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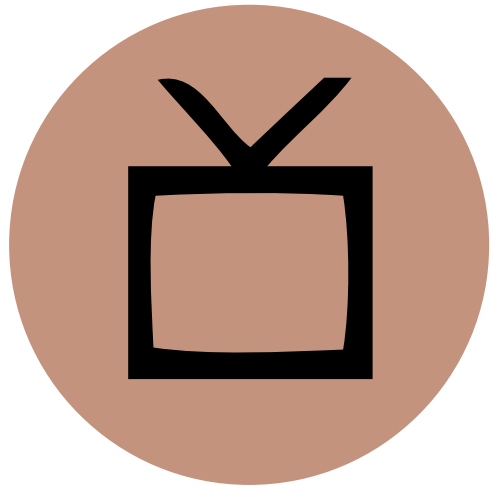
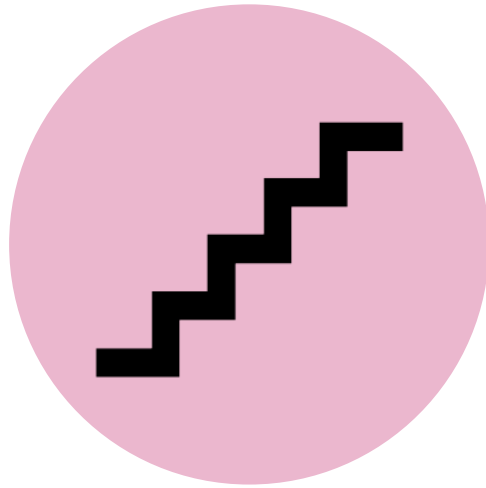
Dementia care in hospitals: costs and strategies





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Dementia care in hospitals costs and strategies

Australian Institute of Health and Welfare
Canberra
Cat. no. AGE 72

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Foreword

Dementia is a major health issue in Australia and poses a significant challenge to current and future health, aged care and social policy. The number of Australians diagnosed with dementia is expected to rise significantly in coming decades, reflecting the ageing of our population. This report presents an estimate of the costs of care for people with dementia in NSW hospitals, and examines innovative strategies designed to improve care in the acute setting.

An estimated 322,000 Australians have dementia in 2013. It is a leading cause of death in this country. Dementia has been formally recognised by governments as a National Health Priority Area. However, there is still much to be done in terms of research, treatment services and options, and understanding the experience of people with dementia, including the stigma and isolation that can result from a diagnosis.

For people with dementia, being admitted to hospital can be a confusing and frightening experience. Cognitive impairment and difficulty communicating within a busy hospital environment can potentially lead to poorer health outcomes through delays in recovery and extended lengths of stay. In addition, the chronic nature of this disease and the increased risk of complications and comorbidities for people with dementia add to the challenge.

As well as influencing health outcomes for people with dementia, their often extended periods of hospitalisation and complex care requirements place a strain on hospital resources and put financial pressures on the healthcare system.

Dementia care in hospitals: costs and strategies aims to inform service providers and governments on several key aspects of dementia care in the acute setting, so that health funding can be directed to the programs and services that appear to make the biggest differences in improving the experience of hospitalisation for people with dementia.

This report and other Australian Institute of Health and Welfare publications on dementia present the most up-to-date estimates, information and statistics to support informed decision-making and policy development.

Dementia care in hospitals: costs and strategies is the result of a successful collaboration between the Australian Institute of Health and Welfare and Alzheimer's Australia, who commissioned it, with funding from the Wicking Trust Fund.

We hope these reports will help contribute to a better understanding and awareness of dementia, and point to opportunities for improving dementia care.

Mr David Kalisch

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This report was commissioned by Alzheimer's Australia with a grant from the J.O. and J.R. Wicking Trust, managed by the ANZ Trustees. The report uses data from the Hospital Dementia Services Project, a 3-year project funded by the National Health and Medical Research Council. The HDS Project involves a team of researchers from the Australian Institute of Health and Welfare, University of Canberra and University of NSW. Project partners and collaborators are NSW Health, Alzheimer's Australia, the Aged and Community Services Association of NSW & ACT, the Benevolent Society, the University of Queensland and La Trobe University.

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Abbreviations

AARCS	acute to aged-related care services
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
AICD	automatic implantable cardioverter defibrillator
ACE	Aged Care Emergency
ACS	Aged Care Services
ACSCs	Ambulatory Care Sensitive Conditions
ACT	Australian Capital Territory
ADRG	Adjacent Diagnosis Related Group
AGU	acute geriatric unit
AIHW	Australian Institute of Health and Welfare
APAC	Acute/Post Acute Care
APDC	Admitted Patient Data Collection
AR-DRG	Australian Refined Diagnosis Related Group
ASET	aged care services in emergency team
BPSD	behavioural and psychological symptoms of dementia
CAPAC	Community Acute/Post Acute Care
CHOPS	Care of the Confused Hospitalised Older Person Study
CII	cognitive impairment identifier
CNC	clinical nurse consultant
COAG	Council of Australian Governments
DBAMS	Dementia Behaviour Assessment and Management Service
DRG	Diagnostic Related Group
ECG	electrocardiograph
ED	emergency department
GP	general practitioner
GRACE	Geriatric Rapid Acute Care Evaluation
HDS	Hospital Dementia Services (Project)
HDS*	Hospital Dementia Services Costing Project
HITH	Hospital in the Home
LOS	length of stay
MAU	medical assessment unit

NARI	National Ageing Research Institute
NHMRC	National Health and Medical Research Council
NHS	National Health Service (UK)
NP	nurse practitioner
NSW	New South Wales
OPERA	Older Persons Evaluation, Review and Assessment
OR	operating room
PCT	Primary Care Trust (UK)
PPV	positive predictive value
RAC	Residential Aged Care
RAID	Rapid Assessment Interface Discharge
RIR	Residential In-Reach
RN	registered nurse
SCU	special care unit
SMHSOP	Specialist Mental Health Services for Older People
T-BASIS	Transitional Behavioural Assessment and Intervention Service
TCP	Transition Care Program
UK	United Kingdom
USA	United States of America

Summary

This report estimates the cost of dementia care in New South Wales public hospitals using a subset of data from the Hospital Dementia Services (HDS) Project conducted by the Australian Institute of Health and Welfare in conjunction with the University of New South Wales and the University of Canberra. New South Wales provides both system and population diversity to be broadly representative of the Australian hospital experience of people with dementia. The report also presents innovative strategies and practices being implemented in Australia and internationally, which might improve the quality and cost efficiency of dementia care in hospitals.

Almost half (47%) of episodes for people with dementia did not have dementia recorded as a diagnosis

The study population includes 20,748 people with dementia who had a completed hospital stay including at least one night in a New South Wales public hospital in 2006–07. Identification and reporting of dementia is often poor in hospitals—for almost half of the episodes for people with dementia in this study, dementia was not recorded as either a principal or additional diagnosis.

People with dementia generally stay in hospital longer and have higher associated costs of care

Results from this study showed that people with dementia generally have a longer length of stay (LOS) within a hospital than other patients, leading to greater costs to the health system. Almost three-quarters of the reasons for hospital care included in this study involved a longer median LOS for people with dementia compared with people without dementia. The average cost of hospital care for people with dementia was higher than for people without dementia ($7,720 compared with $5,010 per episode, respectively). The total cost of care in New South Wales public hospitals for patients who had dementia in 2006–07 was estimated to be $462.9 million, of which around 35% ($162.5 million) may be associated with dementia.

A range of strategies were identified that could improve outcomes for people with dementia and reduce the costs of care

General strategies that might improve outcomes for people with dementia in hospitals were identified through a literature review, HDS site visits and the expert advisory group for this report. This review highlighted a number of different initiatives being implemented in a range of settings, including strategies outside the hospital, strategies within emergency departments, strategies within the hospital, cross-sectoral strategies and environmental strategies.

All of these strategies are ultimately aimed at improving the care experience for people with dementia. The findings of the review of strategies suggest that a multifaceted and integrated approach between hospital, mental health, residential aged care and community services is most likely to ensure that dementia care is delivered in the most appropriate and beneficial setting for the patient.

Introduction

For people with dementia, hospitals can pose greater risks than for other patients. The often noisy and unfamiliar hospital environment can cause confusion and be distressing for the patient, leading to disruptive behaviours that are difficult for staff to manage. Dementia can limit the capacity of patients to engage effectively with the treatment process and to communicate their needs. As a result, providing treatment to people with dementia within a busy hospital ward can be challenging.

People with dementia are major users of hospital services, largely due to the fact that dementia is a chronic health condition which most commonly affects older people who are more likely to have other chronic conditions. Common reasons for hospitalisation of people with dementia include hip fractures and other injuries, lower respiratory tract infections, urinary tract infections and delirium (Draper et al. 2011). In addition, they can face numerous hazards during their stay in hospital and often experience adverse outcomes, including physical and cognitive functional decline, under-nutrition, skin tears and fall-related injuries (Creditor 1993; Cunningham & Archbald 2006; Draper et al. 2011; Forman & Gardner 2005; Torian et al. 1992).

The difficulties experienced in communication and engagement and the often highly complex needs of people with dementia can lead to a delay in their recovery and longer lengths of stay, increasing the risk of complications and affecting the patient's physical and mental state (Draper et al. 2011). Recent estimates from New South Wales show that people with dementia stay in hospital almost twice as long as those without dementia, averaging 16.4 days of care compared with 8.9 days for other patients (Draper et al. 2011).

While many aspects of care can affect a patient's length of stay (LOS), extended hospitalisation in some cases is a symptom of gaps or discontinuities within the health-care system (such as availability of residential aged care or specialist dementia services). Given the potential hazards of hospitalisation for older people with dementia, it is important that unnecessary extended hospitalisations are prevented and potential service gaps are addressed (Caplan et al. 2006).

Data analysis

Analysis in this report is limited to New South Wales hospital admitted patient records for people aged 50 and over, who had a hospital stay that was completed in 2006–07. While this subset is appropriate in studies relating to people with dementia, these data represent a fraction of the total New South Wales hospital admitted patient activity and the total cost for this subset ($3.8 billion) should not be compared with total costs for public hospitals in New South Wales ($9.5 billion) (AIHW 2008).

Identifying the costs of hospital care

As well as potentially contributing to poorer outcomes for the patient, extended lengths of hospital stay place a considerable burden on hospital resources and create financial pressures for the health-care system. Only one report to date has estimated the financial costs associated with extended hospitalisations for people with dementia. The United Kingdom (UK) Government report *Counting the cost: caring for people with dementia on hospital wards*, commissioned by the UK Alzheimer's Society, estimates that £117 million (A$179 million)

could be saved per year across the National Health Service (NHS) by reducing lengths of stay by 1 week for each person with dementia (Alzheimer's Society 2009).

Australian studies agree that estimated costs of care for people with dementia are likely to continue to rise over the coming decades due to Australia's ageing population and the inflation of health-care costs (Access Economics 2009; AIHW 2012a). In 2013, there were an estimated 322,000 Australians with dementia. By 2020, the number of Australians with dementia is projected to increase to almost 400,000, and by 2050 it is estimated that there will be almost 900,000 Australians with dementia (AIHW 2012a).

In the AIHW publication *Dementia in Australia* it was estimated that in 2009–10, expenditure on dementia care in hospitals amounted to $144.5 million nationally (AIHW 2012a). This figure included all hospital costs where dementia was the principal diagnosis and did not include expenditure where dementia was an additional diagnosis or where dementia was not identified or reported. It is therefore likely to be an underestimate of the cost of hospitalisation for people with dementia.

The unique nature of the data source used in this report presents an opportunity to try to address this gap and estimate hospital costs where dementia was an additional diagnosis as well as where dementia was present but was not specifically identified. In Australia, obtaining accurate estimates on hospital LOS and the associated costs is a complex process that is limited by the availability of pertinent data. Detailed information on a patient's hospital stay is available from hospital administrative data sets; however, these are broken down into individual episodes of care that end when a patient:

- changes care type (for example, from acute care to rehabilitation)
- is transferred between hospitals
- is discharged from hospital
- dies.

For some patients, an 'episode' represents their entire hospital stay, while for others an episode represents only a small proportion of their stay. In order to estimate the total LOS for each patient, all records of episodes of care must be linked together from the time a patient enters hospital to the time they are discharged.

This study uses data from the New South Wales Hospital Dementia Services (HDS) Project conducted by the Australian Institute of Health and Welfare (AIHW) in conjunction with the University of New South Wales and the University of Canberra. The HDS Project data have been linked to include all episodes of care and provide a complete record of a patient's hospital stay (AIHW 2011a). This is the first time in Australia that linked data have been used to investigate whether people with dementia have longer lengths of stay, and how this affects costs. The problem of under-identification and reporting of dementia may also be partially overcome using linked data, as several episodes of care can be used to obtain a more accurate estimate of the prevalence of dementia in hospitals. Based on these estimates, the costs associated with hospital care for people with dementia can be calculated.

Because this study uses linked data, as described above, both the definition of a patient with dementia and the associated cost estimates vary from those presented in other reports. While this study's methodology is highly advanced and offers an opportunity for more accurate estimates than before, it is limited to analysis of the 2006–07 HDS data set; the only available source of hospital data linked in this way. Further details on the benefits and limitations of this study are discussed in the methods section which follows.

Identifying strategies affecting hospital use

For people with dementia, admission to hospital may not necessarily be the best way to have their needs met and can be associated with hospital-related health risks, such as delirium, distress and pressure ulcers. In addition, many hospitals do not have adequate procedures or enough appropriately trained staff to manage the increasing number of people with dementia within the general ward setting.

While hospitalisation is necessary and unavoidable for many people with dementia, international research from the UK and Europe suggests that some hospital patients with dementia could receive more appropriate treatment in an alternative care setting, such as an appropriately equipped and staffed residential aged care facility (Bowen et al. 2007; Houttekier et al. 2010). The current over-reliance on hospital services may represent a gap in service provision. Addressing this gap could reduce unnecessary hospitalisation, particularly for people with dementia, in turn allowing funds to be directed towards enhancing the quality of other care settings, such as primary care in the community or residential aged care facilities.

There are many examples of innovative dementia care practices in Australia and overseas aimed at preventing avoidable hospital admissions and, for necessary admissions, reducing lengths of stay. Preventive strategies outside the hospital include the provision of acute care services in the patient's home (Tibaldi et al. 2004), primary care models that improve the identification and management of dementia in the community (Kane et al. 2004), and better management of dementia in residential aged care facilities (Wild et al. 2008).

Simple measures, such as putting a discharge plan into place when the patient enters hospital, can ensure that timely and appropriate treatment is delivered (Shepperd et al. 2010). Strategies within the hospital that address the mental health needs of people with dementia, such as psychiatric liaison services, have also shown considerable success in reducing lengths of stay and enhancing the patient's hospital experience (Parsonage & Fossey 2011). A multifaceted and integrated approach by and between hospital, mental health, residential aged care and community services could help ensure that dementia care is delivered in the most appropriate and beneficial setting.

Structure of report

Cost of dementia care in hospital

The first part of this report 'Cost of dementia care in hospital' provides an overview of the costs associated with caring for people with dementia in hospitals (referred to in this report as 'dementia care'). The methods section provides detailed information on the data sources and costing methods used. The discussion on data sources covers the benefits and limitations of using data from the HDS Project and discusses the relative advantages and disadvantages of using data from a single jurisdiction (New South Wales). The discussion of costing describes the two methods adopted and explores the impact of under-identification on the results and how this has been addressed in the methodologies.

The results section provides estimates of the cost of dementia care in New South Wales public hospitals and quantifies the extent to which dementia is under-reported in hospital records. Estimates are provided for:

- under-identification of dementia in the study population
- total cost of hospital care for patients with and without dementia, adjusted for care type, inter-hospital transfers, unusually long episodes, private hospital episodes and deaths
- cost of hospital lengths of stay for people with dementia compared with people without dementia expressed in 2010–11 health-care prices.

Strategies and practices affecting hospital use

The second part of this report, 'Strategies and practices affecting hospital use', provides an overview of strategies and practices that are currently being used to reduce lengths of stay, prevent avoidable hospital admissions and reduce adverse outcomes for people with dementia. The methods section details the data sources and processes used to identify strategies, including a literature review of national and international reports, studies, practices and plans, analysis of the HDS fieldwork transcripts and information sourced from the expert advisory group for this project.

The results section describes Australian and international strategies. These are grouped based on the settings in which they are delivered:

1. 'Strategies outside the hospital'—focuses primarily on admission prevention strategies
2. 'Strategies within emergency departments'—discusses those strategies that aim to improve identification of dementia and appropriate referral and admission practices
3. 'Strategies within the hospital'—explores strategies that aim to reduce LOS
4. 'Cross-sectoral strategies'—identifies some of the key strategies that cross between settings, such as end-of-life care
5. 'Environmental strategies'—relates specifically to strategies for improving the physical and social environment where care is delivered.

This section will provide, where possible, details of any evaluations of the existing strategies to assist in informing changes to dementia care practice in Australia. An evidence-based approach should ensure that policies are more likely to be effective in achieving their aims.

Cost of dementia care in hospital—methods

Estimating the cost of hospital care for patients with and without dementia is highly complex and relies on the availability of data and information on the entirety of patient hospital stays. The costing estimations for this report therefore use a subset of data from the HDS Project. The first part of this section describes the HDS Project; the relevant hospitals data used by the HDS Project and the characteristics of all HDS patients. The second section details the subset of HDS patients that forms the study population for the costing analysis in this report. The final section describes the costing estimates methods.

Hospital Dementia Services (HDS) Project

The HDS Project is a study funded by the National Health and Medical Research Council (NHMRC) involving expert researchers and data analysts from the AIHW, the University of New South Wales and the University of Canberra. It is a mixed methods study that explores how hospital-based aged care and dementia services influenced outcomes for people with dementia who were admitted to a public hospital in New South Wales in 2006–07.

The study involves linking existing administrative data sets to create a data set containing patient trajectories in hospitals and into residential aged care; a survey of all New South Wales public hospitals about hospital-based aged care and dementia-specific services; and follow-up site visits in selected locations to obtain qualitative data on operational aspects of different hospital-based service models for people with dementia.

The overarching objective of the project is to inform health practitioners, health and aged care policy makers and planners, and consumers about the influence of system-level factors on care outcomes for hospital patients with dementia. Outcomes of interest include hospital admission rates, LOS in hospital, and discharge rates to residential aged care.

The **HDS study population** is people aged 50 and over by 1 July 2006 who had a completed hospital stay in 2006–07 that included at least one night in a New South Wales public hospital. Just over 252,700 people (termed HDS patients) met these conditions (see AIHW 2011a, 2012b for more details).

Hospital patient data used by the HDS Project

Hospital use data for the HDS Project were extracted from the New South Wales Admitted Patient Data Collection (APDC) and included all hospital episodes ending between 1 July 2005 and 30 June 2007. Data from the full 2 years were used to identify complete hospital stays ending in 2006–07 and whether the patient had dementia. The information recorded includes: patient demographics (for example, age and sex); admissions items (for example, source of referral and admission date); clinical information (for example, principal and additional diagnoses); separation items (for example, post-hospital destination and separation date) and codes that reflect resource utilisation (Australian Refined Diagnosis Related Group; AR-DRG) (see Box 1 for details). The data extract also contained a unique patient identifier derived by the New South Wales Centre for Health Record Linkage (CHeReL 2009). This unique patient identifier, along with data on episode start and end

dates and mode of discharge, meant that **hospital episodes** for the same person could be combined into a **hospital stay** (refer to the following section for details).

Box 1: Australian Refined Diagnosis Related Group

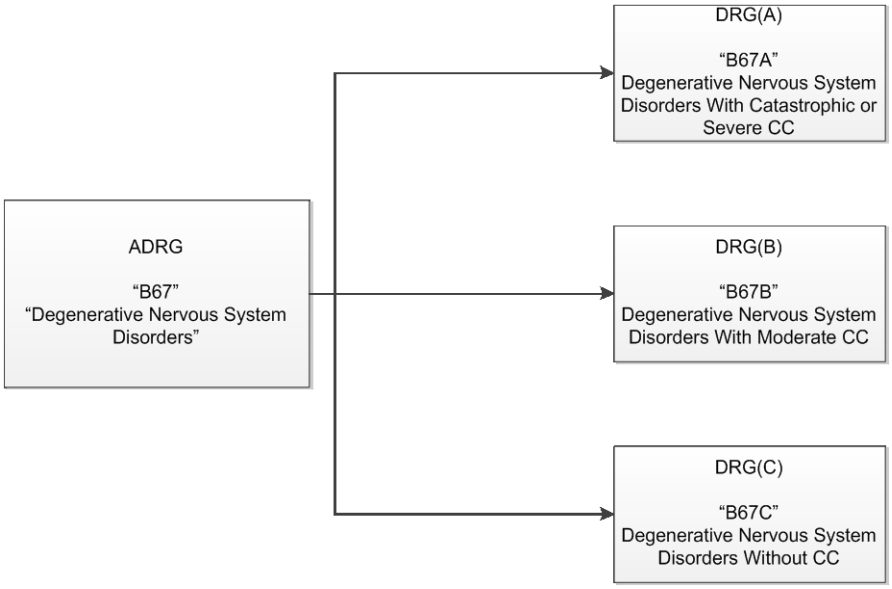
Diagnosis Related Groups (DRGs) are a patient classification system that provides a meaningful way of relating the types of patients treated in a hospital to the resources required by the hospital. Australian hospitals use **Australian Refined Diagnosis Related Groups (AR-DRGs)** to link the characteristics of patients treated to the resources consumed to inform funding, budgeting and policy development.

AR-DRGs are groupings of 'like' combinations, based upon the diagnosed conditions, procedures received and patient clinical complexity level. These combinations are 'like' in that the resource expenditure for them is similar; as such any one diagnosed condition can feature in multiple AR-DRGs as can procedures/treatments or complexities. It is the combination of these factors and the associated expense that determine to which AR-DRG a patient will belong.

AR-DRGs have different levels of resource consumption. These levels are classified on the basis of several factors, including patient clinical complexity, age, diagnoses/procedures, severity, length of stay and same-day status. AR-DRGs are grouped into **Adjacent Diagnostic Related Groups (ADRGs)**, which comprise between one and four 'like' AR-DRGs.

The ADRGs are generally defined by the same diagnosis or procedure and are referred to in this report as the **'reason for hospital care'**. Three examples illustrating the relationship between ADRGs and AR-DRGs are presented below.

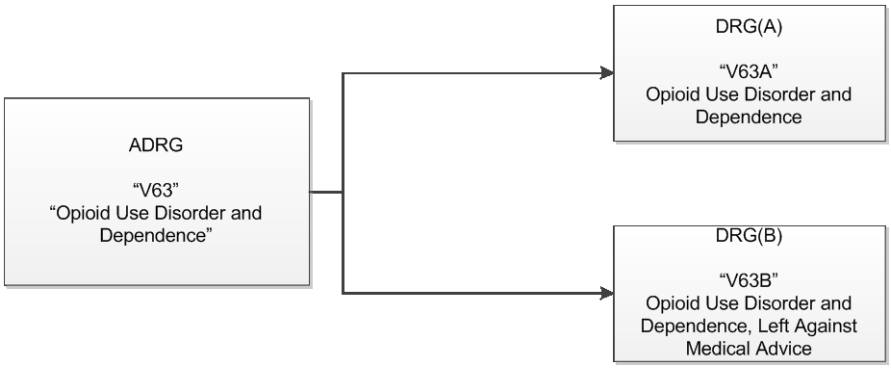
With regard to classification schemes, diagnoses in Australian hospitals are based on the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) and AR-DRGs use the AR-DRG version 5.0.



Example 1: The ADRG 'B67' comprises three AR-DRGs. The three levels of AR-DRGs A, B and C represent different levels of cost of service provision. In this ADRG, the AR-DRGs also represent different levels of complications, as increased complexities result in a higher cost of service provision.

(continued)

Box 1 (continued)



Example 2: The ADRG 'V63' has two associated AR-DRGs. As in the first example, the different levels A and B represent differing levels of cost. However, in this instance, the difference is not due to complications, but varying discharge outcomes associated with the episode of care.

Example 3: The ADRG 'D06' has only a single level of cost. The code Z is applied to represent this.

Source: Department of Health and Aged Care 2002.

Hospital stays and hospital episodes

Each record in the New South Wales APDC extract relates to an episode of care within a hospital. An **episode of care** for an admitted patient (or inpatient) can be:

- a total hospital stay—from admission into hospital to discharge from hospital or death
- a portion of a hospital stay beginning and/or ending in a change of type of care (for example, from acute care to rehabilitation). Episodes ending with a change in care type in the same hospital are reported as ending in a statistical discharge
- a portion of a hospital stay beginning/ending in a transfer from/to another hospital.

A **hospital stay** is defined as the period from admission into the hospital system, to discharge from the hospital system or death in hospital. A hospital stay can therefore:

- start and end on the same day (same-day stay)
- include at least one night in hospital (multi-day stay)
- include one or more transfers between hospitals (multi-episode stay)
- include changes in care type within a hospital (multi-episode stay)
- include an episode as an admitted patient in one hospital while admitted to another (termed a 'visit')
- any combination of the above.

Consequently, a hospital stay may consist of one or more consecutive hospital episodes. Information about the hospital stay for each patient is obtained by linking hospital episode data belonging to that patient. Analyses based on hospital stays are therefore different from previous analysis of hospital care which has generally been episode-based, rather than person-based (AIHW 2007; Karmel et al. 2007).

Advantages of linked hospital data

In general, the advantages of linking hospital episode data include the creation of a robust data set containing a more complete picture of patient trajectories in hospitals, providing information on the full period of a patient's hospitalisation rather than individual episodes of care. In addition, linked data enable all the hospital episodes and stays that belong to one person to be attributed to them, offering an opportunity to calculate information such as hospital readmission rates accurately. From the point of view of this study, the linkage provides more accurate estimates of the total length and cost of hospital stays.

There are a few disadvantages in using HDS data for this study. Firstly, these data are restricted to patients in New South Wales hospitals and specifically those who had an overnight stay in a public hospital. Nevertheless, the unique nature of the linked HDS data provides the most robust and accurate basis for estimation of patient care costs. In addition, New South Wales is Australia's most populous state and is characterised by regional and cultural diversity (AIHW 2011a). During the study period (2006–07), episodes from New South Wales public hospitals represented 31% of all public hospital episodes in Australia (AIHW 2011b) and 34% of patient days in public hospitals. Consequently, New South Wales provides both system and population diversity and a sample size of sufficient statistical power to be broadly representative of the Australian experience.

Secondly, the HDS data are limited to records for people who had a completed hospital stay in 2006–07. While these data are no longer the latest available, the linkages they offer are unique and therefore represent the most complete data set available for measuring hospital stays rather than single episodes of care. The costing methodology uses the most recent New South Wales cost of care data (2009–10) to ensure expenditure amounts are based on the most recent figures available. Hospital data changes over time mean it is likely the results will be a conservative estimate, but they will be more complete than results limited to unlinked data.

Finally, the HDS data coverage includes only patients aged 50 and over and thus does not capture potentially expensive younger people with dementia. However, as the absolute numbers of people in this group are small (AIHW 2012b), it is unlikely to have a significant impact on the cost results reported here.

HDS patient characteristics

The HDS analysis population is people aged 50 years and over by 1 July 2006, who had a hospital stay that was completed in 2006–07, that included at least one night in a NSW public hospital. Just over 252,700 patients met these conditions. In total, these patients had 408,500 multi-day stays, 252,400 same-day stays and 735,045 episodes of care.

Just over 8% of HDS patients (20,793) were identified as having dementia during at least one episode of care during the study period. Of these, less than 4% (759) were aged under 65 years. Around 44% were aged 75–84 (9,062) and a further 42% were aged 85 and over (8,771).

On average, HDS patients with dementia had longer hospital stays than those without dementia (AIHW 2012b; Draper et al. 2011). Over half of all multi-day stays for people with dementia lasted at least 1 week, compared with just over one-third of stays for people without dementia (AIHW 2012b).

Hospitals Dementia Services Costing Project (HDS*)

As part of the costing analysis process (Figure 1), this project uses a subset of the HDS study population which excludes:

- episodes that exceeded 365 days—these were excluded as they may have related to long-stay hospital patients and inclusion of their related costs would skew the costing analysis
- episodes whose AR-DRG was ungroupable—these were excluded as a weighted cost could not be applied in relation to them.

These exclusions accounted for less than 1% of all HDS patient episodes, and some patients were excluded from the costing population as a result. For clarity, the costing study population will be referred to as the HDS* patients to distinguish these results from other HDS patient analysis published elsewhere.

The HDS* population includes 252,313 patients (20,748 people with dementia and 231,565 people without dementia) (see Table 4). These patients had:

- 733,531 episodes of care (59,968 episodes for people with dementia and 673,563 for people without dementia)
- 659,721 hospital stays (49,275 are for people with dementia and 610,446 are for people without dementia).

Under-identification of dementia in hospital data

Identification and reporting of dementia is often poor in hospitals. There are several possible reasons for this, including the difficulties of detection and diagnosis of dementia (Phillips et al. 2011). For example, there are several medical conditions that have similar presentations, including delirium and polypharmacy (use of multiple medications) issues affecting cognition, making differential diagnosis challenging.

The brevity of interactions between doctors and patients and a potential inability of people with dementia to report symptomatic behaviour as a result of cognitive impairments can add to difficulties in early recognition of dementia within a hospital setting (Cummings et al. 2011). Poor identification could also result from a range of both clinical and administrative issues, including inconsistent documentation practices, the requirements of the Australian Coding Standards (refer to Box 2), clinical coding and the limitations of the standard classification systems (Cummings et al. 2011). The challenges facing detection and reporting of dementia in hospital patients affect the quality of the diagnostic information available (Cummings et al. 2011).

Box 2: Australian Coding Standards

Hospital patient record data are coded according to Australian Coding Standards which provide clinical coders with guidelines and standards to use in assigning diagnostic codes from the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM). As part of the collection of data in Australian hospitals, a principal diagnosis is assigned to each episode of admitted patient care. The principal diagnosis is the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of admitted patient care. One or more additional diagnoses may also be assigned.

Thus, people who are admitted to hospital may have dementia recorded as either the principal diagnosis or as an additional diagnosis. However, not all conditions a person has are necessarily coded as an additional diagnosis. The coding rules indicate that only those conditions that were significant in terms of treatment required, investigations needed and resources used during the 'episode of care' are to be coded as an additional diagnosis (NCCC 2010). For example, if a person is admitted for cancer, this would be the principal diagnosis. If the patient also has dementia, this may be recorded as an additional diagnosis, or in some cases it may not be recorded at all, as it does not change the required treatment for the principal diagnosis.

For this reason, the number of hospitalisations with a principal diagnosis or an additional diagnosis of dementia may not capture all people with dementia who were hospitalised in a particular year.

It is evident from HDS data that patients may have dementia recorded in some episodes of hospital care and not others. To counter this, HDS data use diagnostic information from numerous episodes of care relating to an individual patient. This means patients are identified as having dementia if the condition was reported for any of their New South Wales hospital episodes during the study period.

Overall, because of the large scale of the study, it is reasonable to expect that the observable patterns in hospital use for HDS patients with and without dementia are robust (AIHW 2012b). Estimates of under-identification within the study population are presented in the costing results. These are conservative estimates as they do not include people with dementia who have not received a diagnosis or been identified as having dementia during the study period.

Costing estimation method

The costing estimation method involved two distinct modules, each offering a different perspective to the analysis of the cost of care for HDS* patients with dementia. The two modules are:

- estimating the cost of hospital episodes of care for patients with and without dementia, while adjusting for factors that drive hospital costs, such as length of an episode, principal diagnosis, and whether a patient transfers to another hospital
- estimating the cost of hospital lengths of stay for people with dementia relative to people without dementia, given the same reason for hospital care.

The two approaches used in these modules are complementary, with the first providing information about the total cost of dementia care in hospitals and the costs associated with

complications experienced in hospitals. The second approach focuses on additional costs associated with the longer stays experienced by people with dementia. The use of both methods allows a more complete picture of hospital care costs for people with dementia to be presented. The modules and the associated methodologies are further described below.

Estimating the cost of hospital episodes of care

The steps involved in the estimation approach included:

- calculating the difference in average cost of hospital episodes for people with and without dementia
- aggregating these results to obtain total cost estimates for patients 'with' and 'without' dementia
- based on the above, estimating the proportion of costs that might be associated with dementia.

Expert advice on the costing analysis was sought in developing this approach. The Centre for Health Economics Research and Evaluation at the University of Technology, Sydney reviewed the proposed costing methods and recommended that inpatient hospital episodes be calculated using the New South Wales Cost of Care Standards 2009/10 (NSW Health 2012a). The standards provide different cost weights for each hospital episode depending on the patient's principal diagnosis, extent of complications and/or comorbidities. These standards are published annually and include cost-weight data and guidelines for estimating the costs of a range of admitted and non-admitted services.

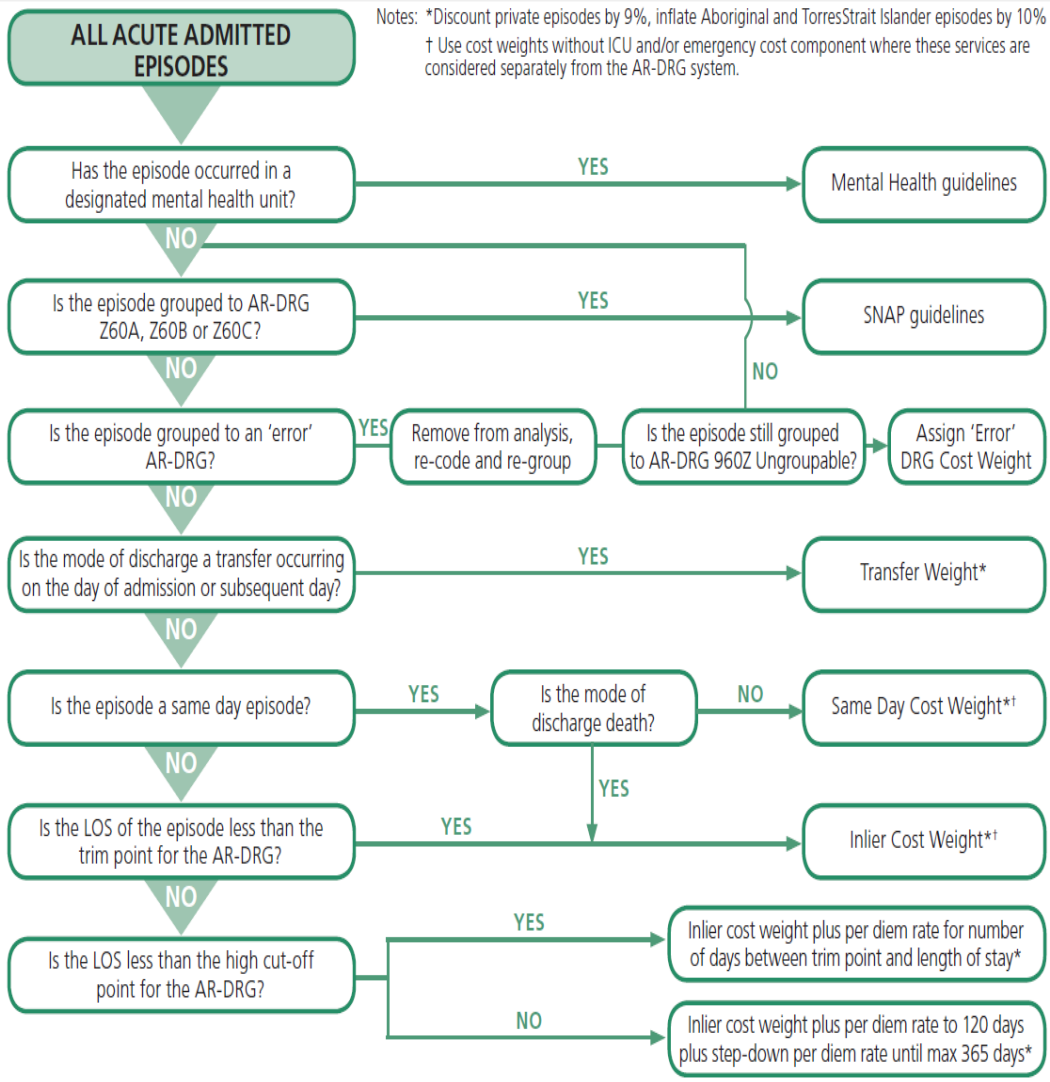
The cost-weight data provide an estimate of the average resources required for each hospital episode, taking account of a set of similar diagnoses, procedures undergone and extent of complications and/or comorbidities experienced as reflected by the AR-DRGs. Every hospital separation (referred to as an episode in this report) is assigned a DRG, which is a grouping that reflects the average resources used for one case within a given set of similar diagnoses and the extent of complications and/or comorbidities (see Box 1). Each DRG has an associated cost weight which allows the average cost of an episode to be calculated. NSW Health has cost weights that map directly to the AR-DRGs; the guidelines for these include cost weights for acute admitted care, sub- and non-acute care and mental health care (the cost analysis for these is described below).

The data also allow adjustments for a range of factors that affect cost of care, including same-day care, inter-hospital transfers, stays longer than the 'trim point' (a set value representing the upper end of an average LOS given a specific DRG), private hospital episodes and deaths.

The costing analysis for **acute care** episodes was carried out as follows (see Figure 1).

- In-scope acute care episodes for HDS* patients were allocated an 'inlier' cost weight, which excluded emergency department (ED) and intensive care unit costs.
- Each AR-DRG had an associated 'trim point' that represented the upper limit of the average length of an episode. Episodes of care with a LOS that exceeded the trim point had an 'outlier' component added to the inlier cost weight to adjust for the additional cost of the stay. This component comprised the additional days multiplied by a per diem (daily) cost dependent upon the AR-DRG. These per diem amounts ranged from $200 to $1,500.

- A third cost weight was applied when the length of the hospital episode exceeded the high cut-off point. Adjustments were also made for transfers and same-day episodes in accordance with the methods outlined in NSW Health Cost of Care Standards (NSW Health 2012a).



Source: NSW Health Cost of Care Standards 2009/10 (NSW Health 2012a).

Figure 1: Application of cost-weight data to acute admitted episodes of care

The costs for **sub- and non-acute care**, including palliative care, rehabilitation, psychogeriatric care, and geriatric care and management, were calculated using the average per diem rate for these case types, $715 for AR-DRG Z60A (Rehabilitation with catastrophic or severe complications or comorbidities) and Z60B (Rehabilitation without catastrophic or severe complications or comorbidities) and $415 for Z60C (Rehabilitation, same day).

Similarly, costs for **admitted mental health bed-days** were derived using a fixed average cost per bed-day of $745. Further adjustments to the final cost estimates were made for private hospital episodes and Aboriginal and Torres Strait Islander status. Finally, all costs were adjusted to 2012 dollars using the health component of the Australian Bureau of Statistics (ABS) Consumer Price Index (ABS 2012).

To calculate the proportion of total cost that might be associated with dementia, the difference in average cost per episode between people with dementia and those without was multiplied by the number of episodes for people with dementia. This gave the total cost that might be related to the dementia status of the person—this cost was 35.1% of the total cost of hospital care for people with dementia. This method builds on previous work undertaken as part of AIHW's *Dementia in Australia* report (AIHW 2012a) and was developed in collaboration with AIHW's Expenditure and Economics Unit.

The following results are presented:

- the average and total costs of episodes of hospital care belonging to HDS* patients with and without dementia (tables 1 and 2)
- the average costs of hospital care for the 10 most common reasons for hospital care for people with dementia, compared with people without dementia (Table 3 and Figure 2)
- costs of episodes summed to obtain the total cost, by dementia status, of a patient's whole hospital stay (Table 4)
- finally, many of the reasons for hospital care (ADRGs) are also disaggregated into AR-DRGs according to level of complexity and/or comorbidities. Where possible, these data were examined to determine whether people with dementia, given the same reason for hospital care, were more likely to experience complications and/or comorbidities in their hospital care. The costs associated with episodes that experience complications and/or comorbidities have also been estimated (figures 3 and 4).

Estimating the cost of hospital lengths of stay

The cost of LOS experienced by people with dementia compared with people without dementia, given the same reason for hospital care, was estimated in three parts. Firstly, those reasons for hospital care for which people with dementia stayed longer were identified and the number of additional bed-days for those people with dementia was calculated. Secondly, daily cost weights for each reason for hospital care were calculated. Finally, the additional bed-days for all reasons for hospital care where people with dementia stayed longer were multiplied by the derived daily cost weight. Each of these parts is now described in more detail.

Additional bed-days: Length of hospital stay was highly skewed. Given this, LOS was determined differently for the calculations of total costs compared with the calculation of episodic costs.

Additional bed-days – total costs: Firstly, for each reason for hospital care (ADRG), the mean difference in LOS for people with dementia was multiplied by the weighted cost per day for that reason for hospital care. Secondly, this figure was multiplied by the number of episodes for people with dementia who had that reason for hospital care; the 35.1% proportion (as calculated above) was then applied to arrive at the amount that might be associated with dementia for each reason for hospital care. Finally, the calculated amounts for each reason for hospital care were added together to produce the total cost of additional bed-days experienced by people with dementia, which might be associated with dementia.

Additional bed-days – per episode: Firstly, the median (as opposed to the mean) LOS was used to provide comparisons within each reason for hospital care (ADRG) between people with and without dementia. The difference therefore showed: the reasons for hospital care where

people with dementia stayed longer and the difference between the median numbers of additional bed-days associated with these longer stays.

Cost due to additional bed-days: Firstly, the additional bed-days for people with dementia, given the same reason for hospital care, compared with people without dementia, were multiplied by the derived ADRG daily cost weights. Then all costs were adjusted to 2012 dollars using the health component of the ABS Consumer Price Index (ABS 2012). Finally, the estimated proportion of costs that may be associated with dementia (35.1%) was applied to the additional bed-days costs.

Daily cost weight: The NSW Health Cost of Care Standards 2009/10 (NSW Health 2012a) provide a per diem cost weight for each AR-DRG but not ADRG. These standards also show the number of separations for each AR-DRG within each ADRG that contributed to the derivation of the cost weights. These separation numbers provide an indication of the frequency of each AR-DRG within each ADRG. To calculate a proportion that reflects the frequency of each AR-DRG within each ADRG, the number of separations for each AR-DRG was divided by the total number of separations for each ADRG. To estimate a daily cost weight for each ADRG, the per diem cost weights for each AR-DRG were multiplied by the derived proportion and then summed.

Reasons for hospital care with fewer than 11 patients in either group were excluded from the analyses. Statistical testing was explored to determine whether the observed differences in lengths of stay were statistically significant. The Mann-Whitney and Wilcoxon Rank Sum tests were the only appropriate tests, given the skewed nature of the data. However, both tests assume equal variances across groups. As this assumption did not hold in the data, no statistical testing was undertaken. Costing results are based upon all stays where people with dementia stayed longer relative to people without dementia given the same reason for hospital care. Without statistical testing, it is possible that the results overestimate the cost of hospital care associated with additional bed-days experienced by people with dementia.

The following results are presented:

- the total cost of additional bed-days experienced by people with dementia, which might be associated with dementia (Table 5)
- the cost of additional bed-days per episode experienced by people with dementia compared with those without dementia, for the 10
  - most common reasons for hospital care for people with dementia (Table 7)
  - reasons for hospital care with the greatest difference in median LOS for people with dementia (Table 8)
  - reasons for hospital care with the highest weighted cost per day (Table 9)
  - reasons for hospital care with the most expensive overall difference in LOS (Table 10).

Cost of dementia care in hospital—results

Under-identification of dementia

The identification and recording of dementia as a diagnosis in hospital records is often poor. As discussed earlier, there are a number of potential reasons for this, including the time constraints on the interactions between patients and doctors, clinical coding practices, the challenges associated with differential diagnosis and cognitive impairment of dementia patients and the systemic limitations and issues with documentation and classification practices (Cummings et al. 2011; Phillips et al. 2011). Under-identification of dementia in hospital data sets has an impact on both the reliability of information and statistics and on the approaches and practices used within the hospital. Ultimately, under-identification has potential negative consequences for patient outcomes. To overcome some of the impact of underidentification on the costing results, people with dementia include those who have been identified as having dementia as a principal and/or additional diagnosis during any episode of hospital care.

For the 20,748 HDS* patients who were identified as having dementia during at least one episode of care, dementia was not recorded as either a principal or additional diagnosis for almost half (47% or 28,029) of their associated hospital episodes. Dementia was recorded as the principal diagnosis for only 5% (3,134) and as the additional diagnosis for 48% (28,805) of episodes belonging to this patient group (Table 1).

Costing hospital episodes of care

People with dementia accounted for 12% of the total cost of hospital care in this study. However, not all of the costs associated with treatment for people with dementia are attributable to dementia. This study uses the difference in average costs between people with and without dementia (Table 1) to calculate the approximate amount of the total cost of care for people with dementia that may be attributable to dementia.

Average costs of hospital care

The average costs of hospital care for people with dementia were higher than for people without dementia (Table 1). Where dementia was the principal diagnosis, the average cost was $13,434 per episode compared with $5,010 for people without dementia, a difference of $8,424. In other words, the average cost of hospitalisation for a person with a principal diagnosis of dementia is almost 2.7 times more than for a person without dementia. The average cost of episodes for those people with dementia, who did not have dementia recorded as a diagnosis for that episode was much closer to the average cost for people without dementia ($5,594). It may indicate that these patients had mild dementia with a minimal impact on care requirements. Overall, this study found that, on average, hospital care cost $2,710 more per episode for people with dementia than for those without dementia ($7,720 compared with $5,010, respectively).

Table 1: Number of episodes of hospital care and difference in average hospital costs in New South Wales public hospitals for HDS* patients aged 50 and over, by dementia status, 2006–07

	Number of episodes		Average cost per episode ($)		Difference between average costs ($)	
Dementia status	**All**	**Age ≥70**	**All**	**Age ≥70**	**All**	**Age ≥70**
With dementia						
Principal diagnosis	3,134	2,818	13,434	13,381	8,424	8,061
Dual diagnosis[(a)]	*911*	*816*	*15,797*	*15,877*	*10,787*	*10,557*
Additional diagnosis only	28,805	27,132	9,166	8,979	4,156	3,659
Dementia not recorded	28,029	24,077	5,594	5,705	584	385
Total with dementia	**59,968**	**54,027**	**7,720**	**7,749**	**2,710**	**2,429**
Without dementia	**673,563**	**362,253**	**5,010**	**5,320**	—	—
All HDS* patient episodes	**733,531**	**416,280**	**5,231**	**5,636**	—	—

(a) Dual diagnosis includes episodes of care where an individual received both a principal and additional diagnosis of dementia during the study period. These episodes are included in principal diagnosis and excluded from additional diagnosis to avoid counting them twice.

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012). Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

The total cost of care for people with dementia in New South Wales public hospitals was estimated to be $462.9 million in 2006–07, of which around 35% ($162.5 million) is estimated to be additional costs that might be associated with a patient's dementia status (Table 2).

Table 2: Cost of care associated with dementia status and total cost of care in New South Wales public hospitals for HDS* patients aged 50 and over, by dementia status, 2006–07

	Costs associated with dementia ($ million)		Proportion of costs associated with dementia (per cent)		Total cost of care for patients ($ million)	
Dementia status	**All**	**Age ≥70**	**All**	**Age ≥ 70**	**All**	**Age ≥ 70**
With dementia						
Principal diagnosis	26.4	22.7	62.7	60.2	42.1	37.7
Dual diagnosis[(a)]	*9.8*	*8.6*	*68.3*	*66.5*	*14.4*	*13.0*
Additional diagnosis only	119.7	99.3	45.3	40.8	264.0	243.6
Dementia not recorded	16.4	9.3	10.4	6.7	156.8	137.4
Total with dementia	**162.5**	**131.2**	**35.1**	**31.3**	**462.9**	**418.7**
Without dementia	—	—	—	—	**3,374.3**	**1,927.3**
All HDS* patient episodes	—	—	—	—	**3,837.3**	**2,346.0**

(a) Dual diagnosis includes episodes of care where an individual received both a principal and additional diagnosis of dementia during the study period. These episodes are included in principal diagnosis and excluded from additional diagnosis to avoid counting them twice.

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012). Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

The proportion of total costs potentially associated with dementia is about 45% for people with an additional diagnosis of dementia and almost 63% for those people with a principal diagnosis. These results show that for those people who were identified in this study as

having dementia, but where their dementia was not recorded, over 10% (more than $16 million) of their total cost of care could be associated with dementia.

Most common reasons for hospital care

As noted earlier, the 'reason for hospital care' (ADRG) is a composite measure that includes information on those diagnoses and procedures which most affect hospital costs. The most common reasons for hospital care for HDS* patients with dementia are shown in Table 3 and Figure 2.

The most common reasons for hospital care for people with dementia were *Admit for renal dialysis* (9.0% of episodes), *Rehabilitation* (6.3%) and *Dementia and other chronic disturbances of cerebral function* (5.3%), followed by *Respiratory infections/inflammations* (4.3%).

Both the most and least expensive reason for hospital care were the same for people with dementia and those without (Figure 2). The reason for hospital care with the lowest total cost for all patients was *Admit for renal dialysis* and the highest total cost was for *Rehabilitation*.

Table 3: Number and cost of episodes for the 10 most common reasons for hospital care, for HDS* patients aged 50 and over, by dementia status, 2006–07

	Number of episodes				Cost of episodes			
	With dementia		Without dementia		With dementia		Without dementia	
Reason for hospital care	Number	Per cent	Number	Per cent	Total ($ million)	Average ($)	Total ($ million)	Average ($)
Admit for renal dialysis	5,414	9.0	133,438	19.8	3.3	605	68.4	512
Rehabilitation	3,751	6.3	30,453	4.5	51.4	13,693	299.6	9,839
Dementia and other chronic disturbances of cerebral function	3,179	5.3	579	0.1	45.9	14,430	13.6	23,441
Respiratory infections/inflammations	2,584	4.3	11,509	1.7	19.0	7,342	64.6	5,616
Other factors influencing health status	2,482	4.1	7,180	1.1	31.0	12,471	43.5	6,060
Kidney and urinary tract infections	2,314	3.9	6,875	1.0	12.5	5,394	29.6	4,304
Injuries	1,455	2.4	5,111	0.8	5.1	3,515	13.2	2,579
Heart failure and shock	1,447	2.4	10,737	1.6	10.3	7,153	59.6	5,555
Oesophagitis, gastroenteritis and misc, digestive system disorders age >9	1,400	2.3	13,976	2.1	6.1	4,333	35.4	2,534
Stroke	1,350	2.3	8,098	1.2	16.5	12,209	73.3	9,056
Total (all reasons)	**59,968**	**100.0**	**673,563**	**100.0**	**462.9**	**7,720**	**3,374.3**	**5,010**

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012). Data in this table have been rounded.

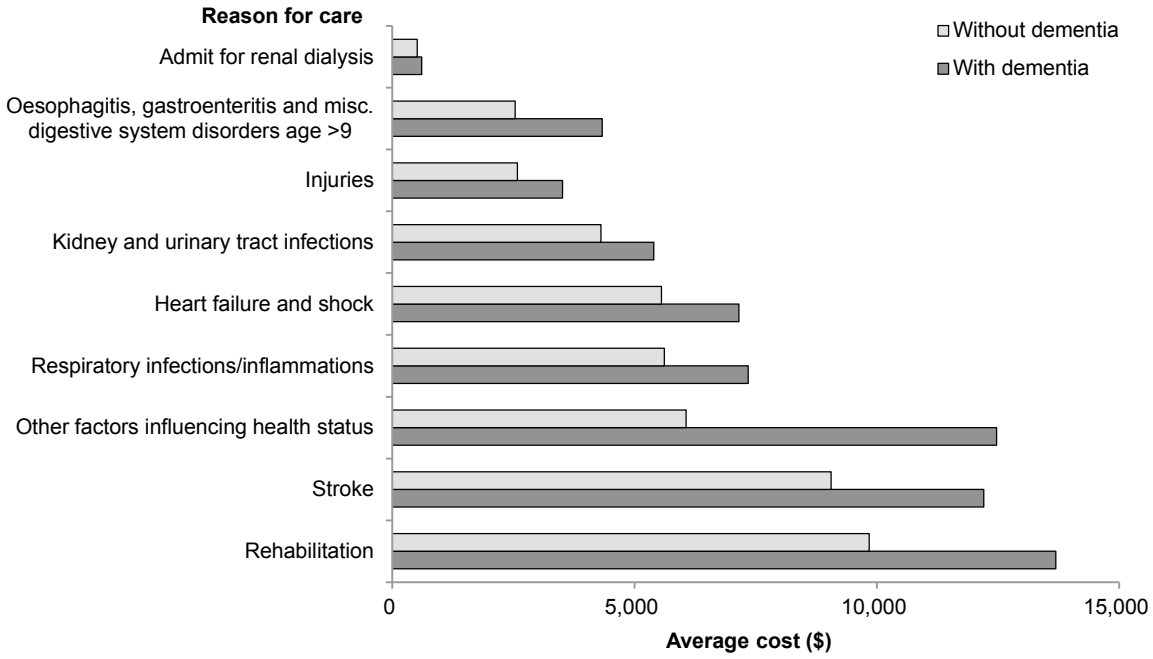
Source: New South Wales APDC data 2006–07 from the HDS Project.

For all reasons for hospital care, average episodes for people with dementia were more expensive than for people without dementia except for the category *Dementia and other chronic disturbances of cerebral function*. In this category, the average cost of episodes was

lower for people with dementia. However, the majority of episodes within the *Dementia and other chronic disturbances of cerebral function* category (85%) had dementia.

Among the small number of episodes within this category for people without dementia, the most common principal diagnosis was *Senility* (75%). It is possible that, due to the nature of *Senility*—a diagnosis inclusive of old age, senescence (without psychosis), asthenia and debility (conditions relating to a loss of strength and energy) (World Health Organization 2001)—some patients within this category had dementia which remained undiagnosed and/or unrecorded.

In addition, results for this group may be more likely to be heavily influenced by age and/or separation modes. For example, a patient with asthenia may require extended care due to additional frailty associated with advanced age. Accordingly, the distinction between people with dementia and those without may not be meaningful.



Notes

1. Excludes *Dementia and other chronic disturbances of cerebral function* as comparisons for this category may not be meaningful.
2. All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012).

Source: New South Wales APDC data 2006–07 from the HDS Project.

Figure 2: Average costs of hospital episodes for the most common reasons for hospital care in New South Wales public hospitals, for HDS* patients aged 50 and over, by dementia status, 2006–07

The greatest difference in the average cost of a hospital episode between patients with and without dementia was for *Other factors influencing health status*. This reason for hospital care includes circumstances where an individual contacts a health service for reasons other than a disease, injury or external cause. It includes a wide range of situations relating to convalescence, screening examinations and follow-up procedures, such as fitting of devices or observation of suspected diseases and conditions.

Within this group, amongst people with dementia, 61% had a principal diagnosis of *Person awaiting admission to residential aged care*. Smaller proportions of people with dementia had a

diagnosis of *Convalescence following other treatment* (7%) and *Need for assistance at home and no other household member able to render care* (5%). The cost per episode for this category is slightly more than double that for patients who had been identified as having dementia, when compared with people without dementia ($12,471 and $6,060, respectively).

For some reasons for hospital care, the difference in average costs was minimal. For example, there was only a marginal difference in the average costs for patients with a principal diagnosis of *Admit for renal dialysis* ($605 versus $512). Modest cost differences were also evident for *Kidney and urinary tract infections* and *Injuries*.

Total hospital stays

Overall, HDS* patients had 659,721 hospital stays consisting of 733,531 different episodes of hospital care during 2006–07 (Table 4). The average cost of a hospital stay for people with dementia was nearly double that of people without dementia ($9,395 compared with $5,528, respectively) (Table 4). The average cost per hospital stay includes same- and multi-day stays and accordingly this difference may reflect the fact that people with dementia are more likely to have multi-day stays (AIHW 2012b). There are several factors that may give rise to multi-day hospital stays including comorbidities, treatment complications, changes in care requirements, limited support in the community and waiting for placement into an appropriate alternative setting.

Table 4: Cost of hospital stays for HDS* patients aged 50 and over, by dementia status, 2006–07

	With dementia	Without dementia	Total
Number of patients	20,748	231,565	252,313
Number of episodes	59,968	673,563	733,531
Number of stays	49,275	610,446	659,721
Average cost of hospital stay ($)	9,395	5,528	5,817
Total cost of hospital stays ($ million)	462.9	3,374.3	3,837.3

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012).

Source: New South Wales APDC data 2006–07 from the HDS Project.

Potentially preventable conditions

There are several conditions for which hospital admissions could be prevented through early disease management or ambulatory care or where hospital care could be provided in an alternative setting such as the patient's home. These avoidable admissions are often referred to as 'ambulatory care sensitive conditions' (ACSCs). ACSCs include hospitalisations of people from conditions that, with appropriate primary care, should not become serious enough to require admission to a hospital (Glover et al. 2007). ACSCs can be divided into three subcategories:

- vaccine-preventable conditions (for example, influenza and pneumonia)
- chronic conditions that can be managed by pharmaceuticals, patient education and lifestyle
- acute conditions commonly prevented with antibiotics or other medical interventions available in primary care (such as dental conditions).

Due to their preventable nature, ACSCs are often used to assess the adequacy, efficiency and quality of primary health care within the broader health system (Glover et al. 2007). People with dementia are frequently admitted to hospital for ACSCs such as cellulitis, dehydration, diabetes, gastroenteritis, urinary tract infections, pneumonia and upper respiratory tract infections (Phelan et al. 2012; Sampson et al. 2009). Research findings suggest that hospitalisation is potentially preventable for one or more of the principal diagnoses within 2 of the 10 most common reasons for hospital care for people with dementia, namely *Respiratory infections/inflammations* and *Oesophagitis, gastroenteritis and miscellaneous digestive system disorders* (Department of Health and Ageing 2003a).

These reasons for hospital care include a number of ACSCs; for example, *Respiratory infections/inflammations* includes, among others, vaccine-preventable conditions such as *Influenza*. *Oesophagitis, gastroenteritis and miscellaneous digestive system disorders* includes *Gastroenteritis,* a viral infection common in family and group settings, including residential care which can be potentially prevented through minimising exposure (Department of Health and Ageing 2003a, 2006; NSW Health 2012b). For people with dementia, *Respiratory infections/inflammations* accounted for 2,584 hospital episodes, of which 920 (36%) belonged to people in residential aged care. *Oesophagitis, gastroenteritis and miscellaneous digestive system disorders* accounted for 1,400 hospital episodes, of which 123 (9%) belonged to people in residential aged care. The combined estimated cost for these episodes is $25 million (Table 3).

Research also suggests that episodes relating to *Kidney and urinary tract infections* may be potentially preventable through timely and effective primary care and that hospitalisations due to injury may be avoidable through injury prevention practices (Chang et al. 2004; Department of Health and Ageing 2003a; Phelan et al. 2012). *Injuries* includes those hospitalisations relating to a fall—a common and potentially preventable occurrence among older people (Department of Health and Ageing 2003a, 2006). This could be particularly important for people with dementia who have a different injury profile leading to hospitalisation compared with people without dementia (AIHW 2012b). For example, people with dementia were more likely than others to be hospitalised due to head or limb injuries (AIHW 2012b). *Kidney and urinary tract infections* and *Injuries* accounted for a further 3,769 hospital episodes, of which 1,255 (33%) belonged to residential aged care residents, and had a total estimated cost of $17.6 million (Table 3). While not all hospitalisations for these reasons are avoidable for people with dementia, it is likely that improved assessment at the onset of symptoms would reduce unnecessary distress through avoidable hospital stays.

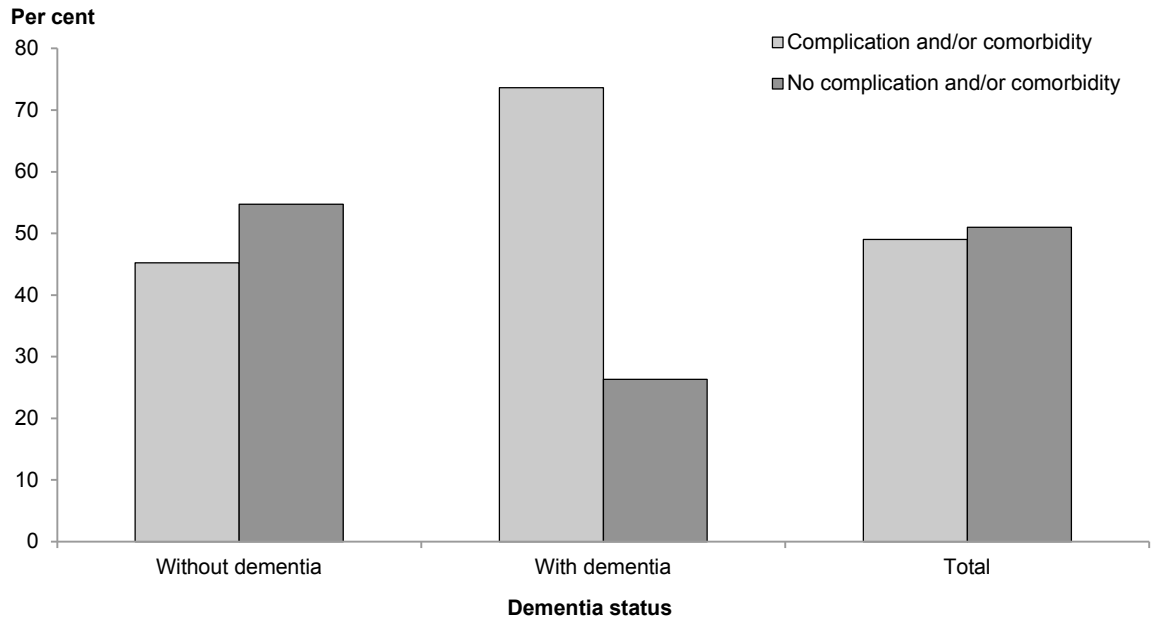
Complications and comorbidities—severity of illness

Treatments for patients during an episode of care can be made more difficult and expensive by existing comorbidities and/or the development of treatment complications (Department of Health and Ageing 2006). The impact of comorbidities and/or complications on severity of illness is factored into the AR-DRG classification system methodology. This system measures level of severity through specific diagnosis codes that identify comorbidity and/or complications that have an impact on resourcing. These codes are referred to as severity weights or complication and/or comorbidity codes.

The classification grouping process assigns a severity weight to each diagnosis on a patient record; an algorithm is then used to measure the patient's clinical complexity level based on the overall severity of illness (Department of Health and Ageing 2006). This project relies on the ADRG groupings and cost weights for analysis; therefore separation of comorbidity and

complications for individual analysis is not possible as they are reported together in the ADRGs.

The data show that people with dementia are more likely to experience comorbidities and/or treatment complications during episodes of hospital care than people without dementia (see Figure 3). The 50 most common reasons for hospital care for people with dementia were examined, accounting for slightly over half of all episodes of care for people with dementia (53.5%).

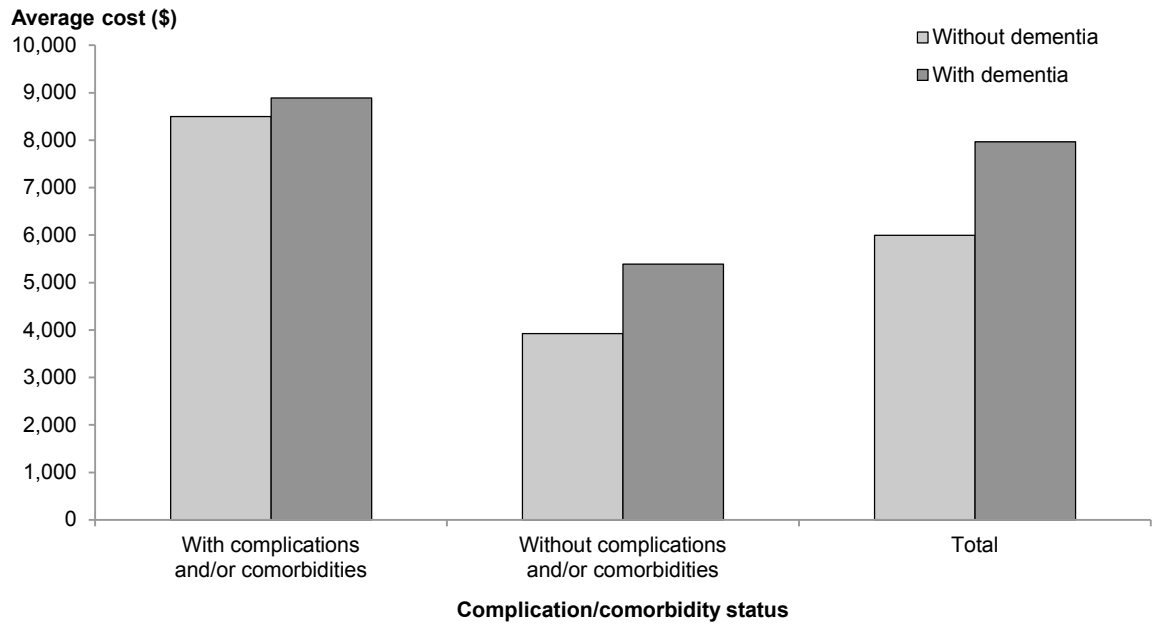


Source: New South Wales APDC data 2006–07 from the HDS Project.

Figure 3: Percentage of episodes of care with complications and/or comorbidities for 50 most common reasons for hospital care for HDS* patients aged 50 and over, by dementia status, 2006–07

Almost three-quarters (74%) of episodes of care for people with dementia had complications or comorbidities (Figure 3). By comparison, fewer than half (45%) of episodes of care for people without dementia involved additional complications or comorbidities. There are a number of potential reasons for people with dementia to experience more complications and/or comorbidities, including the chronic and degenerative nature of the disease and their generally older age profile.

Costs of episodes of hospital care increase with higher levels of complications or comorbidities. As people with dementia are more likely to experience complications or comorbidities during an episode of care, they are more likely to fall into this higher cost category. For the top 50 reasons for hospital care, the average cost of episodes of care for people with dementia without complications or comorbidities was higher than for people without dementia ($5,388 compared with $3,928, respectively) (Figure 4). In contrast, the average costs of episodes of care with complications or comorbidities for people with and without dementia were surprisingly similar ($8,888 versus $8,499, respectively).



Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012).

Source: New South Wales APDC data 2006–07 from the HDS Project.

Figure 4: Average costs of episodes of care with and without complications and/or comorbidities for 50 most common reasons for hospital care by dementia status, 2006–07

Costing hospital lengths of stay

People with dementia generally have longer lengths of stay within a hospital stay than people without dementia for almost all reasons for hospital care. This section explores additional bed-days associated with longer hospital stays and the total and average costs incurred as a result. It is important to note that not all additional bed-days are avoidable; it is possible that for some people with dementia, the additional LOS reflects the provision of necessary treatment and rehabilitation, indicating high-quality care.

The purpose of estimating the costs is to draw attention to the differences in LOS and the resulting financial impact, in order to promote the exploration of treatment requirements for people with dementia and encourage innovation and improvements in care. In turn, this will reduce those cases of unnecessary additional bed-days and minimise the potentially negative impact of long-term hospitalisation.

The distribution of costs and LOS are both likely to be skewed due to the effect of outlier episodes. To obtain the estimate of the total cost of additional bed-days that might be attributable to dementia, this study uses the mean LOS rather than the median LOS for the total cost, as this gives a more conservative estimate of the costs across all reasons for hospital care. The median LOS is used for the average cost per episode to accommodate the most accurate LOS for comparisons between people with and without dementia, given the same reason for hospital care.

Total cost of additional bed-days

The total cost of additional bed-days for people with dementia in New South Wales public hospitals during 2006–07 was over $45 million—this was related to over 150,000 additional bed-days over more than 56,000 episodes (Table 5).

Table 5: Cost of additional bed-days for HDS* patients aged 50 and over, by mean LOS, 2006–07

	Number of episodes	Number of additional bed-days	Cost associated with dementia (35.1% of total)
Reasons for hospital care with shorter mean LOS for people with dementia (16 ADRGs)	1,870	2,011	-$0.9 million
Reasons for hospital care with equal mean LOS for people with dementia (3 ADRGs)	500	—	—
Reasons for hospital care with longer mean LOS for people with dementia (220 ADRGs)	54,024	152,902	$46.5 million
Total (239 ADRGs)	**56,394**	**154,913**	**$45.5 million**

Notes

1. All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012).
2. For the purposes of this table, the mean length of stay is used.
3. The ADRG *Dementia and other chronic disorders of cerebral function* is excluded as comparisons for this reason for hospital care may not be meaningful.
4. Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

Costs of additional bed-days per episode

Of the 239 reasons for hospital care (with a minimum of 11 episodes for patients with or without dementia), almost three-quarters (73%) had a longer median LOS for people with dementia than for those without, compared with 5% of reasons for hospital care where people with dementia had a shorter median LOS (Table 6).

Exploration of those reasons for hospital care where the median LOS was equal to or less for people with dementia is beyond the scope of this research. This report, and particularly this section, focuses on the majority of reasons for hospital care (73%) where people with dementia had a longer median LOS compared with those without dementia.

Table 6: Number and proportion of reasons for hospital care with additional bed-days for HDS* patients aged 50 and over, by median length of stay, 2006–07

	Number of ADRGs	Per cent of ADRGs
Reasons for hospital care with shorter median LOS for people with dementia	12	5.0
Reasons for hospital care with equal median LOS for people with dementia	53	22.2
Reasons for hospital care with longer median LOS for people with dementia	174	72.8
Total	**239**	**100.0**

Notes

1. For the purposes of this table, the median length of stay is used.
2. The reason for hospital care 'Dementia and other chronic disorders of cerebral function' is excluded as comparisons for this reason for hospital care may not be meaningful.

Source: New South Wales APDC data 2006–07 from the HDS Project.

Most common reasons for hospital care

Table 7 shows the 10 most common reasons for hospital care for people with dementia by the median LOS. The difference in LOS and the weighted cost per day are used to calculate the total cost per episode for additional bed-days, and the estimated proportion of cost associated with dementia is then presented.

Table 7: Cost of additional bed-days associated with dementia (per episode) for the 10 most common reasons for hospital care, for HDS* patients aged 50 and over, 2006–07

Reason for hospital care	Median LOS with dementia	Median LOS without dementia	Difference in median LOS	Weighted cost per day ($)	Cost of additional bed-days ($ per episode)	Cost associated with dementia (35.1% of total) ($ per episode)
Admit for renal dialysis	0.0	0.0	0.0	271	0	—
Rehabilitation	14.0	8.0	6.0	850	5,101	1,791
Dementia and other chronic disturbances of cerebral function	11.0	17.0	–6.0	920	–5,518	–1,937
Respiratory infections/inflammations	7.0	6.0	1.0	1,057	1,057	371
Other factors influencing health status	11.0	3.0	8.0	780	6,242	2,191
Kidney and urinary tract infections	6.0	4.0	2.0	808	1,617	568
Injuries	2.0	1.0	1.0	715	715	251
Heart failure and shock	6.0	5.0	1.0	1,098	1,098	385
Oesophagitis, gastroenteritis and misc. digestive system disorders age>9	3.0	2.0	1.0	1,410	1,410	495
Stroke	9.0	7.0	2.0	836	1,672	587

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012). Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

The most commonly occurring reason for hospital care, *Admit for renal dialysis*, had no difference in the median LOS between people with dementia and those without and had the lowest weighted average cost per day ($271). The second most common reason for hospital care, *Rehabilitation*, had a higher weighted average cost per day ($850) and there was a difference in median LOS of 6 days for people with dementia compared with those without. The cost of additional bed-days per episode, which potentially could be attributed to dementia for *Rehabilitation*, was $1,791.

In all but 2 of the 10 most frequent reasons for hospital care for a person with dementia, there were additional bed-day costs when compared with a person without dementia. *Admit for renal dialysis* had no difference and *Dementia and other chronic disturbances of cerebral function*, had additional bed-days associated with people without dementia. This reason for hospital care was discussed in the previous section.

The highest cost of additional bed-days per episode for people with dementia was for *Other factors influencing health status*, a total cost of $6,242 per episode, of which $2,191 is estimated to be associated with dementia. This reason for hospital care has a low-weighted average cost per day ($780) but a bigger difference in median LOS (8 days). *Other factors influencing health status* is a broad category that includes a wide variety of principal diagnoses, ranging from *Stressful life events* and *Strange and inexplicable behaviour* to *Unspecified pain* and *Unspecified surgical follow-up care* (Department of Health and Ageing 2006).

There are several items within this reason for hospital care that relate to the availability of appropriate care in an alternative setting and these diagnoses may be contributing factors to the high level of additional costs for this reason for hospital care. For example, *Living alone*,

Inadequate family support, *Need for assistance with personal care*, *Need for assistance at home and no other household member able to render care, Medical services not available in the home*, *Person awaiting admission to a facility elsewhere unspecified* and *Holiday relief care* are all included in this reason for hospital care (Department of Health and Ageing 2006). In addition, there are many inclusions within this category relevant to older people that may have an impact on the number of episodes, including *Palliative care*, *Reduced mobility* and *Dependency on enabling machines and devices* (Department of Health and Ageing 2006).

Overall, the 10 most common reasons for hospital care for people with dementia account for over 42% of their total number of episodes. The numbers of episodes for these reasons for hospital care are available in the online supplementary tables.

Greatest difference in median length of stay

A key contributing factor to the higher average costs of care for people with dementia is the difference in LOS when compared with people without dementia. Table 8 presents the 10 reasons for hospital care with the greatest difference in median LOS. None of the 10 most frequently occurring reasons for hospital care (see above) appear in the 10 reasons with the greatest difference in median LOS.

Table 8: Cost of additional bed-days associated with dementia (per episode) for the 10 reasons for hospital care with the greatest difference in LOS, for HDS* patients aged 50 and over, 2006–07

Reason for hospital care	Median LOS with dementia	Median LOS without dementia	Difference in median LOS	Weighted cost per day ($)	Cost of additional bed-days ($ per episode)	Cost associated with dementia (35.1%) ($ per episode)
Infective endocarditis	35.0	12.0	23.0	1,623	37,329	13,104
Operating room (OR) procedures for infectious and parasitic diseases	28.0	12.0	16.0	926	14,817	5,201
Microvascular tissue transfer or skin graft, excluding hand	22.0	9.0	13.0	1,534	19,936	6,998
Non-extensive OR procedure unrelated to principal diagnosis	20.0	8.0	12.0	595	7,141	2,507
Peripheral and cranial nerve and other nervous system procedures	14.0	2.0	12.0	586	7,029	2,467
Other knee procedures	11.5	0.0	11.5	866	9,954	3,494
Soft tissue procedures	13.0	2.0	11.0	1,345	14,790	5,192
Implantation or replacement of AICD[(a)]	14.0	4.0	10.0	1,623	16,230	5,697
Lymphoma and leukaemia with other OR procedures	15.0	5.0	10.0	1,234	12,336	4,330
Extensive OR procedure unrelated to principal diagnosis	20.0	11.0	9.0	1,461	13,146	4,615

(a) AICD stands for automatic implantable cardioverter defibrillator.

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012). Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

The reason for hospital care with the greatest difference in median LOS (and equal most expensive weighted cost per day) was *Infective endocarditis*. The total cost per episode of additional bed-days for this reason for hospital care was over $37,000, of which just over $13,000 was estimated to be attributable to the dementia status of the person.

Infective endocarditis is caused by a microbial infection of the endocardial surface of the heart, with the majority of cases coming from *Staphylococcus aureus, Streptococcus* or *Enterococcus* (Connaughton & Rivett 2010). The condition is rare and has a variety of associated presentations, making it difficult to diagnose. Common symptoms, which may be particularly difficult to distinguish in people with dementia, include loss of appetite, weight loss and general malaise. In most cases, a fever is associated, but not always during the initial phases. It is not uncommon for delays in diagnosis to result in patients taking longer than a month to be admitted to hospital (Connaughton & Rivett 2010).

The high weighted cost per day ($1,623) could reflect the treatment regime. Hospital care is common for the initial treatment of infective endocarditis with extended courses of high-dose antibiotics and regular monitoring required (Connaughton & Rivett 2010). The large difference in bed-days resulting from comorbidity of dementia and infective endocarditis (23 days) is potentially affected by the cognitive impairment and communication difficulties experienced by people with dementia. According to Connaughton & Rivett (2010), post-discharge patients with infective endocarditis remain at significant risk of relapse or recurrent infection, and these patients therefore require ongoing monitoring and the capacity to self-report potentially relevant symptoms. It is possible that this may be especially difficult outside the hospital setting for people with dementia.

The reason for hospital care with the second greatest difference in median LOS was *Operating room procedures for infectious and parasitic diseases* (16 days). This reason for hospital care has a lower weighted cost per day of $926, resulting in a total cost per episode for additional bed-days of almost $15,000, of which $5,201 per episode is estimated to be associated with dementia.

This reason for hospital care is associated with a large number and wide variety of infectious and parasitic diseases. According to 2010 mortality data from the ABS, infectious and parasitic diseases accounted for 1.5% of total deaths across Australia (ABS 2010). While the overall proportion of total deaths is relatively low, infectious diseases are of particular concern for Australia's ageing population who are at increased risk as a result of age-associated changes in adaptive and innate immunity (Gavazzi et al. 2004; High et al. 2005; Juthani-Mehta & Quagliarello 2010; Yoshikawa 2000).

Research indicates that older people have predispositions to infectious disease and an increased chance of re-infection as a result of multiple risk factors, including impaired immunity and increased prevalence of comorbidities. These factors enhance the risk of community-acquired infections; for example, pneumonia, urinary tract infections and soft tissue infections. Pneumonia is of particular concern for older people living in residential care (Gavazzi et al. 2004; High et al. 2005; Mylotte 2002).

The additional bed-days associated with people with dementia may be reflecting a combination of the extended antibiotic treatment regime and need for monitoring, increased levels of confusion and reduced capacity for self-care and the enhanced relapse risks in older people that are associated with commonly occurring community-acquired infections.

Overall the reasons for hospital care with the greatest difference in median LOS for people with and without dementia accounted for only 8.5% of the total number of episodes for people with dementia.

Highest weighted cost per day

The weighted average cost per day contributes significantly to the overall cost of additional bed-days. Table 9 shows the 10 ADRGs with the highest weighted average cost per day. There are eight reasons for hospital care that are costed at an average of $1,623 per day. Two of these ADRGs have a difference in median LOS of 10 days or more. The longest difference, and the most expensive—*Infective endocarditis*—is discussed in the previous section.

Table 9: Cost of additional bed-days associated with dementia (per episode) for the 10 reasons for hospital care with the highest weighted cost per day, for HDS* patients aged 50 and over, 2006–07

Reason for hospital care	Median LOS with dementia	Median LOS without dementia	Difference in median LOS	Weighted cost per day	Cost of additional bed-days ($ per episode)	Cost associated with dementia (35.1 %) ($ per episode)
Infective endocarditis	35.0	12.0	23.0	1,623	37,329	13,104
Implantation or replacement of AICD total system	14.0	4.0	10.0	1,623	16,230	5,697
Pancreas, liver and shunt procedures	15.0	10.0	5.0	1,623	8,115	2,849
Diabetic foot procedures	21.0	17.0	4.0	1,623	6,492	2,279
Anxiety disorders	5.0	2.0	3.0	1,623	4,869	1,709
Cardiac pacemaker implantation	6.0	3.0	3.0	1,623	4,869	1,709
Stomach, oesophageal and duodenal procedures	12.0	9.0	3.0	1,623	4,869	1,709
Other endocrine, nutritional and metabolic operating room procedures	12.0	11.0	1.0	1,623	1,623	570
Viral illness	4.0	2.0	2.0	1,567	3,133	1,100
Rectal resection	16.0	11.0	5.0	1,545	7,727	2,713

Notes

1. All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012).
2. Includes only those ADRGs with a longer median LOS for people with dementia.
3. Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

Implantation or replacement of AICD total system had one of the most expensive weighted average costs per day and has a difference in median LOS of 10 days, potentially costing over $16,000 per episode in additional bed-days, of which just under $5,700 is estimated to be attributable to dementia.

Implantation or replacement of AICD total system refers to a procedure to implant or replace an automatic implantable cardioverter defibrillator (AICD). The AICD is a medical device that regulates cardiac rhythm by continuously monitoring the heart and using electrical pulses to restore normal rhythm if required (Mirowski 1985; Winkle et al. 1989; Zhan et al. 2007). According to research, patients who are older, frail or who have comorbid conditions are at increased risk of post-operative complications (Zhan et al. 2007). It is possible that the

additional LOS for people with dementia reflects a compounding effect of dementia on this already increased risk.

Overall, the 10 reasons for hospital care with the highest weighted cost per day accounted for only 9.4% of the episodes of care for people with dementia.

Most expensive difference in length of stay

The cost incurred as a result of the difference in LOS is influenced by a range of factors, including the weighted cost per day of the ADRGs. Table 10 presents the 10 reasons for hospital care with the most expensive total cost per episode for additional bed-days and most expensive cost estimated to be associated with dementia.

As discussed in the previous section, the ADRG with both the highest weighted cost per day and the greatest median difference in LOS between people with dementia and those without was *Infective endocarditis*. This reason for hospital care is associated with a potential additional cost of over $37,000 per episode, of which over $13,000 is may be associated with patients' dementia status, however it is a rare condition and accounts for only 15 episodes for people with dementia in this study group.

Table 10: Cost of additional bed-days associated with dementia (per episode) for the 10 reasons for care with the most expensive difference in LOS, for HDS* patients aged 50 and over, 2006–07

Reason for hospital care	Median LOS with dementia	Median LOS without dementia	Difference in median LOS	Weighted cost per day	Cost of additional bed-days ($ per episode)	Cost associated with dementia (35.1%) ($ per episode)
Infective endocarditis	35.0	12.0	23.0	1,623	37,329	13,104
Microvascular tissue transfer or skin graft, excluding hand	22.0	9.0	13.0	1,534	19,936	6,998
Implantation or replacement of AICD, total system	14.0	4.0	10.0	1,623	16,230	5,697
Operating room (OR) procedures for infectious and parasitic diseases	28.0	12.0	16.0	926	14,817	5,201
Soft tissue procedures	13.0	2.0	11.0	1,345	14,790	5,192
Extensive OR procedure unrelated to principal diagnosis	20.0	11.0	9.0	1,461	13,146	4,615
Lymphoma and leukaemia with other OR procedures	15.0	5.0	10.0	1,234	12,336	4,330
Other major joint replacement and limb reattachment procedures	12.5	4.0	8.5	1,298	11,036	3,874
Craniotomy	16.0	9.0	7.0	1,484	10,390	3,647
Other burns	10.0	3.0	7.0	1,440	10,079	3,538

Note: All costs are expressed in 2010–11 prices as per the health component of the ABS Consumer Price Index (ABS 2012). Data in this table have been rounded.

Source: New South Wales APDC data 2006–07 from the HDS Project.

Microvascular tissue transfer or skin graft (excluding the hand) was the second most expensive reason for hospital care in potential costs for additional days—almost $20,000 per episode with almost $7,000 estimated to be related to dementia. This reason for hospital care had a

difference in median LOS of 13 days between people with dementia and those without. It is difficult to determine why people with dementia might need to stay longer for a skin graft than people without dementia, but it may reflect a reduced capacity to conform to post-graft care requirements in order to maximise healing and minimise the likelihood of infection. Skin grafts often require the application of a single dressing which needs to remain in place until healing occurs (Beldon 2007). It is possible that people with dementia are more likely, either inadvertently or intentionally, to dislodge the dressing before healing. This reason for hospital care was also only associated with 15 episodes for people with dementia in this study cohort.

Overall, the 10 reasons for hospital care with the most expensive differences in lengths of stay accounted for less than 1% of the number of episodes for people with dementia.

There is significant variation in the types of reasons for hospital care that have potentially higher costs associated with additional bed-days for people with dementia. It is likely that each reason for hospital care is associated with a range of factors that contribute to the requirement for people with dementia to stay longer. This diversity is of interest as it may be due to the enhanced vulnerability of people with dementia in a hospital setting and the implications of dementia for treatment regimes.

LOS, which is a main contributor to the total cost of hospital stays, can be affected by a number of factors, including the hospital to which the patient is admitted and its care strategies, which may or may not be condition-focused. In addition, LOS can be influenced by prior health conditions and their management outside the hospital in primary and community care settings, and the availability of long-term care support services. The following section briefly outlines some of the more general strategies and practices being used to improve dementia care in Australia and internationally.

Strategies and practices affecting hospital use—methods

A number of strategies and practices have been used in hospitals and community-based services to improve outcomes for people with dementia by reducing avoidable hospital admissions or facilitating timely discharge from hospital and limiting the length of hospital stays. This report draws on two main sources of information about such strategies: those reported in the literature, and those reported to the research team during fieldwork for the HDS Project. These were supplemented with information provided by members of the expert reference group established for this report.

It is important to note that this study has not uncovered all possible strategies. Nor has it been within the scope of this study to assess their effectiveness, although the report does note the results of any investigations into the strategy's efficacy. The extent of information presented on strategies should not be construed as indicating relative importance or effectiveness; rather, it reflects the available reference material and research processes.

Literature review methods

The literature search was conducted using the following online databases:

- ProQuest
- Medline
- The Cochrane Library
- ScienceDirect
- Joanna Briggs Institute
- Dementia Collaborative Research Centre.

Additional articles were identified through Google Scholar and article reference lists. Various combinations of primary and secondary search terms were used to identify studies, publications and articles (see Table 11).

Table 11: Search terms used in literature review

Primary search terms	Secondary search terms
Dementia	Cognitive impairment
Hospital admissions	Alzheimer's disease
Hospital avoidance	Transition care
Length of stay (LOS)	End-of-life care
Discharge	Joint wards
Services	Hospital at home
Strategies	Aged care homes
Programs	Special care units
	Nurse practitioners
	Diagnosis
	Rehabilitation
	Health service utilisation
	General practitioner (GP) services

Inclusion and exclusion criteria

The review focused on strategies aimed at reducing hospital admissions and LOS for people with dementia. The search encompassed peer-reviewed scientific papers and 'grey literature' published online by government, non-profit, and for-profit organisations. All papers were published in English over the last 10 years.

There are many strategies that aim to reduce hospital admissions and LOS for older people aged 65 and above; however, the scope of the literature review for this report was restricted to strategies that address the specific needs of people with dementia. There is inevitably some overlap between the two populations, and many strategies that would benefit older people would also benefit those with dementia. In some circumstances, examples of programs for older people have been used to demonstrate the success of a strategy in a comparable population.

Selection process

The initial search identified over 50 studies and reports based on their title, abstract and/or executive summary. These papers were reviewed in greater detail to determine whether they met inclusion criteria. Any evidence relating to the efficacy of the strategy was also identified and reported.

Country of origin

A particular effort was made to identify strategies that have been implemented in Australia, United Kingdom, United States of America, Canada, New Zealand, Denmark, Sweden, Norway and the Netherlands. These countries have comparable health-care systems to Australia and/or have been identified as adopting innovative approaches to dementia care. The requirement for publication in English may have restricted the number of strategies identified from non-English-speaking countries.

Hospital Dementia Service Project fieldwork methods

The HDS Project team visited 20 public hospitals (including one pilot test site) across the eight Area Health Services as they were organised during 2010. The criteria for selecting hospitals for fieldwork included that they:

- reflected some of the diversity of hospitals (type, size and service profile) and regions in New South Wales (urban, rural and remote)
- ensured sufficient coverage of hospitals with aged care and dementia services
- had enough cases of people with dementia to contribute to study purposes.

Among other things, the site visits were used to gather information about hospital arrangements, policies and practices that affect people with dementia, and to understand common pathways into, within and out of the hospital by people with dementia. The team also obtained the views of local informants about practices and arrangements that seemed to work well for this patient group at their hospital as well as the challenges they faced in treating and caring for people with dementia. Each visit occurred over 1–2 days, depending on the size and complexity of the hospital operations and relationships. Site visits were

organised and designed in consultation with local associate investigators who were nominated as part of the site-specific research governance approval process.

The mix of activities undertaken by the research team varied between the site visits, but generally included the following:

- semi-structured interviews with key informants within the hospital and in relevant community-based organisations, such as providers of community aged care services, community mental health services and Aged Care Assessment Teams (ACATs)
- seminars/workshops to present data analysis and results and invite discussion about their interpretation
- visits to key wards and facilities to observe the physical structure and layout of facilities and the processes involved in providing treatment and care for people with dementia (including key events such as handovers at shift changes and discharge conferences).

The research teams wrote reports about each site visit and these are the key sources of information about strategies presented here. In addition, over 71 hours of interviews and discussions were recorded and transcribed. These were also key sources of information. All site visit report summaries were reviewed to identify key words and phrases for searching the full reports and relevant transcripts. Most information was obtained from the site visit reports; transcripts were used to clarify or confirm information where the site visit report was insufficiently clear, to ensure accuracy and comprehensiveness in relation to hospital-specific initiatives, and sometimes for additional detail.

Limitations

There were a number of limitations in the use of this fieldwork information for this report:

- HDS site visits had a number of research goals, only one of which was obtaining information about strategies and practices that were effective in caring for hospital patients with dementia. The fieldwork does not represent a systematic or complete record of strategies in use in the site visit hospitals.
- Information about strategies which was of interest to the HDS research team (and consequently discussed most fully) was mainly at the level of organisational structures, processes and programs, covering issues such as staffing positions and roles, referral pathways, relationships and collaborative arrangements, and availability of specialist services. The team was less focused on gathering information about local or 'highly situated' practices which are the type of initiatives undertaken at the individual ward or hospital that respond to local resource, staffing, patient and hospital characteristics. Examples of this kind of practice were mentioned and recorded and some are included here. However, these types of practices can be numerous and only a small number were brought to the attention of the HDS team.
- The strategies presented here are specific to public hospitals in New South Wales. Similar kinds of strategies (perhaps under different names) may be in place in other jurisdictions, but cannot be inferred from the HDS fieldwork.
- Finally, the HDS project did not evaluate or assess the effectiveness of any of the strategies in use. The research team noted the views of local stakeholders about how these strategies affected patient care and outcomes and these are included in this report. These views were mostly from a provider perspective, although there were a limited number of consumer representative organisations who participated in HDS site discussions. However, direct views from consumers and carers were not obtained.

Strategies identified through site visits

In conducting the hospital site visits, the HDS researchers were keen to learn about organisational structures and processes which affected hospital experiences and outcomes for people with dementia—whether or not these were 'dementia-specific'. The HDS fieldwork experience observed that dementia-related services are predominantly found in hospitals that have dedicated ACS or SMHSOP (Specialist Mental Health Services for Older People).

This relationship between the presence of hospital dementia-related services and ACS in particular probably reflects the way dementia services in Australia have largely been funded through aged care resources rather than via state or Australian Government health initiatives (AIHW 2007).

At a hospital level, the reliance on ACS to develop services for people with dementia means that many of the strategies identified through HDS fieldwork are focused on the needs of older patients more generally. The scope of these results is therefore somewhat wider than the scope used for the literature review. The team asked local informants about the use and effectiveness of these strategies for people with dementia. A common response was that many people with dementia appeared to benefit from these practices, but that it depended on the severity of dementia, the presence and severity of behavioural symptoms, and whether the patient had family or other carers. These comments were largely based on experience and observation of patient progress/deterioration rather than research-based evidence. Statistical modelling from the HDS project will provide quantitative data to test whether people with dementia have better outcomes when they receive care in hospitals with different service profiles.

Strategies and practices affecting hospital use—results

The Garling Report (2008) into acute care services in New South Wales noted that treating older patients with complex health needs should be pursued out of the hospital setting wherever possible. Where patients need admission, they should be admitted to the most appropriate part of the hospital directly and discharged home with appropriate support as soon as possible (Garling 2008). This section identifies practical strategies from Australia and overseas that aim to reduce hospital admissions and LOS for people with dementia. Where possible, evidence for the efficacy of a strategy has also been presented. The strategies have been organised and described in terms of their setting:

1. Several strategies have mainly been implemented outside of the hospital setting (in both community and residential aged care settings). These strategies are either designed to avoid or reduce admission to hospital, where possible, and/or to provide care and support to people after discharge from hospital.
2. A second site for strategies is in the emergency departments (EDs) of hospitals. Most older patients and most people with dementia are admitted to hospital from the ED. Strategies implemented here tend to be focused on assessment and treatment of presenting patients, ensuring safe return to the patient's usual residence, where possible, or arranging for admission to the appropriate care team in the hospital.
3. Strategies implemented within the acute hospital setting are designed to ensure appropriate treatment and care through access to staff with the required specialist skills.
4. Some strategies operate across a number of settings; for example, in outreach services from hospitals to residential aged care facilities. These strategies variously attempt to ensure that hospitals are used appropriately in conjunction with other health and care services, thereby avoiding unnecessary admissions and facilitating timely discharges from hospital.
5. An issue relevant to all settings is the physical and social environment within which services are delivered and this is discussed separately.

Strategies outside the hospital

This section outlines strategies and practices that have been implemented outside the hospital to avoid unnecessary hospital admissions and, where possible, provide access to alternatives to hospital care in the community and residential aged care settings.

Hospital care in an alternative setting

Hospital care in an alternative setting refers to strategies which aim to avoid unnecessary acute admissions through the provision of appropriate hospital services within the usual living environment of the person with dementia. This type of care arrangement addresses some of the difficulties people with dementia experience when they are admitted to the unfamiliar and stressful environment of an acute care hospital.

Hospital-at-home services

A **hospital-at-home** service provides all the critical elements of care to the patient in their own home under the supervision of a hospital doctor. There is no universal agreement on what constitutes hospital-at-home care; however, generally speaking, a hospital-at-home service provides acute care in the patient's place of residence for a condition that would otherwise require in-patient hospital care. Hospital-at-home patients receive comparable care from physicians and nurses, have access to medicines, and are treated with the appropriate therapeutic and diagnostic equipment in their home.

For people with dementia, the provision of care at home offers the benefit of receiving treatment in a familiar environment. This reduces the stress caused by hospitalisation, leading to fewer behavioural concerns and less reliance on antipsychotic drugs to manage the behaviours (Shepperd et al. 2009).

Shepperd et al. 2009 identified a set of key objectives for hospital-at-home programs for the provision of high-quality and cost-effective care to people with dementia:

- provide high-quality care in line with best-practice clinical guidelines
- increase patient satisfaction by minimising the disruption to a patient's life
- reduce adverse events commonly associated with inpatient hospital treatment
- reduce avoidable admissions to hospital.

A systematic review of 10 randomised controlled trials published over the last 10 years compared the outcomes of patients who received hospital-at-home services with patients who were admitted to hospital for treatment (Shepperd et al. 2009). The patients recruited to the trials were older patients with a medical condition, such as stroke or chronic obstructive pulmonary disease, who would normally require admission to hospital. Eligible patients were clinically stable and not in need of diagnostic investigation by a specialist or emergency interventions. If their condition unexpectedly worsened, patients were admitted to hospital for care and subsequently excluded from the individual studies. The review found that older patients receiving hospital-at-home care experienced higher levels of satisfaction than those with equivalent care needs receiving care in an acute setting. The mortality rate for hospital-at-home patients was almost 40% lower during follow-up at 6 months and the cost of treatment was significantly less, although this did not take into account the cost of informal care provided by family and friends.

Tibaldi and colleagues (2004) assessed the suitability of hospital-at-home care for people with dementia (Tibaldi et al. 2004). They conducted a randomised controlled trial with 109 older dementia patients in Italy who required admission to the hospital ED for an acute illness. Upon presentation to the ED, patients were randomly assigned to the **Geriatric Home Hospitalisation Service (GHHS)** or the general medical ward (GMW). The objective of the study was to determine whether the GHHS reduced the incidence of behavioural disturbances in patients with advanced dementia compared with patients admitted to the GMW. Both groups were evaluated during admission and before discharge using the same protocol. During hospital admission, the most frequently cited behaviours of concern were agitation, aggression, feeding and sleeping disorders. It was found that patients treated in the GHHS had significantly fewer behavioural disturbances and lower use of antipsychotic drugs compared with patients treated in the GMW. There was no significant difference in the mortality rate between the two groups.

Findings from this study suggest that the hospital-at-home model may be a suitable alternative to inpatient hospital care for some people with dementia. The lower use of antipsychotic medications is a positive reflection of the lower levels of distress and discomfort experienced by the patient, and demonstrates the potential that this model has for reducing adverse outcomes for people with dementia in hospital.

A study by Jacobs and colleagues (2007) described a natural experiment that arose when a 400-patient **home hospitalisation program** was closed in Jerusalem (Jacobs et al. 2007). The program had been established to reduce hospital admissions among the older population; however, funding for the program was withdrawn in 2002 due to financial constraints. The study used hospital utilisation data to analyse fluctuations in the geriatric and general hospital admission rate for older adults in the year following the program's closure. Hospitalisation rates were found to increase by 16,438 days for general hospital admissions and 6,004 days for geriatric admissions. This led to cost increases of US$6.2 million for hospital expenditures, in contrast to cost savings of US$1.3 million from the closure of the program. The ratio of direct costs to savings was therefore five-to-one. The observed shift in care back to the hospital demonstrated the effectiveness of the hospital-at-home program in reducing hospital admissions and costs. Unfortunately, the study did not evaluate the quality of care received or patient outcomes after the program was closed. However, coupled with the findings of Tibaldi et al. (2004), this study provides evidence of the potential for these programs to generate cost savings for hospitals while improving the quality of care for people with dementia.

There are a number of initiatives and pilots being implemented by the UK's NHS in the area of **hospital-at-home** (Arnold-Forster 2010). The models of care are designed to mitigate the effects of an ageing population and the growing pressures on public finance. Time-limited, high-intensity intervention services in the home, delivered over several days and monitored according to clinical guidelines, is the proposed approach. The service is intended to reduce emergency hospital visits, ambulance call-outs and multiple admissions to hospital (Arnold-Forster 2010).

In addition to reducing the adverse outcomes associated with hospital treatment, hospital-at-home programs have the potential to reduce unnecessary hospital admissions. The new model of care has been trialled in the NHS Birmingham East and North Primary Care Trust (PCT) in partnership with Healthcare at Home Ltd (Arnold-Forster et al. 2010). The individual episodes of hospital care were tracked using activity data, and the cost of these episodes was calculated in relation to each service. The cost of providing the home-based health-care services was estimated using business models and various assumptions provided by Healthcare at Home. These assumptions were drawn from Healthcare at Home's previous experience in providing similar services and were tested by the PCT's clinical team to ensure their validity.

Based on this approach, it was determined that NHS Birmingham East and North received 4,400 emergency admissions for nine ACSCs in the 2008–09 financial year at a total cost of £8.9 million. (The nine ACSCs included: chronic obstructive pulmonary disease, diabetes complications, dehydration and gastroenteritis, influenza and pneumonia, cellulitis, asthma, angina, hypertension and iron deficiency anaemia.) The alternative home-based health-care service was estimated to prevent 3,100 of these episodes at a cost of £4.5 million. Taking into account the 1,300 hospital admissions that would still take place at a cost of £2.7 million, the projected net savings to the PCT from the home-based health-care service was £1.7 million. The potential net savings to the NHS as a whole were determined by analysing activity

levels and tariff costs of the nine ACSCs throughout the UK. Nationwide, the new model of care was estimated to produce savings of £180 million per year.

Another UK service targeted towards patients who no longer require the full range of hospital services but are not ready for discharge from hospital is operated by **Medihome**—a private health-care company working in partnership with the NHS and private-sector hospitals to provide acute care services (such as the delivery of intravenous antibiotics) in the patient's home. An intervention trial by Lisk and colleagues (2011) set up an email alert system to notify Medihome and hospital geriatricians when a resident from a nursing home was admitted to hospital (Lisk et al. 2011). A geriatrician then evaluated the patient to confirm whether their admission was justified. If hospital care was required, the patient remained under the care of the admitting team. However, if the admission was related to a chronic infection or end-of-life care, the patient was referred to Medihome. They then liaised with the admitting team, geriatricians and the patient's general practitioner (GP) to determine whether the patient was suitable for acute care in the home. The intervention initially ran for 3 months and involved three nursing homes that had been identified as having a high rate of hospital admission.

In the year before the intervention, the total LOS for residents admitted from the three nursing homes was 90 bed-days over 3 months. During the intervention, this decreased to 33 bed-days, representing a reduction of 57 days over 3 months. Due to the success of the program, it was extended for another 4 months across six nursing homes. A similar pattern of results was observed, with bed-days falling from 455 to 205, representing a reduction of 250 for six nursing homes over 4 months.

An Australian example of the hospital-at-home model is the **Community Acute/Post Acute Care (CAPAC)** strategy adopted by NSW Health (2006). This model, also referred to as **Hospital in the Home (HITH)**, does not specifically target people with dementia; however, it is designed to treat many of the conditions that people with dementia experience, such as pneumonia, chest infections, urinary tract infections and cellulitis. The model requires GPs and the Acute/Post Acute Care (APAC) team to work closely together in a multidisciplinary team to manage the patient's condition in the community. The GP is given responsibility for making a clinical diagnosis and prescribing and administering the first round of treatment. The ongoing clinical management of the patient's condition is then handed over to the APAC team, which continues the patient's care under the supervision of the GP.

According to NSW Health's Clinical Services Redesign Program, successful CAPAC services are characterised by the provision of comprehensive, holistic, multidisciplinary patient-centred care, 24 hours a day by dedicated teams of hospital and community-based staff (NSW Health 2006).

The Garling Report (Garling 2008) noted that the provision of CAPAC services varied across New South Wales Area Health Services with respect to the type and availability of different services. An example of a mature CAPAC service operating across the (then) Northern Sydney/Central Coast Area Health Service treated 3,000 patients in 2005–06 and provided the following services 24 hours a day, 7 days a week:

- medical management and review
- nursing
- physiotherapy
- occupational therapy

- social work
- pharmacy
- community care aides
- other services as required.

The HDS research team was informed about CAPAC services in four rural hospitals in New South Wales. These smaller services offered a more limited range of care. For example, a newly established CAPAC service, consisting of up to 10 virtual beds at one New South Wales rural base hospital, delivered care by the medical officer and nursing staff, as well as physiotherapy and dietetics. Its goals were to avoid infections and allow more individualised care; to stop readmission and address bed block; and to reduce LOS. At another site, the service had been further limited to providing relatively simple procedures such as intravenous antibiotics, but informants felt that even this limited service had reduced hospital LOS.

Informants considered that the viability of this model for people with dementia was currently limited to those with mild to moderate dementia who did not require high levels of support and who had family members able to provide informal care in the home.

Reducing hospital admissions from residential aged care facilities

In Australia, over 50% of Residential Aged Care (RAC) residents have a recorded diagnosis of dementia (AIHW 2012e). Strategies and practices that reduce the hospitalisation rate from residential aged care facilities may therefore prevent further deterioration of the patient's condition which may result from hospitalisation (Ong et al. 2011). Research findings reported below suggest that some complex medical needs of people in the latter stages of dementia could be managed in the RAC setting with intensive specialist care and well-trained staff. Good maintenance of these conditions and appropriate treatment plans can play a major role in reducing unnecessary transfers to hospital and avoiding distress for the patient.

Services within residential aged care facilities

Special care units

Special care units (SCUs) provide a supportive environment that is more responsive to the needs of people with dementia and may reduce the risk of hospitalisation. Generally speaking, the care provided in SCUs differs from standard residential aged care through the provision of:

- specially trained nursing staff, including nurse practitioners
- an environment that is secure and minimises visual and auditory stimuli
- special programs/activities that cater for people with cognitive impairment.

Residential care facilities with a SCU may have a more compassionate and innovative approach to care are more likely to embrace care initiatives and provide dementia-specific training to their staff, and are less reliant on physical restraints and feeding tubes to care for their patients (Luo et al. 2010).

A study by Gruneir et al. (2007) analysed organisational features that affect the hospitalisation rate among cognitively impaired residents of an aged care facility (Gruneir et al. 2007). It was found that the presence of a SCU reduced the risk of hospitalisation for

residents with dementia by 10%. Although this finding could not be attributed to any specific factor, further analysis showed that a combination of organisational features, including better staff training, greater familiarity in dealing with dementia patients and a less aggressive approach to care, led to better outcomes for the residents. Similarly, Nobili et al. (2008) conducted a trial of a SCU for Alzheimer patients and found that those who were cared for in the SCU were 30% less likely to be hospitalised than those who were cared for in a traditional residential aged care facility (Nobili et al. 2008). There was also a significant reduction in the use of physical restraints and antipsychotic medications.

Staffing levels and training

Projections by Access Economics (2009) suggest that by 2029 there will be an acute shortage of carers for people with dementia in Australia. This is a cause for concern given that available research points to the important role of well-trained staff in residential care in providing high-quality care and reducing the number of avoidable hospital admissions.

A US study by Porell & Carter (2005) analysed variations in the hospital admission rates for aged care facility residents with Alzheimer disease to determine the contextual factors that have the greatest impact on discretionary hospitalisations (Porell & Carter 2005). Discretionary hospitalisations refer to those where some clinical judgement is involved in the admission decision. It was found that, relative to the average, residential aged care facilities with 5 additional full-time registered nurses (RNs) per 100 beds had a reduction of 2 discretionary hospital admissions per year for every 100 residents with average care needs. Moreover, the reduction in the admission rate was significantly greater among residents with poor health or functional status. In this case, an additional five nurses, relative to the average, reduced the number of admissions by 17 per year for every 100 residents with Alzheimer disease. These results suggest that adequate clinical staffing levels enable medical conditions to be identified and treated promptly and for routine health-care practices to be adhered to.

Aged care nurse practitioners (NPs) can also play an important role in managing the complex medical needs of people with dementia. NPs are highly trained registered nurses who function collaboratively with physicians and nurses in a clinical setting. They have an expanded nursing role and are responsible for assessing and managing patients. For example, they may provide referrals, prescribe medicines and order diagnostic procedures. Carter & Porell (2005) analysed facility-level contextual factors that influenced the rate of potentially avoidable hospitalisations in residential aged care facilities in Massachusetts, United States of America (USA). It was found that the likelihood of a person with Alzheimer's disease (or related dementia) experiencing an acute care-sensitive hospitalisation was reduced by 62% in care facilities with an on-site NP. This was mainly due to a sharp fall in the hospitalisation rate for infectious acute care-sensitive conditions, which fell by 71% among residents with Alzheimer disease. Similarly, Porell & Carter (2005) reported that aged care facilities which were staffed with a full-time NP had between 19 and 23 fewer discretionary hospitalisations per year for every 100 residents (Porell & Carter 2005).

The Dutch model of dementia care in RAC has been highly successful in reducing hospital admissions and aggressive medical interventions, as well as improving the decision-making process between physicians and carers (Hertogh 2006). A defining characteristic of RAC in the Netherlands is that facilities are staffed with specially trained residential aged care facility physicians. These physicians specialise in treating chronic diseases and have their principal site of practice in the residential care facility, allowing them to develop close

relationships with the patients. A proactive approach to advance care planning is adopted between patients and their families. As a result, hospital admissions for people with dementia are rare in the Netherlands as comorbidities are effectively managed in the facility (Hertogh 2006).

Services provided to residential aged care facilities

Nursing and physiotherapy services

A NHS initiative in Bath and North-East Somerset provided dedicated nursing and physiotherapy teams to three residential care homes (Wild et al. 2008). The initiative focused on three aspects of patient care:

- providing comprehensive routine health assessments for better care planning and intervention
- detection of illness to create opportunities for early intervention and to prevent the patient's health from deteriorating
- supporting care home staff in new health-promoting roles and responsibilities—for example, moving away from a task-orientated care approach towards a more person-centred or case management approach.

An evaluation of the program found that, over a 2-year period, the team was able to prevent between 81 and 197 hospital admissions and facilitated 20 early discharges. Comparisons of hospital data over the same period demonstrated a reduction in hospital stays of more than 48 hours and an increase in hospital stays of less than 48 hours. This intervention suggests the potential for highly trained nursing and allied health staff working with residential aged care facilities to reduce hospital admissions and facilitate early discharge for the general residential aged care population.

GP services and specialist advice

In Australia, the Victorian Government has implemented the **Residential In-Reach (RIR)** service, which aims to prevent emergency hospital admissions for older people in RAC facilities. The key elements of the program include:

- telephone consultations and ongoing liaison with RAC staff
- assessment and management of residents within the RAC facility by the RIR team, which included specialist nurses and doctors, in collaboration with residents and their families.

An evaluation of the pilot program (Dench McClean Carlson 2009) found that it had been successful in reducing unnecessary admissions to hospital without compromising the quality of patient care. Key evaluation findings relating to the success of the pilot included the importance of medical leadership, a collegiate approach to working with RAC staff, and a good mix of acute and community skills in the In-Reach teams. Among suggested changes for improvement was the need for a greater focus on advance care planning and end-of-life issues. Following the success of the pilot project in 2009, the service was been implemented in 13 health services across Victoria.

A similar type of service was observed during HDS fieldwork at a New South Wales metropolitan hospital. The **Aged Care Phone Triage Service** was designed to ensure that patient admissions to hospital were appropriate, that treatment and support were provided to the patient in their own home (including RAC facilities), where possible, and that presentations to EDs were reduced.

The service provided an 1800 phone number from 8 am to 10 pm, 7 days a week, to enable 123 RAC facilities and GPs in a large Sydney region to discuss and triage clinical issues concerning residents in aged care facilities. The service was staffed at the time by RNs with ACATs and aged care experience. The triage service could organise a direct admission to hospital, a referral to an outpatient appointment or visits to the facility by a clinical nurse consultant (CNC), community nurse, geriatrician or psychogeriatrican. Most calls at the time of the site visit came from residential aged care staff (80%), especially from high-care facilities. A large proportion (over 40%) concerned the management of dementia behaviour or acute psychiatric issues.

The hospital's monitoring of the service's effectiveness showed that the number of inpatient days for very old people had remained flat for the last 3–4 years despite population increase, and feedback from ED staff indicated their perception that presentations from RAC facilities had reduced. A major benefit of the service was its ability to link facilities with other services available in the area.

International research suggests that poor access by RAC facilities to GPs can lead to preventable hospitalisations when nursing staff are unable to manage a patient's condition. Several aspects of GP services in the UK have been identified as contributing to a higher hospitalisation rate (Ong et al. 2011):

- having to deal with multiple general practices
- poor service provided by out-of-hours GPs
- a lack of regular patient medical reviews
- a lack of communication between the patient's next of kin, GP and care home.

Lisk and colleagues (2011) identified three residential aged care homes in the UK that had high rates of multiple hospital admissions and implemented four strategies to reduce these admissions over a 3-month period (Lisk et al. 2011). These four strategies were:

- regular medical advisory meetings with GPs
- daily telephone advice to nurses by two consultant geriatricians
- collaboration with a private health-care company providing out-of-hospital nursing for patients who no longer required access to the full range of services in an acute hospital but were not ready for discharge
- liaison with GPs regarding end-of-life care for residents.

Following the intervention, there was a significant reduction in the number of hospital admissions from aged care homes, falling from 5.76 to 2.59 per 1,000 admissions. Due to the success of the program, it was extended to another three homes for 4 months. The results from the initial intervention were replicated, with the hospital admission rate falling from 8.01 to 4.35 per 1,000 admissions. Across all six RAC facilities, the cost savings were estimated to be £74,383 over 4 months.

Primary care and community services

Integrated primary care

Good-quality primary care is a central component of a well-functioning health-care system. The Council of Australian Governments (COAG) has made access to the primary care services of GPs a priority in the National Healthcare Agreement; in 2010–11, there were 2.1

million potentially avoidable GP-type presentations at EDs (COAG 2012). Access to timely primary care services ensures that people with dementia receive appropriate care in the community, leading to better disease management and a lower risk of hospitalisation. For example, reducing unnecessary hospital admissions among dementia patients requires better management of comorbid illnesses (for example, urinary tract infections) by the local GP clinic. Without adequate access to GP services, acute exacerbations of the patient's condition may require hospitalisation. Therefore, improving access to GP services could lead to a reduction in avoidable hospital admissions.

Integrated primary care services for older people have become a defining feature of the health-care system in Denmark. In 1984, the Skaevinge Municipality in Denmark reorganised its departmentalised care for older people and implemented the first fully integrated care initiative in the country (Department of Health and Ageing 2003b; Wagner 2001). The **'Skaevinge Project'**, as it came to be known, prioritised preventive measures and supported each individual in maintaining their health and quality of life within their home. This was achieved through the following initiatives:

- Health personnel from previously independent disciplines were grouped into multidisciplinary teams. These teams underwent training to develop their competencies under the new care structure.
- Residential care homes were converted to 'Health Care Centres', in which private residences were available for rent. A 24-hour integrated health-care service was established within the Centre and made available to the whole community.
- Self-care was emphasised and health-care staff were educated on the importance of developing and supporting citizens in maintaining their independence.

An evaluation of this program 10 years on showed that hospital occupancy rates within the Skaevinge Municipality were considerably lower than the national average and had fallen by 6% over the 10-year period. The cost savings generated through the lower hospital use were used to extend home care services for the population. The Skaevinge model of integrated care has now been adopted by 75% of municipalities in Denmark, and the positive outcomes have been replicated throughout the country (Wagner 2001).

A US example of an integrated primary care framework is the **Evercare Model**, which provides intensive primary and preventive care to people with long-term or advanced diseases, such as dementia. The model targets older people living in long-term care facilities as well as those living in the community with a severe or disabling chronic illness. It was developed on the premise that intensive primary care can reduce the use of more costly health-care services, such as hospitalisation. Two major care strategies are adopted:

- Personalised care plans are developed for all patients and managed by a team of NPs. The NPs are responsible for coordinating services and facilitating communication between physicians, institutions and patients and their families. They receive specialised geriatric training to carry out their duties, which involve cooperating with the primary care physician to provide regular monitoring of the patient's condition and to respond to issues as they arise.
- For RAC residents who would otherwise require hospitalisation, high-level care is provided in the residential care home. A financial incentive, known as an 'intensive service day', is offered to residential care homes to provide this care. However, no checks are carried out to determine whether this additional care is actually provided.

To determine the efficacy of the Evercare program, Kane et al. (2003) examined the incidence of hospitalisations among long-term RAC residents enrolled in the Evercare Model, and compared this with the incidence of hospitalisation among residents who received standard care. More than half the residents in the intervention and control groups had a dementia diagnosis, although the incidence of dementia was slightly higher among the Evercare group (64%). The analysis showed that the average number of hospital admissions per 100 enrolees was approximately half in the Evermore sample compared to both control groups. In addition, the number of discretionary hospital admissions fell by around two-thirds among residents in the Evermore program. A similar pattern of results was observed when the data were stratified according to the resident's level of cognitive impairment.

A report by the UK National Audit Office examined the issues surrounding appropriate access to health-care services for people with dementia (Bowen et al. 2007). The report assessed the extent to which hospital admissions could be reduced through the introduction of **alternative care pathways**. One objective of the report was to determine the reasons behind hospital admissions for people with dementia and to identify alternative care pathways for these individuals. A survey of 863 patients across 23 hospitals and community care homes in the Lincolnshire PCT found that the referral routes into hospital for people with dementia were similar to those without dementia. The survey questions were based on the Appropriateness Evaluation Protocol, an instrument that evaluates current care practices. As well as determining the reasons behind acute care admissions, it provides a range of criteria that can be used to determine the appropriateness of the care setting in terms of the acuity of the patient's condition and their treatment requirements.

The majority of acute admissions among respondents with dementia were driven by medical rather than mental health needs, although some admissions could have been prevented if the patient's dementia status had been known. In addition, a number of alternative care settings were identified for patients who did not meet the acute care admission criteria. The most frequently cited alternatives were:

- non-acute bed with (mental health) therapy
- specialist non-acute bed
- social/general health/specialist home care
- mental health support
- carer respite.

Overall, the survey results suggest there is a need for bed-based care, but not necessarily a need for bed-based care in an acute setting.

A number of Australian states and territories have developed dementia plans and policies, and an example from Western Australia is the **Service Delivery Model of Care for Dementia** policy, aimed at improving and strengthening the services provided to people with dementia (WA Department of Health 2011). Best-practice strategies are outlined according to the person's stage of dementia, which include: (1) Entering Old Age; (2) Transitional Stage; and (3) Frail Aged Stage. Four strategies are recommended for people in the Frail Aged Stage to minimise their risk of hospitalisation:

- increased provision and better coordination of ambulatory care with a greater focus on community case management of the patient's condition
- increased consultation and liaison with specialist, multidisciplinary services, including geriatricians and psychogeriatricians across acute hospital settings

- prevention of premature admission to residential aged care
- building of partnerships with the Australian Government and residential aged care sector to provide accessible options for care after discharge from hospital.

No information is currently available on the implementation of these strategies or their efficacy in reducing hospital admissions and LOS.

Behaviour assessment and management

The **Dementia Behaviour Assessment and Management Service (DBAMS)** project was funded through the Aged Care Innovative Pool Dementia Pilot in 2003–04. This pilot program demonstrated significant potential to prevent hospital admissions for dementia, delirium, depression and other mental or behavioural disturbances (Hales et al. 2006).

The project was carried out in regional NSW to address the unmet need for psychogeriatric services in regional and rural communities. The service provided a coordinated and targeted approach to managing dementia-related behavioural and psychological disturbances. The main components of the model were:

- an outreach service that provided community-based assessments for people with acute dementia and related behavioural symptoms
- a behaviour management program that educated and supported carers and staff in aged care facilities
- a referral pathway to relevant agencies
- a telephone hotline to provide 24-hour support for RAC facilities, small rural hospitals, and families and carers in the community
- the provision of intermediate care in a 16-bed aged care unit with an adjoining day therapy unit. This service carried out assessments, medication reviews and behaviour management programs for people with dementia.

A team of specialist clinicians provided support to psychogeriatric nurses who travelled extensively to perform patient assessments. The nurse visited the patient in their place of residence (either the community or an aged care facility) and completed a detailed assessment of their behaviour, determining whether the patient could be cared for in their current environment or whether they required specialist medical attention. If they required medical attention, they were admitted to an intermediate care facility for intensive clinical workup and observation. If not, a behaviour management plan was developed for the patient so that they could be cared for in their usual environment. The service also delivered an educational program to care professionals and family carers of people with dementia.

The results from the DBAMS pilot project in NSW were promising. Before the program, 10 of the 39 DBAMS patients had been admitted to hospital in the previous 6 months and spent on average 11.6 days in acute care for their dementia-related condition. However, during the evaluation period, only one hospital admission was recorded in the same group of patients. Based on before-and-after reports of hospitalisation of DBAMS clients, the evaluation estimated that a 16-place DBAMS package would result in a reduction of 230 acute care days per year by preventing hospital admissions for dementia, delirium, depression or other mental or behavioural disturbances (Hales et al. 2006).

Informed by the results of DBAMS, the **Dementia Behaviour Management Advisory Service (DBMAS)** has been implemented across all states and territories in Australia. The Australian Government currently provides $11 million per year for the service, which is

available to all people with dementia who seek help through Australian Government–funded aged care services, as well as their carers and families. The program also aims to support clinicians, staff of mental health services for older people, and allied health services to increase their knowledge and confidence to effectively manage patients who present with behavioural and psychological symptoms of dementia. As part of the Aged Care Reform Package, the Australian Government has committed $41.3 million over 5 years to supporting people with dementia across the health system, including expansion of DBMAS to include primary and acute care services. This is designed to enable primary and acute care staff to improve their management of patients who present with behavioural and psychological symptoms. In hospitals, this is anticipated to reduce lengths of stay, minimise the risk of adverse events, and increase the opportunity for patients to return to their preferred place of residence (Department of Health and Ageing 2012).

Strategies within emergency departments

EDs are often a gateway for many patients to hospital and other community-based services. In 2011–12, over 6.5 million presentations were reported by public hospital EDs, an increase of 4.2% on average each year between 2007–08 and 2011–12 (AIHW 2012c). About 28% of these patients were admitted to hospital after their care in ED while most of the remainder (63%) departed without being admitted or referred.

People with dementia are more likely to be admitted to EDs than people without dementia (Natalwala et al. 2008). Some of the issues affecting people with dementia in the ED setting include:

- poor environment with high levels of activity and stimulation which can cause/increase patient confusion and agitation
- poor recognition of delirium and dementia
- lack of staff knowledge and expertise in relation to dementia. In 2006–07, one-fifth of NSW public hospitals had dedicated ED staff with dementia expertise—these were mostly **aged care services in emergency teams (ASETs)**
- high stress levels among carers and families, especially on weekends (HDS fieldwork informants).

Some of the strategies developed to deal with these issues which were reported to the HDS fieldwork teams included the development of specialised positions for the care and management of older patients presenting to ED (ASETs), rapid assessment and response teams, and the use of tools such as the **Adult Patient Assessment Tool** which supports the assessment and referral of patients with suspected cognitive impairment and/or delirium.

Aged care services in emergency teams

ASETs were established in New South Wales in 2002 (Garling 2008). They aim to improve the care and management of older people presenting to the ED by providing appropriate access to services within the hospital and in the community. The role of ASETs is not exclusively in relation to dementia. However, the prevalence of cognitive impairment and confusion among the older patient group means that ASETs frequently have expertise in the assessment and development of treatment and care strategies for people with dementia.

ASET positions were present in 15 out of the 19 site-visit hospitals whose information was analysed. At most sites, ASETs were physically based in the ED, but at some sites they were located with community-based services such as ACATs.

The size and composition of ASETs varied from as few as one health professional (not always full-time) to larger multidisciplinary teams consisting of RNs, allied health professionals such as occupational therapists, physiotherapists and dieticians as well as clinical care specialists. Similarly, coverage varied in site hospitals from as little as 10 hours per week in a small rural hospital to over 90 hours per week over 7 days in a larger metropolitan hospital. None of the site hospitals had ASET coverage after about 7–8 pm, but used strategies such as after-hours referral books where potential patients were listed for their attention. The specific nature of the role and functions performed by ASET members also varied depending on team size and composition and the availability of other services.

In relation to those patients who will not be admitted to hospital, ASETs undertake an assessment of the patient's need for support and care services at home or in the residential aged care facility, taking account of patient functioning, cognition, social circumstances, care needs and services already received. They refer patients to certain short-term post-hospital care services such as ComPacks (see below for detail about this program). They liaise with, and refer outpatients to, service providers, including to community nurse practitioners, SMHSOP and ACATs who assess people for eligibility for Transition Care Program places, aged care packages or residential aged care. A number of hospital sites commented that ASETs had resulted in reduced admissions, including among those who presented after a fall or who were not coping at home. However, ASET advice to ED medical staff about the safety of discharge to home for patients because of social or functional care needs was mostly also respected.

ASETs form a critical link in referral pathways within the hospital setting; for example, referring admitted patients to discharge planners and other specialist staff such as allied health and **acute to aged-related care services (AARCS)** nurses. ASET documentation is transferred with admitted patients to the relevant ward, with many informants commenting on its value for patient care and safe discharge.

Identifying admitted patients who care for someone with a cognitive impairment is an important component of the risk assessment role that ASETs play. ASETs may then be involved in arranging appropriate services and support for the care recipient with dementia while their carer is hospitalised.

Within EDs, ASETs are an important source of information and education about dementia, delirium and the needs of older patients more generally. High ED staff turnover can result in significant amounts of ASET time being spent in this role. In smaller hospitals where the ASET is the main or only source of aged care and dementia expertise, ASETs may also follow patients admitted to wards from ED to conduct assessments for cognitive impairment or delirium and to provide assistance to ward staff in the care and management of patients.

At many sites, ASETs were a vital link between the hospital and non-acute sector, including RAC facilities. Many examples of ASETs working with RAC facilities were recounted; for example, contacting facilities to get more information about patient background, what constitutes normal behaviour for the patient and any deterioration. ASETs may also help facilities to accept residents back from the ED, and to reduce ED presentations from RAC facilities through training of RAC staff (see Box 3 for an example).

Box 3: Example—aged care services in emergency team (ASET) relationship with residential aged care facilities

A regionally based ASET nurse worked with three major local residential aged care (RAC) facilities and the Division of General Practice to develop three clinical pathways for facilities to use in assessing patients before presentation at the emergency department (ED).

The new form used by facilities required them to collect relevant information about matters such as oxygen saturation, electrocardiograph (ECG) results, blood glucose levels and advance care directives before contacting doctors. The process was seen to encourage more triage by nurses in facilities, making it easier for doctors to advise over the phone, and enabling conditions which could be managed within the facility to be identified. This was particularly useful after hours and made any necessary ED presentations more efficient. At this site, bi-monthly meetings were held with the ASET nurse and staff from facilities through which these changes were discussed. The meetings also enhanced communication between the hospital, RAC facilities and general practitioners (GPs) and revealed local service gaps and problems. For example, GPs weren't always receiving discharge summaries from the hospital, local RAC facilities did not have the ECG equipment or registered nurse (RN) staffing levels that the hospital thought they did, and medication information faxed to facilities was not always readable.

The hospital manager and the director of nursing emphasised that since the ASET nurse started work in 2008, there had been improved relationships between the hospital and RAC facilities, with fewer unnecessary presentations to ED. This view was shared by numerous informants at this site who also commented there had been an improvement in the attitudes of ED staff towards older patients, including those from RAC facilities.

Based on HDS fieldwork, the effectiveness of the ASET role appeared to require:

- skill and credibility of people occupying the role (especially in single person situations)
- sufficient coverage of hours to allow for follow-up of patients. Part-time positions made this more difficult. At one site the hospital had been unable to fill its full-time position and informants commented that this had an impact on patient care
- ASET ability to nurture and maintain good relationships within the hospital and between the acute and non-acute sectors.

Rapid assessment and response services

Rapid assessment and response services are designed to reduce waiting and assessment time in ED and, where possible, avert the hospital admission of residential aged care clients. There are a range of rapid assessment and response service programs being implemented across hospitals; for example, the **Aged Care Emergency (ACE)** and the **Emergency Department Senior Assessment and Streaming** models rolled out in NSW (ECI NSW 2011). During the HDS site visits, two key rapid assessment and response service programs were identified—these are described in more detail below.

Geriatric Rapid Acute Care Evaluation program

The **Geriatric Rapid Acute Care Evaluation (GRACE)** program is an example of a rapid assessment and response program designed to convert ED presentations from a 'turn up and wait' system to a 'phone, book and assessment' system to avoid long waiting times in ED (from an average of about 3¬5 hours for a RAC patient to immediate assessment).

The GRACE program involves a number of strategies including:

- a dedicated GRACE CNC who is the focal point for communication between nursing homes, GPs and the ED. This service was provided 5 days a week at the time of the HDS site visit
- a phone triage system with RAC facilities who call the GRACE CNC when they need to send a patient to the hospital. This ensures that the GRACE CNC is aware of when a patient is being sent and has all the information required to ensure that assessment can take place quickly
- Nursing Home Hostel Emergency Decision Index—this is an education tool for use by RAC facilities to guide them about what to look for and do for residents before contacting the hospital, ambulance or doctor, including undertaking some initial checks such as blood pressure and pulse. This information is used by the GRACE CNC to assess if a patient needs to be admitted to hospital
- dedicated beds for the GRACE program in the emergency medical unit
- booking tests or imaging so that these can be done as soon as the patient arrives at the hospital
- working closely with a senior medical officer from an early stage when RAC patients are brought to the ED rather than only involving the senior doctor at a later stage of assessment, facilitating a smoother and more rapid admission to the hospital ward when required
- ensuring that the timing of patient presentation minimises the amount of time they must spend in hospital for procedures such as blood transfusions
- education and capacity building in RAC facilities. The GRACE CNC provides training for nurses/staff at RAC facilities to provide simple clinical care for residents, including the administration of intravenous antibiotics, Percutaneous endoscopic gastrostomy (PEG) feeding tubes and male catheterisation.

Verbal reports from HDS informants indicated that the introduction of this program at a metropolitan hospital had resulted in a reduction in bed-days used by high-care RAC patients from 537 per month to 33 per month over a 5-year period.

Medical assessment units

Medical assessment units (MAUs) were designed and introduced into a number of NSW public hospitals to provide rapid assessment, diagnosis and treatment by senior clinicians for non-critical medical patients who are not categorised as priority patients on presentation to the hospital, and who might previously have had to wait for treatment. MAUs were operational in six of the HDS site hospitals. At June 2010, there were 28 MAUs with 340 beds operational across NSW with additional sites planned (ARCHI 2010).

The ways in which the MAUs operate and relate to other services in the hospital differ. An example observed by the HDS team at a metropolitan hospital operated as part of a suite of services using a model of rapid early multidisciplinary assessment, case conferencing and continuing care planning which occurred in one or more designated units within the emergency department medical assessment unit or as admitted patients in the MAU for up to 48 hours and/or the Older Persons Evaluation, Review and Assessment (OPERA) unit for up to 72 hours. Entry to the early assessment units is based on strict criteria including time-based limits.

The goal of the model is to provide an initially intense focus from geriatricians, nursing and allied health staff on assessing patients. Hospital informants estimated that this system reduced LOS in the acute aged care ward by 'a day or two' and length of time in the ED had also been reduced. The model also has benefits for managing access block issues for EDs and ED informants were enthusiastic about the service model.

Factors that appeared to contribute to the success of the strategy included: continuing care planning, the involvement of senior clinicians, including specialist medical staff and daily multidisciplinary case conferences. The presence of an acute aged care ward–facilitated discharge from the rapid assessment units within the time frames specified for the model. For example, at the site described above, about 40–50% of MAU admissions were transferred to the aged care ward after 48 hours.

Potential weaknesses cited by informants were that it could make it more difficult to identify all relevant chronic conditions during the short time frames involved. The model may also result in a patient having multiple ward transfers. Generally, staff felt that a large proportion of dementia patients coped well with these transfers, but they repeatedly emphasised that it was detrimental to a number of patients, especially those with delirium or challenging behaviours. Continuity of care by health professionals was also sometimes a problem. For example, patients could sometimes be seen by up to four occupational therapists. This could be frustrating for patients' families and confusing for patients.

Strategies within the hospital

It is important to ensure that people with dementia receive high-quality care during their hospital stay. Inadequate care can have a negative impact on the patient and denies them the dignity, respect and opportunity to maintain a good quality of life. This section outlines strategies and practices that have been implemented within the hospital setting, in Australia and overseas, to achieve objectives in relation to appropriate treatment and timely discharge with care and support as required.

Information access

An example of a strategy for hospitals recently launched is **The International Dementia Hospital Hub (Hospital Hub)**. The Hospital Hub is an online resource and information portal managed by a partnership of organisations, and open to all staff who work in hospitals and care for people with dementia. The Hospital Hub shares contributions to the site from any member who wants to share their knowledge and awareness of evidence-based practice. Overall, the Hospital Hub aims to improving the quality of care for people with dementia in hospital settings by enhancing access to, and professional sharing of, sector expert knowledge (IDHH 2012).

Specialised services

A **specialised service** within this context refers to individuals or teams available to provide specialist assessment, advice and care in relation to dementia or associated conditions within the hospital setting. These experts generally have a focus on aged care; for example, a geriatrician and/or a specialisation in another relevant field, such as psychology. This section outlines some strategies and practices, both internationally and within Australia, that involve access to a specialist.

Liaison psychiatry services

Liaison psychiatry services address the mental health needs of people with dementia when they are admitted to hospital. Poor management of the behavioural and psychological symptoms of dementia can lead to poor-quality care, extended lengths of hospital stay and adverse outcomes for the patient. Hospital psychiatric services can promote a wide range of positive outcomes for the patient and health-care provider. Liaison psychiatry services are more common in the UK, given the central role of the psychiatric profession in dementia care. It should be noted that this model of specialised service may be more applicable in Australia if it involved geriatricians rather than psychiatry services.

A pilot project of the **Rapid Assessment Interface and Discharge (RAID)** psychiatric liaison service was launched in the UK at the end of 2009 (Parsonage & Fossey 2011). The service had an average of 250 referrals a month between December 2009 and September 2010. Older people with dementia, delirium and cognitive impairment accounted for 13.6% of all referrals. The key features of the service were:

- a multidisciplinary team that offered a comprehensive range of mental health specialities so that all patients could be assessed, treated, signposted or referred appropriately
- emphasis on the importance of a rapid response with target time for patient assessment—a target of 1 hour for patients admitted to the ED and a target of 24 hours for patients admitted to the wards
- all adult hospital patients with mental health needs are eligible for the service, including older people with dementia and other cognitive impairments
- formal training for acute staff in the hospital
- an emphasis on diverting and discharging patients from the ED and facilitating early but effective discharge from the wards. Follow-up clinics were provided for discharged patients, including a general old age psychiatry clinic and an adjoined memory clinic.

An evaluation of the RAID service was carried out by the London School of Economics (Parsonage & Fossey 2011). The analysis focused on the ability of the service to promote faster discharge from hospital and fewer re-admissions leading to fewer inpatient hospital days. A pair-matched control research design was employed to ensure that the effects of the RAID service could be isolated. The intervention group consisted of two subgroups: (1) the 'RAID subgroup', consisting of all patients in the intervention group who were directly managed by the RAID service; and (2) the 'RAID-influence subgroup', which consisted of the remaining patients in the control group who benefitted from the training and support provided by the RAID team to hospital staff during their stay. For the statistical analysis, only a proportion of the intervention group could be matched to a control, which reduced the sample size to 79 matched patients.

The results showed that the average LOS for the RAID subgroup was 0.9 days shorter than for the controls, while for the RAID-influence subgroup the difference was 3.2 days. Extrapolating these figures over the full (unmatched) sample, it was estimated that a total of 9,290 bed-days were saved over the 8-month study period, equating to 13,935 bed-days per year. It was also found that RAID assessments in the short-stay unit led to a reduction of 160 hospital admissions per year. In addition, the likelihood of re-admission was 70% lower in the RAID subgroup; although no effect was found for the RAID-influence subgroup. The lower rate in the RAID subgroup equated to approximately 1,800 prevented re-admissions per year, or 8,100 bed-days based on an average LOS of 4.5 days. With respect to costs, it was estimated that the incremental cost of the RAID service was £0.8 million per year, while the

incremental benefit was £3.55 million. Hence, the ratio of benefits to cost was greater than 4:1.

Similar services with a focus on people with dementia have been introduced to other PCTs in the UK. For example, NHS Bristol has introduced **'mental health liaison teams'** into hospital wards with a high proportion of patients with dementia. These teams are trained to identify and manage dementia and to facilitate the treatment of primary medical conditions. They aim to provide prompt mental health assessments and follow-on reviews for patients, increase the accuracy of their diagnosis and enable the appropriate treatments to be provided. The team collaborates with social workers and discharge teams with a view to increasing return home rates, reducing extended lengths of hospital stay, and preventing re-admissions to hospital following discharge. Early evidence from the evaluation suggests that the liaison teams have helped to reduce average LOS by 3.6 days, while simultaneously improving the quality of care provided.

Specialist wards

Specialist wards or units may lead to better dementia care and be more cost-effective than conventional hospital wards. A specialist unit, such as a joint geriatric and psychiatric ward, allows the collaboration of specialist care providers—for example, geriatricians and psychiatrists—to work together and be supported by nurses who are specially trained to provide medical and psychiatric care.

A number of the key characteristics of the care provided by specialist joint units, such as geriatric and psychiatric wards, are difficult to achieve and maintain in standard acute medical and surgical wards (George et al. 2011), including:

- joint working between psychiatrists and geriatricians to ensure that an accurate diagnosis was made and to avoid unnecessary ward transfers
- a multidisciplinary clinical care team who had specialist training in dementia and the management of behavioural problems without recourse to physical or chemical restraints
- a homely, secure rehabilitation environment that catered for the specific needs of people with dementia and provided better observation of patients
- person-centred care with greater involvement of families and carers in the planning process.

A review of 13 papers published between 1980 and 2010 by George et al. (2011) on joint wards in the UK, USA, Australia, Germany and Netherlands noted that none of the studies involved a high-quality randomised controlled trial but half of the studies involved an evaluation of their effects in relation to various clinical outcomes. The evidence was not considered strong enough to make definite conclusions but the evaluative studies suggest there were better clinical outcomes for people with dementia compared with the relevant comparison group. Two of the evaluative studies reported longer LOS for patients in these joint wards (both in the UK), but the remaining studies all reported reduced LOS.

In Germany, a combined medical and psychiatric inpatient unit, known as the **Centre for the Elderly**, aims to improve treatment quality and reduce LOS for older patients with psychiatric comorbidities (Maier et al. 2007). The centre consists of 160 beds for older inpatients and is divided into beds for geriatric, psychogeriatric and interdisciplinary patients. Patients are admitted to the centre by GPs or hospital physicians and care is provided by a multidisciplinary team of health-care staff who have specialist training in the

field. Following the opening of the centre in 2000, the median LOS fell significantly from 16 to 14 days in the geriatric department and from 34 to 26 days in the psychogeriatric department. Further decreases in LOS were observed in subsequent years. Structured interviews with staff revealed that older patients with comorbidity, in particular dementia and depression, benefited from the interdisciplinary treatment model. It was also reported that the close cooperation between geriatric and psychiatric departments was a critical factor in reducing LOS.

In NSW, the HDS fieldwork team visited six site hospitals which had HDS-defined **Aged Care services** (ACS) (see Box 4). These services do not have an exclusive focus on people with dementia but usually have a significant proportion of people with dementia. In the NSW public hospital system, they have become areas of dementia expertise within the acute care setting. These services are mostly based in medium–large metropolitan hospitals.

Box 4: HDS survey definition of Aged Care Service

An individual or individuals employed by the hospital (on a full-time or part-time basis) or a department, unit or program

…with specific responsibilities for the assessment and/or management of complex health and functioning problems of older people AND which has designated beds in which to provide these services for admitted patients.

A visiting or consultant geriatrician alone (private or employed by another organisation) and/or residential aged care (high or low care) beds alone do not constitute an Aged Care Service.

Source: Hospital Dementia Services Project survey. Survey instruments can be found at:

<http://www.aihw.gov.au/survey-hospital-services-hsdp/>

Two of the more mature services provide examples of integrated care across acute aged care wards (often secured), secure behavioural units, and aged care rehabilitation, rehabilitation and orthogeriatric wards. Services and specialist staff include geriatricians, psychogeriatricians, orthogeriatrians, ASETs, ACATs and allied health staff working across wards. Both these services are also integrated with community-based aged care services sharing the same clinical leadership under geriatricians. Operation of the inpatient services included the following features:

- shared care models (orthopods and geriatricians, and psychogeriatricians and geriatricians)
- strong relationships between the different wards and clinical leaders, resulting in beneficial practices for patients
- strong relationships and co-location (either on the same campus or the same building) of acute, subacute, outpatient and community services
- provision of aged care rehabilitation for older, frailer patients with comorbid conditions
- good teaching and learning opportunities for junior medical staff in relation to aged care
- secure environments for wandering patients and specialised wards for the management and care of patients with extreme behaviour.

Senior management at these hospitals was likely to acknowledge that older patients were becoming core hospital business and at one site expressed support for the model of care—'brilliant'—although noted the need for more beds in order to keep pace with demographic

change and consequent demand. Senior management noted there is a very high level of clinical engagement in relation to aged care which led to strong workforce engagement and a strong relationship between aged care and rehabilitation.

At one of these hospital sites, the community-based services preceded the hospital services and still manage them. Communication between services and programs occurs through a central intake system and involves use of a common database for all programs run from there. A single file per client is maintained which supports the high level of cross-referral between teams. This has been designed as a 'one-stop shop' for older patients in the area. Examples of the types of services provided through the community-based hub include:

- ACATs
- ASETs
- community nurses
- transitional care (community-based)
- Community Options/Compacks
- community rehabilitation
- continence nursing and support
- geriatrician outpatients
- dementia monitoring
- dementia respite (day care)
- dementia education resources
- frail aged respite care
- aged care information and liaison
- hostel/nursing home consultations
- medication review and monitoring
- allied health
- transport services.

Part of the effect of these integrated services was observed in the expressed attitudes of staff and management toward older patients and people with dementia. Staff working in these services saw dementia and aged care as everyday work and appeared committed to ongoing improvement of service delivery. People with dementia were seen as having special care needs which were increasingly able to be met.

Challenges to sustaining these models of care arise from the multiplicity of funding sources required to support them and the administrative and management load involved in obtaining and reporting on these; potential workload issues for specialist staff, especially in the context of an ageing population and the demands on hospital resources arising from this as well as workforce shortages in some areas; continuing gaps in certain specialties such as speech therapy; and sometimes poorly designed physical environments.

Behavioural units

Three site hospitals had specialised **behavioural units** to manage the care of acutely ill patients with behaviour problems within the acute setting. Across all three sites, these units were part of an integrated aged care service and their operation shared a number of characteristics:

- a focus on behavioural and environmental approaches to care and the use of non-pharmacological therapies such as music therapy and dog therapy
- avoiding the use of restraints, wherever possible, apart from those medically indicated for psychiatric or medical conditions
- a secure ward environment which supported safe mobilisation, including an outdoor area with features such as garden beds (with gardening implements provided), bus stops and bird aviaries
- minimisation of excessive noise and stimuli, including the use of conducive colours and lighting
- areas for dining and relaxing with activities such as card games
- having sufficient well-trained staff
- developing good relationships between staff and patients, with staff learning the personal history of patients. Knowing someone's story and becoming a familiar caregiver can help reduce agitated and aggressive behaviour.

The kinds of patients who were admitted to these units included delirious patients whose behaviour could not be managed in an open ward, people with dementia whose illness and hospitalisation had exacerbated behavioural issues (the goal with this group was often to help them settle back to their usual level and pattern of behaviour) and some patients with very difficult behaviour which residential care facilities had not been able to manage.

The benefits of these units for patient outcomes have been examined by Gonski and Moon (2012) who reviewed the medical records from 45 consecutive admissions (Gonski & Moon 2012). Compared with care in general aged care wards, there was no reduction in LOS, possibly due to delayed placement in appropriate long-term care. However, there was a marked reduction in fall incidence and less use of 'specials'(one-on-one nursing for a given patient) to constantly monitor patients whose behaviour placed them at higher risk of injury to themselves or/as well as to others in the unit.

Informants during site visits also commented on the value of having these units:

> We're also very fortunate having ward X which you may have seen today. It's an enclosed ward. The staffing of that ward are very used to looking after, you know, behaviourally disturbed patients. It also means for us that if we have got dementia patients in the medical wards with medical problems or behavioural problems and they're very difficult to manage because they're trying to leave, abscond, as you know these days with limited nursing in the medical wards that's a very difficult patient to look after and it's often hard to get specials for those patients, although we do occasionally. If they're trying to wander off it really means either restrain them in some way—be that physical or be that medical—and it's often not the type of thing you like to do.
>
> So we've got the advantages of getting them into ward X and that way they can be mobile, they can run off their excess energy, but it also gives us a chance to treat their medical problem and the psychogeriatrician to involve when they see them *(Informant, HDS site hospital).*

Transitional Behavioural Assessment and Intervention Service (T-BASIS) units

T-BASIS units are non-acute mental health inpatient beds treated and mapped as a ward of the relevant hospital even where they are a physically stand-alone unit (NSW Health 2007). An evaluation of T-BASIS units completed in 2011 noted there were five T-BASIS Units in

operation across three Area Health Services (Bird et al. 2011). Two of these services were visited by HDS fieldwork teams.

T-BASIS units are managed under the **Specialist Mental Health Services for Older People (SMHSOP)**. They provide psychiatric rehabilitation for older people under a model of care that involves a non-acute assessment–treatment/management–discharge inpatient service for older people with severe behavioural and psychological symptoms of dementia. The goal of the units is to comprehensively assess the patient and develop a behaviour management plan to support the patient on discharge.

In most cases, patients admitted to a T-BASIS unit have a diagnosis of dementia, are over 65, are mobile, very confused and disoriented and probably experiencing disturbed behaviour patterns (HNEMH 2012). The evaluation of T-BASIS units found that they primarily provide care for people with dementia and challenging behaviour, though a minority had mental illness as their primary diagnosis (Bird et al. 2011). A significant proportion of patients had mental health comorbidities and almost all had multiple medical/physical comorbidities.

Referrals come from hospital, residential aged care facilities and the community. For HDS site hospitals, the T-BASIS unit was an important transfer option. Medical cover was provided by local GPs or geriatricians with input from visiting psychogeriatric services.

In keeping with the short-term care model, the length of stay is intended to be a maximum of 3 months. The evaluation of T-BASIS units found the median length of stay varied between 8 and 15 weeks (Bird et al. 2011).

The evaluation of the units noted that statistical evidence using standard instruments to assess decline in behaviour as a result of the patient's stay was equivocal, but they concluded that the units are performing a useful clinical function which is 'actually or potentially more cost-effective than treating people with dementia in acute inpatient settings' (Bird et al. 2011).

Factors that appeared to contribute to the effectiveness of the units included:

- high-quality physical environment for people with dementia and behavioural and psychological symptoms of dementia (BPSD)
- skilled staff and a high staff-to-patient ratio
- a model of care that provides some level of follow-up support after patient discharge.

Challenges to the model arise from the difficulties in discharging patients due to lack of appropriate longer term care options, such as residential care facilities with secure units and staff skilled in the management of BPSD or of options for low-level care patients with severe BPSD. Family and carer responses to the T-BASIS units, as reported by T-BASIS nurses, are mostly positive:

> By the time we see family, they've been in the system for a while. It's confronting for them. Especially the stigma associated with the behaviours. Very grateful for this environment. They often have financial, guilt, psychosocial issues. They are often exhausted as well. It takes 1, 2, 3 weeks for them to settle and behave more normally. We do referrals for the carers, for specialised counselling. They often vent to staff, they stay here all day, we treat them as well. *(T-BASIS nurse)*

Hospital education programs

As noted earlier in this report, under-identification of people with dementia is a significant concern in the hospital setting. **Hospital education programs** to inform clinicians and hospital staff about dementia can assist in improving identification and equip staff with the appropriate skills to manage people with dementia within that setting. There is a range of hospital education programs being implemented across Australia including the Dementia Online Program (refer to 'Cross-sectorial strategies'). Some of the programs identified during the literature review and fieldwork visits are discussed in more detail below.

In 2003, a hospital education program was implemented by the Victorian Government, in partnership with Alzheimer's Australia, to improve the awareness of dementia in hospitals and to facilitate better identification of people with dementia and enhanced communication between patients and staff. The following two initiatives were implemented:

- a bed-based **cognitive impairment identifier (CII) graphic**, which was intended to alert staff of the patient's cognitive impairment
- a hospital-wide education program to improve dementia care in the hospital, which was based on several themes that were identified through a series of focus groups. The training sessions were 30 to 40 minutes in length and were administered by the Clinical Director of Sub-acute Medicine and a CNC.

An evaluation of the program found that 80% of staff reported that the CII graphic had improved their practice and 40% reported that it had improved their response to carers. Carers also reported greater satisfaction with the care their family member received. Overall, the education program and CII graphic helped to improve the hospital processes that supported people with dementia. The program has since been integrated into the **Dementia Toolkit**, which is offered to all hospitals through the Victorian Government's Long Stay Older Persons Program (Foreman & Gardner 2005).

The HDS fieldwork team noted that clinical leaders including geriatricians, psychogeriatricians, ASETs, Dementia CNCs and NPs in Dementia, Aged Care or Psychogeriatrics were often an important source of information, education and training for hospital staff (see section below on 'Interface positions' for more discussion about some of these).

The use of various tools, such as the **Confusion Assessment Method,** is often an important means of embedding dementia and delirium knowledge and understanding in care practices. One example of the education role of a Dementia CNC in a regional hospital with few aged care services was their development of two tools for use by staff on a general medical ward that had many older patients, including people with dementia:

- the **Cognitive Impairment Pathway** is a comprehensive tool which includes the Confusion Assessment Method, the Mini-Mental Status Examination and the 'Clockface Test'.
- a **behaviour monitoring chart** designed to show the patient's behaviour as a graph throughout the day using colour coding to indicate when there have been aggressive incidents, the times that they may have occurred, as well as the severity of the incident. Staff are also asked to identify activities which trigger positive behaviours as well as anything which might have triggered negative behaviour.

Better management of associated health conditions

Rehabilitation following a fall

A fall can often precipitate a rapid decline in the patient's condition and a prolonged hospital stay, which can in turn lead to an increase in the cost of care (Devanand & Schultz 2011). Research suggests that **rehabilitation therapy** following a fall can offer benefits such as improved function and ambulation, and a lower risk of future falls. This can lead to shorter recovery periods in hospital, prevent future admissions to hospital, and improve the patient's quality of life (Allan et al. 2009; Morghen et al. 2011).

A randomised control trial in Finland was conducted on 243 older people with dementia who received an operation for a hip fracture (Huusko et al. 2000). All patients had been living independently and could walk unaided before their fall. The intervention consisted of the following rehabilitation activities:

- initial assessment by a geriatric team to evaluate the patient's condition
- physiotherapy sessions twice a week and daily physical activities with nurses
- evaluation of the patient's need for daily living aids by an occupational therapist
- patient and family counselling by physiotherapists and nurses
- home visits by a physiotherapist before the patient was discharged to assess their home environment, and 10 follow-up visits from the physiotherapist following discharge.

Following the intervention, there were fewer post-operative complications in the intervention group, including fewer urinary tract infections, delirium, nutritional deficiencies and falls. Furthermore, the length of hospital stay was dramatically reduced for people with mild to moderate dementia. For this group, the median LOS was 47 days in the intervention group compared with 147 days in the control group; while for mild dementia, the median LOS was 29 days in the intervention group compared with 46.5 days in the control group. Three months after the operation, patients in the intervention group with mild dementia were equally successful in returning to their independent living arrangements as people without dementia. Unfortunately, the intervention did not lead to measurable benefits for people with advanced dementia.

A randomised controlled trial in Sweden by Stenvall et al. (2012) aimed to reduce post-operative complications and improve functional recovery for people with dementia after a fall. The intervention consisted of the following activities:

- a staff education program
- an individualised care plan for each patient
- a tailored rehabilitation program
- early detection of post-operative complications.

The staff worked in teams to deliver comprehensive geriatric assessments, and patients were followed up after 4 months to identify any complications and provide further rehabilitation. Once again, patients in the intervention group had fewer complications, including urinary tract infections, nutritional problems and post-operative delirium. In the intervention group, there was a statistically significant improvement in the ability of patients to walk independently, and one participant achieved better walking performance than before their fracture. A larger proportion of patients regained their ability to perform normal daily activities in the 12 months after their fall. There was also a significant difference in the

hospital LOS between the two groups. The length of post-operative stay, including rehabilitation, was 20.0 days (+/– 12.0 days) in the intervention group, compared with 32.1 days (+/– 35.3 days) in the control group. In the 12 months after the fracture, the average LOS for all hospitalisations was 23.8 days (+/– 16 days) in the intervention group, compared with 41.3 days (+/– 57.3 days) in the control group.

These interventions demonstrate the potentially significant benefit from rehabilitation to people with dementia following a fall, both in terms of improving patient outcomes and reducing hospital use.

Identifying and treating delirium

Delirium is defined as an acute stage of confusion that is usually precipitated by an underlying condition, such as infection, pain, dehydration or polypharmacy. With prompt identification and treatment, delirium can often be reversed; however, identification can be difficult among people with dementia due to the overlapping symptoms and uncertainty surrounding the patient's baseline mental status. As a result, delirium is often mismanaged in hospital and has been linked to extended hospital stays, further declines in function and cognition, re-hospitalisation after discharge, and death (ANZSGM 2012; Fick & Mion 2007; Witlox et al. 2010).

There is strong evidence that **comprehensive geriatric assessment** with multicomponent intervention is effective in preventing and managing delirium (Inouye et al. 1999)—for example, targeting key delirium risk factors of cognitive impairment, vision/hearing impairment, immobilisation, psychoactive drug use, dehydration and sleep deprivation—and such an approach is encouraged by the Delirium Care Pathways produced for Australian Health Ministers' Advisory Council (Traynor & Britten 2011).

The **Care of the Confused Hospitalised Older Person Study (CHOPS)** is an initiative of the NSW Agency for Clinical Innovation in collaboration with the Clinical Excellence Commission and GP NSW, funded by the Department of Veterans Affairs and currently being piloted in five hospitals across NSW. CHOPS aims to develop a training, education and support program to enhance care and minimise harm to the confused older person (including people with delirium and/or dementia), allowing for methodical prevention, assessment and management across wards within the five pilot hospitals. Following evaluation, the long-term goal will include a roll-out across all hospitals in NSW (ACI 2012).

Nearly all HDS site hospitals indicated that there have been significant improvements in staff understanding and awareness of delirium, although all acknowledged there was room for improvement. Among the strategies reported to the HDS teams were:

- developing delirium policies (although knowledge of these was variable)
- using tools such as delirium risk screens on patient admission forms prompting referrals for assessment using the Confusion Assessment Method
- placing delirium alerts on the patient's bedside chart and documenting intervention strategies on the patient care plan
- producing delirium resource folders available at nurses' stations, including evidence-based literature, a flowchart of the process, all necessary tools and supporting documents
- providing brochures about delirium for patients and their family/carers

In those hospitals that described their strategies and noted improvements in relation to delirium identification and treatment, it was usually as a result of the efforts of key staff members, including Dementia CNCs, Delirium CNCs, and NP in psychogeriatrics. The Alzheimer's Association in the USA has proposed a standardised tool to measure delirium in hospitalised dementia patients. The **Delirium Superimposed on Dementia Algorithm (DSDA)** recommends a process for assessing delirium in patients with pre-existing dementia. This tool recognises that the patient's baseline mental status is a key parameter for assessing and treating delirium. It makes the following recommendations:

- review the patient's medical record for indicators of pre-existing dementia
- check with the patient's family or carer to determine whether the patient has been diagnosed with dementia or displays any of the signs or symptoms of the disease
- if the patient is admitted from a RAC facility, a nurse should question staff at the facility to establish the patient's baseline mental and functional status.

The DSDA tool aims to break down the current barriers that prevent delirium from being detected in older patients as there is a tendency for clinicians to attribute cognitive disturbances as being an inevitable progression of the disease (Fick & Mion 2007).

An intervention trial by Naughton et al. (2005) in the USA aimed to improve the recognition and management of delirium in older adults admitted to the hospital emergency department. Patients with delirium were transferred to an **acute geriatric unit (AGU)** where they received treatment for their condition. Several protocols were implemented in the AGU to improve the assessment and pharmacological management of delirium and cognitive impairment:

- Clear guidelines were developed for staff in the ED and AGU based on published literature, data collected during the baseline period and clinical experience. Guidelines were developed to standardise the assessment of behavioural disturbances, increase non-pharmacological management of behavioural disturbances and reduce the inappropriate use of antipsychotic medications.
- Education programs were conducted for staff in the ED and AGU. In the ED, triage and charting procedures were changed to remind physicians to evaluate adults aged 75 and older for cognitive impairment and delirium. In the AGU, staff were trained to conduct mental status assessments and introduced to the guidelines described above.
- An audit and feedback program was implemented to assess nurses' performance of mental status assessment and the prescribing patterns for cognitively impaired patients.

In all, 374 patients received full assessments. At baseline, the prevalence of delirium was 40.9% among enrolled patients. This decreased to 22.7% at 4 months and 19.1% at 9 months. The average LOS for delirious patients at baseline was 11.5 days. For non-delirious patients in the 4-month and 9-month cohorts, the average LOS was 8.2 days. Based on these figures, it was estimated that for each episode of delirium that was prevented, 3.3 days of hospital care could be saved, on average. This intervention suggests that evidence-based guidelines may be effective in managing hospital patients with delirium; it is therefore likely that they could be useful for patients with delirium superimposed on dementia.

Chronic infections

Chronic infections have been linked to an increased risk of hospitalisation (Carter & Porell 2005) and extended lengths of hospital stay (Malyuk et al. 2012). However, identifying and treating infections is complicated by the communication difficulties among people with

dementia (Edlund et al. 2007). Canadian researchers Malyuk et al. (2012) conducted a retrospective database analysis to determine whether identifying and treating infections led to better functional outcomes and reduced LOS for geriatric psychiatry patients. They found that more than one-in-five newly admitted hospital patients required antibiotic treatment for an infection within 14 days of admission, and urinary tract infections accounted for the majority of these infections (82%). With **early identification and treatment**, patients had a significantly shorter LOS than those who were admitted to hospital without a comorbid infection. Furthermore, those who received treatment showed functional improvements in mobility and cognition after being discharged from hospital. This preliminary research suggests that better identification and treatment of underlying infections has merit and should be explored further.

Cross-sectoral strategies

Integrated approaches

Under a new **integrated approach** to dementia care launched in France in 2008, doctors and nurses are being provided with education and training about the condition. In addition, the plan includes new programs to support families affected by dementia, more memory clinics for patients, and funding for research. The plan includes a commitment of almost €2 billion from the French government and is being recognised internationally as a leading dementia care and management approach (Comer 2009). The progress of elements and strategies included in the plan are being monitored to identify the best and most cost-effective approaches. The plan has the main dimensions (Lustman 2011):

- improving the quality of life for patients and carers—an approach that involves improving access to diagnosis, ensuring a continuous chain of care and improving support for carers
- knowledge for action—involving the creation of a Foundation for Scientific Cooperation to develop relationships among the scientific and research community and ensure that results and information are shared appropriately
- mobilising around a social issue—the main aim of this dimension is to provide information and awareness to the general public.

The plan builds on previous approaches used within the health sector in France and uses a multifaceted approach to streamline access to services, improve the experience of people with dementia, enhance the evidence base and reduce hospital lengths of stay.

Discharge planning

Difficulties often arise when discharging people with dementia from hospital into mainstream services, such as rehabilitation units, home and social care, and non-acute beds. This may be due, in part, to the limited capability that these services have in managing people with dementia (Bowen et al. 2007). **Discharge planning** refers to the development of an individualised care plan for patients as they enter the hospital system (Shepperd et al. 2010). It ensures that each patient receives the services they need in a timely manner, in line with the objectives of providing high-quality care, reducing extended hospital stays, and containing costs. Previous research has shown that a well-structured discharge plan can be successful in achieving these goals (Shepperd et al. 2010).

The literature review found discharge planning studies in the UK and Australia. These studies are focused on specific interventions or practices at the point of transition from hospital to home or long-term care. They do not describe discharge planning systems and practices in hospitals or report on the effectiveness of hospital discharge planning processes.

In the UK, the NHS has developed a discharge checklist to help hospitals plan for people with dementia before and after discharge. It is based on the **'Good Practice Checklist'**, which is used to assess the discharge arrangements for general hospital patients. The checklist targets the following aspects of care:

- hospital processes, such as 'Are hospital discharge processes regularly reviewed?'
- health service capacity, such as 'Do you have a sufficient range of services including home-based care, rapid response, housing-based options and intermediate care that is available to people with dementia?'
- funding and resources, such as 'Have the primary care trust and social services considered the use of pooled budgets for dementia care services in intermediate care?'
- structures and systems, such as 'How effective are your overall arrangements for partnership working in relation to dementia care across the whole system of health and social care?'

The Good Practice Checklist has been used widely by health-care providers in the UK and is available for download from the UK Department of Health website (UK Department of Health 2003).

An Australian project to develop **interagency care coordination protocols** to assist transitions in care for people with dementia and their carers at home (Spanio & Michaels 2007) noted that service coordination should take particular account of the 'home-to-hospital interface'. While primarily focused on community-based care arrangements, the project made the following suggestions about hospital discharge of people with dementia:

- Discharge planning should begin earlier than normal due to the greater complexity of dementia care.
- Carers should be involved in the hospital admission and discharge planning process. They should be provided with information on medication regimes, the discharge summary and links to post-discharge services. Their advice should be listened to and recorded by the hospital.
- Hospitals should be provided with accurate information on the patient's preferred name, sleeping habits, daily routines, behaviours and other issues that may affect their care.

In most HDS site hospitals there were dedicated discharge planning positions or established team arrangements. In these hospitals, discharge planning began early during a patient's hospital stay and those involved in discharge planning participated in multidisciplinary team meetings on wards on a regular basis. Two programs for post-hospital care were prominent in discussions at all sites—**ComPacks** and **Transition Care**.

Community Packages (ComPacks)

ComPacks is a NSW Health program consisting of a case-managed package of care for up to 6 weeks after discharge from hospital (NSW Health 2006). The concept is to case-manage community support jointly with a multidisciplinary hospital team, starting before discharge and continuing for a short time after discharge, with the aim of facilitating access to mainstream community services. Eligibility is not age-restricted, but people must:

- be assessed as requiring two or more community services on discharge, and
- require ComPacks support to facilitate discharge.

In addition, people may be eligible if they are:

- assessed as having clinical needs capable of being jointly met in the community by a ComPack and a clinical team such as CCAPAC
- referred from EDs if the ASET has assessed them as having in-home care and support needs rather than a need for inpatient care.

Hospital staff who refer an inpatient to ComPacks include social workers, discharge planners, discharge liaison services, continuum of care coordinators and ASET case managers.

The types of services that can be accessed during the ComPack and/or to which referral can be made during the ComPack include:

- domestic assistance
- personal care
- meals
- social support
- centre-based day care
- transport
- respite care
- other services such as falls management, dementia support services, equipment, home modifications and maintenance, accommodation issues support, medication support, carer support, allied health services including physiotherapy, occupational therapy, dietitian, podiatry, speech therapy, community nursing and continence management, financial services, and bilingual services and interpreters.

HDS site visit informants were universally positive about ComPacks and commented that it has become a key component in discharge planning from hospital. In particular, its referral pathways and processes were compared favourably with those required for Transition Care places. Waiting times for access to ComPacks were minimal—in contrast to waiting times for longer term support through Home and Community Care (HACC) services or aged care packages. Hospitals that did not have access to ComPacks places noted this was a serious gap in their post-hospital care options.

People with dementia are neither excluded nor specifically targeted by the program. However, a number of site visit informants felt that ComPacks was not suitable for people with dementia who also had high needs—6 weeks was seen as too short a period to provide the support needed by this group. ComPacks was also not seen as suitable for wanderers, those with severe dementia and those who did not have a carer living with them. Informants noted some risks as the service does not provide any overnight support which may raise safety and ethical issues for discharge planning in some cases. In some locations, informants noted that ComPacks may be used for people with dementia as an interim arrangement while they wait for longer term care arrangements to be established. At least one informant expressed a desire for dementia-specific ComPacks which would provide more intensive support for longer durations.

The HDS project did not directly obtain consumer views about services. However, at one site, informants commented that consumer feedback about ComPacks was generally

positive. At a stressful time (hospital discharge) when patients are not functioning as they previously did, consumers felt ComPacks helped with the transition from being an inpatient to living in the community again and gave the family time to make whatever accommodation and care arrangements might be necessary.

Transition care

In Australia, the **Transition Care Program (TCP)** is a jointly funded initiative between the Commonwealth and state governments, which aims to help older people in hospital return safely to their homes (AIHW 2012d). The program does not specifically target people with dementia. Patients are provided with a package of services, including low-intensity therapy, nursing support, and/or personal care. Patients who require more time in a non-hospital setting are able to complete the restorative process, optimise their functional capacity and finalise their long-term care arrangements. The TCP can be delivered in a patient's home or RAC facility and is coordinated by a multidisciplinary team with a designated case manager.

An initial ACAT approval given in hospital is essential for access to TCP as care recipients must be eligible for entry to at least low-level residential aged care at the end of their hospital stay, and the person must enter Transition Care directly from hospital. The person must have completed acute and any necessary subacute care (for example, rehabilitation) and be medically stable and ready for discharge at the time of assessment. In addition, the person must wish to enter the program and have the capacity to benefit from goal-oriented, time-limited and therapy-focused care.

An early evaluation of the program found that it significantly reduced the risk of a patient re-entering hospital or RAC facility in the 6 months following entry to the TCP (Department of Health and Ageing 2008). The cost of preventing hospital and RAC admission was estimated to be $888 per day in the first 6 months and $344 per day after 6 months. The evaluation also found that the risk of hospital readmission decreased with more nursing hours, while the risk of RAC admissions decreased with more allied health hours. Issues identified by the evaluation included the need to clarify the interface between Transition Care and hospital rehabilitation services and the need to consider and further develop a broader range of interventions and models in the program, including for people with dementia. A limitation was that patients required an ACAT assessment to be completed before they were admitted to the program. This sometimes resulted in delays accessing the service that prevented patients from being discharged from hospital. Nonetheless, at the individual level, positive outcomes had been achieved and it seemed to increase the options for older people following hospitalisation.

A more recent evaluation conducted by Gray et al. (2012) noted that while the early evidence suggests the program is well targeted to create real opportunities for patient gains, there remains a lack of a robust systematic evaluation to produce evidence of improved patient outcomes and cost reductions.

TCP places were available at most HDS site hospitals, although hospital-based informants noted access barriers and difficulties arising from eligibility and entry requirements. The suitability of the TCP for people with dementia was seen to be limited by the requirement that the patient has the capacity to decide they wish to enter the program, to set goals and to comply with and benefit from the therapy. Local interpretations of guidelines sometimes appeared to restrict access to the TCP by people with dementia. For example, some informants noted that restorative goals of therapy are sometimes perceived as physical rehabilitation only.

Coordinated care services

Coordinating dementia care from initial diagnosis through to end-of-life care is an important step in improving the delivery of health-care services. It also increases the likelihood that hospital care is used appropriately in conjunction with other health services. Developing a **coordinated care pathway** involves creating good links across traditional health service boundaries, including:

- acute care, community care and residential care
- health care, social care and housing providers
- government, private not-for-profit, and private for-profit sectors
- federal and state government departments
- primary and secondary care.

Coordinating the ongoing care needs of a person with dementia through a single provider who assumes responsibility for assessing, planning and monitoring the delivery of these services could lead to greater accountability and better care for the patient (Hales et al. 2006).

A recent report from the UK entitled *Understanding out-of-hospital dementia care* was released by Healthcare at Home, a private health-care company providing high-tech home health care across the UK (Kafetz & Bedford 2011). It was produced by a group of policy-makers, practitioners, academics, patient and carer representatives, and organisation leaders. Participants were asked to identify features of a 'gold standard' model of care that they believed would improve patient care and lead to cost savings for the health system. The main recommendation from the report was that dementia care should be coordinated through a centralised nurse-led care bureau. The provision of 24-hour access to a full range of dementia services was considered to be a key factor in ensuring that the appropriate services were delivered in a timely manner. In terms of reducing hospital admissions, the following service elements were recommended:

- regular monitoring of comorbidities
- specialist dementia home visits/care management
- self-referral for diagnosis
- compliance monitoring of medicines
- crisis management prevention
- hands-on palliative care.

The report quantified the potential financial costs of the new care model by looking at the costs of a similar model in Bristol. The Bristol model had previously demonstrated a 12% reduction in hospital admissions and cost savings of 40%. Extrapolating these figures across the NHS, it was estimated that implementing the Gold Standard Framework would lead to cost savings of at least £300 million per year on hospital admissions. Taking into account the costs of providing services outside the hospital, this would lead to net savings of at least £127 million per year.

Interface positions

The use of **trans-boundary aged care NPs** is another viable strategy for providing collaborative and multidisciplinary care. NPs are highly skilled and cost-effective clinical practitioners, and there is growing evidence documenting their ability to improve patient

outcomes (ACT Health 2008). In 2004–05, an **Aged Care Nurse Practitioner Pilot Project** was carried out in the Australian Capital Territory (ACT). The project aimed to evaluate the role of NPs in providing aged care services and was jointly funded by the Australian Government Department of Health and Ageing and the Australian Capital Territory Government (Arbon et al. 2008). The pilot found strong support for the use of aged care NPs in providing integrated care and managing patients as they moved between different care settings. NPs were invaluable in providing timely access to assessments and interventions, fostering collaboration between health professionals, and brokering with the respective health-care service(s). This led to a reduction in acute hospital admissions from residential care and fostered a multidisciplinary approach to the provision of care.

Following the success of the project, ACT Health established a framework for developing and expanding the role of NPs in aged care (ACT Health 2008). Since then, the Australian Government has announced an investment of $18.7 million to expand the role of NPs in residential and community-based care settings. The program aims to achieve the following objectives:

- identify effective, economically viable and sustainable models of practice
- facilitate the growth of the aged care NP workforce
- improve access to primary health care for patients in residential and community aged care settings.

Funding has been granted for 32 projects and will be carried out by a variety of organisations in rural, regional and remote areas. Qualitative and quantitative data will be collected on the service delivery models to evaluate their success in achieving their stated aims.

The HDS fieldwork team also observed the role and operation of NPs in aged care, dementia and psychogeriatrics at a number of hospital sites. Their roles varied to some degree depending on the availability of other services, but generally included:

- clinical work, including ordering investigations, making referrals to specialists and assisting with diagnosis, assessment and management
- education and advice to professionals within hospital, community and residential care settings
- service development across sectors (such mentoring, support, developing network relationships).

Informants noted that NPs provided a key service in improving access to assessment and diagnosis of dementia and delirium. They also often acted as dementia champions in their local area and were a source of information and advice for other health professionals. Examples of some local initiatives and activities undertaken by NPs at HDS sites included:

- a clinical placement trial to provide nurses in RAC facilities with the opportunity to **upgrade clinical skills** (such as intravenous antibiotic administration), with the goal of reducing presentations to the ED from nursing homes and facilitating earlier discharge of admitted patients back to nursing homes
- developing and supporting the 10-month **Dementia Online Program** (developed by Newcastle University)—the program tries to build positive approaches to, and develop clinical champions of, the care of older people in hospitals
- participating in local aged care or **dementia forums,** including community-based aged care and dementia-specific services.

- supporting **safe discharge** home from the ED.

Other specialist staff operating at the interface between the hospital and community-based settings also make a major contribution to patient care and patient pathways through the hospital system. In addition to NPs, HDS fieldworkers observed the following kinds of positions in operation: AARCS, Dementia Clinical Nurse Consultants and Aged Care Clinical Nurse Consultants. These positions were more likely to be in place at hospitals with ACS.

Acute to aged-related care services

AARCS is a COAG Long Stay for Older Persons initiative with funding from the Australian Government. They provide early and appropriate identification of the discharge support needs of older people admitted to hospital. The service model uses a patient-centred process that provides coordinated early identification, holistic assessment, care recommendations and facilitation via case management through the hospital system (AHMAC 2008). AARCS positions were filled in five of the HDS site hospitals, three in *Inner regional* areas and two in *Major cities*.

The AARCS nurse functions as a specialist liaison position between the acute and community sectors. They formally engaged with both sectors by participating in regular cross-sectorial meetings. For example, at one site the AARCS nurse participated in the local ACS meeting which also included 2–3 Nurse Unit Managers from the hospital, local community-based aged care service providers and the Division of General Practice. At the same site, the AARCS nurse also attended multidisciplinary team meetings on the orthopaedic ward, along with the discharge planner, medical staff and allied health staff, where patient progress and discharge planning took place.

The AARCS nurse is integral to discharge planning and is part of the referral pathways within the hospital setting; for example, referrals from ASETs. In site hospitals, AARCS nurses therefore worked closely with discharge planners, ACATs and ASETs as well as with community-based providers. Generally, informants were positive in their assessment of the value of the AARCS role, including for people with dementia—ACAT informants at one site noted that the establishment of the AARCS position had significantly improved the quality and efficiency of the referral process through working with the Dementia CNC in promoting basic cognitive screening.

Dementia/Psychogeriatric/Aged Care clinical nurse consultants

CNCs in dementia, psychogeriatrics or aged care were, or had been, present in 16 of the hospital sites. The main role of the Dementia CNC is to improve outcomes for people with dementia, their families and carers through clinical leadership, clinical advice, consultation, education and support of other professionals on all issues pertaining to dementia and psychogeriatrics. They are frequently local advocates for people with dementia across care settings and also function as champions driving change and improvement to the care of these patients. Fourteen of the site visit hospitals had access to either a Dementia CNC or Aged Care CNC. Some larger hospitals had access to both.

In many sites, including those in major cities, Dementia CNCs worked across a number of hospitals. They played a key role in service development—identifying service gaps, sourcing funding and delivering projects, developing policies and procedures in relation to dementia and delirium, providing education and advice to staff on acute wards and in aged care facilities as well as to families and carers, building networks within and across the acute and community sector and mentoring staff. Dementia CNCs also facilitated assessment and

diagnosis of patients with suspected dementia and delirium. Particularly in settings where there are limited or few acute aged care services, they provide a focal point for linkages between sectors and are a source of clinical advice, particularly for patients with behavioural symptoms.

At most sites, Dementia CNCs commented that education was a large part of their function. An example of this at one major city hospital was the delivery of training in Critical Incidents Positive Outcomes. This training focused on self-defence, de-escalation of a critical incident, safety restraint, team work, communication understanding how aggression forms in dementia. The training over 3 days was mandatory for mental health staff and for staff on the secure psychogeriatric ward. Staff members from local residential aged care facilities were also invited to attend.

Dementia CNCs were often pivotal in facilitating communication between the hospital and community sectors through establishing interagency meetings for service providers. These groups were not only a valuable information exchange forum, but frequently developed local-level strategies such as information cards for families and carers, transfer forms for clients being admitted to, or discharged from, hospital which documented information such as medications and functioning.

In most sites, Dementia CNCs appeared to be functioning effectively. Informants reported improved recognition of delirium and dementia by acute care staff, better understanding of dementia and reduction in the use of restraints on wards as tangible outcomes. Difficulties in establishing the role, building visibility and credibility with local health professionals (especially across multiple hospitals) and workload pressures were also cited as factors that compromised the effectiveness of this function.

Aged Care CNCs were another key liaison position that performed a similar function to Dementia CNCs but with a broader focus on older patients more generally. However, at many sites, the Aged Care CNC was also responsible for dementia and delirium. Case conference attendance and involvement in discharge planning featured more heavily in the role of Aged care CNCs than for Dementia CNCs, as did liaison between the hospital, ACAT and aged care services in relation to individual patients.

End-of-life care

End-of-life care in residential aged care settings

People with advanced dementia are often subjected to distressing transitions between residential care and hospital at the end of life (UK Department of Health 2008). These transitions are associated with several poor-quality care markers, including pressure ulcers and late enrolment in hospice care (Gozalo et al. 2011). Ensuring that residents are comfortable during the final stages of their illness and reducing the stress caused by avoidable hospital admissions is a key priority for health-care services.

Over the last decade, there has been a growing awareness in Australia of the inadequacies of end-of-life care (Detering et al. 2010). One of the major improvements within the field has been advance care planning, whereby a patient and their family, in collaboration with health-care providers, make advance decisions about the health-care and treatment options for when or if the person becomes incapable of making these decisions as a result of their condition (Detering et al. 2010).

Caplan et al. (2006) conducted a controlled evaluation of a system designed to educate residents, their families, staff and GPs on the outcomes of dementia and the benefits of advance care planning. The **'Let Me Decide' Advance Care Directive** was used, as it takes into account the role of a 'responsible person' in acting as a decision-maker for people who do not have the capacity to give consent. Each resident's cognitive capacity was assessed using the Mini-Mental State Examination. The intervention was conducted in 2 hospitals and 21 residential care facilities in Australia, and compared with a control group of 1 hospital and 13 care facilities. Before the program began, hospital bed use days per resident were similar in both areas. Following implementation of the program, there was a progressive decline in the hospital admission rates among residents in the intervention group, which fell by 22.7% in the first year. In contrast, admissions rates in the control group increased by 4.2% over the same period. The admission rates in the intervention group continued to fall over the next 2 years. Overall, there was a 35.4% decrease over 3 years, whereas the control hospital experienced a 20.1% increase during this time. Importantly, there was no significant difference in the annual mortality rate between residents in the intervention or control groups, except in the final year when mortality increased slightly in the controls.

In 2002, Austin Health in Melbourne, Victoria, piloted the **Respecting Patient Choices (RPC) Program**, supported by the National Institute of Clinical Studies and the Australian Government Department of Health and Ageing. The program provided training and support to health-care professionals to help facilitate the often difficult end-of-life discussions with patients and guidance on appropriate documentation of advance care plans (Silvester & Detering 2011). The pilot program was evaluated, resulting in ongoing funding and providing the opportunity for expansion with a community extension of the program rolled out into residential aged care facilities. A final evaluation of the community extension determined that advance care planning had a significant impact on the level to which patients were involved in decisions about their future care. The findings showed that, of the patients introduced to the program who subsequently passed away, 100% had their treatment wishes respected. The majority of these patients (88%) died in a residential facility receiving palliative care, as requested. This is in contrast to those residents whose wishes were unknown, with between 64–80% dying in hospital. Overall, the evaluation noted that those residents in facilities where the RPC Program was not introduced were more than twice as likely to die in hospital as those residents of a facility where the program was implemented. In addition, the evaluation suggested that involvement in the RPC Program had a positive impact on the skills and confidence of health-care providers in facilitating end-of-life planning processes (Silvester 2006).

The Gold Standards Framework in Care Homes (GSFCH) is a program from the UK that aims to improve the quality of end-of-life care for RAC residents. The GSFCH program consists of an organisational tool for facilitating end-of-life care. The program involves adopting several end-of-life strategies (for example, an integrated care pathway), prescribing anticipatory medication (such as pain relief), conducting routine medication reviews and developing protocols for bereavement care. A retrospective analysis of the program by Ong et al. (2011) showed that the number of residents who died in the care home increased by almost 10% during the study period. This was mainly due to a fall in the proportion of residents who were admitted to hospital in an emergency during the final 6 months of life, which fell from 37.8% of residents to 26.3%.

Residential aged care physicians in the Netherlands are also experienced in assessing whether patients require palliative care rather than a curative approach (Hertogh 2006). A study by Houttekier et al. (2010) found that the number of people with dementia who die in

hospitals is only 3% in the Netherlands, compared with 46% in Wales. Further analysis showed that the provision of **appropriate long-term care facilities** with adequate staffing was an important factor in determining whether people with dementia died in an acute care setting.

End-of-life care in a hospital setting

While the progressive and incurable nature of dementia is commonly accepted, the ultimate terminal nature of the illness is less understood (Bloomer et al. 2012; Long 2009). Advanced dementia is typically not recognised as a terminal condition by patients or their families; this often results in situations where **advance care directives** have not been developed while the patient still had the capacity to participate in care planning decisions. In addition, the limited recognition of dementia as a terminal illness can lead to prolonged aggressive medical management of the condition as opposed to a palliative care approach (Holmerová et al. 2007; Long 2009). Unfortunately, as a result of the lack of validated prognostic indicators for patients with end-stage illness, many do not receive appropriate referrals to palliative care or prescriptions for palliative medication in the hospital (Sampson et al. 2006). Strategies are needed to avoid the use of aggressive hospital treatments and to prevent protracted interventions that cause discomfort for patients with terminal illness.

An intervention trial in the USA implemented a **pro-active case management** approach to end-of-life care for patients with advanced dementia (Campbell & Guzman 2004). A palliative care team screened the hospital intensive care unit daily to identify patients who met the study criteria for advanced-stage dementia. Most patients who were identified had infections and respiratory difficulties due to prolonged immobility. While most of the acute illnesses were treatable, the patient's dementia status was diagnosed as terminal. The following interventions were implemented for these patients:

- news about the patient's terminal diagnosis was communicated to family and carers
- assistance was provided to locate the patient's advance care directive and identify their preferences for end-of-life care
- treatment options were discussed with the patient's guardians
- palliative care strategies were adopted when the treatment goals became 'comfort measures only'
- education was provided to staff on palliative care strategies.

It was reported that proactive interventions from a palliative care consultant shifted the goals of care to comfort sooner, reduced the time between identification of the patient's terminal condition to the establishment of do-not-resuscitate goals, and reduced the use of non-beneficial hospital resources. The hospital LOS decreased from 12.1 days in a historical control group to 7.4 days in the intervention group, while intensive care unit LOS decreased from 6.8 days to 3.5 days. The reduction in superfluous resources was accompanied by greater comfort and psycho-emotional support for the patient and family during the final stages of life.

Environmental strategies

Dementia-friendly environments—outside the hospital setting

The important role of the physical, social and attitudinal environment in supporting a person with dementia is becoming more prominent within the care sector (Davis et al. 2009a, 2009b; Fleming et al. 2003; O'Sullivan 2008). It is widely acknowledged that the environment can have significant impact both on care outcomes and in determining the level of independence achievable for a person with dementia. Simple design elements, including the addition of handrails, can provide the opportunity for self-reliance in a safe and supported way (Davis et al. 2009a). In Australia, the **Dementia Enabling Environments Project (DEEP)** is an example of an innovative resource for providers and consumers alike. DEEP is an online information clearinghouse for resources relevant to dementia enabling interior design (including simple home modifications), architecture and garden/landscape design, and offers a range of training and consultancy programs for consumers, service providers and design professionals (Dementia Enabling Environments 2013).

A range of strategies and resources is available to assist in creating dementia-friendly environments, both targeted at injury prevention and broader safe environments. Some of the key strategies and resources identified in the literature and through site visits are described below.

Prevention of falls and associated injuries

Falls are a major cause of hospital admissions for people with dementia. People with dementia are at increased risk of falls for a number of reasons, including the abnormalities in gait and disturbance to balance as a result of cognitive impairment associated with dementia, the effects of commonly prescribed psychotropic and cardioactive medications, and the progressively impaired capacity of dementia patients to interact with and understand their environment (Allan et al. 2009; Shaw & Kenny 1998; Tinetti & Kumar 2010; van Dijk et al. 1993; Van Doorn et al. 2003).

According to research, most falls among older people, including those with dementia, are associated with a range of identifiable risk factors; for example, unsteady gait, confusion, and certain medications. The research also indicates that **multifactorial strategies** addressing these factors can significantly reduce rates of falling for individual patients (Campbell & Robertson 2007; Rubenstein 2006).

Campbell & Robertson (2007) conducted a literature review of interventions aimed at preventing falls in order to determine if evidence supports interventions with multiple components as opposed to single strategies in community-based fall prevention. The review had a set of eight strict inclusion criteria which were used to determine if a trial was suitable and involved calculating rate ratios for trials testing multifactorial and for single interventions and comparing the overall efficacy using meta-regression. The results indicated that, while multifactorial approaches were more effective in reducing falls for individual patients, at the community level of populations at risk, **single interventions** were as effective as multifactorial.

The National Ageing Research Institute (NARI) has been involved in a range of fall prevention strategies within Australia. Some of these are discussed below; however, more detailed information, including evaluation results for some of these strategies, is available on the NARI website (NARI 2012).

- **Reducing falls among older people in Victoria: Better evidence, better targeting, better outcomes** is a National Health and Medical Research Council (NHMRC)–funded initiative involving four components aimed at improving programs and practices to minimise risk of falls. As part of this project, NARI undertook an evaluation of best-practice guidelines for falls prevention activities within community agencies, involving a literature review, developing guidelines and a training program, and the evaluation of both. The guidelines and training program were trialled in four regions across Victoria and are available to download from the Monash University website (Monash University 2011).
- The **'No Falls' peer education program** was a rolled out across five Victorian communities (Bayside, Kingston, Glen Eira, Stonnington and Port Phillip) in October 2006. The project was part of the wider **Whole of Community Falls Prevention Projects** and the associated peer education program was evaluated by NARI. The aim of the evaluation was to identify the strengths, weaknesses, opportunities and threats of the 'No Falls' peer education program. NARI found that there was limited evidence to suggest that peer education would be effective in changing the health behaviours of older people when used in isolation from other strategies, but there was benefit to peer education in a community-based program to increase awareness of risk factors.
- **STAR Project:** an individualised, facilitated and sustainable approach to implementing the evidence in preventing falls in residential aged care facilities aimed to implement best-practice guidelines in fall prevention in nine residential care facilities across Victoria, Queensland and Tasmania. The STAR Project used a multifactorial approach which was individualised to support the specific requirements of each facility. The project ran action research approaches within each facility, involving staff in the process. Action research involves undertaking research into current practice, identifying problems and developing potential solutions. According to the evaluation findings of the STAR Project, an action approach was successful in achieving the aim of implementing best-practice guidelines in falls prevention in the participating residential aged care facilities (NARI 2009).

Adapting the living space in the home

An environment designed to be **dementia friendly** can support a person with dementia to remain an active participant in everyday life and to stay connected to their existing social world (O'Sullivan 2008). Many changes can be made to the home environment to capitalise on the strengths of the person living there and minimise both reliance on formal care services and the risk of avoidable hospitalisation. Several guidelines are available from Australian researchers, government departments and peak advocacy and support agencies (Davis et al. 2009a, 2009b; O'Sullivan 2008).

Overall, there seems to be agreement that **dementia-friendly design** should be governed by high-level ideals such as:

- familiarity—routine and familiarity are known to be helpful for a person with dementia
- orientation—help the person identify where they are and how to get where they want to go
- engagement—provide opportunities to participate in tasks and activities
- memory aid—stimulate their memories
- safety and independence

- ensure the physical and psychological setting is comfortable.

The strategies identified in the literature seem to be focused within two areas: strategies for the social environment and for the physical environment.

Strategies for the social environment

Social environment strategies promote opportunities for social interaction and maintenance of connections to family, community and self. Examples of these strategies include simple things such as placing a chair in a central location—for example, near the kitchen area—to provide the opportunity for a person with dementia to engage with others during daily life activities, even in situations where that person is no longer able to directly participate. Techniques recommended as memory aids, such as keeping a whiteboard, diary, calendar and/or notebook to record important phone numbers, reminders, details of appointments and information on the social network (for example, the people living there or who are expected to be visiting) encourage involvement with the social environment and promote a safe level of independence in daily activities.

There are several strategies associated with identity, including photographs of family and friends, and of the person throughout their life; scrapbooks of recent excursions and activities; displaying arts and crafts that the person has done; boxes of objects/hobbies that the person enjoys; and the creation of a 'life book' (filled with pictures and stories from the person's life to remind them) which can be implemented to assist a person with dementia in retaining connections with their social circle and remembering aspects of their personal identity.

Strategies for the physical environment

The aims of these strategies are to enable the person with dementia to maintain the capacity to participate in daily living tasks such as cooking, washing-up, showering/bathing and independently using the toilet. There are several strategies and examples for designing a dementia-friendly environment within the home and its surrounds. O'Sullivan et al. (2008) have developed a manual available through Ageing, Disability and Home Care, NSW Department of Family and Community Services, which provides a comprehensive **evidence-based toolkit** for assisting people with dementia and their carers to implement strategies focused on maximising independence and supporting people to remain safely at home for as long as possible. Some of the common adaptive strategies from this manual are outlined briefly below (O'Sullivan 2008).

Kitchen, bathroom and toilet safety

Stove accidents, burns from touching hotplates, dangers of unlit gas, understanding hot/cold taps, and other issues relating to use of appliances are common concerns for people with dementia. There are a few simple strategies that can be implemented within the home to assist in addressing these issues, including: clearing away clutter from bench tops, displaying commonly used items and using labels or signs to help identify an object and to direct a person to where things are stored. Using automatic cut-off and cordless appliances reduce risks associated with leaving appliances on, as does installing a timer for the stove and setting either an upper time limit or an average time after which the stove will automatically turn off. A flame failure feature on gas ovens automatically cuts off gas if it is not ignited.

Difficulty recognising the toilet, trouble getting on and off the toilet, depth perception issues with a bathtub, scalds from hot water, taps left running, resistance to undressing and washing and difficulties with personal care can be commonly occurring issues for people

with dementia. Signage, grab rails, colouring the toilet water to help aim, contrasting toilet seat colour, removing loose mats, using a shower chair, replacing shower doors with shower curtains, use of slip-proof bath mats, and removing the locks on doors can all assist in minimising both unnecessary distress and safety risk to a person with dementia.

Way finding

Disorientation is a common problem associated with the cognitive function decline experienced by a person with dementia. Use of pictograms and signs to identify the location of key rooms—such as the bathroom, toilet and bedroom; using contrasting colours on walls and doorways; adding arrows in hallways with signs to show which room the hallway goes to; and using adhesive lighting strips along hallways and around switches can all be helpful in orientating a person with dementia to their surroundings.

Adapting the living space in residential aged care

Many of the principles and strategies identified for use in the home are applicable to design concepts for dementia-friendly residential aged care facilities. In addition to these strategies, the other key elements to adaptations within a residential setting are the safety and comfort of staff and the challenges in finding a balance between the medical and social models of care.

In recent years, there has been a focus on moving residential aged care facilities away from the traditional medical model of care and towards a more person-centred approach and social model—a model that shifts focus from being condition-based to the experience of the person. This approach is particularly important for people with dementia, given the known impact of the environment (physical, social and attitudinal) on a person's lived experience or capacity to remain involved in a life situation (World Health Organization 2001). In addition, there are concerns that current medical models have the potential to overlook the impact of the environment on a person with dementia and attribute functional difficulties to the condition (Davis et al. 2009a, 2009b).

Davis et al. (2009a) identified seven **'living experiences'** within residential care facilities that the authors believe should be factored into the creation of dementia-friendly environments in residential settings. These experiences include: the presentation of self; eating; personal employment; bedtime; family involvement and community connections; staff; and end of life. The strategies proposed within these life experiences can also be categorised into strategies for the social environment and strategies for the physical environment. For example, the eating experience is a life activity which can be enhanced for people with dementia by creating an environment in which eating is as much about social interaction and the pleasures of meal time as it is about nutrition and the consumption of food.

Encouraging involvement in meal preparation, menu planning, vegetable gardens, setting the table and cleaning up after the meal (where possible) are simple approaches which promote social engagement with others and can invoke memories of other occasions in life when meal times have been shared. The physical environment can also be adapted to enhance meal-time experiences—family-style dining rooms, small tables, tablecloths that are a contrasting colour to the dishware, large print signage and a large clock to assist identifying meal times are all simple low-cost strategies which can be used to promote a better eating experience for residents with dementia.

Dementia-friendly environments—inside the hospital

Improved hospital design and dementia-friendly environments are needed to meet the specific needs of people with dementia. Poorly designed hospital wards contribute to greater confusion and stress for the patient, as well as an increased risk of falls and adverse events. Simple measures such as ensuring that toilet doors are painted with an easily identifiable colour and illustrating ward signs with pictures could help to minimise confusion for the patient. Other measures, such as ensuring that there is good colour contrast between the floor, bed and toilet may help to prevent falls during the patient's stay (Leung & Todd 2010).

An Australian hospital design manual by Fleming et al. (2003) outlines 10 principles of a well-designed hospital environment for people with dementia. Based on the findings of more than 20 years of research, hospital environments were recommended to:

- be safe and secure
- be small
- be simple and provide good 'visual access'
- reduce unwanted stimulation
- highlight helpful stimuli
- provide for planned wandering
- be familiar
- provide opportunities for both privacy and community
- provide links to the community
- be domestic.

These principles were used in the design of specialist dementia care units in NSW, known as the Confused and Disturbed Elderly (CADE) units (Fleming & Bowless 1987), and applied to other specialist environments in the UK and Japan. The manual provides an audit tool to assist hospital staff and management to develop short- and long-term goals for improving the physical environment. There is also a section outlining specific issues that should be addressed when designing facilities for Indigenous people with dementia.

> I just believe though that no matter how much education (of staff)—although that helps and it will have an impact—and in certain places and depending on the patient, will help—but the environment has the ultimate impact, and if it's not a suitable environment for these types of patients and there's unsuitable mix, and the quantity of these people you're putting together is quite a lot—I think even with the education that it can still be very, very challenging and difficult to manage them safely and effectively. *(Nurse Unit Manager, HDS site hospital)*

The physical environment of HDS site hospitals varied enormously. However, the physical design and layout of hospital wards was regarded by nearly all informants as a critical facilitator or barrier to providing good hospital care, ensuring the safety of all patients and assisting in the management of certain types of behaviours, including wandering, agitation and aggression. The majority of site hospitals had poor physical environments for people with dementia. EDs in particular were frequently busy, noisy and cluttered areas with only a couple of hospitals having a quieter area where confused patients might be located. Many site hospitals had confusing layouts with few orientation guides; storage space was at a premium, resulting in cluttered areas; shared gender wards were sometimes a problem when

there were patients with intrusive or disinhibited behaviours; and ageing buildings and designs were seen to increase difficulties in caring for high-needs patients.

Security for patients with behavioural symptoms was generally viewed as a minimal requirement, ideally including a secure outdoor area in addition to the ward. Types of secure systems observed by the HDS team ranged from gated wards with access by PINs, swipe access or buzzers to the use of stable doors retrofitted to an existing four bed ward with access using an electronic key. Site hospitals which lacked these types of secure facilities typically resorted to locating dementia patients in particular parts of the ward, sometimes close to the nurses' station (unfortunately also a busy and noisy area), at other times in quieter areas away from the nursing station. The latter strategy was usually only possible if the ward had access to some form of supervision for patients. Where possible, nursing staff preferred to use Assistants in Nursing, but sometimes needed to resort to using security guards to sit with dementia patients (which sometimes increased a patient's anxiety and agitation). Other strategies observed included the use of high-low beds and bed alarms, and keeping ward doors closed, with signs alerting people to the need to keep patients secure (by no means a foolproof strategy).

Local responses to poor physical environments included, at one site hospital where closed (but not secure) ward doors were the main security option, the doors having a cliff-top scene painted on them. This had been observed to be effective in providing some wanderers with a sense that they could go no further. Another hospital without physical security measures attached a security pass to patients at risk of wandering. The pass triggered the hallway alarm when a patient wandered past the ward's boundaries. Unfortunately, the system was not always effective as patients have been able to learn how to deactivate the system.

A number of informants commented on the dilemmas which can arise in terms of providing a safe environment for people with dementia in units or wards which are also caring for other patients. For example, some informants felt it was preferable to have a secure room/s within a ward rather than having to lock down a whole ward where every patient is then confined. Nurses at another site hospital where the acute aged care ward is secured by a gate noted that this had led to the ward sometimes being labelled as the 'dementia ward'—a descriptor not always welcomed by other patients and their visitors. Similarly, at this same hospital, a secure outdoor courtyard included a bus stop feature which 'can feel demeaning to some people but for those patients who are insistently wanting to catch a bus it can be helpful'.

Considerations raised by informants in relation to planning for appropriate physical environments included:

- careful planning of the number and location of entrances and exits to wards and other clinical spaces
- lines of sight from the nurses' station to outdoor areas, entry/exit gates
- the size and ambience of patient lounges, including the availability of activities
- the use of safety features, including soft-fall surfaces in outdoor areas
- the need for measures to ensure the active exit-seekers were deterred—for example,the use of solid walls for outdoor areas
- the need for quiet peaceful areas.

The level of stimuli in a typical acute ward is very high and can also be a source of stress for people with dementia. Quieter and more tranquil ward environments were observed in

small rural hospitals. However, none of these hospitals had any physical security measures in place.

The highest standard physical environment observed by the HDS team was a relatively new purpose-built aged care unit at a metropolitan hospital. This unit included an acute aged care ward, a rehabilitation unit and a secure behavioural unit. There were areas of interest including carpeted couch nooks and eating areas with clear views of outdoor gardens. The unit was gated with secure access and seemed calm, spacious and had a lot of natural light.

Conclusions

Busy hospital wards can be confusing places for people with dementia, and providing appropriate care in these settings presents many challenges. The cognitive impairment and associated communication and engagement difficulties often experienced by people with dementia can lead to poorer outcomes through delays in recovery, extended lengths of stay in hospital and an increased risk of complications.

Results from this study showed that people with dementia generally have a longer LOS within a hospital than other patients, leading to greater costs to the health system. The average cost of hospital care for people with dementia was higher than for people without dementia ($7,720 compared with $5,010 per episode, respectively). The total cost of care in New South Wales public hospitals for patients who had dementia in 2006–07 was estimated to be $462.9 million, of which around 35% ($162.5 million) may be associated with dementia.

In Australia and internationally, innovative dementia care strategies and practices are being used to prevent avoidable hospital admissions, and to reduce LOS and improve quality of care when admission is necessary. The strategies identified in this report vary dramatically in size, complexity, cost and approach. Preventive strategies being piloted outside the hospital are focusing on unnecessary admissions, and the distress frequently associated with these, for people with dementia. Simple measures being implemented in the hospital setting to reduce LOS and improve outcomes include staff training, discharge planning, dementia-friendly ward adaptations, and mental health and ageing liaison services. These strategies are showing signs of success in reducing LOS for people with dementia, and improving the overall hospital experience.

The costing results from this study draw attention to those reasons for hospital care with the greatest difference in LOS and resource requirements for people with dementia. *Infective endocarditis* was the reason for hospital care with both the greatest difference in LOS and the highest total cost of additional bed-days for people with dementia compared with other patients. The reason for hospital care with the second greatest difference in LOS was *Procedures for infectious and parasitic disease*. However, none of the strategies identified in the literature specifically addressed these reasons for hospital care. Indeed, most identified strategies were not focused on specific reasons for hospital care, other than several examples of fall and injury-related prevention measures.

A review of these findings and a more detailed clinical investigation of these reasons for hospital care would provide a clearer understanding of the impact of dementia upon the treatment and care for these health conditions. In addition, better management of associated health conditions may lead to avoiding unnecessary and potentially harmful hospital admissions and reductions in the LOS where admission is required.

Ultimately, appropriate and timely treatment could improve both the efficiency of practices and the experience of care for people with dementia. There is a need for a thorough review and consultation with stakeholders to identify models of best practice, informed by providers and service users, across hospital, residential and community care settings, which could be implemented nationally to reduce avoidable hospital admissions and improve the quality of care for people with dementia.

Appendix A: Literature review strategies

The table below provides a list of all the strategies identified in the literature review.

Table A1: Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Strategies within the hospital				
Liaison psychiatry service	To manage the behavioural and psychological manifestations of people with dementia during their hospital stay To ensure that patients receive a comprehensive assessment upon admission to determine their mental health needs	Rapid Assessment Interface Discharge (RAID) psychiatric liaison service	United Kingdom (UK)	Parsonage M & Fossey M 2011. Economic Evaluation of a Liaison Psychiatry Service. London: Centre for Mental Health.
		Mental Health Liaison Teams	UK	Project overview available online: NHS South of England (2010) 'Mental Health Liaison Services supporting Bristol's older people'
Managing delirium in an acute care setting	To promptly identify and treat underlying conditions that precipitate delirium To establish baseline mental status as a key parameter for assessing delirium To improve the pharmacological and non-pharmacological management of delirium by providing clear guidelines to clinical staff	Delirium Superimposed on Dementia Algorithm (DSDA)	United States of America (USA)	Fick & Mion (2007).'Assessing and managing delirium in older adults with dementia'
		Intervention trial of an acute geriatric unit (AGU) by Naughton et al. (2005)	USA	Naughton et al. (2005). 'A multifactorial intervention to reduce prevalence of delirium and shorten hospital length of stay'
		Comprehensive geriatric assessment	USA Australia	Inouye et al. (1999). 'A multicomponent intervention to prevent delirium in hospitalized older patients' Traynor & Britten (2011). 'Delirium care pathways'
		Care of the Confused Hospitalised Older Person Study (CHOPS)	Australia (NSW)	ACI (2012)
Rehabilitation following a fall	To reduce the risk of post-operative complications and help patients regain function following a fall To reduce the likelihood of future hospital admissions from falls To help patients return to independent living	Randomised control trial by Huusko et al. (2000)	Finland	Huusko et al. (2000). 'Randomised, clinically controlled trial of intensive geriatric rehabilitation in patients with hip fracture: subgroup analysis of patients with dementia'

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Strategies within the hospital (continued)				
Rehabilitation following a fall (continued)		Randomised control trial by Stenvall et al. (2011)	Sweden	Stenvall et al. (2011). 'A multidisciplinary intervention program improved the outcome after hip fracture for people with dementia—subgroup analyses of a randomized controlled trial'
Specialist wards	To provide psychiatric rehabilitation for older people	Transitional Behavioural Assessment and Intervention Service (T-BASIS) units	Australia (NSW)	Bird et al. (2011). 'Evaluation of the T-BASIS Unit Initiative and Model of Care'
Joint geriatric and psychiatric wards	To enable geriatricians and psychiatrists to work collaboratively alongside nurses who have specialist training in dementia care	Joint geriatric and psychiatric wards: A review of the literature by George et al.(2011)	UK USA Australia Germany Netherlands	George et al. (2011). 'Joint geriatric and psychiatric wards: a review of the literature'
		Joint geriatric and psychiatric wards: Centre for the Elderly	Germany	Maier et al. (2007). 'Combined medical-psychiatric inpatient units'
Managing chronic infections	To improve the identification and treatment of chronic infections among people with dementia To prevent the onset of delirium caused by an unidentified infections	Retrospective study by Malyuk et al. (2012)	USA	Malyuk et al. (2012). 'The interplay of infections, function and length of stay (LOS) in newly admitted geriatric psychiatry patients'
Discharge planning	To ensure that people with dementia are discharged from hospital in a timely manner To ensure that people with dementia receive appropriate follow-up care post-discharge	Good Practice Checklist for discharging people with dementia	UK	UK Department of Health (2003) 'Discharge from hospital: getting it right for people with dementia'
		Transition Care Project	Australia (Victoria)	Spanio & Michales (2007). 'Transition Care Project: planning to assist transitions in care for people with dementia and their carers at home'
		ComPacks	Australia (NSW)	NSW Health (2006). 'Community Acute/Post Acute Care (CAPAC): Incorporating Hospital in the Home, Acute / Post Acute Care and other models'

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Strategies within the hospital (continued)				
Discharge planning (continued)	To provide early and appropriate identification of the discharge support needs of older people	Acute to aged-related care services (AARCS)	Australia (NSW)	AHMAC (2008). 'From hospital to home: improving care outcomes for older people 2006–07'
End-of-life care	To ensure that patients with terminal dementia are not subjected to aggressive hospital treatments that cause distress To shift the goals of end-of-life care from treatment to comfort at the appropriate time To establish advance care plans so that the wishes of the patient and family are taken into account	Intervention trial by Campbell & Guzman (2004)	USA	Campbell ML & Guzman JA (2004). 'A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia'
		'Let Me Decide' Advance Care Directive	Australia (Victoria)	Caplan et al. (2006). 'Advance care planning and hospital in the nursing home'
		Respecting Patient Choices Program	Australia	Silvester & Detering (2011). 'Advance care planning and end-of-life care' Silvester (2006). 'Final evaluation of the community implementation of the Respecting Patient Choices Program'
Hospital education program	To improve the awareness of dementia in hospitals	Hospital education program.	Australia (Victoria)	Foreman & Gardner (2005).'Evaluation of education and training of staff in dementia care and management in acute settings'
Interface positions	To provide integrated care To manage patients as they move between different care settings	Aged Care Nurse Practitioner Pilot Project	Australia (ACT)	ACT Health (2008).' Nurse practitioners in the Australian Capital Territory: the framework' Arbon et al. (2008). 'Reporting a research project on the potential of aged care nurse practitioners in the Australian Capital Territory'
		Clinical nurse consultants (CNCs)	Australia (NSW)	Hospital Dementia Services (HDS) observation
Information access	To share knowledge and awareness of evidence-based practice with staff who work in hospitals and care for people with dementia	The International Dementia Hospital Hub (Hospital Hub)	Australia UK	IDHH (2012). 'International Dementia Hospital Hub'

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Strategies outside the hospital				
Hospital-at-home services	To reduce the demand for hospital services by providing a viable alternative to inpatient care To facilitate early discharge from hospital by providing patients with post-acute care in their home	Geriatric Home Hospitalisation Service	Italy	Tibaldi et al. (2004) 'A randomized controlled trial of a home hospital intervention for frail elderly demented patients'
		Jerusalem Home Hospital Program	Israel	Jacobs et al. (2007) 'Closure of a home hospital program: impact on hospitalisation rates'
		Hospital care at home	UK	Arnold-Forster et al. (2010). 'Hospital care at home: supporting independent and healthy lives'
		Intervention trial by Lisk et al. (2011)	UK	Lisk et al. (2011). 'Geriatrician input into nursing homes reduces emergency hospital admissions'
		Community Acute/Post Acute Care (CAPAC) or Hospital in the Home (HITH).	Australia (NSW)	NSW Health (2006). 'Community Acute/Post Acute Care (CAPAC): Incorporating Hospital in the Home, Acute/Post Acute Care and other models'
Reducing hospital admissions from RAC facilities	To improve the management of ambulatory care sensitive conditions in the aged care home by providing intensive nursing care in a special care unit (SCU)	Intervention trial by Nobili et al. (2008)	Italy	Nobili et al. (2008) 'Alzheimer special care units compared with traditional nursing home for dementia care'
	To ensure that residential aged care (RAC) facilities have enough highly-trained nursing staff to manage the complex care needs of residents.	Intervention trial by Wild et al. (2008)	UK	Wild et al. (2008) 'Providing nursing support within residential care homes'
		US study by Porell & Carter (2005)	USA	Porell & Carter (2005). 'Discretionary hospitalization of nursing home residents with and without Alzheimer's disease: a multilevel analysis'
		Dutch model of care (Hertogh 2006)	Netherlands	Hertogh (2006). 'Advance care planning and the relevance of a palliative care approach in dementia
	To ensure that RAC staff are provided with regular advice and guidance from a GP.	Intervention trial by Lisk et al. (2011)	UK	Lisk et al. (2011). 'Geriatrician input into nursing homes reduces emergency hospital admissions'

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Strategies outside the hospital (continued)				
Reducing hospital admissions from RAC facilities (continued)	To avoid unnecessary hospital transfers during end-of-life by providing high-quality palliative care in the RAC facility.	'Let Me Decide' Advance Care Directive	Australia	Caplan et al. (2006). 'Advance care planning and hospital in the nursing home'
		Gold Standards Framework in Care Homes	UK	Ong et al. (2011). 'High mortality of older patients admitted to hospital from care homes and insight into potential interventions to reduce hospital admissions from care homes: the Norfolk experience'
		Service Delivery Model of Care for Dementia	Australia (WA)	WA Department of Health (2011) 'Dementia Model of Care'
Dementia outreach programs	To improve primary care services for people living in rural and remote communities	Dementia Behaviour Assessment and Management Service (DBAMS)	Australia (NSW)	Hales et al. (2006). 'National evaluation of the Aged Care Innovative Pool Dementia Pilot: Final report'
Diagnosis and early intervention	To address the difficulties in obtaining an accurate dementia diagnosis and assessment To ensure that people with dementia have timely access to formal assistance programs	Dementia Rehabilitation at Home	Australia (NSW)	Hales et al. (2006). 'National evaluation of the Aged Care Innovative Pool Dementia Pilot: final report'
Cross-sectoral strategies				
GP services and specialist advice	To reduce presentations to the emergency department	Residential In-Reach (RIR)	Australia (VIC)	Dench McClean Carlson (2009). 'Residential aged care in-reach clinical support pilot program evaluation'
		Aged Care Phone Triage service	Australia (NSW)	HDS observation
Integrated primary care	To maintain health and quality of life within the home To reduce the use of more costly health-care services, such as hospitals To identify alternative care pathways To outline best-practice strategies according to the individuals stage of dementia	'Skaevinge Project'	Denmark	Wagner (2001). 'Integrated health care for older people in Denmark: evaluation of the Skaevinge Project "ten years on"'
		Evercare Model	USA	Kane et al. (2003). 'The effect of Evercare on hospital use'

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Cross-sectoral strategies (continued)				
Integrated primary care (continued)		Alternative care pathways	UK	Bowen et al. (2007). 'Identifying alternatives to hospital care for people with dementia'
		Service Delivery Model of Care for Dementia	Australia (WA)	WA Department of Health (2011). 'Dementia Model of Care'
		Integrated approach	France	Comer (2009). 'French lessons: leadership in Alzheimer's disease' Lustman (2011). 'National French plan for Alzheimer and related diseases'
Behaviour assessment and management	To prevent hospital admissions for dementia, delirium, depression or other mental or behavioural disturbances To address the unmet need for psychogeriatric services in regional and rural communities	Dementia Behaviour Assessment and Management Service (DBAMS)	Australia (NSW)	Hales et al. (2006) 'National evaluation of the Aged Care Innovative Pool Dementia Pilot'
Coordinated care services	To create links across traditional health service boundaries to improve the delivery of health care services To coordinate continuing care through a single provider	Coordinated care pathway	UK	Kafetz & Bedford (2011).'Understanding out-of-hospital dementia care' Hales et al. (2006). 'National evaluation of the Aged Care Innovative Pool Dementia Pilot: final report'
Strategies within emergency departments				
Aged care services in emergency teams	To support the assessment and referral of patients with suspected cognitive impairment and/or delirium To improve the care and management of older people presenting to the ED	Adult Patient Assessment Tool	Australia (NSW)	HDS observation
		Acute Age Related Care Service	Australia (NSW)	HDS observation

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Strategies within emergency departments (continued)				
Rapid assessment and response services	To convert ED presentations to a 'phone, book and assessment' system to avoid long waiting times	Geriatric Rapid Acute Care Evaluation (GRACE)	Australia (NSW)	HDS observation
	To reduce waiting and assessment time in the ED To, where possible, avert the hospital admission of residential aged care clients	Aged Care Emergency (ACE) Emergency Department Senior Assessment and Streaming	Australia (NSW)	ECI NSW (2011). 'Emergency Care Institute New South Wales'
	To provide rapid assessment, diagnosis and treatment for non-critical medical patients	Medical assessment units (MAUs)	Australia (NSW)	ARCHI (2010) 'Australian Resource Centre for Healthcare Innovation'
		Older Persons Evaluation, Reviewand Assessment (OPERA) units	Australia (NSW)	HDS observation
Environmental strategies				
Dementia-friendly environments	To reduce stress and risk of adverse events for people with dementia	Dementia-friendly environments—Confused and Disturbed Elderly (CADE) units	Australia (NSW)	Leung & Todd (2010). 'Dementia care in the acute district general hospital' Fleming & Bowless (1987). 'Units for the confused and disturbed elderly: development, design, programming and evaluation'
Prevention of falls and associated injuries	To reduce the rate of falls among people with dementia	Multifactorial strategies to reduce falls and single interventions study by Campbell & Robertson (2007)	Australia (Victoria)	Campbell & Robertson (2007).'Rethinking individual and community fall prevention strategies: a meta-regression comparing single and multifactorial interventions' Rubenstein (2006). 'Falls in older people: epidemiology, risk factors and strategies for prevention'
		Reducing falls among older people in Victoria: better evidence, better targeting, better outcomes	Australia (Victoria)	NARI (2012). 'National Ageing Research Institute'

(continued)

Table A1 (continued): Literature review strategies

Strategy	Objective	Program/intervention	Location	Source/reference material
Environmental strategies (continued)				
Prevention of falls and associated injuries (continued)		'No Falls' peer education program	Australia (Victoria)	NARI (2012). 'National Ageing Research Institute'
		STAR Project	Australia (Victoria, Queensland and Tasmania)	NARI (2009). 'Star Project: final report'
Adapting the living space in the home	To minimise the reliance on formal care services To minimise the risk of avoidable hospitalisation	Dementia-friendly design guidelines	Australia	O'Sullivan (2008).' At home with dementia: a manual for people with dementia and their carers' Davis et al. (2009a). 'Guiding design of dementia friendly environments in residential aged care settings: considering the living experiences' Davis et al. (2009b). 'Environments that enhance dementia care: issues and challenges'
Strategies for the physical environment	To maximise independence To support people to remain safely at home for as long as possible	Evidence-based toolkit	Australia	O'Sullivan (2008). 'At home with dementia: a manual for people with dementia and their carers'
		Dementia Enabling Environment Project (DEEP)	Australia	Dementia Enabling Environments (2013). 'Dementia Enabling Environment Project'
Adapting the living space in residential aged care	To encourage involvement in daily activities	Living experiences	Australia	Davis et al. (2009a). 'Guiding design of dementia friendly environments in residential aged care settings: considering the living experiences' Davis et al. (2009b). 'Environments that enhance dementia care: issues and challenges'
Adapting the hospital	Improving the physical environment of hospitals for people with dementia	Australian hospital design manual	Australia	Fleming et al. (2003). 'Adapting the ward for people with dementia'

Appendix B: Data quality statement

Hospital Dementia Services (HDS) linked hospital data

Summary of key issues

- Without a patient identifier, hospital episode data provide an incomplete picture of the patient's hospital experiences and outcomes. The inclusion of a person identifier in the hospital data for this project allows the identification of: complete hospital stays; patient re-admissions; and people with a hospital diagnosis of interest (for example, dementia) in any of their episodes in the database.
- The post-hospital destination reported in the hospital episode data for people either returning to residential aged care or being admitted into such care often does not reflect the type of patient move actually being made. Data linkage between hospital and residential aged care data has been used to improve the identification of people moving from hospital to residential aged care.
- It is expected that people may provide different (possibly erroneous) personal demographic information on different occasions and some information might be missing. For the hospital data, the CHeReL (Centre for Health Record Linkage) used a probabilistic data-linking technique to identify episodes relating to the same patient. The Australian Institute of Health and Welfare used stepwise deterministic linkage to identify people moving from hospital to residential aged care. Both these processes involve uncertainty and so a small percentage of links may have been missed or matched incorrectly.
- of links may have been missed or matched incorrectly.

Description

The Hospital Dementia Services (HDS) hospital service use database is housed at the Australian Institute of Health and Welfare (AIHW). It contains data derived from the New South Wales Admitted Patient Data Collection (APDC) provided to AIHW using codes consistent with the National Hospital Morbidity Database housed at the AIHW (see <http://www.aihw.gov.au/publication-detail/?id=10737421633&tab=2> for a data quality statement for the National Hospital Morbidity Database).

Each record in the New South Wales APDC extract provided for the HDS Project related to an episode of care within a NSW hospital ending between 1 July 2005 and 30 June 2007 for a person aged 50 and over as at 1 July 2006. An episode of care for an admitted patient (or inpatient) can be either a total hospital stay—from admission into hospital to discharge from hospital or death—or a portion of a hospital stay—beginning and/or ending in a change in care type or hospital transfer. Episodes in both public and private hospitals are included.

Previous analyses have shown that the post-hospital destination reported in the hospital episode data for people either returning to residential aged care or being admitted into such care often does not reflect the type of move actually being made. Consequently, the hospital data for this project were linked to residential aged care data to derive information providing improved identification of people moving from hospital to residential aged care.

The hospital data extract provided for the project included a person identifier derived by the Centre for Health Record Linkage (CHeReL). Using this identifier, episodes in the database for a person were grouped into completed stays. The person identifier also allows identification of patient re-admissions and of people with a hospital diagnosis of interest (for example, dementia) in any of their episodes in the 2-year period covered by the database. Consequently, the database allows for analysis at the person, hospital stay and hospital episode levels.

Institutional environment

The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the *Australian Institute of Health and Welfare Act 1987* to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent statutory authority established in 1987, governed by a management board, and accountable to the Australian Parliament through the Health and Ageing portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The Institute also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The Institute works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national datasets based on data from each jurisdiction, to analyse these data sets and disseminate information and statistics.

The *Australian Institute of Health and Welfare Act 1987*, in conjunction with compliance to the *Privacy Act 1988* (Cwlth), ensures that the data collections managed by the AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.

For further information, see the AIHW website <www.aihw.gov.au>.

Timeliness

The HDS hospital service use database relates to hospital use within a NSW hospital between 1 July 2005 and 30 June 2007. The HDS database is a unique, linked database produced to undertake a series of analytical work for data specifically from this period; as such, the costing study in this report was not able to be done with more recent data.

Accessibility

A number of publications using the HDS database have been released. (see <http://www.aihw.gov.au/hospital-dementia-services-project/>).

The feasibility and possible costs of any proposals for further work involving the HDS database should initially be discussed with one of the HDS Project's contact officers in the AIHW (<phil.anderson@aihw.gov.au> or <rosemary.karmel@aihw.gov.au>). Researchers

may be able to access the HDS database if their study generally meets the following set of conditions:

- the study focuses on health issues
- the study has been approved by relevant ethics committees—this could include: the Cancer Institute NSW Human Research Ethics Committee; the University of Canberra Ethics Committee; the AIHW Ethics Committee; and any additional ethics committees required by the researcher's host institution
- the study has been approved by data custodians
- the study is scientifically valid (as judged by a peer review process)
- the study results will be placed in the public domain (e.g. published papers or books, conference presentations, feedback to patients)
- the study will not break confidentiality provisions
- the study investigators comply with the AIHW legislation under which the data are released.

Interpretability

The data items provided in the data extract use the same codes as those in the National Hospital Morbidity Database, with the exception of the linkage-based variable describing post-hospital destination. A data quality statement for the National Hospital Morbidity Database can be found at <http://www.aihw.gov.au/publication-detail/?id=10737421633&tab=2>.

Descriptions of the derivation of person dementia status, hospital stays and post-hospital destination are given in the AIHW publication *Deriving key patient variables: a technical paper for the Hospital Dementia Services Project*, and can be accessed at <http://www.aihw.gov.au/publication-detail/?id=60129542290>.

Relevance

The purpose of the HDS Project hospital services use database was to provide data which allowed the identification of patients with and without dementia and the statistical comparison of the hospital experiences and outcomes of the two groups in New South Wales in 2006–07.

Accuracy

Incorrect linkages can result because of errors or incorrect details in personal information supplied on different occasions—in either the hospital or residential aged care data. Probabilistic linkage methods were used by CHeReL to identify hospital episodes for the same person. The CHeReL's probabilistic linkage procedures are designed to achieve false positive and false negative rates around 5/1,000. A discussion of the accuracy of these links can be found at <http://www.cherel.org.au/quality-assurance>.

Stepwise deterministic linkage based on 5 letters of name, date of birth, sex, postcode of residence and transfer dates was used to link hospital patients and residential aged care residents to identify post-hospital destination (see <http://www.biomedcentral.com/1472-6963/10/41> for description). Comparisons in another project using a similar linkage process found that this linkage strategy was highly effective in identifying matches, with a positive

predictive value (PPV) of 99.7% and a sensitivity of 98.5% (see <http://www.aihw.gov.au/publication-detail/?id=10737418279>).

Coherence

Five per cent of hospital patients in the database did not have name information. Matches for these patients to residential aged care admissions were identified by matching hospital stays to residential aged care admissions and reported periods in hospital using transfer dates and date of birth, sex and postcode of residence. The quality of these matches is not as high as that using name information: in a previous study, the PPV of matches made using these data was around 98% with sensitivity of 90%.

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This report estimates the cost of caring for people with dementia in New South Wales hospitals, and presents strategies and practices being implemented in Australia and internationally that might improve outcomes and reduce care costs. The average cost of hospital care for people with dementia was generally higher than for people without dementia ($7,720 compared with $5,010 per episode). The total cost of hospital care for patients with dementia was estimated to be $462.9 million, of which about $162.5 million may be associated with dementia.