improving public and professional awareness and understanding of dementia.

NICE dementia quality standard 3:

People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

National Dementia Strategy Objective 2:

Good-quality early diagnosis and intervention for all.

NICE Clinical Guideline 42 (Dementia):

1.4: Diagnosis and assessment of dementia.

NICE dementia quality standard 2:

People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

6.3 IMPROVING DIAGNOSIS

Up to 50% of people with dementia are not diagnosed. This is largely because dementia develops slowly, and can cause a range of problems in elderly people who often have other health problems. Encouraging staff to use protocols and standard memory tests can increase the diagnosis rate in primary care, but patients are most likely to benefit from an early diagnosis if there is a coordinated team with representatives of different types of health and social care to plan the care of the patient.⁵⁶

Patients and carers prefer to be told the diagnosis early, as this ends their uncertainty about the problem, allows them to learn more about the condition and how to cope with it. It also gives them an opportunity to access support and allows them to achieve unfulfilled ambitions in the short term. They will still have to live on knowing that they have a disease that can dominate their lives and limit their activities.⁵⁶

6.3.1 Improving quality

Training GPs and establishing a multidisciplinary team approach can increase diagnosis rates for dementia in the community.

A study in France found that training GPs on the use of simple tests for dementia, such as MMSE, increased the accuracy of their diagnosis. The best cut-off point for the MMSE test was to use a score of 20 points or lower as the threshold for diagnosing dementia.⁵⁷

Several studies have shown that a multidisciplinary team approach to evaluating people with suspected dementia could also increase diagnosis rates, such as the Croydon Memory Service Model. The teams typically consisted of a GP, specialist in elderly medicine, a nurse and a social worker.^{17, 58} However, another study found that the addition of a multidisciplinary standardised consultation twice a year did not improve outcomes, such as survival, decline in ability to function or risk of being admitted to residential care, for people who were already being managed via a memory clinic.⁵⁹

CASE STUDY - PARTNERSHIP WORKING IN SUFFOLK TO AID EARLY DIAGNOSIS

Suffolk Mental Health Partnership NHS Trust is only one of 14 trusts in England to have been awarded the highest grade from the Royal College of Psychiatrists' national accreditation programme (MSNAP) for its community memory assessment clinics in Ipswich and Bury St Edmunds.

Accreditation is based on several criteria, including partnership working with other voluntary and statutory agencies. Among others, the service works closely with Age UK and the Alzheimer's Society, on the grounds that no one team can provide all the support required for the complex needs of those with dementia, their carers and family, including out of hours when problems often arise.

Nettie Burns, service line manager for the Later Life Community Mental Health Service, explains:

'Our strategy is very clear about who does what, what the pathways are, who to refer to, and accepting others' judgement.'

'It's about calling the right person in, and cutting out mountains of paperwork. And you don't have four people going in when you only need two. That's good for patients and it's good for costs.'

As part of the collaboration, the Alzheimer's Society provides fully trained dementia support workers for each of the memory clinics. They help those with dementia, their relatives and carers, access the information and services they need to exert more control over their lives and maintain their independence for as long as possible. Clients can access this support at home and by phone and email.

The Society and the memory clinic team also make a point of talking to GPs, raising awareness of the clinical and social manifestations of dementia and its progression, promoting the importance of interviewing the carer/partner in the surgery to get the overall picture, and advising doctors of the breadth of client and family support services available.

(Continued)

GPs are kept in the loop after diagnosis. They are sent a comprehensive assessment letter – also copied to the client and carer if they want it – detailing how the diagnosis was reached; the type and length of recommended drug treatment; and contacts made with social services. GPs then receive six-monthly updates.

The partnership with the Society extends to running carers' information programmes three times a year across the county, home support (respite) for carers, and working with the complex care team in the acute trust. This team ensures that dementia patients receive appropriate care (and diagnosis) while in hospital, and don't end up in unnecessary residential care.

The Society and Age UK have also worked with the trust on its Respect for Dementia campaign, which aims to raise awareness of the condition and de-stigmatise it. Their efforts were rewarded with first prize for tackling inequalities at the East of England 2010 Innovations Competition.

Nettie says:

“The prime objective is to increase the quality of life, and we’ve just had excellent service users feedback. Collaborative working increases [their] confidence, because they know they will be cared for without experiencing big gaps or long waits, and they won’t be told, “there’s nothing we can do for you”.”

6.4 IMPROVING COLLABORATIVE AND INTEGRATED CARE IN THE COMMUNITY

Improving quality: capacity, effectiveness and patient-centredness

Multiple studies have shown the benefits of collaborative and integrated care for people with dementia. Coordination of GPs, specialists, nurses and social workers has been effectively carried out by appointing care managers, and has been shown to reduce the need for residential care by 18% compared with usual care in one UK study.⁴⁰ This study found that the coordinated care service was more expensive for patients who continued to live at home, averaging £23,402 per year, compared with £19,053 for the usual care group. This was largely because of increased visits from staff: an average of 63 days with coordinated care, totalling 13.3 hours per week, compared with 33.5 days for usual care, or 4.7 hours per week.

Compared with usual care, coordinated care has also been shown to promote patient-centred care, reduce behavioural problems in patients and psychological problems in their carers and increase adherence to clinical guidelines by staff.^{60, 61, 62, 63, 64}

The impact of coordinated care on other health and social outcomes is still uncertain. One US study involved a GP and nurse care manager, with a support team of an elderly care physician, elderly care psychiatrist and psychologist, who offered education on communication and coping skills, legal and financial advice, exercise guidelines for patients, a carer's guide produced by the Alzheimer's Association, a regular assessment of memory and behaviour problems and anti-dementia drugs when appropriate.⁶¹ The study found no differences in independent living, hospitalisation rates, need for residential care or mortality.

The voluntary sector can play a key role in coordinated care across different sectors, and will become even more important as services are localised more in the community. Voluntary organisations have provided training and support for carers, with a subsequent reduction in the need for health and social care visits or hospital admission, and a decrease in the need for residential care in the following 12 months, from 33% of people receiving education alone to 16% of people receiving individualised dementia care, counselling and support consultations.^{65, 66}

Another strategy to deliver coordinated care is to provide a comprehensive geriatric assessment of elderly people. This approach is a way of caring for elderly people with multiple problems and is often carried out in specialised hospital units. It has been shown to significantly reduce mortality when used in the community or for inpatients, but has not been shown to be beneficial when used in an outpatient setting, or to improve other outcomes such as quality of life or the ability to function independently.⁶⁷

National Dementia Strategy Objective 6:

Improved community personal support services.

NICE Clinical Guideline 42 (Dementia):

1.5, 1.6: Promoting and maintaining independence; interventions to maintain function.

NICE dementia quality standard 4:

People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

CASE STUDY - COGNITIVE STIMULATION THERAPY USED AT A DEMENTIA ACADEMY IN NORFOLK

Norfolk and Waveney Mental Health Foundation Trust started offering cognitive stimulation therapy (CST) in addition to memory drugs to people with mild to moderate dementia in 2008 after NICE guidance recommended its use. CST combines themed group activities and discussions with implicit learning to boost cognitive capacity and confidence. Research in the British Journal of Psychiatry 2006 suggested that not only did it improve memory and quality of life, but it was also potentially more cost effective than memory drugs.⁶⁸

The trust runs 90 minute sessions, twice a week, in several locations across Norfolk for seven weeks, followed by weekly maintenance sessions for 16 weeks. The themed sessions, designed to be fun and stimulating, are run in mixed age groups of six to eight people with similar levels of dementia. Carers' groups, facilitated by support workers, are run at the same time, with the aim of building up supportive peer networks. A wide range of professionals facilitate the sessions – just one day of training is required and the groups cost relatively little to run – averaging out at less than £30 per person per week.

Extended mini mental state exam scores in one group of six showed that while one person's score fell from 27 to 24 and another stayed the same, those among the other four increased by between one and five points. User and carer feedback indicates that participants enjoy the sessions and experience improved quality of life.

Gemma Ridel, clinical psychologist, says:

'It's really positive to see people laughing and singing. Staff enjoy it too, so people feel they are giving not just getting.'

The trust is now extending the programme into residential homes and day centres, while the community mental health team is working with the Alzheimer's Society to train its staff to run sessions for those who don't get referred to the trust's service. CST is part of a concerted effort to improve dementia services across Norfolk, including dementia champions in each of the four localities, dementia primary care link workers attached to clusters of GP surgeries, and a programme of education and training.

The latter includes the Norfolk Clinical Academy for Dementia, which focuses primarily on experiential learning through shadowing relevant staff on the job – backed up by more formal training – and which aims to ensure that everyone trains and educates everyone else, including patients and carers.

‘We are mostly targeting those working in care homes, general hospitals and those providing services in the home,’

Explains lead clinician Dr Hugo De Waal, who came up with the idea for the Academy.

‘If we can increase their skills, we can improve patients’ quality of life, delay residential care and avoid unnecessary admissions to hospital. Where our staff are engaged in training, their skills grow. Being a teacher turns you into a learner.’

The Academy has received extra funding for educational supervisors and administrative support.

6.5 IMPROVING SYMPTOMS AND BEHAVIOURAL PROBLEMS

Improving quality: safety, effectiveness, capacity, patient-centredness

Home-based training for carers and residential care staff improves their ability to manage challenging behaviour and can reduce inappropriate prescribing and the need for residential care in patients still living at home.

Challenging behaviour is often managed inappropriately by prescribing antipsychotic medication to sedate the patient. These drugs have a small effect on behavioural problems, such that, out of five to 11 people given the drugs, one would show a significant improvement. However, one in every hundred people given the drugs would die and one in every 58 would have a stroke or mini stroke caused by the medication.¹⁹ Banerjee (2009)¹⁹ estimated that approximately 180,000 people in the UK are taking antipsychotic drugs for behavioural problems, of whom no more than 36,000 are likely to benefit from the treatment. This is the equivalent of 50% of people with dementia, or over 5% of all people aged 65 and over. The inappropriate use of these drugs accounts for 1,800 additional deaths and 1,600 strokes a year, and the harms outweigh any benefits of treatment in two-thirds of patients taking the medication.¹⁹

This inappropriate prescribing in residential care has been effectively reduced over three months by offering psychosocial interventions for patients in residential care and training for staff from a multidisciplinary team involving a GP, specialist in elderly medicine and a pharmacist, or a psychiatric liaison service.^{69, 70}

Multiple studies have consistently shown that offering training and psychosocial support to carers of people with dementia can increase their ability to manage challenging behaviour appropriately, without the need for medication. Effective strategies have included home-based sessions with occupational therapists or community consultants. Most studies offered a mixture of initial face-to-face meetings with follow-up telephone contact, for a total of four to 12 sessions over one to six months.^{71, 72, 73, 74, 75, 76, 77} These studies found that the training could be cost saving because of the reduced need for healthcare and carer time, and could delay the need for residential care by approximately 200 days in one study.⁷⁸ Special care units in nursing homes have not been shown to improve outcomes for people with behavioural problems and dementia compared with standard care.⁷⁹

Another challenging behaviour in people with dementia is wandering, especially at night. There is little evidence on effective strategies to reduce wandering, although one evidence review suggested that moderate exercise and a multi-sensory environment may reduce wandering.⁸⁰ Although physical exercise may reduce the risks of developing vascular dementia, another evidence review on physical activity programmes for patients found no evidence that exercise improves mental function, depression or mortality compared with usual care in people who already have dementia. Again, very little research has been carried out in this area.⁸¹

National Dementia Strategy Objective 6:

Improved community personal support services.

NICE Clinical Guideline 42 (Dementia):

1.5: promoting and maintaining independence.

NICE dementia quality standard 7:

People with dementia who develop non-cognitive symptoms or challenging behaviour are offered an early assessment to establish generating and aggravating factors. Interventions to improve such behaviour or problems are recorded in their care plan.

CASE STUDY - INTEGRATING CARE IN NORTH MERSEY

Mersey Care NHS Trust, which serves a deprived area, has spearheaded a whole systems approach to dementia care, using the Quality Innovation Productivity and Prevention (QIPP) programme as a spur to improve quality and contain costs amid rising demand. It is part of a consortium of public and independent sector healthcare providers and the local authority, who have come together to integrate care and curb costly general hospital admissions for dementia patients, around 40% of whom don't need to be admitted and would benefit from being treated elsewhere.

Dr David Anderson, old age psychiatrist at the Royal Liverpool NHS Trust, explains the reasoning behind the consortiums development, saying:

'Dementia appears in all areas of health and social care, but policies and services have moved further and further apart. Public and independent sector care providers interface, but rarely is there a common agenda. Around 600 people with dementia are admitted to the hospital each year, where they are more likely to die, stay in for longer than other patients, or go into long-term residential care as a result, rather than being able to live independently at home.'

These admissions cost the local health economy £10.5m in bed-days alone. The consortium is therefore focusing on four high-impact interrelated areas: inpatient care, care homes, reducing antipsychotic drug prescribing and home treatment services.

A key step in the partnership arrangements was to forge an explicit agreement for risk sharing among all the participants before signing up to a shared agenda for change, which is firmly rooted in evidence of clinical and cost effectiveness.

The change agenda includes:

- A clinical lead in dementia to develop a training programme to skill up staff and the provision of liaison psychiatry services in general hospital, both of which improve the quality of care and outcomes for dementia patients.
- The deployment of specialist mental health nurses to work alongside care home staff, training them to understand dementia better and to see the person rather than just the disease.
- The evidence shows this can halve inappropriate drug prescribing for behavioural problems and cut unnecessary hospital admissions: one in five general hospital admissions among dementia patients come from care homes.

- The creation of designated proactive care home teams, comprising mental health nurses, a geriatrician, community matrons, and primary care staff to integrate mental and physical care services.
- The inclusion of 24-hour crisis home treatment services for people over the age of 65, which cut admission to hospital and care homes, the evidence shows.
- The creation of a ‘dementia network’ throughout the area rather than a dementia service, to cut out the administration, costs and waiting associated with a formal referrals system.

Dr Anderson says:

‘Dementia is a big problem and it’s getting bigger. We wouldn’t claim that we have the solution, but there are things that can be done. The ‘do nothing’ option is disastrous because it is such an expensive condition. Dementia has to be a priority area.’

Improving quality: effectiveness, capacity, patient-centredness

Anti-dementia drugs may reduce the decline in mental and physical function in people with dementia and may therefore reduce the need for residential care and overall healthcare costs, but brain training has not been proven to be effective.

Several studies have found that anti-dementia drugs can slow the decline in mental functioning compared with placebo in people with mild to moderate dementia, and could be cost effective by delaying the time when residential care is needed.^{82, 83, 84} One UK study estimated that the need for residential care could be reduced by 12% if the drugs were taken for six months or more, meaning that one year of residential care could be averted for every four to five patients who received the drug treatment.⁸⁵

A review concluded that the evidence was weak that brain training and rehabilitation can improve mental function in people with early Alzheimer’s disease and few studies had been done.⁸⁶

6.6 IMPROVING SUPPORT FOR CARERS

Improving quality: capacity

Psychosocial interventions for carers may improve their knowledge and reduce their stress, and may reduce the need for residential care.

Offering carers training and support from trained professionals has been shown to increase carer knowledge and elevate mood and confidence in their ability to cope with the demands of being a carer.^{78, 87} Such training can lead to better care of the patient, freeing up to an hour a day of the carer's time.⁷⁶ But befriending carers by volunteers has not shown to improve outcomes if carers are already receiving a range of health, social care and information resources. One UK study quoted such an intervention as costing an additional £1,800 per year.⁸⁸

Respite care is the temporary provision of care for a person with dementia that gives the main carer time to recuperate from the stresses. One study found that only half of carers offered the service made use of it.⁸⁹ There is only poor quality evidence of its effects, with no consistent improvement in outcomes for patients or carers.^{89, 90}

National Dementia Strategy Objective :
Implemented carers' strategy.

NICE Clinical Guideline 42 (Dementia):
Carers to have an assessment of needs and to be offered appropriate psychological therapy.

NICE dementia quality standard 6:
Carers of people with dementia are offered an assessment of emotional, psychological and social needs and receive tailored interventions identified by a care plan to address those needs.

NICE dementia quality standard 10:
Carers of people with dementia have access to respite/short break services that meet the needs of the carer and the person with dementia.

CASE STUDY - LIVING WELL WITH DEMENTIA IN MANCHESTER

The community mental health team for later life at Manchester Health and Social Care Trust offers a range of support services for people with dementia and their carers living in the north of the city. These include carers' assessments, memory training groups, carers' support groups, and post diagnostic support (PDS) groups.

The PDS groups are run by Admiral nurses with other members of the community mental health team. Admiral nurses are specialist mental health nurses, specialising in dementia. Admiral nurses seek to improve the quality of life for people with dementia and their carers. The service is developed and supported by the charity Dementia UK. The groups are run in three different locations, and are intended for those recently diagnosed with dementia and their carers and/or family members. The structured programme entails six weekly sessions, each lasting two and a half hours, with a maximum of seven pairs of participants.

Admiral nurse service manager, Sue Ashcroft-Simpson, explains:

'The programme is designed to help people learn about their diagnosis, to understand their symptoms and what impact these might have. Dementia changes people's lives completely. It's all about helping them live well.'

To take part, participants need to be able to acknowledge their diagnosis and be willing to talk about it openly, so inevitably that will exclude people with severe dementia. The programme might be structured, but the sessions are very informal and include an activity or practical exercise, and lunch.

During the session, carers and clients are split into two groups to enable them to talk freely about their experiences.

Ms Ashcroft-Simpson says:

'It's an opportunity to discuss issues with peers, learn from each other, and realise they are not on their own.'

(Continued)

The programme comprises:

Week 1: explanation of what dementia is and what symptoms to expect; participants are invited to share their experiences of getting a diagnosis.

Week 2: coping with symptoms; helping carers realise what it is like for the person with dementia.

Week 3: recognising and coping with anxiety and stress; strategies to avoid it.

Week 4: understanding how communication might change; opportunity to create a life book, filled with photos and certificates, to act as a memory prompt for later on and help carers see the person rather than just the dementia; advanced planning for end-of-life care.

Week 5: understanding how memory works and why it goes wrong; simple memory enhancement techniques.

Week 6: round-up; queries; further resources.

The programme is currently being evaluated, but participant feedback is universally positive.

Ms Ashcroft-Simpson says:

'People say that they don't feel scared anymore, and that they can live their lives again, because they often feel it stops after a diagnosis. The key is to give them a positive perspective.'

Once the programme has finished, there are intermittent workshops for clients and carers, dealing with tricky issues, such as guilt, and options to join any of the five monthly dementia cafes, dotted around the city. These are facilitated by Admiral nurses to provide a safe, informal peer support network over tea and sandwiches, building on the relationships forged in the PDS group.

6.7 IMPROVING HOSPITAL CARE

Assessing elderly people for dementia when they are admitted for other acute health problems can lead to more efficient care and reduce the duration of hospital stays. The risk of the patient becoming institutionalised or developing a hospital-acquired infection also reduces.

As described above, 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 substantial cost savings.

Quality improvement: effectiveness, access

Psychiatric consultation liaison for patients admitted to hospital reduces the length of stay and healthcare costs, but general screening by nurses, or admission to specialist units, may not be beneficial.

Interventions that have been shown to reduce the length of hospital admission include a psychiatric consultation liaison service for patients over 60 admitted for acute hospital treatment for conditions such as hip fracture.⁹¹

In contrast to this specialist input, general screening of elderly patients by nursing staff using standard protocols has not been shown to improve outcomes.⁹² Admitting elderly people to a specialist dementia care unit in acute hospitals has not been shown to reduce the length of admission. It may reduce the need for residential care after one year, compared with usual care, with an overall relative risk of 0.78 calculated by one evidence review.⁹³

National Dementia Strategy Objective 8:
Improved quality of care in general hospitals.

NICE Clinical Guideline 42 (Dementia):
1.9: Inpatient dementia services.

NICE dementia quality standard 8:
People with suspected or known dementia in acute hospitals have access to a liaison service that specialises in the diagnosis and care of dementia.

6.8 IMPROVING INTERMEDIATE CARE

Quality improvement: access

Hospital-at-home programmes can reduce the length of hospital stay. The National Dementia Strategy Impact Assessment calculated that a hospital-at-home rehabilitation scheme could reduce the average length of hospital stay by almost seven days per patient, at an average cost of £3,780 per care episode. An estimated 10,100 patients are likely to benefit from the service. This could save almost 70,000 bed-days and save the NHS £38m per year.²⁰

National Dementia Strategy Objective 9:
Improved intermediate care for people with dementia.

6.9 IMPROVING RESIDENTIAL CARE

Quality improvement: effectiveness, patient-centredness

Increasing social activity in residential care can improve wellbeing and sleep patterns.

Carers are often concerned that patients with dementia in residential care do not have enough to do.⁵⁴ Quality of life for residents has been improved by offering social activities for one to two hours a day, and by implementing person-centred care by means of such tools as dementia care mapping.⁹⁴ These strategies include the Enriched Opportunities Programme in UK care homes, where a senior staff member leads a structured and holistic programme of multi-level activity to identify the needs of 127 residents with dementia and improve their wellbeing.⁹⁵ They have been shown to improve sleep patterns and reduce agitation or depression in patients.^{95, 96, 97}

As described earlier, inappropriate prescribing of antipsychotic drugs in residential care can be reduced by implementing a psychiatric liaison service.⁷⁰ Access to specialist advice for staff may also be improved by teleconsultations, which can be used to assess new patients and to supplement standard assessment and follow-up of patients.⁹⁸

National Dementia Strategy Objective 11:
Living well with dementia in care homes.

NICE Clinical Guideline 42 (Dementia):
1.7: Interventions for non-cognitive symptoms and challenging behaviour.

6.10 IMPROVING END-OF-LIFE CARE

Quality improvement: access, capacity, patient-centredness

End-of-life care planning can support carers and reduce healthcare costs.

One of the challenges for carers of patients nearing end of their lives is making decisions on behalf of the patient. A palliative care service can reduce the pressure on carers and improve their mental health, especially if it involves developing advance care plans when the patient still has some capacity to participate in making the decisions.⁹⁹ Such a strategy has been shown to result in significantly shorter admissions to hospital or the intensive care unit (7.4 days in the hospital compared with 12.1 days for the control group and 3.5 days in intensive care compared with 6.8 days in the control group), fewer non-beneficial treatments and lower healthcare costs compared with usual care.¹⁰⁰

Innovative approaches such as a video decision support tool has been shown to increase the accuracy of the carer's prediction about what the patient would want at the end-of-life compared with a control group.¹⁰¹

National Dementia Strategy Objective 12:

Improved end-of-life care.

NICE Clinical Guideline 42 (Dementia):

1.10: Palliative care, pain relief and end-of-life care.

NICTex.

6.11 BETTER-INFORMED STAFF

Quality improvement: capacity, effectiveness, patient-centredness

Training staff who provide community or residential care increases the quality of care they provide and improves clinical outcomes for patients.

Training is crucial for all health and social care staff, carers and other volunteers who work with people with dementia. The benefits of training and supporting carers have been discussed in section 6.5. Training for staff has also been shown to improve outcomes and the quality of care delivered.

A study in the UK found that community mental health nurses trained in managing people with dementia were more able to assist carers in reducing problem behaviour compared to those with no training.¹⁰² Similarly, training residential care staff on problem management can reduce behavioural problems in patients with dementia, as well as improving stress and depression in the staff and improving communication with patients.^{103, 104}

Training that was interactive and multifaceted, and where the inputs were repeated, could improve dementia patient management and outcomes more than traditional, non-interactive techniques.¹⁰⁵

Training GPs has been found to increase the accuracy of their diagnosis of dementia,⁵⁷ but one study showed there was no improvement in GP management of dementia after a three-hour training session plus structured guidance.¹⁰⁶

National Dementia Strategy Objective 13:

An informed and effective workforce.

NICE Clinical Guideline 42 (Dementia):

Adequate training of all staff working with older people in health, social care and voluntary sectors.

NICE dementia quality standard 1:

People with dementia receive care from staff appropriately trained in dementia care.

6.12 MORE RESEARCH

The Ministerial Dementia Research Summit which took place in July 2009 involved 140 leading experts from charities, industry, public bodies, universities and voluntary organisations, including people with experience of living with dementia. The summit aimed to identify gaps in current evidence and prioritise new areas for dementia research, including ways to improve the quality of dementia care services. Priorities identified by this summit for future research on how to improve dementia care included:¹⁰⁷

- how to involve people with dementia in all aspects of research
- knowledge transfer – how to draw together existing research and integrate it into practice
- the physical and social context
- how the micro and macro environment affects quality of life
- service evaluation – what works best for whom, when and where.

The summit also highlighted the lack of high-quality evidence on the most cost-effective ways to deliver high-quality care for people with dementia in England. It recommended that this evidence gap be addressed urgently, and that extra funding for such research should be campaigned for. The summit led in turn to the formation of the Ministerial Advisory Group on Dementia Research (MAGDR), with the aim of maintaining the momentum gathered at the summit towards improvement of the volume, quality and impact of dementia research.

MAGDR aims to help scientists access research funding, and is developing a strategy to increase public support for dementia research. It also provides advice on government dementia policy, and on wider national and international initiatives. The group comprises the main organisations with a stake in dementia research, including the government (DH/NIHR and Research Councils), charities, the pharmaceutical sector and carer input.

As a result of this activity a major new funding call was opened by the NIHR in March 2011. Research will be funded that may lead to improvement in the prevention, diagnosis, assessment, treatment, management or care of people with dementia. It is clear that any research which supports multi-disciplinary and cross-professional collaborations is particularly encouraged. To ensure research gets funded it should seek to demonstrate benefits to the health and/or wellbeing of individuals with dementia or their carers, and/or improvements in the delivery of care.

7. Bridging the quality gap: a summary of the evidence

7.1 EFFECTIVENESS

Use of the following may reduce costs:

- Anti-dementia drugs could improve mental and physical function in people with dementia, and may therefore reduce the need for residential care and overall healthcare costs.
- Psychiatric consultation liaison for patients admitted to hospital reduces the length of stay and healthcare costs.
- Education and support for patients and carers in the home, provided by occupational therapists, helps carers manage challenging behaviour and reduces healthcare costs over three months.
- A proactive palliative care service may reduce healthcare costs and duration of hospital admission at the end of life. Advance care plans and interventions to support carers can reduce the burden on carers of people at the end of life and reduce symptoms in the patient.

Use of the following may improve quality of care:

- Physical exercise and providing a multi-sensory environment may reduce wandering in people with dementia, but the evidence is poor quality.
- Providing more social activity during the day improves sleep patterns at night.

7.2 ACCESS

Use of the following may reduce costs:

- A multidisciplinary approach to early diagnosis and care of people with dementia in the community, such as the Croydon Memory Service, is cost saving after six to 10 years. However, adding a comprehensive multidisciplinary standardised consultation may not improve care compared with standard memory clinic services.
- Training GPs about tests for dementia could increase the early diagnosis rate in primary care.
- A psychiatric liaison service for care homes reduces antipsychotic drug use and need for GP or hospital care over nine months.

The following have not been shown to be effective:

- Routine screening of elderly inpatients for dementia by nurses has not been shown to improve outcomes.
- Special care units within nursing homes have not consistently been shown to improve care or outcomes compared with standard care. Resources would be better spent in implementing best practice on traditional units than setting up special care units.

The following may improve quality of care:

- Telecare can improve access to specialist advice about people in residential care and may improve quality of care, although the evidence is not strong.

7.3 CAPACITY

Use of the following may reduce costs:

- Collaboration with the voluntary sector has been used to educate patients, carers and primary healthcare staff about dementia, and to produce multidisciplinary guidelines. This collaboration can reduce the need for residential care and decrease healthcare costs.
- Integrated multidisciplinary care may improve behavioural problems and health outcomes in patients, although the evidence is contradictory. Integrated care may reduce the need for residential care, and can be cost effective compared with usual care.

The following may improve quality of care:

- Home-based training and support for carers improves their ability to manage challenging behaviour and can reduce the burden of care.
- Training staff who provide community or residential care increases the quality of care they provide and improves clinical outcomes for patients, such as improving behavioural problems. Trained staff also report better ability to cope and less depression.
- There is little evidence to show whether or not respite care or befriending of carers improves symptoms and ability to cope in patients or carers.

7.4 SAFETY

The following may improve quality of care:

- A psychosocial treatment may be as effective as drug treatments at improving behavioural problems and improves the quality of care.

The following has not been shown to be effective:

- Haloperidol drug treatment does not reduce agitation in people with dementia and can cause adverse effects.

7.5 PUTTING THE PATIENT FIRST

The following may improve quality of care:

- Providing training for carers and residential care staff enables them to manage challenging behaviour without the need for inappropriate antipsychotic medication.
- Making care more patient-centred, such as dementia care mapping, improves the quality of life of people with dementia and reduces agitation.
- Coordinated and multidisciplinary care from health, social care and the voluntary sector can reduce the need for residential care.
- Proactive end-of-life planning can help patients get the care they want even if they are no longer able to contribute effectively to decision making.
- Anti-dementia drugs may reduce the decline in mental and physical functioning in people with mild to moderate dementia and delay the time when they need residential care.

7.6 EQUITY

The following may improve quality of care:

- Psychosocial treatments such as cognitive-behavioural group interventions can effectively support carers from ethnic minorities.

8. Commissioning cost-effective and high-quality services

8.1 SUMMARY

In this section, we summarise the evidence on what services and care strategies have been shown to offer more cost-effective care for people with dementia and their carers, which commissioners of services need to consider when deciding on the future provision of dementia services.

The main issues around commissioning of services relate to:

1. the scarcity of high-quality data on comparative costs of different services, and the difficulties of extrapolating the results of cost-effectiveness studies from different countries and at different times to current practice in the UK.
2. the uncertainties that remain about the long-term benefits from early diagnosis when applied on a population-wide basis rather than in relatively small pilot sites.
3. the ability of commissioners to establish multidisciplinary teams across health and social care services.

It is also important for commissioners to understand how similar the services they may be commissioning are to those that have been evaluated in research studies, and therefore how confident they can be that they would deliver similar clinical benefits in day-to-day practice as has been found in the more rigorously controlled environments of clinical research.

Although there are many uncertainties about the long-term effects of dementia services when applied across the whole population, some sensible conclusions can be drawn from the existing data and evidence which can inform the commissioning of high-quality services. These include the following:

- The main costs of dementia care are for residential care, so the greatest opportunity to save overall resources is to reduce the need for residential care.
- Informal carers carry the brunt of care for patients in the community. Providing training and support for carers is the most cost-effective way of delaying the time when patients need residential care.
- Multidisciplinary coordinated care in the community, including the voluntary sector, can improve the diagnosis of dementia and quality of care and reduce the need for residential care.
- Clinical directors can help to ensure that development and implementation of a coordinated multidisciplinary care pathway for people with dementia during and after a hospital admission, reflects and provides for local needs.
- Specialist multidisciplinary input, based on these care pathways, can reduce the length of hospital admission and prevent complications and institutionalisation.

- Psychiatric liaison services in residential care can improve the quality of care and reduce unnecessary use of antipsychotic drugs.
- Training residential care staff on behaviour management and providing more activities and stimulation for people with dementia in residential care can improve quality of life for patients and staff.
- Proactive end-of-life planning while the patient is still able to contribute to decision making reduces the burden on carers at the end of life and reduces healthcare costs.
- Future research projects should focus on testing the assumptions about likely cost savings from promising strategies to improve the quality of care, in particular whether scaling up innovative ways of delivering care and support will be efficacious when implemented nationally in the longer term.

8.2 IMPROVING DIAGNOSIS

A multidisciplinary team that uses standard protocols increases diagnosis of dementia by an extra 20 patients per hundred elderly people.⁵⁸

An economic study has calculated that any service that reduces the need for residential care by 10% would, in time, result in 25,000 fewer people nationally residing in care homes or needing to move to a care home. This would translate to cost savings of £120m in public spending and £125m in private spending by patients and their carers after 10 years, a total saving of £245m. A service such as the Croydon Memory Service would cost an estimated £220m a year across England and has the potential to save £130m a year for social services by reducing the number of patients requiring residential care.^{17, 20}

8.3 COLLABORATIVE CARE

Collaboration with the voluntary sector to provide individualised counselling about dementia and support can reduce the number of people needing nursing home care by 17%.⁶⁵

Case managers who coordinated care for people in the UK with dementia reduced the need for residential care by 18% over two years, but were approximately £4,400 more expensive per year for the 49% of patients who were still living independently.⁴⁰ In contrast, three studies from the US failed to show a reduction in hospital admissions with case management, but did show improved quality of care.^{61, 62, 64}

8.4 REDUCING SYMPTOMS AND BEHAVIOUR PROBLEMS

Anti-dementia drugs (acetylcholinesterase AChE inhibitors) slow the decline in mental function in people with mild or moderate dementia and may therefore reduce health care and residential care costs to some extent.⁸² One study estimated that the use of galantamine in the UK might yield cost savings of up to £1,380 per patient by reducing the need for residential care, compared with no anti-dementia drug treatment.⁸⁵

In addition, memantine is now recommended as an option for managing moderate Alzheimer's disease for people who cannot take AChE inhibitors, and as an option for managing severe Alzheimer's disease.

However, too often a different type of drug is prescribed and more than 140,000 people in the UK are being prescribed antipsychotic drugs inappropriately. They are at increased risk of dying or having a stroke, and the money spent on the medication is being wasted.¹⁹

Psychosocial treatments may be as effective as antipsychotic drugs at improving behavioural problems in patients.⁷¹

The Alzheimer's society has produced a best practice guide to help health and social care professionals to ensure that people experiencing behavioural and psychological symptoms of dementia, such as agitation, aggression, hallucinations and delusions, get the most appropriate treatment, without rushing to prescribe pharmacological interventions.¹⁰⁸

8.5 SUPPORT FOR CARERS

A number of studies have shown that training and supporting carers helps them cope and reduces costs of residential care. An occupational training programme of coping skills for patients and carers can reduce healthcare costs by £1,200 per patient over three months, by increasing the patient's ability to function and reduce the number of hours of informal care needed by about an hour a day.⁷³

Training carers in coping skills may also delay the date when the patient needs to move to residential care by approximately 200 days, although the evidence for this is weak.⁷⁸

8.6 IMPROVING HOSPITAL AND INTERMEDIATE CARE

Specialist psychiatric assessment of elderly people when they are admitted for acute health problems can lead to more efficient care, and reduce the duration of hospital admission and the risk to the patient of becoming institutionalised or developing a hospital-acquired infection.⁹¹

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 £64m and £102m a year nationally.⁶

Admitting patients to a special geriatric evaluation and management unit significantly reduced the decline in the ability of the patient to function independently at discharge compared with standard care, and also reduced the likelihood of needing residential care after one year compared with standard care (relative risk of 0.78), with no significant difference in mean length of stay, number of readmissions or mortality.⁹³

Intermediate care such as hospital-at-home schemes could save almost 70,000 bed-days in delayed discharges for people with dementia in hospital, with an estimated annual saving of £38m a year nationally.²⁰

8.7 RESIDENTIAL CARE

A psychiatric liaison service for care homes reduces antipsychotic drug use and the need for GP or hospital care over nine months.⁷⁰

Telehealth may be a cheaper way of improving the quality of life of people with dementia, either at home or in residential care, but the evidence base is weak as this is an innovative type of care.⁹⁸

8.8 END-OF-LIFE CARE

An end-of-life service for people with dementia who are admitted to hospital acutely unwell can reduce the duration of stay in intensive care by three days and overall hospital stay by almost five days.¹⁰⁰

Appendix 1

METHODOLOGY

The evidence review aimed to answer the following research question:

What works to improve the quality of health and social care for people with dementia in England?

We focused on how to improve aspects of care that have been identified as either most important to delivering the requirements of the policy documents, or where there is greatest need for improvement in quality of care.

The search strategy was drafted to capture literature relating to improvement and has been extensively tested. It operates using both MeSH and free-text syntax to ensure both iterations are captured in databases that do not index with MeSH.

In testing we sampled a methods cluster but this has been rejected as it impeded specificity of returns and relevancy. As a net result of testing we used the strategy below which is broader in its scope and therefore reduces the opportunity of bias.

- dementia.mp. or Dementia/
- Alzheimer Disease/ or alzheimer?.mp.
- or/1-2
- improv*.mp.
- (care or caring or social care or health care or quality* or effectiveness* or social care).mp. or “Quality of Health Care”/ or “Quality of Life”/ or Patient-Centered Care/
- (delivery* or service* or provi*).mp. or delivery of healthcare/
- 3 and 4 and 5 and 6
- limit 8 to (humans)
- limit 9 yr= “1990 – Current”

Databases

- Medline
- Embase
- Health Management Information Consortium (HMIC)
- Psycinfo
- Social Policy and Practice (SPP)
- Web of Knowledge
- Econlit

Inclusion criteria

We followed a best evidence approach to identifying studies for inclusion. Studies were screened on abstract initially and included if they met the following criteria:

1. Published since 2000.
2. Reporting on research done in a high income (OECD) country.
3. Reporting on an intervention that was aiming to improve the quality of care for people with dementia or their carers.
4. Reporting original data – that is, not a narrative review or reporting just the author's opinions.

We coded each of the studies that met these initial inclusion criteria according to the methodology used and the particular National Dementia Strategy objectives or NICE-SCIE guideline recommendations to which it was most relevant. We then selected the studies for each objective that had the highest quality methodology for full text data extraction and inclusion in this report. As we mainly wanted to evaluate the effectiveness and cost effectiveness of interventions, we selected systematic reviews, randomised controlled trials and cost-effectiveness studies as highest priority, followed by non-randomised controlled trials, then comparative pre-post intervention studies, and finally case studies from the UK.

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The Health Foundation
90 Long Acre
London WC2E 9RA

Tel 020 7257 8000
Fax 020 7257 8001
info@health.org.uk

Registered charity number: 286967
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