

# Advance care planning and hospital in the nursing home

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## Abstract

**Background:** the number of nursing home residents (NHRs) in hospital is increasing although hospital admission may be deleterious to their health.

**Objective:** to evaluate a system of educating residents, their families, staff and general practitioners about outcomes of dementia, advance care planning (ACP) and hospital in the home.

**Methods:** we employed one clinical nurse consultant, who utilised the 'Let Me Decide' Advance Care Directive. The intervention area consisted of two hospitals and the 21 nursing homes (NHs) around them compared with another, geographically separate, hospital and the 13 homes around it. We conducted a controlled evaluation monitoring emergency admissions to hospital.

**Results:** emergency calls to the ambulance service from intervention NHs decreased (intervention versus control; -1 versus +21%;  $P = 0.0019$ ). The risk of a resident being in an intervention hospital bed for a day compared with in a control hospital bed, per NH bed, fell by a quarter from being initially similar [Relative Risk (RR) = 1.01; 95% confidence interval (CI) 0.98–1.04;  $P = 0.442$ ] to being lower (RR = 0.74; 95% CI 0.72–0.77;  $P < 0.0001$ ). There was no significant change in mortality in the intervention homes, but in the control homes mortality rose in the third year to be 11.2 per 100 beds higher than in the intervention area ( $P < 0.05$ ).

**Conclusion:** ACP and hospital in the home can result in decreased hospital admission and mortality of NHRs.

**Keywords:** nursing homes, advance care planning, living with advance care directive, dementia, hospitalisation, home care services—hospital based, elderly

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## Introduction

The number of nursing home residents (NHRs) being admitted to hospital has been increasing [1, 2]. The resultant risk of iatrogenic complications is high [3], and many return in a worse state [4–7]. These residents, many of whom suffer from terminal dementia [8, 9], require appropriate care for their acute condition and specialised care for their chronic conditions. This specialised chronic care is difficult to replicate away from the nursing home (NH). Schemes to reduce admissions to hospital have been NH based, meaning an extra staff member in each NH, which limits generalisability [10].

There is evidence that treating residents in the NH improves outcomes. A study of hospital in the home (HITH) including 25% NHRs found that patients treated at home or in the NH experienced less confusion and other geriatric complications [11]. Three North American studies

found decreased mortality with treatment in the NH compared with in hospital [6, 7, 12]. Advance care planning (ACP) helps residents plan for their treatment to occur in the NH [12], but only 0.2% of Australian NHRs have a plan [13], and Emergency Department (ED) presentation is common and usually results in admission [14].

In late 2001, we set up a programme for residents aimed at improving their care by educating about dementia, encouraging ACP and the use of HITH where appropriate.

## Methods

The intervention was based at the Prince of Wales and St Vincent's Hospitals. This area is bounded on three sides by water and so is geographically relatively isolated.

We educated residents, their families, staff and general practitioners about the terminal nature of dementia, ACP and

HITH. ACP is the discussion held by a person with their health adviser, carers and families with the intent of framing an Advance Care Directive (ACD), a written, legally binding documents that express preferences for future medical treatment. HITH offers intravenous antibiotics and blood transfusions administered by a hospital outreach team. The service was offered to all NHs around Prince of Wales and St Vincent's Hospitals, both tertiary referral teaching hospitals. There were 21 NHs (one 40 bed facility closed during the course of the project) providing a total of 1,344 residential aged care beds for the  $\geq 65$ -year-old population of about 44,000 people.

The 'Let Me Decide' ACD was utilized as it includes the role of the 'person responsible' as substitute consent giver [15]. Capacity screening determined which residents were mentally competent [16]. This was a two-step process, with registered nurses performing the basic screening to exclude residents with severe cognitive impairment. Unexcluded residents were assessed by a Mini-Mental State Examination. Those who scored  $\geq 16$  were educated about ACDs, and their capacity was assessed via the Decisional Aid for Scoring Competency to Complete an Advance Directive [17]. In New South Wales (NSW), when a resident lacks capacity, a 'person responsible', defined under NSW law (Guardianship Act 1987) as the person/s able to give a substitute consent to medical treatment for an adult who is not capable of giving their own consent, may indicate via a plan of treatment (POT) the types of treatments for the resident to which they would or would not give consent, similar to the 'proxy plans' used in America [18].

Residents were individually registered in the programme if they gave their consent to ACP, and their NH agreed to participate. Where the resident lacked capacity to give consent, it was obtained from their 'person responsible'. The funding provided for the project specified that we could not conduct a randomised controlled trial. We have therefore collected data in a number of different ways, some retrospectively before the programme started and some prospectively after the programme commenced, but using the same method of data collection to ensure consistency. We recorded the number of referrals, how many discussions about ACP commenced and how many discussions proceeded to a written form of either an ACD (when completed by the resident) or a POT (when completed by the 'person responsible'). We monitored the subsequent ED presentations and hospital admissions for those referrals.

We also monitored the effect of the programme on the health system by measuring emergency ambulance calls from all the NHs in our area, emergency and elective admissions to hospital and bed-days occupied by residents in hospital. This was done by cross-matching the addresses for NHs with the Department of Health database of hospital admissions.

We have obtained control data from a nearby hospital within our area health service which has similar demographics but did not have such a programme, to control for other trends in the health system, such as possible increased ambulance diversion and the trend for increasing admission by NHRs. Statistical analysis was performed by comparing the results for the two areas, per NH bed.

To estimate the effects of the programme on health outcomes, we obtained data from the *NSW Registry of Births,*

*Deaths and Marriages* of the number of deaths registered to the address of each NH in the geographical areas served by the intervention and control hospitals. The total for each NH for each year was also divided by the number of beds in each NH, and this ratio was averaged across the two areas.

Approval was obtained from the hospital Research Ethics Committee. Statistical analysis was carried out using SPSS and Epi Info.

## Results

Of the 21 NHs approached, 19 agreed to participate, and educational meetings were held in each facility. Three meetings were also held with relatives, three with general practitioners and 15 meetings with a variety of community service providers.

During the first 12 months, referrals were received for 63 NHRs. Of these, 45 residents (71%) and their NHs agreed to proceed with ACP. Five of those residents (11%) were judged to have capacity, and their discussions and decisions were documented in their notes. Of those without capacity, one had previously completed an ACD with their GP and three 'persons responsible' completed a POT; for 20 residents, the discussion was completed and preferences for treatment were recorded in the notes, but no document was signed, and for 10 residents, the discussion was completed, but it was decided not to formally document anything in the notes. Six 'persons responsible' declined discussion of ACP. After a second 12 months, we found that of these 45 residents, 32 (71%) had died, 27 in their NH, three in hospital, one in hospice and one at home. All had died in the location specified in their declared wishes. Although few residents completed a plan, NH staff reported a significant culture change in attitudes towards hospitalisation.

The Ambulance Service data on the number of 000 (emergency) calls from NH showed that, comparing calendar year 2003 with calendar 2002, in our area these calls had decreased by 1%, whereas in the control area they had increased by 21% ( $P = 0.0019$ ). We observed a significant progressive decrease in NHRs being admitted to the intervention hospitals. In the first year, 2001/02, there was a 22.7% decrease in admissions from NHs, whereas at the control hospital the number increased by 4.2%. The marked decrease noted was not entirely due to HITH substituting for hospital, as HITH episodes of care from NH increased from 31 in 2000–01 to 37 in 2001–02. Over the next 2 years, we experienced a further 16.5% decrease in hospital admissions (overall 35.4% decrease in 3 years), whereas the control hospital increased by a further 15.2% (overall 20.1% increase over 3 years) [Please see the figure Appendix 1 in the supplementary data on the journal website (<http://www.ageing.oxfordjournals.org>)]. However, the annual rate of admissions of residents per NH bed was initially higher at the intervention hospitals (1.341 versus 1.044, RR = 1.07; 95% CI 1.03–1.11;  $P = 0.0005$ ), whereas by 2003–04, it was lower at the intervention hospitals (0.865 versus 1.254; RR = 0.89; 95% CI 0.85–0.93;  $P < 0.0001$ ) (Table 1).

Before the programme started, hospital bed-day use per NH bed was similar in both areas (9.441 versus 9.042; RR = 1.01; 95% CI 0.98–1.04;  $P = 0.442$ ), whereas after 3 years the rate was more than double in the control area (5.734 versus 12.755; RR = 0.74; 95% CI 0.72–0.77;  $P < 0.0001$ )

Table 1. Admission and mortality data

	1999–2000	2000–01	2001–02	2002–03	2003–04
Admissions of NH residents					
POW/StVH	1,730	1,802	1,393	1,198	1,163
POW/StVH per NH bed	1.287	1.341	1.036	0.891	0.865
Control hospital	450	546	569	645	656
Control hospital per NH bed	0.860	1.044	1.088	1.088	1.254
Relative risk of a NH resident being admitted to POW/StVH compared with control					
	1.10	1.07	0.99	0.94	0.89
95% CI	1.06–1.14	1.03–1.11	0.95–1.03	0.90–0.98	0.85–0.93
P value	<0.0001	0.0005	0.5214	0.0066	<0.0001
Bed-days occupied by NH residents					
POW/StVH	13,718.	12,689	8,878	7,730	7,707
POW/StVH per NH bed	10.207	9.441	6.606	5.751	5.734
Control hospital	5,193	4,729	5,284	5,669	6671
Control hospital/NH bed	9.929	9.042	10.103	10.839	12.755
Relative risk of a NH resident being in a hospital bed for a day, POW/StVH compared with control					
	1.01	1.01	0.87	0.80	0.74
95% CI	0.98–1.04	0.98–1.04	0.84–0.90	0.78–0.83	0.72–0.77
P value	0.629	0.442	<0.0001	<0.0001	<0.0001
People over 70 <sup>a</sup>					
POW/StVH area			33,405		
Control hospital area			19,229		
Mortality of nursing home residents per 100 nursing home beds					
POW/StVH area	29.7	32.1	30.2	29.5	30.3
Control hospital area	32.1	33.6	30.4	29.2	41.6

NH, Nursing Home; POW/StVH, Prince of Wales and St Vincents Hospital.

<sup>a</sup>Australian Bureau of Statistics—population estimates by age and sex, NSW, at 30 June 2002.

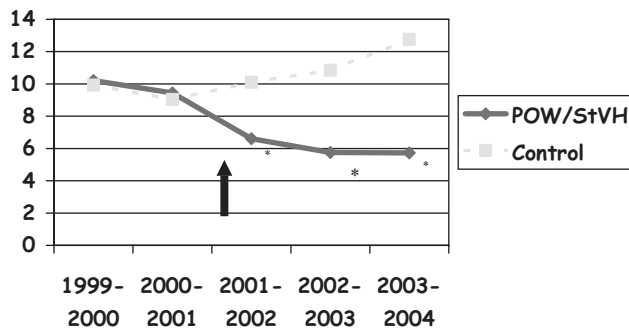


Figure 1. Bed-days occupied by nursing home residents per nursing home bed in the local area of the hospitals. Arrow indicates start of programme. \* $P < 0.0001$ ; POW/StVH, Prince of Wales and St Vincent’s Hospital.

(Table 1 and Figure 1). By the third year, the bed-day saving equated to 10,000 per annum [Please see the figure Appendix 2 in the supplementary data on the journal website (<http://www.ageing.oxfordjournals.org>)].

There was no significant difference in annual mortality between the NH in the intervention or control areas, except for the third year of the programme when the rate rose in the control NHs (30.4 versus 41.6 deaths per 100 beds;  $P = 0.0425$ ) (Figure 2).

## Discussion

We implemented a system of education about the terminal nature of dementia, promoting ACP and HITH in the NH,

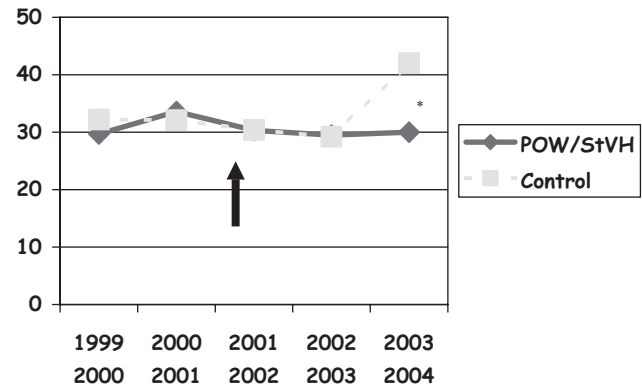


Figure 2. Mortality of nursing home residents per 100 nursing home beds in the nursing homes in the Prince of Wales and St Vincent’s Hospital (POW/StVH) areas compared with the control hospital’s area. Arrow indicates start of project. \*Comparing the two groups for 2003–04 ( $P < 0.05$ ).

which was associated with marked decreases in the use of emergency ambulance and hospital admission by residents and decreased mortality.

Intuitively, someone watching the NH system might assume that residents must be hospitalised when they are acutely ill, for their own benefit [19]. However, for a long time, doctors who care about what happens to residents have been looking for ways to reduce these transfers and the risks of relocation trauma and hospitalisation [1, 3]. Some authors have not been so restrained, describing the

effects of 'brutal hospitalization' on NHRs [4], with hospitals described as places where residents receive futile, but 'gruelling procedures' [5].

The reasons for poor outcomes are manifold. Many residents are in the final stages of terminal diseases, mainly dementia [8, 9], but elderly people with end-stage cardiac, respiratory and non-dementing neurodegenerative diseases may also be admitted to NH. In Australia, 78% of residents have either a diagnosis of dementia or significant cognitive impairment consistent with dementia [20], whereas in the US, many people are admitted to NHs for short-term rehabilitation [21]. Acute exacerbations are a feature of many of these chronic diseases, which require good maintenance and occasional fine rebalancing of treatments, but over-vigorous investigation or treatment is often counterproductive. Because of their frailty, many residents require regular repositioning in a gentle manner to prevent skin tears and decubitus ulcers. Because of their mental state, they may be restrained in hospital, which leads to more problems [22]. Because of their medical instability, they require carefully maintained routines with multiple steps, most of which they cannot remember so that they cannot remind ED or ward staff when steps are omitted.

We have not conducted a detailed economic analysis of this scheme, but a previous detailed economic analysis that we conducted shows that HITH treatment is less than half the cost of in-hospital treatment [23]. Although this scheme does undoubtedly allow more efficient use of the health system, our motivation for introducing it is to improve care for residents by preventing unnecessary and unhelpful transfers to hospital, not to prevent all transfers. We do not believe that NHR should never be admitted to hospital. There are some clear indications for hospitalisation which can almost never be managed in a NH, such as a fractured neck of femur.

The ACDs and POTs we describe are not euthanasia; no active steps were taken to shorten anybody's life. There was no significant difference in mortality between NHRs in the two areas, until the third year of the programme, when it was 11.2% lower in the study area ( $P < 0.05$ ). It has been widely observed that admission to NH is happening at an older age and permanent residents are having shorter stays. Because very few permanent residents are discharged alive, annual mortality must be increasing. The evidence from the only randomised controlled trial of ACD in NH showed that in the NHs where ACDs were implemented, mortality decreased by 4% per year, from 20.6 to 16.3%, suggesting a number of 25 needed to treat to prevent one death, whereas in the control NH where residents continued to be transferred to hospital in similar numbers, annual mortality increased by 1% [12]. The reduction of mortality, against the usual trend, by avoiding transfer to hospital, confirms two observational studies [6, 7] and multiple anecdotal observers that hospital treatment is difficult for NHR [1, 3–5].

One should not assume that life was extended for very long. People admitted to NHs have short subsequent life expectancies. Of those admitted with advanced dementia, 71% die within 6 months compared with 92% with terminal cancer [8]. It is an important principle of palliative care, which all these residents are receiving in one form or another, that

quality of life be maximised, and it should be done so according to the viewpoint of the resident. ACDs and POTs are methods of ensuring that this will be so. They also seem to protect the resident from harmful transfers to hospital.

As this was not a randomised controlled trial, we cannot be certain that the changes we have observed were caused by our programme. However, the control hospital data confirmed the expected trend of increasing admissions and mortality. The populations of the two areas are demographically similar, but not identical in size or composition. The hospitals are also different: the interventions are tertiary referral teaching hospitals, whereas the control is a district hospital that does not have a HITH.

These results, a large impact on admissions to hospital despite a relatively small number of ACDs and POTs completed, because people are reluctant to sign these documents as they felt a signed document was too constraining if they needed to change their mind, indicate people absorbing the lessons of ACP and thus a culture change occurring. Part of the culture change occurred in the emergency services. The relative decrease in emergency ambulance calls is not as great as the decrease in admissions and use of hospital bed-days. This suggests that some residents were either being assessed by the ambulance officers and not transported to hospital or after arriving in the ED and being assessed, they were returned to the NH for treatment there. Our ED tells us they have noticed a perceptible decrease in the number of residents being treated there, but we have no data on this.

However, a much greater culture change occurred in the participating NH and amongst residents and their families. We found that most families said that previously no one had explained to them what the natural history of dementia was or that their relative in a NH was actually dying. They were relieved to have this information, which allowed them to think more clearly about what treatment would be helpful and what would not.

NH staff also reported a culture change. They felt better able to discuss ACP with residents and their families, in some cases incorporating the discussion into a routine interview, rather than waiting till the resident suffered an event that might require transfer to hospital, and felt better for being proactive. Staff also felt more comfortable with the decision not to hospitalise the resident because they knew the families' opinions. Staff in one NH reported that they started receiving comments such as 'it was as they would have wanted it' or 'they would not have wanted to die in hospital' after residents died peacefully in the NH, because families were happier with a good death amongst friends and loved ones in the NH.

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### Key points

- Education about dementia and ACP in NHs leads residents to receive treatment for acute illness in the NH rather than in hospital.
  - Decreasing NHRs' admissions to hospital decreases their mortality.
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## Supplementary material

Supplementary material is available online at <http://humrep.oxfordjournals.org/>.

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NSW Department of Health Chronic and Complex Care Implementation Group.

## Conflicts of interest

There are no competing conflicts of interest. B. Squires and W Willett work for NHs in the intervention area.

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