OCTOBER 2011

The Health Foundation
Inspiring Improvement

Highlight: DEMENTIA CARE

Introducing the Health Foundation improvement report

Identify Innovate Demonstrate Encourage

Introduction

The Health Foundation is committed to improving the quality of care in the UK and helping healthcare professionals ensure the care they provide is safe, effective, patient-centred, timely, efficient and equitable.

We have commissioned the improvement report *Spotlight on dementia care* because of the importance and urgency of the need to improve services for people with dementia and their carers.

In this *Highlight* document, we pick out some of the key findings from the full report, which is available to download or order from www.health.org.uk/dementia

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.

The report brings together the key recommendations from five major policy documents [1, 2, 3, 4, 5] and demonstrates 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 care provision is not meeting people's needs and, in addition to a poor experience of care for patients, they actually lead to higher costs. The rising numbers of people with dementia could be a crushing burden for the NHS in the years to come. However, if we can get this right, high-quality and cost-effective dementia care represent 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.

Spotlight on dementia care collates the evidence and presents a snapshot of the current state of dementia care. We hope to contribute to raising the quality of dementia care by signposting people to sources of research and good practice evidence which they can use to improve the lives of people with dementia and their carers.

WHAT'S IN THE SPOTLIGHT?

The *Spotlight on dementia care* improvement report contains:

- Background and context to dementia – how many people are affected and how the disease manifests itself and impacts sufferers.
- Summaries of key policy guidance and national quality standards – a comparison of the recommendations available, providing an overview of the key messages and common themes.
- How much dementia costs the NHS and the economy as a whole – the costs of caring for people in the community, in residential care and in acute hospitals.
- The current state of dementia care – data on current performance, highlighting where improvements need to be made and where there is variability in quality and access to care.
- Evidence for improving care – a synthesis of the best quality evidence on how quality of care can be improved for people with dementia and their carers in the most cost-effective way, including case studies of good practice from across the UK.
- Summary of the evidence of quality care – what can reduce costs and improve quality of care, and what has been shown not to be effective.
- Considerations for commissioners of care services – a summary of the evidence on what services and care strategies have been shown to offer the most cost-effective care for people with dementia, and what commissioners of services need to consider when deciding on the future provision of dementia services.

Dementia in numbers

- There are 750,000 people with dementia in the UK in 2011 – more than one in every 100 people.
- Over the next 10 years, this figure will increase to more than a million people.
- An estimated 58% of older adults in long-term care homes have dementia, and 78% of these people have behavioural and psychological symptoms of dementia.[6]
- Most GPs in the UK can expect to have between 12 and 20 people with dementia to care for at any one time.
- Dementia costs £8bn in direct care costs, rising to more than £20bn costs to the economy as a whole.[7]
- 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 to an acute hospital for another condition or injury.
- Dementia costs the UK economy more each year than the combined costs of cancer and heart disease.
- Dementia receives 6% of the combined research funding that is available for cancer, stroke and heart disease.
- Anti-Alzheimer drugs cost £720 per patient, per year.[8]
- Inappropriate use of medication costs £84m a year for 140,000 people in England given antipsychotic drugs who are unlikely to benefit and may be harmed by them.[9]

- Long-term residential care for dementia patients costs an estimated £9bn a year in the UK.
- Informal care of people with dementia costs an estimated £12bn a year in the UK.
- Community social services costs for people with dementia costs an estimated £2.4bn a year in the UK.
- 36% of carers for a person with dementia have reported having been psychologically abused by the person with dementia in the previous three months, and 6% reported being physically abused.[10]
- By summer 2009, only 21% of acute trusts had appointed a clinical dementia lead.
- 40% of the total costs of care for people with dementia are for long-term residential social care, and 55% are for informal care. Only 5% are for primary or secondary care.[7]
- In 2008 there were 7 million GP consultations for people with dementia, half of which were home visits.[7]
- Almost 300,000 visits a year to emergency departments are for people with dementia.[7]
- Each person with severe dementia living in the community requires an estimated 46 hours of carer support per week.[11]
- 14% of admissions to hospital for people with dementia are because of a fall.[12]

Key findings

SUPPORT IN THE COMMUNITY

Late diagnosis and lack of community support mean that people and carers are not helped and advised in the crucial early stages of the disease. 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.

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

TRAINING FOR STAFF

Training is crucial for all health and social care staff, carers and other volunteers who work with people with dementia. This training has 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.[13] 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.[14,15] 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.[16]

Training GPs has been found to increase the accuracy of their diagnosis of dementia, but one study showed there was no improvement in GP management of dementia after a three-hour training session plus structured guidance. [17, 18]

ACUTE HOSPITAL COSTS

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

People with dementia who are admitted to hospital often become more confused and distressed. They 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%).[12]

A recent report found that for people with dementia the average duration of stay in hospital after a hip fracture was 43 days, compared with 26 days in patients who were psychiatrically well.[19]
In *Counting the cost*, the Alzheimer's Society (2009)[12] reported DEMHOS study data that 25 – 35% of patients with dementia admitted with these problems remained in hospital for over one month. The table below 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.

In 2008-09, over 7 million 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.

Potential cost savings from reducing the duration of admissions by seven days for people with dementia admitted with acute health problems.[19]

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**

INAPPROPRIATE PRESCRIBING

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.

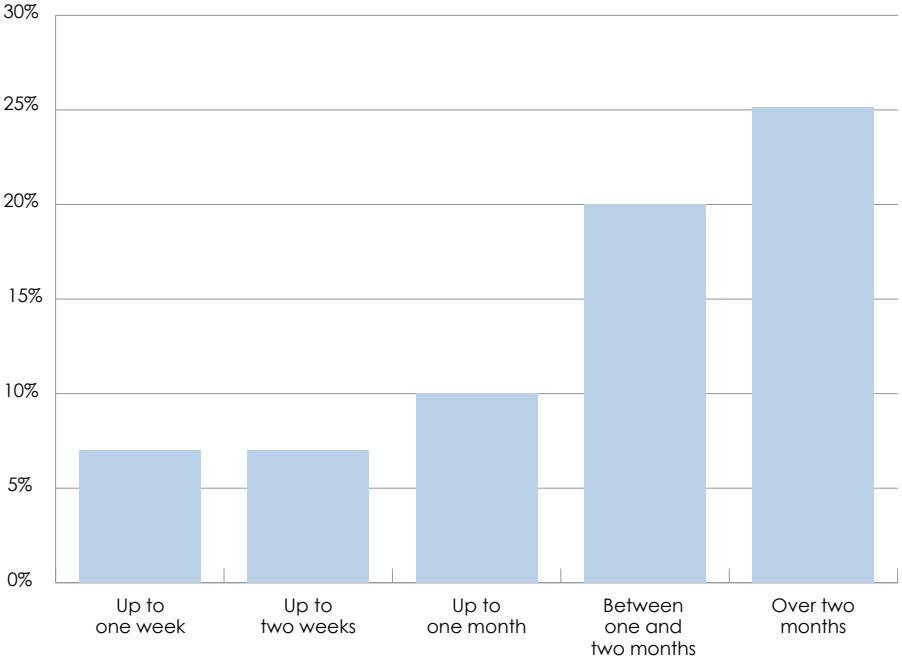
Challenging behaviour is often managed inappropriately by prescribing antipsychotic medication to sedate the patient. These drugs have a small effect on behavioural problems – out of five to 11 people given the drugs, only one would show a significant improvement. However, one in every hundred people given the drugs would die and one in every 58 would have a stroke or mini stroke caused by the medication.[9]

Banerjee (2009)[9] 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.

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.[13, 20]

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.[9]

Proportion of people with dementia on antipsychotics according to length of stay.[12]

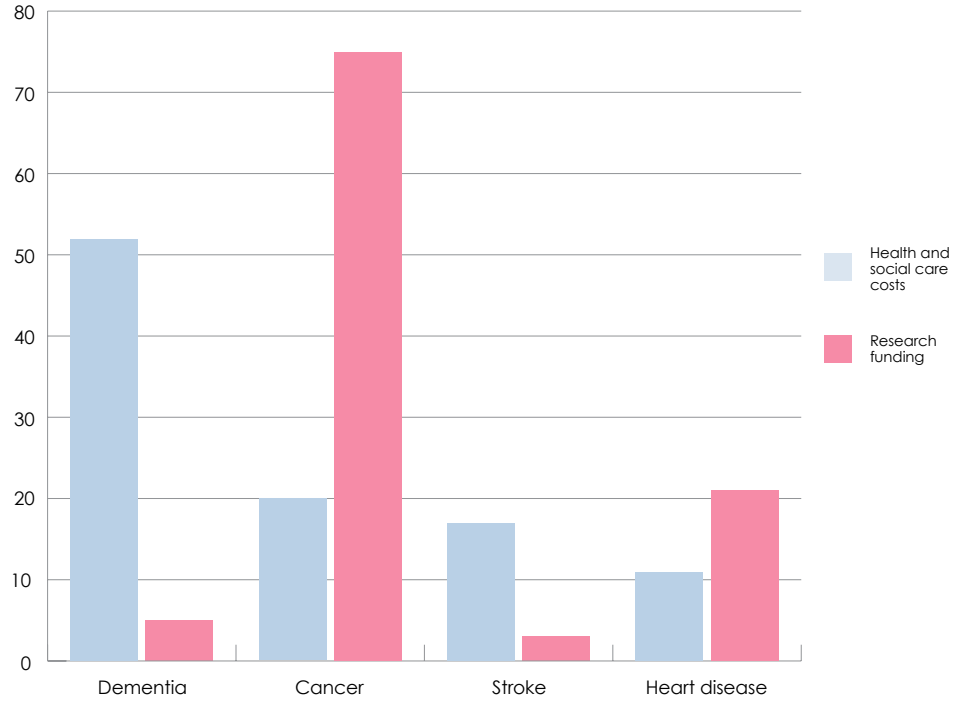


RESEARCH

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.

Proportion of total health and social care costs and research funding spent on dementia, cancer, stroke and heart disease.[6]



Funding for research on dementia in the UK has been estimated as follows:[7]

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

Spotlight on dementia care 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 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.

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.

Find out more

The Health Foundation wants to assist with, and contribute to, raising the quality of dementia care in the UK. *Spotlight on dementia care* signposts sources of research and good practice evidence which can be used to improve the lives of people with dementia and their carers.

Visit www.health.org.uk/dementia to:

- order or download the full report
- download individual chapters
- read case studies
- see the underlying data from the report.

The report also contains useful links to other sources of information about dementia and dementia care.

References

1. National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) *Dementia: Supporting people with dementia and their carers in health and social care.*

2. Alzheimer's Society (2007) *Dementia UK: The full report* The Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London.

3. Department of Health (2009) *Living well with dementia: A National Dementia Strategy.*

4. National Institute for Health and Clinical Excellence (2010) *Dementia quality standards* http://www.nice.org. uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp

5. Skills for Care, Skills for Health (2011) *Common Core Principles for Supporting People with Dementia.*

6. Seitz D, Purandare N, Conn D. Prevalence of psychiatric disorders among older adults in long-term care homes: a systematic review. *Int Psychogeriatr*, 2010, 4:115.

7. Alzheimer's Research Trust (2010) *Dementia 2010 The economic burden of dementia and associated research funding in the United Kingdom.*

8. British National Formulary. http://www. bnf.org/bnf/bnf/current/130019.htm

9. Banerjee, S. (2009). *The use of antipsychotic medication for people with dementia: time for action.* Department of Health, London.

10. Cooper C, Selwood A, Blanchard M, Livingston G. Abusive behaviour experienced by family carers from people with dementia: the CARD (caring for relatives with dementia) study. *J Neurol Neurosurg Psychiatry*, 2010, 81:592-596.

11. Langa KM, Chernew ME, Kabeto MU, et al. National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *J Gen Intern Med*, 2001, 16(11):770-8.

12. Alzheimer's Society (2009) *Counting the cost.*

13. Crotty M, Halbert J, Rowett D, Giles L, Birks R, Williams H, Whitehead C. An outreach geriatric medication advisory service in residential aged care: A randomised controlled trial of case conferencing. *Age and ageing,* 2004, 33; 6: 612-7.

14. Kuske B, Hanns S, Luck T, Angermeyer MC, Behrens J, Riedel-Heller SG. Nursing home staff training in dementia care: A systematic review of evaluated programs. *International Psychogeriatrics,* 2007, 19; 5: 818–841.

15. Burgio LD, Allen-Burge R, Roth DL, Bourgeois MS, Dijkstra K, Gerstle J, Jackson E, Bankester L. Come talk with me: Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist,* 2001, Vol. 41; No. 4: 449–460.

16. Rampatige R, Dunt D, Doyle C, Day S, Van Dort P. The effect of continuing professional education on health care outcomes: lessons for dementia care. *International Psychogeriatrics,* 2009, 21; Supplement 1: S34–S43.

17. Rondeau V, Allain H, Bakchine S, Bonet P, Brudon F, Chauplannaz G, Dubois B, et al. General practice-based intervention for suspecting and detecting dementia in France. *Dementia: the international journal of social research and practice*, 2008, 7; 4: 433-450.

18. Wenger NS, Roth CP, Shekelle PG, Young RT, Solomon DH, Kamberg CJ, Chang JT, et al. A practice-based intervention to improve primary care for falls, urinary incontinence, and dementia. *Journal of the American Geriatrics Society,* 2009, 57; 3: 547-555.

19. Henderson C, Malley J, Knapp M. Maintaining good health for older people with dementia who experience fractured neck of femur: report for phase 2. 2007, Report for the National Audit Office.

20. Ballard C, Powell I, James I, Reichelt K, Myint P, Potkins D, et al. Can psychiatric liaison reduce neuroleptic use and reduce health service utilization for dementia patients residing in care facilities' *International journal of geriatric psychiatry* 2002; 17:140-145.

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
Registered company number: 1714937

www.health.co.uk

Follow us on Twitter:
www.twitter.com/HealthFdn