

# Counting the cost

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Caring for people with  
dementia on hospital wards

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Alzheimer's Society  
Devon House  
58 St Katharine's Way  
London  
E1W 1JX  
T 020 7423 3500  
F 020 7423 3501  
E [info@alzheimers.org.uk](mailto:info@alzheimers.org.uk)

[alzheimers.org.uk](http://alzheimers.org.uk)

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Report researched and written by Louise Lakey, Senior Policy Officer, Alzheimer's Society.

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# Foreword



Seeing my mother in hospital was one of the hardest times in my life. I remember being struck with a desperate sorrow watching how vulnerable and helpless she was in an unfamiliar environment. Her battle was not just with the emphysema and bronchitis: it was with the strange environment, the people she didn't know and the intrusive medication she couldn't understand. There were frightening and scary moments. She was so dependant on those who were caring for her. But she was incredibly brave; that's my mother.

I now realise my mother was not alone in her vulnerability. A quarter of hospital beds are occupied by people with dementia and although good care does exist, some hospitals remain a challenging environment. The majority of people with dementia leave hospital worse than when they arrived. Many stay much longer than is usual. Every day in hospital the chance of being prescribed unnecessary antipsychotic drugs or entering a care home increases.

Good care can make an incredible difference. On her first visit to hospital my mother received brilliant care. The kindness and skill of the hospital staff reassured and comforted her. However, when she was admitted for the second time no one even realised she had dementia. The doctor didn't have time to find her notes and was under the impression my mother had to go home to look after my father despite the fact that my father has been dead for five years.

The challenge laid down in this report is to get people out of hospitals more quickly or to make sure they don't ever need to go there in the first place. Research shows this is possible through developing the skills of those working in hospitals, clear leadership, access to intermediate care and investing in community services. We also need to ensure we are reducing the use of antipsychotic drugs and that people are being supported to do the simple things like eating and drinking through the provision of person-centred care. Alzheimer's Society is calling for hospitals to reduce the time a person with dementia spends on wards by just one week. This could save at least £80 million a year and the figure is probably nearer to hundreds of millions of pounds. Most importantly people can be treated effectively in the community while enjoying a high quality of life.

Together we can get people back in the community quicker. In this report 97% of nurses told us they work with people with dementia. Most want more training and support to help them deliver the best care possible. By working with nursing staff and equipping them with the right tools and support, good hospital care is possible.

Alzheimer's Society is committed to putting care right in hospitals. More than a million people will develop dementia in the next ten years and the numbers will keep rising. It is up to all of us to make a serious commitment to raise the standard of care.

To find out more visit [www.alzheimers.org.uk/countingthecost](http://www.alzheimers.org.uk/countingthecost)



Angela Rippon, OBE and Alzheimer's Society Ambassador

# Executive summary

## 1 Summary

**People with dementia over 65 years of age are currently using up to one quarter of hospital beds at any one time.**

Much has been achieved in recent years in the NHS to drive down waiting lists and reduce delayed discharge for significant numbers of people. This result has required the hard work and dedication of significant numbers of hospital staff. Now that it has been possible to improve access to hospital care by increasing capacity and reducing waiting times, there is an opportunity to shift the focus to the quality of the care being provided.

**Attention is increasingly focused on the quality of dementia care in an acute setting.** This report finds that there is unacceptable variation in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland. There are many examples of excellent local action, where the challenges of dementia are being recognised and addressed. However, there are also examples of mediocre or neglectful care.

**People with dementia stay far longer in hospital than other people who go in for the same procedure.** The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and the individual's physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used.

**As well as the cost to the person with dementia, increased length of stay is placing financial pressure on the NHS.**

**It is clear from the evidence presented in this report that improving the experience of the large number of people with dementia in hospitals is key to improving the NHS overall and delivering the reform agenda.**

- If people with dementia were supported to leave hospital one week earlier than they currently do, this report suggests that savings of hundreds of millions of pounds might be achievable across the system as a whole. The National Audit Office will be publishing a further report into dementia in late 2009 which should add evidence to support the case for change.

- Much of the large sums of money currently spent on dementia in hospitals could be more effectively invested in workforce capacity and development, and community services outside hospitals to drive up the quality of dementia care on the wards, improve efficiency and ensure that people with dementia only access acute care when appropriate.

## 2 Purpose of report

This report provides evidence from over 2,000 carers and nurses on the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland. This evidence is for commissioners, healthcare services providers as well as health and social care professionals to support the case for a specific focus on improving the care for people with dementia on a general hospital ward within the current policy context.

## 3 Methodology

Alzheimer's Society collected quantitative and qualitative evidence via a questionnaire from the following groups:

- Carers – 1,291 responses received
- Nursing staff – 657 responses received
- Nurse/ward managers – 479 responses received.

## 4 Key findings

### 4.1 Dementia care in hospitals – why must it be addressed?

- 97% of nursing staff and nurse managers reported that they always or sometimes care for someone with dementia.
- 47% of carer respondents said that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn't a direct result of the medical condition.
- 54% of carer respondents said that being in hospital had a significant negative effect on the symptoms of dementia, such as becoming more confused and less independent.
- Over a third of people with dementia who go into hospital from living in their own homes are discharged to a care home setting.
- 77% of nurse managers and nursing staff said that antipsychotic drugs were used always or sometimes to treat people with dementia in the

hospital environment. Of those nurse managers and nursing staff who said that antipsychotics were used, up to a quarter thought that they were not appropriately prescribed to people with dementia.

- 86% of nurse managers felt that people with dementia either always or sometimes have a longer stay in hospital than people without dementia admitted with the same medical condition.
- 49% of carer respondents said that the hospital stay was overall longer than they expected it to be.
- The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used.
- Additional financial pressure is being placed on the NHS by people with dementia staying in hospital longer than expected.
- This report finds that supporting people with dementia to leave hospital one week sooner than they currently do could result in savings of at least £80 million a year, from work in four condition areas identified in four Hospital Episode Statistics (HES) data codes. It would not be unreasonable to assume that there are savings to be made in care for people with dementia running into hundreds of millions of pounds, which could be more effectively reinvested.

## 4.2 What is going wrong? Evidence from people with dementia and nurses

- 77% of carer respondents were dissatisfied with the overall quality of dementia care provided.
- 89% of nursing staff respondents identified working with people with dementia as very or quite challenging.
- Key areas of dissatisfaction as identified by carer respondents were: nurses not recognising or understanding dementia; a lack of person-centred care; not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the person with dementia being treated with a lack of dignity and respect.
- Key areas of concern as identified by nursing staff respondents were: managing difficult/unpredictable behaviour; communicating; not having enough time to spend with patients and provide one-to-one care; wandering/keeping people on the ward and ensuring patient safety.
- Problems with the discharge process, including lack of access to additional support such as a physiotherapist, were also identified by carer and nurse respondents.

- There are similarities between the concerns of nurses and the unmet needs of people with dementia that carer respondents have identified. However, nurses do not focus as strongly on person-centred care as a key challenge or as a training need and the majority think that people with dementia are being treated with dignity and respect.
- Nurses are responsible for providing or supervising much of the day-to-day care of people with dementia. They can play a key role in improving dementia care by being supported to place more focus and prominence on person-centred care. Training that addresses the concerns of nurses within the context of person-centred care for people with dementia, and raises awareness of the unmet needs of people with dementia as identified by carers, is vital.

## 5 Recommendations

Recommendations for change are set out which identify some of the biggest opportunities to deliver on dementia in hospitals to create a more cost-effective system that provides good quality care to people with dementia and carers.

Ensuring implementation of the National Dementia Strategy for England (2009) by recognising the importance of the dementia challenge, prioritising the improvement of dementia care and fulfilling the recommendations of the Strategy is paramount to securing change. Commissioners will therefore need to focus attention on this to achieve urgent changes across the health and social care system as a whole. The forthcoming Wales Dementia Plan will also address care on a general ward and it is essential that it is addressed in a dementia plan for Northern Ireland. Priority must be given to developing and implementing these Plans.

**Recommendation 1.** The NHS as a whole and individual hospitals need to recognise that dementia is a significant, growing and costly problem for them, which lies at the heart of the agenda to drive efficiency and quality improvement.

**Recommendation 2.** Reduce the number of people with dementia being cared for in hospitals.

- 2.1 Commissioners need to work with partners to shift funding from inappropriate acute usage for people with dementia into alternative services provided in the community.
- 2.2 Shifting investment and reconfiguring services in the community will require better co-ordination with social care services and joint working with community partners.
- 2.3 An improved system of care will also require that people with dementia have much better access to intermediate care services.

**Recommendation 3.** Hospitals to identify a senior clinician to take the lead for quality improvement in dementia and for defining the care pathway.

**Recommendation 4.** Commission specialist liaison older people's mental health teams to facilitate the management and care of people with dementia in hospitals.

**Recommendation 5.** Ensure that there is an informed and effective acute care workforce in hospitals for people with dementia.

- 5.1 Hospitals need to look at staff capacity for delivering high quality dementia care. They will also need to prioritise workforce development budgets for dementia. These need to be a priority in the current financial context to help increase the capacity and throughput of the service by supporting people with dementia out of hospital as quickly as possible.
- 5.2 Pre-registration training should be improved in line with the requirements of the acute care workforce. The Nursing and Midwifery Council (NMC) consultation on pre-registration training is a vital opportunity to adapt the curricula and requirements to include as mandatory the core competencies required in dementia care. Alzheimer's Society will work with the NMC to inform their work.
- 5.3 To support recommendations 5.1 and 5.2, government departments need to work with all bodies involved in professional and vocational training and continuing professional development to reach agreement on the core competencies required in dementia care.

**Recommendation 6.** Reduce the use of antipsychotic drugs to treat people with dementia on a general ward.

- 6.1 In the National Dementia Strategy for England, the Department of Health committed to publishing a review of the inappropriate use of antipsychotic drugs for people with dementia across the health and care system. At the time of this report going to print, Alzheimer's Society is awaiting the findings and looks forward to working with relevant bodies to reduce the prescribing of the drugs. This work needs to take place across England, Wales and Northern Ireland.

**Recommendation 7.** Involve people with dementia, carers, family and friends in the care of people with dementia to improve person-centred care.

- 7.1 Having an individual care plan is essential for good quality care and it must be ensured that every person with dementia has one.
- 7.2 Carers and the person with dementia should feed information into planning as soon as the person with dementia is admitted to hospital in order to build up a profile of an individual's likes, dislikes and needs to ensure person-centred care.

- 7.3 Carers and people with dementia where possible, must be involved in day-to-day care and treatment decisions.

**Recommendation 8.** Make sure that people with dementia have enough to eat and drink.

- 8.1 The patient profile and individual care plan as discussed in recommendation 7 should be used to understand an individual's needs and preferences at mealtimes.
- 8.2 Nutritional screening must be carried out for all people with dementia as soon as they are admitted to a ward to ensure that those at nutritional risk are identified and appropriate actions implemented.
- 8.3 Carers, family and friends must always be allowed to assist at mealtimes if they wish.
- 8.4 Hospitals should encourage volunteers to support people with dementia at mealtimes.
- 8.5 In the long term, dementia-specific education is required to empower and inform hospital staff. This could incorporate tools such as Alzheimer's Society guide to catering for people with dementia (2009). The Dementia Services Development Centre, Stirling also has useful material, for example a video developed in 2002 to help staff encourage people with dementia to eat and drink well (Dementia Services Development Centre, 2002).

**Recommendation 9.** Begin to change the approach to care for people with dementia to one of dignity and respect.

# 1 Introduction

## 1.1 Background to the report

The unacceptable variation in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland is well documented in the numerous anecdotal reports Alzheimer's Society receives each year from people with dementia and carers. Their experience has highlighted an urgent need for research into care in this setting. This report is intended to reveal the reality of the situation by putting evidence from carers and nurses at the heart of the issue.

We need to understand what care people with dementia are being provided with and what they actually need if we are to ensure that individuals receive good quality care appropriate for both their physical needs and their dementia needs. The report also highlights the key challenges in providing good dementia care, and the realities of working on a ward, from the perspective of nurses.

Whilst much of the acute workforce has a role to play in providing good dementia care, it is nursing staff that play a vital role in supporting people with dementia on a day-to-day basis on a general ward. We know that good quality care from nursing staff can make a huge difference to the overall hospital experience of a person with dementia. Therefore, we must also explore what challenges in the system can prevent them from providing the care people with dementia need and address this urgently.

Following the launch of *Living well with dementia: A National Dementia Strategy* (Department of Health, 2009) in England and the development of similar plans elsewhere in the UK, there is an increasing focus on the needs of people with dementia. This, together with the need to drive care out of hospitals and care homes into care provided in the community, means that commissioners are looking for evidence to support the case for change on dementia care specifically. This report provides important evidence for commissioners, providers and health and social care professionals to support the case for a specific focus on improving the care for people with dementia on a general hospital ward.

## 1.2 Background to dementia

The Dementia UK report (Alzheimer's Society, 2007) found that the number of people with dementia in the UK is growing. 700,000 people have dementia

and this is forecast to increase to 940,000 by 2021 and 1,735,087 by 2051 – an increase of 38% over the next 15 years and 154% over the next 45 years.

The report also found that the total costs of dementia amount to £17.03 billion per annum, or an average of £25,472 per person with late onset dementia. The King's Fund (2008) has said that the financial cost of dementia is currently £15 billion per year in England and that by 2018, this cost is likely to rise to over £23 billion per year if nothing is done to improve the cost-effectiveness of dementia services.

Despite this spend, a series of reports in the last two years have shown that services are struggling to deliver good quality dementia care:

- Alzheimer's Society's report *Home from home* (2008) found that many care homes are not providing good dementia care, with key problems including the provision of activities, treating residents with dementia with dignity and respect, and the relationship between the care home and relatives/friends.
- The All Party Parliamentary report *Always a last resort* (2008) found that over 100,000 people in care homes are inappropriately prescribed antipsychotic drugs.
- Alzheimer's Society report *Dementia out of the shadows* (2008) found that GPs' knowledge of dementia and their ability to respond effectively and sensitively varies enormously and consequently diagnosis can be slow and ineffective. Access to information and support following a diagnosis also varies considerably.
- In 2007 the National Audit Office (NAO) report, *Improving services and support for people with dementia*, confirmed that dementia care services can lead to poor outcomes for people with dementia and their families and are not delivering value for money. However, the NAO found that there are ways to make money available by providing better care and this can release significant investment, for example a more effective provision of community services can shift care out of acute hospitals.

As a result of this evidence, the Department of Health developed *Living well with dementia: A National Dementia Strategy* (Department of Health, 2009) in England. This sets out a five year transformation plan under four themes (raising awareness and understanding; early diagnosis and support; living well with dementia; making the change). Currently, a Dementia Plan for Wales is in development and work is ongoing for a Dementia Plan for Northern Ireland.

The NAO is preparing a follow-up report to their 2007 work, due to be published shortly. This will focus on whether the Department of Health and partners involved in the implementation of the National Dementia Strategy

(Department of Health, 2009) in England are geared up to ensure effective delivery. Some of the key questions they have investigated are:

- Do the partners involved have the capability to deliver the Strategy?
- Are adequate mechanisms and levers in place to ensure delivery?
- Is there sufficient data to understand on an ongoing basis whether delivery is taking place?
- Are people with dementia and carers beginning to see the difference?

The size of the dementia challenge is considerable. Given the rising numbers of people with dementia and the corresponding rising costs of caring for them, it is vital that addressing dementia is seen as a priority across the health and social care system. Creating a more cost-effective care service, which provides good quality care to its users, cannot be achieved unless the challenge of dementia is tackled.

### 1.3 Dementia in an acute care context

The current healthcare policy context, and recent national reports and initiatives, have recognised the need to improve care in hospitals on a general ward and to move care away from costly acute settings into the community. For example:

- Darzi's report High Quality Care for All (2008), which aims to put quality at the heart of the NHS.
- The Dignity in Care Campaign, which works to end the tolerance of care services that do not respect the dignity of those using them.<sup>1</sup>
- The Department of Health Nutrition Action Plan (2007), which outlines how nutritional care and hydration can be improved.
- The Essence of Care programme, which outlines a benchmarking process that helps practitioners to take a structured approach to sharing and comparing practice, enabling them to identify the best and to develop action plans to remedy poor practice.<sup>2</sup>

Increasingly, there is also a move towards more focused attention on dementia in an acute setting, with a growing recognition that this is a challenge that must be addressed if the NHS is to improve overall and to be transformed in the way that is envisaged by the Darzi review.

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1 [www.dh.gov.uk/en/socialcare/socialcarereform/dignityincare/index.htm](http://www.dh.gov.uk/en/socialcare/socialcarereform/dignityincare/index.htm)

2 [www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_4005475](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4005475)

- The Department of Health in England has commissioned NICE to develop quality standards from the evidence-based recommendations in NICE guidance and from sources accredited by NHS evidence. Four standards are being developed for publication in April 2010, including one for dementia, and Alzheimer's Society is involved with this work.
- In 2006 the Royal College of Psychiatrists was asked by the Healthcare Commission to look into priority areas for improving services for people with dementia. A national audit of general hospitals was recommended and all hospitals that provide general acute services in England and Wales are now invited to participate in a core audit. This will evaluate the adequacy of structures and processes across the hospital that enable the provision of high quality care to people with dementia and will collate data from case notes about admission, assessment and discharge. Data collection from the core audit will begin in January 2010. A limited number of hospitals will also participate in a more in-depth audit. This will evaluate the quality of person-centred care provided at ward level, and the experience of patients and carers, and will begin in March 2010 (The Royal College of Psychiatrists, 2009<sup>3</sup>).
- The care of people with dementia on a general ward is also addressed in the National Dementia Strategy for England. Objective 8 outlines the need to improve the quality of care for people with dementia in general hospitals by identifying leadership for dementia, defining the care pathway for dementia and commissioning specialist liaison older people's mental health teams to work in general hospitals. Objective 9 outlines the need for improved intermediate care for people with dementia to avoid initial unnecessary hospitalisation and to enable a pathway out of hospital. The care of people on a general ward is also addressed in the forthcoming Wales Dementia Plan and is a likely objective for the future Northern Ireland Plan.
- The National Institute for Health and Clinical Excellence (NICE) is developing a clinical guideline on the diagnosis, prevention and management of delirium for use in the NHS in England and Wales. Delirium in a person with dementia is very common. Research suggests that two thirds of cases of delirium occur in people with dementia, and this is likely to increase in the future (Fick et al., 2002). The guideline scope includes pharmacological and non-pharmacological interventions for people with delirium to prevent the major consequences of delirium including dementia.<sup>4</sup>

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3 [www.rcpsych.ac.uk/clinicalservicestandards/centreforqualityimprovement/nationalauditofdementia.aspx](http://www.rcpsych.ac.uk/clinicalservicestandards/centreforqualityimprovement/nationalauditofdementia.aspx)

4 [www.nice.org.uk/guidance/CG/Wave17/21](http://www.nice.org.uk/guidance/CG/Wave17/21)

- Alzheimer's Society is funding research to establish what really happens to people identified with dementia after their general hospital admission. The research is in two parts: study one aims to investigate the range of outcomes, the family and societal costs of care and the key predictors of better outcomes for people with dementia identified in general hospital. Study two aims to explore the personal experience of the transition from general hospital to a care home. The study runs until March 2011 and is being led by Dr Sheehan, Associate Clinical Professor in Old Age Psychiatry, University of Warwick.<sup>5</sup>
- There are also many examples of local action, where the challenge of dementia is being recognised and addressed. For example, the Strategic Health Authority in the West Midlands is funding a two year programme to be undertaken by the Royal Wolverhampton Hospitals NHS Trust, Wolverhampton Primary Care Trust and Wolverhampton Metropolitan Borough Council. The aim is to raise the standard of person-centred care for people with dementia at the Royal Wolverhampton Hospitals, the results of which will be shared nationally and internationally. The Directorate of Services for Older People, University Hospitals of Leicester NHS Trust, commissioned an audit of dementia care in 2008, which looked at improving the environment, communication, patient safety, patient assessment, nutrition and continence. Work is currently ongoing to implement recommendations based on the results and in line with recommendations from the National Dementia Strategy.

This report is intended to support the improvement of the quality of dementia care in hospitals, within the current policy context, by providing robust evidence of the current situation from the perspective of carers and nurses, and recommendations for urgent action. This will require significant focus and new investment. But alongside that, tackling the dementia challenge brings significant opportunities for releasing savings for reinvestment, joint commissioning and integrated working and the movement of care from acute settings into the community. The result will be a more cost-effective and efficient system that provides good quality care to people with dementia and carers.

## 1.4 The research methodology

Alzheimer's Society collected quantitative and qualitative evidence from people with dementia and carers, nursing staff and nurse/ward managers via a questionnaire (see section 1.4.1 and 1.4.2). The results from these questionnaires will be referred to as the dementia hospital (DEMHOS) research throughout the report.

The questionnaire for people with dementia and carers was piloted with members of Alzheimer's Society Living with Dementia group (a group of people with dementia who contribute to the work of the Society) and a group of carers who use the Society's online discussion forum Talking Point. Experts within Alzheimer's Society and the Royal College of Nursing provided advice on the questionnaires for nurses.

It was acknowledged that the respondents to the questionnaires would be a self-selecting sample and that the evidence would reflect their perspective. We therefore also collected evidence from national reports and published research literature in order to inform the results. Database searches, including specific Medline searches conducted on behalf of Alzheimer's Society by the British Medical Association, revealed key literature.

In addition, Alzheimer's Society had access to a systematic review of the literature on the perspective of people with dementia and carers on the dementia care provided in hospitals on a general ward, conducted by a research team on behalf of the Royal College of Psychiatrists National Audit of Dementia project. The main aim of the literature review was to investigate the experience of being in hospital from the perspective of acutely ill patients with dementia, chronic confusion, delirium or cognitive impairment and to help identify:

- the issues of importance to patients during their hospital stay
- what might constitute a good care experience from the patient perspective?
- what could be improved in the care experienced by patients?

#### **1.4.1 People with dementia and carers questionnaire**

The questionnaire was sent to the entire Alzheimer's Society membership via a monthly newsletter, which represents around 21,000 people. Because information on how many of these have had an episode in hospital is not available, it is not possible to calculate an accurate response rate. We received 1,291 responses in total, which suggests that a large number of people with dementia will be admitted to a hospital general ward at some time.

2% of respondents were people with dementia and 96% carers (2% did not respond to this question). This report therefore represents the carers' view. It must also be noted that the respondents are more likely to have responded to the questionnaire if they have had an unsatisfactory experience and therefore are likely to be a biased sample in this respect. The majority of respondents were from England (91%), with 6% from Wales and 2% from Northern Ireland (1% did not respond to this question).

## 1.4.2 Nursing staff questionnaire and nurse manager questionnaire

Nurses play a vital role in supporting people with dementia in hospitals and providing the day-to-day care that they need, and are faced with the realities of front line practice. The Society therefore wanted to explore the situation from the point of view of nursing staff and nurse managers.

Questionnaires were sent to all ward managers and nurse managers in England, Wales and Northern Ireland extracted from two databases (specialist nurses and NHS management). The information was purchased from a health and care information specialist organisation. The recipients of the questionnaires were asked to distribute the questionnaire to relevant nursing staff.

For the nursing staff questionnaire we received 657 responses (89% from England, 5% from Wales and 6% from Northern Ireland). Job titles included staff nurse, sister and registered nurse. The number of responses from staff describing themselves as care assistants or healthcare assistants was too small to be significant and therefore the results cannot be generalised to this group. The majority of respondents had been working as a nurse for over seven years (72%).

We received 479 responses to the nurse managers questionnaire (86% from England, 6% from Wales and 7% from Northern Ireland), with respondents including ward managers, senior sisters and matrons. Again, the majority of respondents had been working for over seven years (90%).

The high number of responses highlights the seriousness with which nurses take this aspect of their work and the willingness that there is to engage with this issue.

## 1.5 Structure of the report

Chapter 2 outlines why it is vital that dementia in a hospital context is addressed by setting out the scale of the challenge. It provides statistics from the DEMHOS research on why and where people with dementia are in hospital and the poor outcomes that have resulted from a hospital stay for people with dementia and carers. The DEMHOS research findings are compared to the research literature.

Chapter 3 explores why people with dementia have poor outcomes from being in hospital in the DEMHOS research. It sets out the evidence received from carers and nurses on the quality of dementia care provided in hospital and focuses on the key areas of need that are not being met and key challenges faced on the front line.

Chapter 4 explores how the findings discussed in chapters 2 and 3 can best be addressed.

## 2 Dementia care in hospitals – why must it be addressed?

### Summary

- People with dementia over 65 years of age are using up to one quarter of hospital beds at any one time.
- 42% of individuals aged over 70 years with unplanned admission to an acute hospital have dementia, rising to 48% in those aged over 80 years (Sampson et al. 2009).
- 97% of nursing staff and nurse managers who responded to the DEMHOS research reported that they always or sometimes care for someone with dementia.
- 47% of carer respondents said that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn't a direct result of the medical condition.
- 54% of carer respondents said that being in hospital had a significant negative effect on the symptoms of dementia, such as becoming more confused and less independent.
- Over a third of people with dementia who go into hospital from living in their own homes are discharged to a care home setting.
- 77% of nurse managers and nursing staff said that antipsychotic drugs were used always or sometimes to treat people with dementia in the hospital environment. Up to a quarter of those nurse managers and nursing staff thought that antipsychotic drugs are not appropriately prescribed to people with dementia.
- 86% of nurse managers felt that people with dementia either always or sometimes have a longer stay in hospital than people without dementia admitted with the same medical condition.
- 49% of carer respondents said that the hospital stay was overall longer than they expected it to be.
- The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and physical health; discharge to a

care home becomes more likely and antipsychotic drugs are more likely to be used.

- Additional financial pressure is being placed on the NHS by people with dementia staying in hospital longer than expected.
- Supporting people with dementia to leave hospital one week sooner than they currently do can result in savings of at least £80 million from only four Hospital Episode Statistics (HES) data codes. It would not be unreasonable to assume that there are savings to be made in care for people with dementia in hospitals running into hundreds of millions of pounds that could be more effectively reinvested.

## 2.1 People with dementia in hospital

People with dementia are substantial users of hospital care. In 2001 the National Service Framework for Older People found that older people (over 65 years of age) are the core patient group in acute hospitals, accounting for 60% of hospital bed days in the UK (Department of Health, 2001). Of this 60%, research found that up to 40% have dementia (Holmes and House, 2000), meaning that people with dementia over 65 years are using up to one quarter of hospital beds at any one time.

Recent research has suggested that the prevalence of dementia in the acute hospital population increases with age. Sampson et al. (2009) studied individuals aged over 70 with unplanned acute admission to a north London general hospital. They found that 42% of individuals aged over 70 (average age 83) had dementia. In individuals aged over 80 years 48% had dementia. Sampson et al. (2009) found that only 21% had received a diagnosis of dementia prior to the research.

### 2.1.1 Why are people with dementia in hospital?

The DEMHOS research found that the majority of people with dementia entered hospital from their own home (60%), although admission for people with dementia from a care home was also common (33%). This reflects the split in residential status estimated in Dementia UK (Alzheimer's Society, 2007) with two thirds of people with dementia living in their own homes and one third living in care homes.

In the DEMHOS research, the primary cause of admission for people with dementia was a physical health issue. 37 reasons were cited for entry to hospital, with the top five reasons (with the highest percentage of respondents) shown in Table 1.

Table 1

**Proportion of people with dementia admitted to hospital by primary diagnosis (the top five reasons with highest percentage of respondents)**

Reason for admission	Proportion of total number of carer respondents reporting reason for admission for the person with dementia
Following a fall	14%
Broken/fractured hip or hip replacement	12%
Urine infection (including urinary tract infection)	9%
Chest infection	7%
Stroke/minor stroke	7%

These results are supported by the research literature. For example, a Birmingham-based study (Natalwala et al., 2008) explored the lack of evidence to explain why people with dementia are admitted to a general hospital. The results found that more people with dementia were admitted as emergency cases and that the proportion of patients admitted for dementia as their primary diagnosis was small. Primary diagnoses included syncope (loss of consciousness) and collapse, bronchopneumonia, urinary tract infection and dehydration. Sampson et al. (2009) found that 43% of admissions of people with dementia were for pneumonia and urinary tract infection.

### 2.1.2 What wards are people with dementia being admitted to?

The DEMHOS research looked at the type of ward that people with dementia are admitted to. As expected, with a range of acute physical conditions being the cause of admission, people with dementia are prevalent in a variety of general medical and surgical wards. Indeed, 97% of nursing staff and nurse managers who responded to the DEMHOS research reported that they always or sometimes cared for someone with dementia.

The research also found that the prevalence of people with dementia varies by type of ward, as estimated by nursing staff. For example, 10% of nursing staff respondents said that they currently worked on an elderly care/acute medical ward. Of these respondents, 25% estimated that around one in three people on the ward is a person with dementia at any given time and 50% estimated that at least one in five people on the ward is a person with dementia. Table 2 shows estimated prevalence across five different ward types with the highest percentage of nursing staff currently working on them (out of 24 different types of ward logged in the research).

Table 2

**Breakdown of nursing staff respondents by type of ward and their estimated prevalence of people with dementia on the ward**

Type of ward and percentage of nursing respondents working on that ward		Nursing staff estimated prevalence of people with dementia by type of ward					
		One in three	One in four	One in five	One in ten	One in 15	Other
Elderly care/ acute medical	10%	25%	20%	5%	1%	1%	5%
Surgical	9%	3%	3%	8%	15%	13%	17%
General medical ward	9%	8%	11%	16%	7%	2%	2%
Orthopaedic	8%	7%	12%	13%	8%	5%	2%
Rehabilitation unit	6%	4%	15%	7%	5%	3%	0%
Other ward/no ward mentioned	58%	53%	39%	51%	64%	76%	74%

## 2.2 Outcomes of being in hospital

Research literature has found that poorer outcomes result from a person with dementia being admitted to a general hospital ward for a medical procedure than a person without dementia being admitted for the same procedure.

For example, Holmes and House (2000) found that presence of dementia had an effect on several important outcomes when elderly people were admitted to hospital with a hip fracture compared to those without dementia. Including increased length of stay, decreased chance of survival after six months, an increased chance of discharge to a residential or nursing home, and an increased likelihood of physical dependence (and increased physical dependence was significantly related to residence in institutional care).

Many of these reported poor outcomes are supported by the DEMHOS research findings.

### 2.2.1 Effect on physical and mental health of the person with dementia

Carer respondents to the DEMHOS research reported that people with dementia are deteriorating whilst in hospital; they experience a worsening of the symptoms of dementia and the development of physical health problems.

In terms of physical health, in the DEMHOS research:

- 47 % of carer respondents said that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn't a direct result of the medical condition. A further 21 % said it had a little effect (68 % in total), 23 % said no and 5 % didn't know.
- Physical effects reported included perceived weight loss, malnutrition and dehydration. In addition, constipation, incontinence, exhaustion, pressure sores, bruising and a worsening of mobility were frequently mentioned.

'Weight loss, generally looked more dishevelled than when she was in the care home'.

'Confined to bed and not allowed to walk. The use of cot sides. Catheterized which promoted incontinence (previously continent)'.

'Sores from incontinence pads not being changed. Diabetes unbalanced'.

'My wife was bedridden for two weeks. After leaving hospital, she was unable to walk although the discharging doctor said she was satisfied with my wife's mobility'.

This finding is supported by the research literature. For example, Mecocci et al., (2005) looked at physical health problems that developed in elderly patients admitted to medical or elderly acute wards during a 20 month period in Italy. They found that people aged 85+ had a significant increased risk of several health issues during the stay in hospital, particularly if the person was cognitively impaired and the stay was long (over three weeks). The most common issues were pressure sores, urinary and faecal incontinence, and falls.

In terms of an individual's dementia, in the DEMHOS research:

- 54 % of carer respondents said that being in hospital had a significant negative effect on the symptoms of dementia and a further 25 % said it deteriorated a little (79 % in total), 15 % said no and 5 % didn't know.
- Reported effects included the person becoming more confused, less independent and more distressed which resulted in the worsening of behavioural and psychological symptoms such as shouting out. In addition, other effects frequently mentioned included loss of communication skills, depression and loss of confidence.

'She was definitely more confused in hospital; when she returned to the care home she seemed more content and gained a few pounds'.

‘Became more confused, stopped talking in sentences, became afraid, became upset/emotional’.

‘His condition got far worse. He cannot speak now’.

‘From a happy, carefree personality to a virtual drone’.

‘My wife has Alzheimer’s and when she came out of hospital she just seemed to be another step down’.

The effect on physical health and the symptoms of dementia are reported by carer respondents to become worse the longer the stay in hospital (see Tables 3 and 4).

Table 3

**Breakdown of carer responses to the question ‘Do you think that being in hospital had a negative effect on the general physical health of the person with dementia (which wasn’t a direct result of the medical condition)?’ according to length of stay**

Responses	Proportion of carer respondents giving response broken down by length of stay				
	Up to one week	Up to two weeks	Up to one month	Between one and two months	Over two months
Yes, a lot	31 %	44 %	55 %	63 %	63 %
Yes, a little	21 %	23 %	21 %	18 %	22 %
No	39 %	23 %	15 %	13 %	10 %
Don’t know	6 %	6 %	4 %	2 %	4 %

Table 4

**Breakdown of carer responses to the question ‘Do you think that being in hospital had a negative effect on the person’s dementia and the symptoms of dementia?’ according to length of stay**

Responses	Proportion of carer respondents giving response broken down by length of stay				
	Up to one week	Up to two weeks	Up to one month	Between one and two months	Over two months
Yes, a lot	44 %	47 %	57 %	66 %	69 %
Yes, a little	30 %	25 %	24 %	19 %	20 %
No	19 %	18 %	10 %	10 %	10 %
Don’t know	4 %	6 %	5 %	5 %	1 %

## 2.2.2 Increased likelihood of discharge to residential care setting

The DEMHOS research shows that there is an increased likelihood of being discharged to a care home following a stay in hospital. Table 5 gives an overall breakdown of results and shows that the likelihood of entering a care home after a stay in hospital is very high. The data shows that over a third of people who enter hospital from their own home go into a care home. 60% of people with dementia in the DEMHOS research entered hospital from their own home and this was reduced to 36% returning to their own home.

Table 5

### Person with dementia's place of residence before and after entering hospital as reported by carer respondent

Place of residence response options	Proportion of carer respondents giving response	
	Place of residence before hospital	Place of residence after hospital
Care home	33%	42%
Own home	60%	36%
Other	1%	6%
Not applicable	—	9%*

\* This 9% can be explained by situations where the person with dementia has not yet been discharged from hospital or where the person with dementia died whilst in hospital.

The DEMHOS research also shows a possible correlation between discharge to a care home with length of stay in hospital (Table 6).

Table 6

### Proportion of total number of people with dementia discharged to care home and own home according to length of stay as reported by carer respondents

Where the person with dementia is discharged to	Total number of people discharged to care setting as reported by carer respondent	Proportion of total number of people with dementia discharged to care setting according to length of stay				
		Up to one week	Up to two weeks	Up to one month	Between one and two months	Over two months
Care home	42%	38%	44%	37%	45%	52%
Own home	36%	48%	39%	37%	26%	17%
Other	6%	6%	6%	7%	7%	6%
Not applicable	9%	4%	8%	11%	10%	15%

### 2.2.3 Overuse of antipsychotic drugs in the hospital environment

The DEMHOS research has identified that antipsychotic drugs are often used to treat people with dementia in the hospital environment as reported by nursing staff and nurse managers. It is however unclear from the nurses' responses what proportion of people with dementia are on antipsychotic medication or whether medication is initiated while the person was in hospital or prior to admission.

The data also shows that both nurse and carer respondents perceive that antipsychotic prescriptions are not always appropriate. Antipsychotics are prescribed to people with dementia to treat the behavioural and psychological symptoms of the disease. According to the NICE-SCIE guideline on supporting people with dementia and their carers in health and social care (2007) the use of the drugs is only appropriate in very specific circumstances and many prescriptions are inappropriate. See section 3.3.3 of this report for further detail.

#### Nurses

There was strong agreement between nursing staff and nurse managers on the prevalence of use, which adds validity to the data presented:

- 77% of nurse managers and 77% of nursing staff said that antipsychotic drugs were used always or sometimes to treat people with dementia in the hospital environment showing that use is widespread.

Of the 77% of nursing staff and nurse managers who said that the drugs were used always or sometimes:

- 6% of nursing staff thought that antipsychotic drugs are always appropriately prescribed; 48% thought that they are appropriately prescribed sometimes and 24% thought that antipsychotic drugs are not appropriately prescribed to people with dementia (21% didn't know).
- 7% of nurse managers thought that antipsychotic drugs are always appropriately prescribed; 49% thought that they are appropriately prescribed sometimes and 20% thought that antipsychotic drugs are not appropriately prescribed to people with dementia (24% didn't know).

#### Carers

When carers were asked whether the person with dementia was prescribed an antipsychotic drug while in hospital:

- 12% said yes they were prescribed; 57% said no and 29% said that they didn't know. The low percentage of carers reporting that antipsychotic drugs were prescribed may in part be explained by the fact that, in Alzheimer's Society's experience, many carers do not know what 'antipsychotic drugs' are and this may have reduced the numbers responding to this question in the survey.

- Of those carers who did think the drugs were prescribed, 29% thought this was appropriate but 49% didn't (19% didn't know).

Importantly, an analysis of the 12% of carers who identified that antipsychotics were used reveals that use appears to increase with length of stay (Table 7).

Table 7

**Analysis of carers' perception of use of antipsychotic drugs by length of stay**

Was person with dementia on antipsychotic drugs?	Total percentage of people with dementia as reported by carer	Proportion of total number of people with dementia on antipsychotics according to length of stay				
		Up to one week	Up to two weeks	Up to one month	Between one and two months	Over two months
<b>Yes</b>	12%	8%	8%	10%	20%	25%
<b>No</b>	57%	64%	59%	56%	53%	46%
<b>Don't know</b>	29%	27%	31%	33%	26%	28%

There is a lack of research in the UK on the use of antipsychotic drugs for people with dementia in the acute care environment. However, there is research from other countries that highlights a link. For example, Pitkala et al. (2004) explored the prevalence of various behavioural and psychological symptoms among people with dementia in nursing homes and acute geriatric wards in Finland and the administration of various psychotropic medications (including antipsychotics) to these people. They found that symptoms were very common among people with dementia in both settings and the use of antipsychotics was also common, with 55% being prescribed these drugs across the two settings.

## 2.2.4 Increased mortality

Although the DEMHOS research was not able to investigate mortality, it is important to recognise this outcome as it has been highlighted in previous research. Freedberg et al. (2008) explored the link between cognitive impairment and mortality in hospital stays. They found that hospitalised patients over age 85 with cognitive impairment had an increased mortality rate (increased risk of death within the hospital, in the first year after hospitalisation and cumulatively). Sampson et al. (2009) found that 24% of acute medical inpatients with severe cognitive impairment died during admission.

## 2.2.5 Increased length of stay

Both the research literature and the DEMHOS research have found that people with dementia are staying in hospital for longer than is often expected and longer than other people who go in for the same procedures.

### Nurse manager respondents

- 86% of all nurse managers felt that people with dementia either always or sometimes have a longer stay in hospital than people without dementia admitted with the same medical condition (7% of nurse manager respondents said that people with dementia did not have a longer stay and 6% didn't know).
- Nurse managers who always or sometimes worked with people with dementia were more likely to state that people with dementia always or sometimes have a longer stay. See Table 8 for a breakdown of results.

Table 8

**Proportion of total number of nurse managers describing the length of stay for the person with dementia as always, sometimes or not longer than the length of stay for other patients with the same medical condition according to whether the respondent works with people with dementia**

Does the person with dementia have a longer stay in hospital than other patients with the same medical condition?	Proportion of total number of nurse managers describing the length of stay for the person with dementia as always, sometimes or not longer than the length of stay for other patients with the same medical condition according to whether the respondent works with people with dementia		
	Yes, always works with people with dementia	Yes, sometimes works with people with dementia	No, does not work with people with dementia
Yes always	33%	20%	20%
Yes sometimes	59%	65%	40%
No	6%	7%	13%
Don't know	1%	7%	27%

### Carer respondents

- 49% of carer respondents said that the hospital stay was overall longer than they expected it to be suggesting that a large proportion of people are staying longer than people are being told to expect. 34% said it wasn't longer than expected and 15% didn't know.
- The longer the person with dementia was reported to be in hospital, the larger the proportion of carer respondents saying that the stay was longer than expected. Table 9 gives a breakdown of results according to length of stay.

Table 9

**Proportion of total number of carer respondents describing the length of stay for the person with dementia as longer than expected or not longer than expected according to length of stay**

Responses	Proportion of total number of carer respondents describing the length of stay as longer than expected or not longer than expected according to length of stay				
	Up to one week	Up to two weeks	Up to one month	Between one and two months	Over two months
<b>Longer than expected</b>	18%	39%	65%	74%	84%
<b>Not longer than expected</b>	65%	40%	16%	10%	7%
<b>Don't know</b>	13%	19%	16%	15%	8%

People with dementia having longer lengths of stay in hospital than expected is supported in the research literature (for example, Holmes and House, 2000; Savaray et al 2004; King et al. 2006).

The DEMHOS research also highlights that the length of stay is dependent on the primary cause of admission to hospital. The two most common reasons for a person with dementia being admitted to hospital in the DEMHOS research (following a fall and a hip-related condition) are also the conditions found to have the longest reported length of stay. See Table 10 for a further breakdown of the results for the top five reasons for admission to hospital (out of 37 different reported reasons for admission).

Table 10

**Length of stay according to reason for admission to hospital as reported by carer respondents**

Reason for admission according to DEMHOS research (number of respondents)	Proportion of people with dementia in hospital for the top five reasons for admission broken down by length of stay				
	Up to one week (seven days)	Up to two weeks (14 days)	Up to one month (30 days)	One to two months (60 days)	Over two months (61 days or more)
A fall (184)	27%	16%	23%	21%	12%
Broken/fractured hip or hip replacement (154)	14%	28%	23%	18%	16%
Urine infection (including urinary tract infection) (111)	16%	30%	23%	20%	10%
Chest infection (92)	28%	28%	15%	13%	12%
Stroke/minor stroke (91)	24%	16%	22%	26%	9%

The DEMHOS research, based on the perceptions of carer and nurse respondents, also suggests that the longer people with dementia are in hospital:

- the worse the effect on the symptoms of dementia and physical health (section 2.2.1)
- discharge to a care home becomes more likely (section 2.2.2)
- the more antipsychotics are likely to be used (section 2.2.3).

### 2.2.6 Comparing length of stay for people with dementia with length of stay for all NHS patients by reason for admission

If we directly compare length of stay for people with dementia and length of stay for all NHS patients, by reason for admission for which data is available, we can see how much longer stays tend to be (Table 11).

Table 11 compares respondents to the DEMHOS research with Hospital Episode Statistics (HES) data from 2007/8, the most recent year available. HES provides data on all admissions to NHS hospitals in England and aims to collect a detailed record for each 'episode' of admitted patient care delivered in England by NHS hospitals or delivered in the independent sector but commissioned by the NHS.

Table 11

**Length of stay for DEMHOS respondents and median length of stay for all NHS patients (including people with dementia) from Hospital Episode Statistics (HES) data**

Reason for admission – DEMHOS response	Reason for admission – HES data code – comparator	HES median length of stay in days (and the length of stay it corresponds with in the DEMHOS research)	Mean age of patient according to HES data	Percentage of DEMHOS respondents staying longer than the median (based on the results from Table 10)
Broken/fractured hip or hip replacement	Total prosthetic replacement of hip joint using cement	Six (up to one week/seven days)	72	85 % staying one week or more 57 % staying two weeks or more (at least median plus eight days) 34 % staying one month or more (at least median plus 24 days)
Broken/fractured hip or hip replacement	Fracture of femur	16 (up to one month/30 days)	78	34 % staying one month or more (at least median plus 14 days)
Urine infection (including urinary tract infection)	Urinary tract infection, site not specified	Four (up to one week/seven days)	67	86 % staying one week or more (at least median plus three days) 53 % staying two weeks or more (at least median plus ten days) 30 % staying one month or more (at least median plus 26 days)
Stroke/minor stroke	Cerebral infarction	14 (up to two weeks/14 days)	75	35 % staying one month or more (at least median plus 16 days)
Stroke/minor stroke	Transitory Ischemic Attack (TIA)	One (up to one week/seven days)	73	73 % staying one week or more (at least median plus six days) 57 % staying two weeks or more (at least median plus 13 days) 35 % staying one month or more (at least median plus 29 days)

Because the categories used in the DEMHOS research are broad they have been compared with available and relevant HES codes. This has allowed three reasons for admission in the DEMHOS research to be looked at in detail: broken/fractured hip or hip replacement, urinary tract infection and stroke. The comparisons used here are not exact and are only indicators.

The HES data provides the median length of stay for all patient groups and the figures will include people with dementia. As the DEMHOS research shows that people with dementia are staying longer in hospital than people without dementia, the inclusion of people with dementia in the HES data median will have already have inflated the median. It is therefore important to note that a comparison between the HES median excluding people with dementia and the DEMHOS research would show an even greater difference in length of stay.

## 2.3 The effect of length of stay on cost

People with dementia staying in hospital longer than expected will undoubtedly place additional financial pressure on the NHS. In Table 12 the additional cost to the NHS of people with dementia staying in hospital is estimated.

Table 12 is based on length of stay as reported by carer respondents in the DEMHOS research (and outlined in Table 11). A factor of the excess day tariff has been used for the calculations, which is used by the NHS when calculating clinical productivity. The median has been chosen to calculate excess cost, rather than a higher threshold. This is because the HES median includes people with dementia, who have a longer length of stay than people without dementia. Secondly, there is no reason why people with dementia should remain in hospital longer than other patients of the same age. As such, it is not unreasonable to use the median as the base for calculating additional costs.

Table 12

**Cost of a patient remaining in hospital one month or more beyond the median, taken as a multiple of the excess day tariff**

Reason for admission – DEMHOS response	Reason for admission – HES data code	Applicable PbR tariff*	Excess day tariff*	Additional cost for patient staying one month or more longer than the median based on multiple of excess day tariff
Broken/fractured hip or hip replacement	Total prosthetic replacement of hip joint using cement	Primary hip replacement – cemented Elective tariff: £5,220 Non-elective tariff: £7,304	£248	Cost of patient staying one month or more (median plus 24 days): <b>£5,952</b>
Broken/fractured hip or hip replacement	Fracture of femur	Extracapsular neck of femur fracture with fixation w cc**: £7,265	£219	Cost of staying one month or more (median plus 14 days): <b>£3,066</b>
Broken/fractured hip or hip replacement	Fracture of femur	Neck of Femur Fracture with hip replacement w cc**: £7,815	£216	Cost of staying one month or more (median plus 14 days): <b>£3,024</b>
Urine infection (including urinary tract infection)	Urinary tract infection, site not specified	Kidney or urinary tract infection Non-elective tariff: £2,638	£176	Cost of patient staying one month or more (median plus 26 days): <b>£4,576</b>
Stroke/minor stroke	Cerebral infarction	Non-transient stroke: £4,102	£171	Cost of patient staying one month or more (median plus 16 days): <b>£2,736</b>
Stroke/minor stroke	Transitory Ischemic Attack (TIA)	Transitory Ischemic Attack (TIA): £1,628	£178	Cost of patient staying one month or more (median plus 29 days): <b>£5,162</b>

\* Tariff data from 08/09 as data from 2007/8 not available. Where relevant the tariff used for comparative purposes is that which applies to people over 69 as the majority of people with dementia will fall into this age bracket. The non-elective (not from a waiting list) tariff is used except where highlighted.

\*\* w cc = with complications or pre-existing conditions

### 2.3.1 Estimated savings by reducing the length of stay for people with dementia by one week

The data comparison between HES data and the DEMHOS research shows clearly that people with dementia are routinely staying longer than other people who go into hospital for the same procedures. This is supported by the views of nurse managers and carers in the DEMHOS research. The data also shows that a significant number of people with dementia are staying in hospital for many weeks longer than other people who go in for similar procedures.

Alzheimer's Society believes that as a starting point it would be reasonable for hospitals to work towards supporting people with dementia to leave hospital one week sooner than they currently do. Based on the understanding that up to a quarter of people in hospital have dementia (25%) (see section 2.1), Table 13 shows estimated savings which could be made in one year from only four HES data codes.

As can be seen from Table 13, savings in excess of £80 million are estimated for four HES codes. These four codes represent only a very small fraction of the range of reasons for admission found in the DEMHOS research. For example the DEMHOS research found that the most common reason for admission for

Table 13

#### Estimated savings which could be made by reducing the length of stay of people with dementia in hospital by one week

Diagnosis/operation	HES total number of admitted cases in 07/08	Estimated number of admitted cases with dementia (based on 25% of the total number of people admitted being people with dementia)	Excess day tariff (08/09)	Estimated savings (England wide) in one year
Fracture of femur	74,111	18,500	£216	£28 million
Total prosthetic replacement of hip joint using cement	32,836	8,200	£248	£14 million
Urinary tract infection, site not specified	123,273	30,800	£176	£38 million
Transitory Ischemic Attack (TIA)	19,163	4,800	£178	£6 million

people with dementia was following a fall. This does not have a comparable code in the HES data. The overall saving if people with dementia are supported to leave hospital one week sooner is therefore likely to be much higher than £80 million. It would not be unreasonable to assume that there are savings to be made in care for people with dementia in hospitals running into hundreds of millions of pounds. These figures are supported by the NAO (2007) finding that in just one condition (fractured hip), more effective identification, management of care and discharge could produce savings of between £64 and £102 million a year nationally. These savings could be more effectively reinvested in workforce capacity and development, and community services outside hospitals.

## 2.4 Summary

The DEMHOS research highlights that there are a range of poor outcomes that can result from a person with dementia being admitted to hospital. In particular, nurse managers reported that people with dementia have longer stays in hospital than a person without dementia with the same medical condition. The DEMHOS research also suggests that the longer people with dementia are in hospital:

- the worse the effect on the symptoms of dementia and physical health
- discharge to a care home becomes more likely
- the more antipsychotics are likely to be used.

Chapter 2 compared the length of stay for people with dementia in the DEMHOS research and length of stay for all NHS patients based on Hospital Episode Statistics (HES) data. This clearly demonstrates that DEMHOS respondents are staying in hospital longer than would be expected according to HES data.

People with dementia staying in hospital longer than expected will undoubtedly place financial pressure on the NHS. An analysis of available cost data suggests that the care of people with dementia on a hospital ward is more costly than the average cost for people who are admitted to hospital for a similar medical condition. Reducing length of stay in hospital is therefore a key issue to address, as this will save costs and could ultimately result in the acute ward becoming more efficient.

Chapter 3 will now explore the factors that have been highlighted by the DEMHOS research as contributing to the outcomes of a stay in hospital for a person with dementia. We must understand what factors are contributing to the outcomes described – such as increased length of stay and deterioration in physical health and the symptoms of dementia – before we can begin to suggest solutions that will work to move people out of the hospital quicker and support rehabilitation in the community.

# 3 What is going wrong? Evidence from people with dementia, their carers and nurses

## Summary

- 77% of carer respondents were dissatisfied with the overall quality of dementia care provided.
- 89% of nursing staff respondents identified working with people with dementia as very or quite challenging.
- Key areas of dissatisfaction as identified by carer respondents were: nurses not recognising or understanding dementia; a lack of person-centred care; not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the person with dementia being treated with a lack of dignity and respect.
- Key areas of concern as identified by nursing staff respondents were: managing difficult/unpredictable behaviour; communicating; not having enough time to spend with patients and provide one-to-one care; wandering/keeping people on the ward and ensuring patient safety.
- Problems with the discharge process, including lack of access to additional support such as a physiotherapist, were also identified by carer and nurse respondents.
- There are similarities between the concerns of nurses and the unmet needs of people with dementia that carer respondents have identified. However, nurses do not focus as strongly on person-centred care as a key challenge or as a training need, and the majority think that people with dementia are being treated with dignity and respect.
- Nurses are responsible for providing, or supervising healthcare assistants in providing, much of the day-to-day care of people with

dementia. They can play a key role in improving dementia care by being supported to place more focus and prominence on person-centred care. Training that addresses the concerns of nurses within the context of person-centred care for people with dementia, and raises awareness of the unmet needs of people with dementia as identified by carers in the DEMHOS research, is vital.

## 3.1 Introduction

The DEMHOS research found that people with dementia are receiving poor quality dementia care when admitted to a general ward for a physical health problem. This study found that:

- 77% of carer respondents were dissatisfied with the overall quality of dementia care provided and 20% were satisfied.
- The longer people with dementia are in hospital the more dissatisfied the carer became.

**‘I was told more than once, patient is here for fracture and pain relief – other care can pick up again when patient moves’.**

This dissatisfaction has resulted in over a third of respondents going through the complaints system. 35% of people had made a complaint; 38% would have liked to make a complaint but didn't and 25% did not make a complaint. Of those who had made a complaint, only 7% were happy with the outcome, with 44% not at all happy and 45% only partly happy.

Many people praise individual members of staff for their help and patience and believe that the difference this can make to an individual's overall experience is dramatic. When asked what was most positive about the person with dementia's stay, people said:

**‘I was quite satisfied with the care in the ward; the staff were friendly and helpful’.**

**‘One or two staff members were not as yet beaten down by the lack in the NHS system and continued to try to respond to questions and requests promptly’.**

**‘My wife was well looked after and the staff generally were very kind and helpful’.**

**‘Nursing staff work very hard’.**

Indeed, the high number of responses to this study shows that nurses are aware that providing care to people with dementia is an important aspect of their work, want to engage with it and want to do a good job. However, the majority find it extremely challenging.

When nursing staff were asked how challenging do you find working with people with dementia:

- 89% identified it as very or quite challenging (31% very challenging).
- 10% did not find it challenging (1% not at all challenging).
- Interestingly, this response doesn't vary much when you look across length of service and so cannot be described as just a lack of experience.

### 3.1.1 Overview of the areas of concern in dementia care for carer and nurse respondents

The DEMHOS research highlights the key ways in which carers have identified that general wards are not meeting the needs of people with dementia. Looking at the percentage of respondents who are dissatisfied (very or quite dissatisfied) with particular aspects of care shows that the following five areas are of particular concern:

- 1 Understanding of dementia – 76% dissatisfied versus 20% satisfied.
- 2 Being helped to eat and drink – 68% dissatisfied versus 23% satisfied.
- 3 Person-centred care (recognising that each person with dementia is an individual with likes, dislikes, routines and needs that are unique to them and delivering care that acts on this) – 68% dissatisfied versus 21% satisfied.
- 4 Recognition of dementia – 67% dissatisfied versus 30% satisfied.
- 5 Opportunities for social interaction – 62% dissatisfied versus 23% satisfied.

In addition, people with dementia and carers are not being involved in decisions on the ward. Carer respondents perceive that people with dementia are not involved in decisions about their care and treatment as much as they would like to be. Only 9% of carers said that the person with dementia was involved as much as they wanted to be, 19% said they were sometimes involved as much as they wanted to be and 42% said the person with dementia was not involved as much as they wanted to be. When reporting on their own involvement, 17% of carers said they were always involved as much as they wanted to be in decision-making; 33% were sometimes involved as much as they wanted to be and 43% were not involved as much as they wanted to be.

The importance of not being treated with dignity and respect was also highlighted by carer respondents. 19% of carers said the person with dementia was always treated with respect and dignity, 41% said that they were sometimes and over one third (36%) said the person with dementia was never treated with respect and dignity.

Other results, which are also important to acknowledge, but will not be covered in this report were:

- help with continence needs – 60 % dissatisfied versus 30 % satisfied
- maintaining personal hygiene – 60 % dissatisfied versus 32 % satisfied
- pain recognition – 51 % dissatisfied versus 38 % satisfied
- being helped to take medication – 44 % dissatisfied versus 46 % satisfied.

In the DEMHOS research nursing staff were asked what two things they found the most challenging when working with people with dementia. This was an open-ended question and the following were cited by the highest percentage of respondents as the main challenge:

- 1 Managing difficult/unpredictable behaviour – 27 %
- 2 Communicating – 23 %
- 3 Not enough time to spend with patients/not enough time for one-to-one – 11 %
- 4 Wandering/keeping people on the ward – 8 %
- 5 Ensuring patient safety – 7 %

Other responses included: managing the needs of people with dementia alongside the needs of other patients (5 %), administering medication (5 %), managing nutrition and hydration needs (4 %) and dealing with families (4 %).

In addition, the DEMHOS research highlights that problems with the discharge process are perceived as a key difficulty by both carer and nurse respondents.

This chapter will look at each of these concerns in some detail, to build a picture of the issues affecting the quality of care provided on a general ward.

## 3.2 Understanding and recognition of dementia

*‘One staff nurse told us that, “He shouldn’t be in here” and that they were not trained to look after people with his illness’.*

*‘Some staff were lovely. It was mostly clean but they just couldn’t cope with dementia’.*

Carer respondents identify that at the heart of the problem is a failure to identify dementia or understand the needs of the person with a diagnosis of dementia, with the result that the patient can be treated for the physical condition for which they were admitted, but not for the additional needs arising from their dementia.

Caring for people with dementia requires a trained workforce with the right knowledge, skills and understanding to offer the best quality care and support. This study highlighted that the training needs of nursing staff working in hospitals with people with dementia are not being met.

The DEMHOS research found that in terms of pre-registration training:

- 54 % of nursing staff said that they have not received any pre-registration training in dementia;
- 33 % said they had received some training but not enough and only 12 % said they have received enough training.

It is important to note that the majority of nursing staff (72 %) had been working for over seven years. However, dementia is not currently identified by the Nursing and Midwifery Council (NMC) as mandatory content within either the common foundation programme, or in any of the four branches of the pre-registration nursing programmes. This is because the NMC sets broad overarching programme requirements, the detail being for universities to determine in the development of each local programme. Therefore the inclusion of dementia varies according to institution but as each provider uses current evidence-based practice and policy drivers in the development of their curriculum dementia should increasingly become a major component of current programmes. The Nursing and Midwifery Council are currently consulting on pre-registration training and this is discussed in section 4.2, recommendation 5.2.

The DEMHOS research also explored work-based development and learning opportunities and found that:

- 52 % of nursing staff have not received any work-based development or learning opportunities in dementia care, 34 % have received some but not enough and only 14 % have received all they need.
- When asked about the challenges faced in providing dementia care on a general ward, nurse managers stated that staff not having pre-registration training (76 % found this challenging/quite challenging) and lack of work-based learning (73 % found this challenging/quite challenging) were problems.
- 83 % of nursing staff felt that learning and development opportunities would help them to provide care.

These results fit with other research findings. For example, the Healthcare Commission report *Equality in later life: A national study of older people's mental health services* (2009) found that carers expressed general dissatisfaction with the care their relatives received on the general wards in acute hospitals. In particular, they referred to staff in hospitals not being trained or equipped to deal with patients with mental health problems, especially dementia.

In the NAO report (2007) over half of community mental health teams felt that acute hospital nurses were inadequately trained in dementia needs. Fessey (2007) researched the perceptions of nurses on working with people with dementia and found that 85% felt they only partly have the required knowledge and skills.

### 3.2.1 Content of training

The DEMHOS research found that nursing staff would like more training in the following top five areas:

- Responding to the behavioural and psychological symptoms of dementia – 77% found this was needed/vital versus 14% who thought it would be quite useful/not needed.
- Communicating with the person with dementia – 72% needed/vital versus 20% quite useful/not needed.
- Being able to recognise pain in people with dementia – 71% versus 20%.
- The use of antipsychotic drugs – 71% versus 20%.
- The use of restraint – 67% versus 22%.

The next two areas identified were Mental Capacity Act/decision-making and benefits of social interaction, followed by continence needs, administering medicine, nutrition and hydration, recognising the symptoms of dementia and providing person-centred care. There were no topics where more people said training was quite useful/not needed than said training was needed/vital indicating the strength of opinion about the role of all topics in dementia care training. However, nursing staff place less emphasis on the need for training in areas identified as critical to improve by carer respondents (for example nutrition and hydration and person-centred care). Therefore these must be included in training (see section 3.7 for further explanation).

## 3.3 The provision of person-centred care

People with dementia experience a lack of person-centred care, with 68% of respondents being dissatisfied overall with this aspect of care.

Person-centred care is a key factor in providing effective care for people with dementia. Whilst an understanding of dementia and its symptoms is equally important, it must also be recognised that each person with dementia is an individual with likes, dislikes, routines and needs that are unique to them. It is essential to get to know the person and then think about how their dementia is affecting them.

Person-centred care underpins two areas identified in the DEMHOS research as vital to address:

- 1 Eating and drinking is a major concern reported by carer respondents. Food for thought (Alzheimer's Society, 2004) emphasises the importance of a person-centred care approach at mealtimes. Knowledge of the person and an understanding of how dementia affects them is an important aspect of ensuring that people with dementia eat and drink well.
- 2 The behavioural and psychological symptoms of dementia, identified as particularly challenging by nurse respondents. For example, knowing an individual's routine can help to reduce anxiety at mealtimes (Alzheimer's Society, Food for thought, 2004).

### 3.3.1 Lack of help with eating and drinking

'Mum needs to be prompted to eat, either meals went back untouched, or other patients tried to help her! I explained her needs at every visit, because they kept complaining that she wouldn't eat'.

'My mother is in the later stages of Alzheimer's and needs help and encouragement to eat and drink, this help was lacking on the ward and often her food/drink was taken away uneaten or with very little eaten'.

Lack of help with eating and drinking is one of the biggest areas of dissatisfaction for carers, with 68 % of respondents being dissatisfied with this area of care, compared with 23 % who were satisfied.

There is much evidence on the impact of admission to a general ward on the risk of malnutrition and dehydration and there has been significant work undertaken to improve nutritional care and practice.

A report in 2006 from the charity Age Concern (Hungry to be heard: the scandal of malnourished older people in hospital) revealed that 60 % of older patients are at risk of becoming malnourished or seeing their health get worse. A Care Quality Commission survey (2009) found that one in five hospital patients who have trouble feeding themselves do not get help with meals.

A poll in 2007 from the Royal College of Nursing found that hospital patients are at risk of malnutrition because there are insufficient nurses to provide assistance to eat.<sup>6</sup> Almost half (46 %) of nurses said there were not enough staff to help patients who may need help with eating and drinking. A similar number (42 %) said they did not have enough time to make sure patients ate properly.

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6 [www.rcn.org.uk/development/communities/rcn\\_forum\\_communities/management\\_and\\_leadership/news\\_stories/lack\\_of\\_nurses\\_raises\\_nutrition\\_fear\\_23\\_april](http://www.rcn.org.uk/development/communities/rcn_forum_communities/management_and_leadership/news_stories/lack_of_nurses_raises_nutrition_fear_23_april)

The research literature has also linked a lack of education about dementia to problems with malnutrition. For example, Archibald (2006) recognises that one of the main difficulties in preventing dehydration and inadequate nutrition in people with dementia is the lack of dementia education and training provided for nurses.

Carer respondents in the DEMHOS research perceived that being in hospital has a negative effect on the physical health of people with dementia, and dehydration and malnutrition are key manifestations of this (see section 2.2.1). Alzheimer's Society (Food for thought, 2004) suggests that providing nutritious food for people with dementia that is actually eaten does not have to be a complex or expensive task. Often a few inexpensive measures, combined with knowledge of the person and an understanding of how dementia affects them, are all that is needed.

### **3.3.2 The behavioural and psychological symptoms of dementia**

The data from the DEMHOS research shows that the key challenges that nursing staff perceive they face and the training needs that they have fall largely under the issue of the behavioural and psychological symptoms of dementia (BPSD) – responding to the behavioural and psychological symptoms of dementia, managing difficult/unpredictable behaviour, wandering/keeping people on the ward and ensuring patient safety.

More than half of all people with dementia experience behavioural and psychological symptoms at any one time as part of their condition (Ballard, Waite and Birks, 2006). Symptoms may include becoming more prone to aggression, depression, psychosis, or loss of inhibitions. For example, an individual may hit out at staff trying to provide care, or they may shout repeatedly. Restlessness or 'wandering' is also common and is estimated to occur in 15 – 60% of people with dementia (Robinson et al., 2007), although prevalence is difficult to assess. The finding that nurses are concerned about ensuring patient safety can be partly related to this wandering behaviour.

It is important not to trivialise the challenging behaviour that can be shown by people with dementia, and the complications that this can cause on a general ward. These symptoms can be distressing for people with dementia and professionals, and can potentially put both at risk. For example, a survey by Alzheimer's Society of nearly 200 care homes across the UK found a high level of aggression over a three month period. 137 care homes (73%) had recorded incidents of verbal or physical aggression from a person with dementia, and 71 (35%) had recorded an injury to a member of staff as a result of this aggression (Berry, 2006). Although not in a directly comparable care setting, this highlights the problems that can result from BPSD.

However, evidence shows that BPSD is not only a symptom of dementia, but is also an expression of the unmet needs of an individual (All-Party Parliamentary Group on dementia, 2008). Unmet needs can result from boredom, discomfort, fear, pain or environmental factors and can cause or exacerbate BPSD.

This is highlighted by the results from this study, with carers highlighting that symptoms such as aggression and shouting out actually became worse after being admitted to hospital. This suggests a vicious cycle, with nurses viewing the behaviour as a challenging symptom of dementia, without perhaps understanding the link with unmet need. It is vital that this is addressed.

**‘She was confused with a happy disposition when admitted, but became unhappy, aggressive and very demented by the time of her discharge’.**

This is supported by the research literature. Burgess and Page (2003) carried out a survey in 1999 and found that 77% of nurses found considerable stress in trying to respond to challenging behaviour. However, the authors highlight that a person with dementia when admitted to a ward will experience feelings of trauma, extreme stress and insecurity. An inability to articulate this can lead to a change in behaviour generally regarded as problematic by nurses.

Cunningham (2006) noted that aspects of the environment and care practice can lead to problems for the person with dementia which may then be misinterpreted and lead to challenging behaviour, including the stress of hospitalisation, transfer trauma (for example when being transferred from A&E to the ward), being around unfamiliar people and in an unfamiliar environment. Cunningham (2006) also notes that pain, dehydration and delirium are potential triggers for challenging behaviour. Nurses need to understand the causes of any behaviour and use strategies to reinforce familiarity and minimise any distress.

The NICE-SCIE guideline (2007) states that treatment approaches would need to reflect the range of possible causes of the behaviour and that professionals should always ask the vital question of whether the behaviour is a serious problem, and if so, for whom. To simply see such behaviour as a symptom of dementia would be to miss psychosocial factors, which interact with biological factors and influence greatly the presenting picture.

It is vital that the exacerbation of BPSD by a range of factors found in the hospital environment is acknowledged and addressed. Section 2.2.1 showed that carer respondents perceive a key outcome of being in hospital for a person with dementia is a worsening of their dementia symptoms and increased BPSD is one manifestation of this deterioration.

### 3.3.3 The behavioural and psychological symptoms of dementia and antipsychotics

‘They gave her sedatives because she wandered and got upset’.

‘The reason (I think) for these drugs was to keep the patient (my mum) in a comatose state so she was no trouble to the nurses’.

It is very important to link BPSD with the finding that antipsychotics are widely used to treat people with dementia in a hospital environment.

Whilst our findings do not allow us to know whether the medication was initiated in hospital, some responses from carers suggest that antipsychotics can be prescribed as a response to BPSD. However, as discussed, these symptoms are experienced not only as a result of the condition but also as a result of a wider and more complex set of problems. These problems include being in a new environment, a change in familiar routine and a lack of person-centred care.

The finding that there is widespread use of antipsychotic drugs in a hospital environment, and that up to a quarter of these are thought by nursing staff to be inappropriate (see section 2.2.3) is of serious concern. Side-effects include excessive sedation, dizziness and unsteadiness, which can lead to increased falls and injuries, as well as body rigidity and tremors. Research also shows that there is almost a doubling in the risk of mortality (Food and Drug Administration, 2005) and an increase in the risk of stroke by up to three times (Committee on Safety of Medicines, 2004).

### 3.3.4 Staffing issues impacting on person-centred care

Nurse respondents raised staffing issues as a key challenge in providing good dementia care, which were also noted by many carers in their responses. The key issues are:

- staff not having enough time on wards – 89% of nurse managers identified this is a key challenge in providing dementia care on the ward
- not enough staff – 86% of nurse managers identified this is a key challenge. Carer respondents also identified this as a problem, with 70% identifying it as a problem
- 70% of carer respondents also identified a lack of consistency in staff as a large problem.

A key result of these issues is that nurses on the ward perceive that they do not have enough time to provide the one-to-one person-centred care that people with dementia need. Nursing staff identified lack of time to provide one-to-one care as the third biggest challenge to providing dementia care

(after BPSD). The issue of lack of consistency in staff can also be said to be linked to person-centred care, where an understanding of the individual is paramount.

The research literature has shown that dementia can raise issues for nurses who may be faced with the smooth running of the ward taking precedence over the individual needs of the patient with dementia (Burgess and Page, 2003). Therefore, tensions can develop for nurses between giving individualised care and other priorities on the ward (Pritchard and Dewing, 2001; Marshall, 1999).

It is vital that hospitals consider staff capacity for delivery of high quality dementia care. It is also important to link staff capacity to the fact that people with dementia are staying longer in hospital. This will reduce the throughput and capacity of wards and staff, and actions to reduce length of stay are therefore a vital part of any solution.

## 3.4 Issues with communication

‘A senior nurse told me that the NHS did very well with general patients but could not deal with dementia patients because of communication problems’.

‘As he could not make staff understand he was just left except when I tried to get help.’

Both carers and nurses identified problems with communication in the DEMHOS research. Nurses recognise that communication with people with dementia requires particular skills, which they do not have:

- 23% of nursing staff respondents found this a challenge (second most challenging after BPSD).
- 72% of nursing staff said that training was vital or needed in this area.

Nursing staff lacking the skills to communicate with people with dementia contributes to the lack of person-centred care, which carers have identified as not being provided, including not being helped to eat and drink.

Communication would facilitate the provision of person-centred care through helping nurses to understand people’s needs and preferences.

Enabling nurses to communicate with people with dementia would also help to meet two further areas that carers reported being particularly dissatisfied with in the DEMHOS research – a lack of social interaction and a lack of involving people with dementia in decision-making. These are discussed in sections 3.4.1 and 3.4.2.

### 3.4.1 Involvement in decision-making

‘Talk to carers please, or family members! Don’t assume you (hospital staff) know it all. You don’t!’

‘I feel staff should realise that talking to the carer and giving the carer daily information is vital when the patient has dementia as they cannot relay this’.

The DEMHOS research found that people with dementia and carers are not being involved in decisions on the ward.

- Carer respondents perceive that people with dementia are not involved in decisions about their care and treatment as much as they would like to be. Carers said that only 9% of people with dementia were involved as much as they wanted to be. 19% of carers said that people with dementia were sometimes involved as much as they wanted to be and 42% said that people with dementia were not involved as much as they would have liked.
- When reporting on their own involvement, 17% of carers said they were always involved in decision-making as much as they wanted to be. 33% said that they were sometimes involved as much as they wanted and 43% said that they were not involved as much as they wanted to be.

The research literature confirms this issue as a problem and also highlights why it is so important that this is addressed. The literature focuses on the importance of carers being involved, but it must not be forgotten that every effort must be made to involve people with dementia in decisions concerning their own care and treatment.

Douglas-Dunbar and Gardiner (2007) addressed the relationship between nursing staff and carers in an acute setting and highlighted the need for nursing staff to develop a therapeutic relationship with the carer as well as the person with dementia. They suggested that the nurse should be proactive in making contact and recognise the carer – not themselves – as the expert on the personal care of the person with dementia. Walker and Dewar (2000) suggested that nurses can find the relationship with carers a source of stress and anxiety, with complaints taken as personal criticism, creating a barrier to effective communication.

### 3.4.2 Opportunities for social interaction

‘Get people out of bed, help them walk, radio, books, magazines. Get them more involved in social surroundings’.

The evidence from this study suggests that opportunities for social interaction is an area for concern for carer respondents, with 62% of carers dissatisfied with the opportunities available.

This appears to be an area that has not been explored to any great degree in the research literature in an acute care setting, with research particularly focusing on the importance of occupation and engagement in a care home setting. Research in care homes has clearly identified that opportunities for occupation and pleasure significantly improve outcomes for residents (Home from home, Alzheimer's Society, 2008).

Kitwood, Buckland and Petre (1995) highlight that 'doing activity' is only one way of creating engagement. They note that 'All that is required for engagement is that the person's mind is consciously active or mindful'. Having opportunities to engage in conversation and interaction with staff and other patients, or time simply spent connecting with another person and being comforted, can make a huge difference to quality of life.

### 3.5 Dignity and respect

'I can think of nothing positive from the moment my mother arrived. She was treated like a drunk on a Saturday night'.

'When we came to visit he had no bed and was lying on a mattress on the floor wearing nothing but an incontinence pad and a unbuttoned pyjama top. The door to the room was wide open and he was in full view of other patients and their visitors. When we enquired as to why this was, we were told that he had fallen out of bed the previous night and because of a shortage of special low beds he was on the floor for health and safety reasons. We found this very undignified and distressing'.

'Typical of the circumstances was illustrated when on three occasions when I visited my wife, she was sitting in the corridor, half dressed sometimes, and nobody seemed concerned or aware!'

'Completely disgusted. If animals were treated in the same way as Ida they would have been prosecuted'.

Underpinning the care of people with dementia is the issue of dignity and respect. Over one third of carers perceive that people with dementia are not being treated with dignity and respect (36%). 19% of carers said the person with dementia was always treated with respect and dignity and 41% said 'sometimes'.

Crucially, nurses were asked whether they felt people with dementia are treated with respect and dignity and they responded differently to carers. 31% of nurses said they thought people with dementia were always treated with respect and dignity while in hospital. 58% said they thought people with

dementia were sometimes treated with respect and dignity, and only 7% said that they thought people were not (and 2% did not know).

It is important to note that nurses are not saying dignity and respect isn't important. Both are addressed very strongly in a hospital environment through the Dignity in Care campaign and there is some excellent material available which supports the emphasis on dignity and respect. For example, the Royal College of Nursing guidance *Defending Dignity – challenges and opportunities for nursing* (2008) and the Royal College of Nursing *Dignity campaign pack*, which is a resource for promoting dignity in the workforce.

Two possible reasons for these DEMHOS findings are that there is a discrepancy between what people with dementia and carers, and nurses, think dignity means. Alternatively, it could be that nurses (and other professionals) are not aware of their hidden attitudes towards people with dementia. In either case, it would be helpful for the dignity in care agenda to understand and address what dignity means to people with dementia in particular.

### 3.6 Problems with discharge

Carer responses highlight that people with dementia are likely to be discharged to a residential setting and that this is more likely as length of stay increases (see section 2.2.2). The DEMHOS research also looked at whether respondents were offered additional support on leaving hospital to help them recover, such as help from a physiotherapist or occupational therapist:

- Only 18% were offered additional support to help them recover.
- 53% were not being offered support.
- 20% thought this was not applicable to them and 4% didn't know.

If the 20% reflects instances where additional support is not required or already in place, the results suggest that over half of carer respondents perceive that they were not offered support. This suggests a lack of access to intermediate care for the person with dementia, such as a physiotherapist, once they are discharged. The National Audit Office (NAO) report (2007) noted that intermediate care services can be reluctant to admit people with dementia, making discharge from hospital difficult (NAO, 2007).

The issue of people with dementia being able to access intermediate care services was also addressed in the National Dementia Strategy for England (2009). Objective 9 stated that intermediate care should be accessible to people with dementia and meet their needs, with the recommendation that the Department of Health's 2001 guidance on intermediate care should be revised to explicitly include and address the needs of people with dementia. This revised guidance was published in July 2009. The guidance now includes

people with dementia, highlighting that without specialist help people with dementia are likely to have a prolonged stay in hospital and that appropriate rehabilitation therapies have been successful in enabling people with dementia to return home and remain out of institutional care.

Nursing staff were also asked what they felt were the key challenges in discharging a person with dementia. They describe problems which may result in delayed discharge, an increase in the likelihood that an individual is discharged to a care home and which highlight the lack of support available:

- Ensuring safety/discharge to safe environment – 20% of respondents identified this as a key challenge.
- Ensuring appropriate care package/organising care package – 18%.
- Finding placement/lack of EMI nursing places – 15%.
- Adequate support for carers/family support – 11%.
- Ensuring support at home – 10%.

Other responses included lack of available support in the community, lack of an appropriate environment for discharging to, no support/involvement from family and funding/financial issues.

The nursing staff responses highlight a wide range of problems in the discharge system that must be considered. Problems with the discharge system have also previously been highlighted by the National Audit Office. In 2007 they noted that, whilst delayed discharges overall have reduced significantly following the introduction of legislation to charge social services for delays – where delayed discharge is still a problem, around half of those affected are people with dementia.

### 3.7 Summary

The key problems that carers reported show why a focus on nurses is so essential. Nurses are responsible for providing, or supervising healthcare assistants in providing, much of the day-to-day care of people with dementia such as help with eating and drinking. This is where carers perceive people with dementia to have unmet needs and is where such a difference can be made to the overall experience of a person with dementia.

The unmet needs of people with dementia that carer respondents have identified can be said to fall under the issues of a lack of training and a lack of person-centred care. There are similarities between the concerns of nurses and the unmet needs of people with dementia. For example, nurses have identified that communication with people with dementia is something that they find particularly challenging and need training in. This very closely links with

person-centred care – if a nurse cannot communicate with a person with dementia then they cannot understand that individual's needs, preferences and concerns, and so cannot address these (for example individual needs around eating and drinking). Communication also underpins involvement in decision-making for carers and people with dementia, and social interaction, which have both been identified as areas of concern by carers. Nurses and carers also strongly identify the need for training in dementia and perceive that there is not enough staff or time to provide one-to-one care.

However, nurses do not identify person-centred care per se as a key challenge or a training need, for example they do not name person-centred care as a challenge, do not focus as strongly on aspects of person-centred care such as eating and drinking and do not see the link between this and the behavioural and psychological symptoms of dementia. The majority also think that people with dementia are being treated with dignity and respect.

Nursing staff can play a key role in improving dementia care by being supported to place more focus and prominence on person-centred care. Training that addresses the concerns of nurses within the context of person-centred care for people with dementia, and raises awareness of the unmet needs of people with dementia as identified by carers in the DEMHOS research, is vital.

# 4 Recommendations: improving dementia care, shortening length of stay and reducing costs

## 4.1 Introduction

Much progress has been secured in the NHS in recent years through the reduction in waiting times for treatment and this is in large part down to the hard work of people working across the service. There is evidence of some good practice in hospitals in relation to the care of people with dementia and many respondents in the research for this report talked about how helpful hospital staff had been. However, what is clear is that nurses as a whole (and presumably others) do not yet feel equipped to provide high quality dementia care. As the eye of the NHS moves from access to services to quality, innovation and improved efficiency it is clear from the evidence presented in this report that improving the experience of the large number of people with dementia in hospitals will be key to delivering the reform agenda.

The previous chapter explored the factors that nurse and carer respondents highlighted as key areas of concern about hospital care for people with dementia. This chapter explores how these factors can be best addressed to improve quality of dementia care, reduce length of stay and support the workforce. It is vital to identify opportunities to meet the scale of the dementia challenge and in doing so to create a more cost-effective system that provides good quality care to people with dementia and carers.

## 4.2 Discussion of recommendations

In this section, recommendations for change are set out which identify some of the biggest opportunities to deliver on dementia in hospitals. Some recommendations are simple solutions that can be implemented immediately. Others will require planning by commissioners to begin to meet the challenge of dementia by commissioning appropriate services to improve the overall dementia care pathway. All recommendations will work towards improving the quality of dementia care, shortening the length of stay, supporting the workforce and making the care of people with dementia in hospitals more cost-effective.

Some of these recommendations are also key objectives in the National Dementia Strategy for England. Ensuring implementation of the Strategy, by recognising the importance of the dementia challenge, prioritising the improvement of dementia care and fulfilling the recommendations of the Strategy is therefore paramount. Commissioners will therefore need to focus attention on this to achieve urgent changes across the health and social care system as a whole.

The forthcoming Dementia Plan in Wales will also address care on a general ward and it is essential that it is addressed in a dementia plan for Northern Ireland. Priority must be given to developing and implementing these Plans.

**Recommendation 1. The NHS as a whole and individual hospitals need to recognise that dementia is a significant, growing and costly problem for them, which lies at the heart of the agenda to drive efficiency and quality improvement.**

- People with dementia over 65 years of age are using up to one quarter of hospital beds at any one time. Sampson et al. (2009) found that 42 % of individuals aged over 70 years with unplanned admission to an acute hospital have dementia, rising to 48 % in those aged over 80 years.
- In the current climate where quality needs to improve but capacity and funding is stretched, dementia is an important area where investment can be shifted through careful planned work with other agencies.
- People with dementia stay far longer in hospital than other people who go in for the same procedure. If people with dementia were for example to be supported to leave hospital one week earlier than they currently do, this will result in savings that can instead be invested in more appropriate community services. This report suggests that savings of hundreds of millions of pounds might be achieved across the system as a whole. The National Audit Office will be publishing a further report into dementia in late 2009 which should add evidence to support the case for change.

**Recommendation 2. Reduce the number of people with dementia being cared for in hospitals.**

- 2.1 Commissioners need to work with partners to shift funding from inappropriate acute usage for people with dementia into alternative services provided in the community.**
- 2.2 Shifting investment and reconfiguring services in the community will require better co-ordination with social care services and joint working with community partners.**
- 2.3 An improved system of care will also require that people with dementia have much better access to intermediate care services.**

People with dementia must have the same right of access to acute care when appropriate as people without dementia, and must stay on the ward for as long as is appropriate to meet an individual's needs. However, it is also vital to acknowledge that many people with dementia cared for in acute beds could have been more appropriately cared for elsewhere.

- The National Audit Office (2007) carried out a county-wide bed survey in Lincolnshire and found that 68 % of people with dementia in the acute hospital were no longer in need of acute care on the day the survey was conducted.
- Sampson et al. (2009) found that 43 % of admissions for people with dementia were caused by pneumonia and urinary tract infection, which they state are 'ambulatory care sensitive conditions' for which admissions could have been prevented or treated in the community. These were amongst the range of reasons for admission in the DEMHOS research.
- The DEMHOS research shows very clearly that length of stay for a person with dementia is longer than length of stay for a person without dementia who is in hospital for the same treatment or procedure.
- The NAO (2007) identified a number of alternatives to admission to acute-based care, and alternatives to a continued stay on an acute care ward, including carer respite, specialist home care, general healthcare at home, social care at home and specialist nurse/rehabilitation support at home.

**Recommendation 3. Hospitals need to identify a senior clinician to take the lead for quality improvement in dementia and for defining the care pathway.**

One of the clearest findings of this report is that dementia has a significant impact across the hospital environment but that this is not effectively recognised or planned for. Nursing staff were asked 'what would help you to care for people on a general ward?' and 87 % responded that good leadership in dementia care was necessary. The start of this work requires the identification of a senior clinician in each hospital who can lead the work across each hospital and more clearly define a simple care pathway for dementia.

There is much work already underway on developing dementia care pathways. For example Healthcare for London, the ten year programme for improving health and healthcare in the capital, launched a dementia services guide in October 2009. This will support London commissioners during the planning

stages of developing improved services for people with dementia. The guide includes recommendations for a general care pathway, developed during consultation with key stakeholders.

**Recommendation 4. Commission specialist liaison older people's mental health teams to facilitate the management and care of people with dementia in hospitals.**

For this report nursing staff were asked what would help them to care for people with dementia on a general ward and 91 % responded that more access to specialist advice and help was important.

There is a wealth of evidence around the benefits of commissioning specialist liaison older people's mental health teams. The task now is to make sure that this happens across hospitals. The Academy of Medical Royal Colleges (2008) states that the good management of mental health problems can make a significant contribution to the effectiveness and efficiency of acute hospitals and improve the outcome for patients. The NHS Confederation (2009) particularly notes that the service can reduce length of stay for people with dementia. In addition, the National Audit Office report (2007) suggests that reduced costs resulting from better management and reductions in length of stay should help primary care trusts to fund the commissioning of assessment and associated community support needed from local specialist services, for example specialist old age psychiatric liaison services, intermediate mental health care teams and community mental health teams.

**Recommendation 5. Ensure that there is an informed and effective acute care workforce in hospitals for people with dementia.**

**5.1 Hospitals need to look at staff capacity for delivering high quality dementia care. They will also need to prioritise workforce development budgets for dementia. These need to be a priority in the current financial context to help increase the capacity and throughput of the service by supporting people with dementia out of hospital as quickly as possible.**

Ensuring that there are work-based learning and development opportunities is vital, to ensure that the current workforce is supported and trained to work with people with dementia. PCTs need to commission a trained and competent workforce using regional and local workforce development resources.

- There are examples of good practice where hospitals are developing their own dementia courses based on the needs of staff and there needs to be a sharing of good practice. In addition, an Alzheimer's Society course on dementia in acute settings is available. Older people's mental health liaison teams could also have a role in providing training for current staff.

- Alzheimer's Society has developed a course 'working with people with dementia in acute hospital settings' with content to address the needs identified by both carer and nurse respondents in the DEMHOS research. The course is designed to enable staff to understand and appreciate the experience of people with dementia in acute hospital settings. Using the principles of person-centredness, the course introduces participants to ways of working with people with dementia, assessing health and wellbeing and planning and delivering person-centred care.
- The NICE/SCIE guideline (2007) emphasises that liaison teams should have a central educative role. It states that liaison teams from local mental health and learning disability services should offer regular consultation and training for healthcare professionals in acute hospitals who provide care for people with dementia. This should be planned by the acute hospital trust in conjunction with mental health, social care and learning disability services. The AMRC report (2008) also suggests that mental health staff should have explicit responsibility in delivering training.
- Some hospitals are also implementing and delivering dementia training based on the needs of their staff. For example the Cardiff and Vale University Health Board has developed a five day dementia training course specifically for general hospital nurses. A specific course has been developed that aims to support general hospital staff in their care of people with dementia through clinical skills training. Teaching methods include group work, role play, DVD, poster presentation and simulations of the care environment. Participants are encouraged to enter the 'lived reality' of a person with dementia and develop empathy in a supportive workshop environment.
- The Let's Respect programme is also a highly valuable resource and should be a resource that all hospitals draw on. The Let's Respect toolkit provides information and practical suggestions of how to better meet the mental health needs of older people focusing particularly on acute care settings.<sup>7</sup>

## **5.2 Pre-registration training should be improved in line with the requirements of the acute care workforce.**

- **The Nursing and Midwifery Council (NMC) consultation on pre-registration training is a vital opportunity to adapt the curricula and requirements to include as mandatory the core competencies required in dementia care. Alzheimer's Society will work with the NMC to inform their work.**

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7 [www.mentalhealthqualities.org.uk/our-work/older-life/lets-respect](http://www.mentalhealthqualities.org.uk/our-work/older-life/lets-respect)

The Nursing and Midwifery Council is currently in the process of reviewing pre-registration nursing education. The review focuses on how nursing programmes across the UK will need to look in order to enable nurses to meet the needs of patients safely and effectively. The outcome of the review will be standards for pre-registration nursing education which should be published by the autumn of 2010 with new programmes introduced from autumn 2011. The review is a two-stage process. The first stage focused on the principles for a future framework for pre-registration nursing education. The second phase of the review looked at generic and field specific competencies (the knowledge, skills and attitudes that nurses need to provide safe and effective care to their patients and clients). A final consultation on the stages will take place between January and April 2010. This project is a vital opportunity for the pre-registration nursing education curricula to include as mandatory the core competencies required in dementia care.<sup>8</sup>

**5.3 Government departments need to work with all bodies involved in professional and vocational training and continuing professional development to reach agreement on the core competences required in dementia care.**

**Recommendation 6. Reduce the use of antipsychotic drugs to treat people with dementia on a general ward.**

**6.1 In the National Dementia Strategy for England (2009), the Department of Health committed to publishing a review of the inappropriate use of antipsychotic drugs for people with dementia across the health and care system. At the time of this report going to print, Alzheimer's Society is awaiting the findings and looks forward to working with relevant bodies to reduce the prescribing of the drugs. This work needs to take place across England, Wales and Northern Ireland.**

The NICE-SCIE clinical guideline on dementia (2007) states that pharmacological interventions for behaviour that challenges should only be offered in the first instance if an individual is extremely distressed or there is an immediate risk of harm to the person or others.

In all other cases, people with dementia should be offered an assessment to establish the factors that may be causing or exacerbating the behaviour, with individually tailored care plans put in place to address the behaviour. Prescribing antipsychotic drugs is not acceptable for mild behaviour or behaviour that is a problem for the professional team.

**Recommendation 7. Involve people with dementia, carers, family and friends in the care of people with dementia to improve person-centred care.**

- 7.1 Having an individual care plan is essential for good quality care and it must be ensured that every person with dementia has one.**
- 7.2 Carers and the person with dementia should feed information into planning as soon as the person with dementia is admitted to build up a profile of an individual's likes, dislikes and needs to ensure person-centred care.**
- 7.3 Carers, and people with dementia where possible, must be involved in day-to-day care and treatment decisions.**

84% of nurses said that more involvement with family carers and relations would help them to care for people with dementia. 79% of nurses said that having access to a care plan would help them to care for people with dementia on a general ward.

Respondents also mention as important the need for individual patient profiles and a care plan provided by family carers so that they can understand likes/dislikes. This must be addressed immediately. Having an individual care plan is essential for good quality care and asking carers to feed information into planning as soon as the person with dementia is admitted can really make a difference. Simple tools such as information gathering sheets have been trialled. Completing a patient profile and involving carers and people with dementia in decisions on treatment and care will begin to help deliver person-centred care.

**Recommendation 8. Make sure that people with dementia have enough to eat and drink.**

- 8.1 The patient profile and individual care plan as discussed in recommendation 7 should be used to understand an individual's needs and preferences at mealtimes.**
- 8.2 Nutritional screening must be carried out for all people with dementia as soon as they are admitted to a ward to ensure that those at nutritional risk are identified and appropriate actions implemented.**
- 8.3 Carers, family and friends must always be allowed to assist at mealtimes if they wish.**
- 8.4 Hospitals should encourage volunteers to support people with dementia at mealtimes.**

**8.5 In the long term, dementia-specific education is required to empower and inform hospital staff. This could incorporate tools such as Alzheimer’s Society guide to catering for people with dementia (2009). The Dementia Services Development Centre, Stirling also has useful material, for example a video developed in 2002 to help staff encourage people with dementia to eat and drink well (Dementia Services Development Centre, 2002).**

There have been initiatives to improve hospital mealtimes, but the evidence from the DEMHOS research proves that these are not impacting on the care provided to large numbers of people with dementia and further work is needed if change is to happen now. For example, the Protected Mealtimes Initiative was a national initiative that formed part of the Better Hospital Food Programme to allow patients to eat their meals without unnecessary interruption and to focus on providing assistance to those patients unable to eat independently. Since launching its Hungry to be heard report in 2006, Age Concern and Help the Aged have been working with hospitals across the country to implement seven steps to improve hospital mealtimes for older patients. This includes using red trays, protected mealtimes and trained volunteers where appropriate. As part of the campaign a number of materials have been produced to help hospitals and members of the public tackle the issue of malnutrition.

There is also guidance available on nutrition for people with dementia and this should be implemented. The NICE-SCIE guideline (2007) states that health and social care staff should identify the specific needs of people with dementia arising from problems with nutrition and the care plan should record and address these needs. The NICE guideline on nutrition support in adults (2007) is also essential to implement to ensure that the practice of nutrition support is improved.

**Recommendation 9. Begin to change the approach to care for people with dementia to one of dignity and respect.**

There has been significant work on the dignity agenda in hospitals in recent years. However, it is evident that although there is a developing view within the NHS that dignity is important, the next stage of this work needs to be looking at how dementia can be promoted for the significant numbers of people with dementia in hospitals.

- Evidence from carers in the DEMHOS research is that the approach to dignity for dementia is not just about having a detailed understanding of dementia. Instead it means approaching the care of people with dementia in a different way – with more compassion, patience and gentleness, based on the needs of the individual.

- Work-based learning and pre-registration training will start to make a difference to the culture of dementia care on the wards by giving an understanding of dementia and the importance of person-centred care.
- It is also vital to challenge attitudes now. Addressing dementia through the dignity in care agenda would really begin to make a difference. The Royal College of Nursing has produced a range of helpful dignity materials, for example, *Small changes make a big difference: how you can influence to deliver dignified care* (2008). It would also be helpful for the dignity in care agenda to understand and address what dignity means to people with dementia in particular.



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