Palliative Care Provision in ACT Residential Aged Care Facilities

A report by Alzheimer’s Australia ACT
Vikki McDonough BSc (ANU)
May 2006
Table of Contents

Executive Summary 1

Introduction 4

Scoping Study Assessing the transfer arrangements between the sectors 5

Outcome 1 Protocols and Procedures on decision making 17

Outcome 2 Assessment of Hospital in the Home arrangements 24

Outcome 3 Mechanisms to facilitate the return of aged palliative care patients 27

Outcome 4 Improved continuity of care 29

Appendix A Questionnaire and interview questions for Aged Facilities. 32

Appendix B What is Advanced Care Planning? How do I make an Advanced Care Plan? 35


Appendix D Directors of Care responses to “Do you think your current overnight staffing levels impact on the provision of palliative care in your facility? In what way?” 38

Appendix E Directors of Care responses to “What is your opinion of a ‘fly in squad’?” 40

Appendix F Directors of Care responses to “Do you have any ideas on what more could be done to assist aged palliative patients to return ‘home’ from hospital to die?” 42

Appendix G Directors of Care responses to “Do you have any suggestions on what could be done to improve the continuity of care for patients who have to transfer between your facility and hospital? What is working well and what could be improved?” 44

Figures

Figure 1 Number of operational places in residential aged care facilities in the ACT August 2005 6

Figure 2 Number of operational places in nursing homes in the ACT August 2005 6

Figure 3 Number of operational places in hostels in the ACT August 2005 7

Figure 4 Number of residents who died in residential aged care facilities in the ACT July 2004 – June 2005 8

Figure 5 Number of hospital leave days for residents from aged care facilities in the ACT July 2004 – June 2005 8

Figure 6 Presentations to Emergency Departments in the ACT of individuals with a referral source ‘residential aged care’ July 2004 – June 2005 9
Table 1
In your experience what are the main reasons aged palliative care patients end up dying in hospital rather than returning to their facility? (Question 7 Questionnaire Appendix A)

Table 2
The term advanced care directive means giving directions about one’s care in advance of incompetence. Does your facility recommend or require any of the following? (Question 12 Questionnaire Appendix A)

Table 3
After hours care

Table 4
Fate of aged care residents assessed in hospital for palliative care needs from January 2005 to March 2006
Executive Summary

Twenty three residential aged care facilities in the ACT had a total of 1565 operational places as of August 2005. 632 of these places were located in seven nursing homes and 933 were in hostels.

During the 2004–2005 financial year Directors of Care across twenty facilities reported that 356 residents from a resident population of 1362 spent more than 24 hours away from their facility on hospital leave.

Collected data and anecdotal evidence from both hospital staff and facilities indicate that this group of people were transferred primarily for the purposes of receiving acute care; for investigations, the management of infections and fractures. Directors of Care consistently stated that it was rare for individuals for whom there was an acknowledged clinical intent for palliative care to be transferred, or alternatively for individuals to be transferred for the purposes of receiving palliative care.

These statements were further evidenced by;

- Data collected by ACT Health which identified 152 episodes of individuals presenting to Emergency Departments from residential aged care facilities. Of these 76 were assessed as needing acute care and were admitted to hospital.

- Information collected by the Australian Institute of Health and Welfare which stated that there were 396 episodes of palliative care separations in the ACT in 2004 – 2005. 354 of these occurred at Clare Holland House of which 6 episodes (identified from the records of Clare Holland House) involved individuals from residential aged care facilities.

- The Canberra Hospital Palliative Care Service assessed 692 patients since data collection commenced in January 2005. Of these 62 or approximately 8.9% were residents from aged care facilities and of these 23 were returned to their facilities for the provision of palliative care.

- Directors of Care from across all facilities in the ACT reported a total of 446 deaths for the 2004-2005 financial year, 289 in nursing homes and 157 in hostels. Of the 289 deaths in nursing homes 31 occurred away from the facility, in other words nursing homes looked after 89% of those residents that died, within their facility as opposed to transferring them elsewhere. They also provided virtually all of these residents with some form of palliative care. The corresponding figures for hostels are 40 deaths out of 157 occurred away from facilities which equates to the provision of palliative care to 75% of those that died on site.

- Finally the Home Based Palliative Care team which operates out of Clare Holland House provides specialist palliative care support to staff in residential aged care facilities and to residents’ GPs. Their goal is to enable facility staff and GPs to manage residents with complex needs that are beyond the expertise of the primary care providers – and to manage those residents in the facility which is their home. During 2004-2005 the Home Based Palliative Care team conducted 37 consultations to residents across 16 facilities in the ACT with 107 corresponding follow up visits.

In summary the bulk of residents that died in aged care facilities in the ACT during the period July 2004 – June 2005 received palliative care within their facility. Facilities accessed the services of the Home Based Palliative Care Team for support with the management of residents with complex needs that were beyond the expertise of staff and GPs. Those residents that received palliative care away from their facility were most likely to have been originally transferred for acute care. These people either died during the acute episode or did not return to their facility because of, family wishes or they had care needs that were beyond the capacity of the organization. With regards to the process of transferring people for the purposes of receiving palliative care, the direction of these transfers is primarily from hospital back to the residential aged care facilities.
Recommendations

The following recommendations speak to the four outcomes originally proscribed for this project by the Palliative Care Partnership Team, a local advisory body on the issue of palliative care in the ACT. The outcomes sought to determine how best to assist aged patients when there is a change in their health status, that requires them to transfer between acute, geriatric and palliative care services for the purposes of receiving palliative care.

Outcome One: Protocols and Procedures on decision making
- Residential aged care facilities take a proactive role in raising the awareness of potential residents and their family members regarding the importance of planning for future medical decision making. This would involve providing information during pre-admission contact on advanced care planning and the Power of Attorney form used in the ACT.
- Facilities consider the identified model of best practice regarding palliative care policy.
- Facilities consider the identified model of best practice for procedures for the canvassing and documenting of residents wishes with regards to their end of life care either during or shortly after the time of admission.
- Facilities consult the ‘End of life care and decision making’ document produced by NSW Department of Health for the provision of decision making guidelines on the management of acute care episodes.

Outcome Two: Assessment of the Hospital in the Home arrangements
- The Hospital in the Home service could not, in its current form be considered appropriate for assistance with the provision of after hours palliative care in residential aged care facilities within the ACT.
- Further investigation be undertaken to ascertain the feasibility of establishing an after hours ‘fly in’ service for assistance with the provision of palliative care to residents in aged care facilities – particularly hostels where there is no registered nurse available on site overnight.

Outcome Three: Mechanisms to facilitate the return of aged palliative care patients to their facility following an acute episode requiring specialist palliative care
- Given the small number of aged care residents who receive specialist palliative care away from their facilities there is currently no need to establish and implement standard mechanisms for the return of these individuals. Negotiation on a case by case basis is the most appropriate mode of operation under the present circumstances.

Outcome Four: Improved continuity of care
- Continuity of care and the return of palliative patients from hospital will not be greatly assisted by the provision of written resources to facilities or hospitals. What is required is a better working relationship between the two sectors and particularly for hostels greater and more consistent provision of practical support. Within this framework the following recommendations are made.
  - Transfer arrangements
    Aged care facilities are given 24 hours notice of discharge of palliative care patients, unless negotiated otherwise with a director of care.
    Palliative care patients should not be returned on Friday afternoon, at night or on the weekend.
  - Improved information exchange
    Aged care facilities are given the opportunity to be involved in case conferencing of residents in hospital with palliative care needs.
Hospital staff involved in discharge planning should gain an understanding of the capabilities of individual nursing homes and hostels or at least consult the expertise available in Ward 11A.

Hospital staff should provide a completed and legible discharge summary and medication chart when a patient is discharged from hospital back to their aged care facility.

Consideration should be given to the appointment of a discharge planner within both The Canberra Hospital and Calvary, dedicated solely to residents from aged care facilities.

- Family education

Repeated and timely opportunities are provided by aged care facilities for residents and their families to undertake advance care planning.

Advanced care plans should accompany residents to hospital and back.

- Required resources

Hospital staff need to ensure a supply of discharge medications and appropriate scripts accompany a resident on their return from hospital. If required by the facility this medication should be presented in a Webster pack.

That where appropriate a referral to the Home Based Palliative Care team be organized prior to a resident being discharged from hospital.

If support services are not going to be re-instated then consideration should be given to the provision of costly bandages to aged care facilities accepting a patient with complex wound management.
Introduction

The main focus of this project is to report on the transfer of aged persons between acute, geriatric and palliative care services within the ACT for the purposes of receiving palliative care.

‘Palliative care is the specialized care provided to a person whose condition has progressed beyond the stage where curative treatment is effective and attainable, or where the person chooses not to pursue curative treatment. A person receiving palliative care will have an active, progressive and far-advanced disease, with little or no prospect of cure. The central aim of palliative care is to achieve the best quality of life, both for the person who is dying and for their family.’

The Commonwealth Department of Health and Aging’s National Palliative Care Strategy recognizes that palliative care:

• Affirms life, and regards dying as a normal process
• Neither hastens nor postpones death
• Provides relief from pain and other distressing symptoms
• Integrates the physical, psychological, social, emotional and spiritual aspects of care, with coordinated assessment and management of each person’s needs
• Offers a support system to help people live as actively as possible until death
• Offers a support system to help the family cope during the person’s illness and in their bereavement

This project has been undertaken by Alzheimer’s Australia ACT, funded as part of the National Palliative Care Program and administered by ACT Health.

The following report consists of two components:

1 A scoping study that investigates the current transfer arrangements of residents from aged care facilities for the purposes of receiving palliative care; and

2 Reporting against the four outcomes listed below, proscribed by the Palliative Care Partnership team, a local advisory body on the issues of palliative care in the ACT. The outcomes sought to determine how best to assist aged patients when there is a change in their health status, that requires them to transfer between acute, geriatric and palliative care services for the purposes of receiving palliative care.

• Development of a set of protocols and procedures on decision making for use in residential aged care facilities to assist with the provision of high quality, effectively planned care for people in aged care facilities who have palliative care needs
• An assessment of Hospital in the Home arrangements to determine the suitability for palliative care patients requiring outside hours assistance.
• Identification of mechanisms to facilitate the return of aged palliative care patients to a residential aged care facility following an acute episode requiring specialist palliative care.
• The development for implementation of new resources to improve the continuity of care for aged persons who, as a result of a change in their condition, are required to transfer between facilities to receive palliative care.

1 Australian Institute of Health and Welfare 2003. Admitted patient palliative care in Australia 1999-00. AIHW cat.no.HSE 27
Scoping Study

Assessing the transfer arrangements between the sectors

The first and most basic step towards gaining a clearer picture on the issue of aged persons transferring between the geriatric, acute and palliative care sectors in the ACT is to document what transfers are currently occurring. This was determined by approaching the organizations involved in this process and analyzing the various datasets held. Data was also collected directly from management staff in aged care facilities in the ACT via a questionnaire and interview process conducted in November/December 2005 and March 2006.

This section names the organizations from which data was requested and describes and presents the data made available. It also describes the methodology used, and the pertinent results collected from the questionnaire and interview process with the Directors of Care / Care Managers / Village Managers of the 23 aged care facilities in the ACT. A brief analysis is subsequently made of the information collected.

Commonwealth Department of Health and Aging

Information obtained from the Commonwealth included, the number of operational places in each of the 23 facilities in the ACT, the number of deaths in facilities and the number of hospital leave days used across all facilities. As part of their funding arrangements with the Commonwealth, residential aged care providers are required to present on a monthly basis data regarding resident leave and separation from their facility. Consequently de-identified information on the number of deaths in facilities and the number of hospital leave days used across all the facilities is available. While this data provides reliable aggregate figures it gives no detail on the reasons for hospital leave.

As shown in Figure 1 in August 2005, there were 1565 operational aged care places within the ACT, of which 632 were in nursing homes and 933 in hostels.

Figure 2 indicates that the 7 nursing homes in the ACT ranged in size from 52 to 134 beds. Across the 16 hostels there was a much greater variety of sizes, ranging from 20 to 102 (Figure 3). It is important to note however, that the majority of aged care facilities are connected through ownership networks both within the ACT and more widely throughout Australia.

Across all the facilities 419 residents died during the 2004/2005 financial year. 283 of these were in nursing homes and 136 in hostels. The range in number of deaths was from 29 to 55 for nursing homes and from 1 to 23 for the hostels. Six hostels had less than five deaths across the year. Thus palliative care is provided much less frequently in hostels than nursing homes.

With 1565 operational places and 419 deaths, the ACT during the 2004/2005 financial year experienced a deaths to beds ratio of 27%. For the year 2003/2004 the ratio of deaths to beds was 26% across Australia.

The total number of hospital leave days was 7,283; 2,156 were from nursing homes and 5,127 from hostels (Figure 5). The Commonwealth data does not give any detail about the proportion of these days that involved palliative care. Nevertheless other data, discussed below, indicates that it is a low proportion, with most hospital leave being associated with the provision of acute care.

---

4 Commonwealth Department of Health and Aging – September 2005
Figure 1
Number of Operational Places in Residential Aged Care Facilities in the ACT August 2005

Figure 2
Number of operational places in Nursing Homes in the ACT August 2005
Figure 3
Number of operational places in Hostels in the ACT August 2005
ACT Health – Hospital records

ACT Health maintains two data sets of interest to this project, one on patients presenting to Emergency Departments, the other on patients admitted to care. Information is collected and collated from both The Canberra Hospital and Calvary, and records presentations and episodes. This means that individuals who present or alternatively are admitted more than once in the course of the year will have more than one record in the database. Of interest, are patients who either presented to the Emergency Department or were admitted whose source of referral was residential aged care. The data has limitations as residents can be admitted under a number of other referral sources. With regards to the Emergency Department data, in cases where a resident has been seen by their GP prior to presentation at the Emergency Department they may be categorized as referred by GP, rather than an aged care facility. With regards to Inpatient data if a resident proceeds through the Emergency Department to be admitted their source of referral is Accident and Emergency. Most other residents admitted within the hospital system have their source of referral as either Specialist or GP. As a result only a small proportion of admitted patients from aged care facilities can be identified in the data.

During the period July 2004 – June 2005 there are records of 152 presentations of aged care residents to Emergency Departments within the ACT. Of these 71 were returned to their aged care facility without being admitted and 76 were assessed as in need of acute care and admitted. Three were referred to another hospital (Figure 6).

Regarding the inpatient records there is an inconsistency with only 48, of the above mentioned 76 referrals from the Emergency Department identified, along with 573 referrals directly from aged care facilities. Inpatient records identify 621 episodes, across 64 individuals from residential aged care facilities. Eight of these individuals came from outside the ACT. 561 of these episodes were for renal dialysis, and every other episode was associated with acute care. Acute care is however the default category under which patients are routinely admitted to the hospital. Palliative care could be a subset of the 60 acute episodes, but the data is not discriminating enough to determine this (Figure 7).

---

7 Data requested and released from Information Management Section ACT Health in August 2005.
8 Follow up conversations and e-mails with the Manager of Hospital Reporting Section October 2005

8 Conversation with a representative of Hospital Records ACT Health 30th March 2006
Currently the state and territory authorities provide data on palliative care separations from hospitals to the Australian Institute of Health and Welfare for collection in the National Hospital Morbidity Database. Within this data set is information on admitted patients receiving palliative care in all public and private hospitals, and private free standing day hospital facilities. Records detail the number of separations as opposed to the number of patients, so patients who had more than one episode of palliative care in the year will have more than one record in the data base. Limitations in this data are that it may under represent the number of palliative care separations in total. This is because patients who undergo an acute phase of care in hospital, followed by a palliative phase of care, without being physically discharged from the hospital, may not have a statistical separation recorded between the phases. In addition, it is not possible to identify within the data, residents from aged care facilities as a category of care recipients. Unfortunately at this stage an inclusion code that will identify patients admitted from aged care facilities for palliative care is still only being considered.9

The ACT component of the Morbidity data for the financial year 2004/200510, identifies 396 palliative care separations, 354 of these occurred in a “designated unit” (Clare Holland House). The remaining 42 episodes were coded as “palliative principal clinical intent”, meaning that a patient is principally managed by a medical practitioner who is a specialist in palliative care or when, in the opinion of the treating medical practitioner, the care provided is palliative, even if the doctor is not a palliative care specialist11 (Figure 8).

In summary the Morbidity data tells little about palliative care and residents from aged care facilities, other than only a small number of people are identified as undergoing palliative care within the ACT hospital system. As opposed to the 396 separations for palliative care, the hospitals had 65,751 separations for other care types.

10 Data requested from and released by Information Management Section ACT Health – December 2005. Follow up personal conversations 2006
Clare Holland House

Information was requested and obtained from records kept by Clare Holland House regarding the number of patients cared for in the hospice who came from residential aged care facilities in the ACT. In total six residents from facilities within the ACT were admitted either for the purposes of complex symptom management and support or end of life care during July 2004 – June 2005 (figure 9). All died at Clare Holland House. For three individuals the duration of their stay was five days or less. For the other three the length of stay ranged from 33 – 113 days (figure 10).

The Canberra Hospital Palliative Care Service

The Clinical Nurse Consultant based at The Canberra Hospital, provided the following data, collected by the Palliative Care Service, commencing January 2005 till March 2006. During this time 692 patients were assessed for the provision of palliative care. Of these 34, or approximately 4.9% were from nursing homes and 28, or approximately 4% were from hostels (figure 11). All of these patients would have been initially assessed and admitted for an acute episode.

Figures 12 and 13 show the locations in which patients from aged care facilities, assessed by the team, subsequently received palliative care.

Of the hostel patients, ten were provided with palliative care within the hospital, five were returned to their facility, nine went to the hospice and four were assessed as not for palliative care.

Eighteen patients from nursing homes were returned to their facility, while fourteen received palliative care in hospital and two were assessed as not for palliative care.
Aged Care Facilities – Questionnaires

Questionnaires were developed to gain information from aged care facilities on the transfer of residents for the purposes of receiving palliative care. Expert opinion on the various project outcomes was also canvassed through the questionnaire (see Appendix A).

Development of the questionnaire occurred in consultation with:

- Deborah Parker, Chief Investigator, Department of Palliative and Support Services, School of Medicine, Flinders University South Australia. Deborah was consulted for authorization to use questions developed by a South Australian research team into palliative care in residential aged care13. Questions 1, 2, 3, and 8 were taken directly from the questionnaire developed by Deborah’s team and questions 7 and 12 were also taken and adapted for the purposes of this project (see Appendix A).
- Dr Mike Bird, Senior Clinical Psychologist, Co-ordinator Aged Mental Health, Southern Area Health Service. Mike was consulted in October 2005 and suggested the use of a semi structured interview process to capture a richer data set than would be available simply through the use of a questionnaire.
- Helen Walker, Manager Education Services, Alzheimer’s ACT. Provided feedback and supervision.

In November 2005 an introductory letter and questionnaire was mailed out to the 23 individuals who held positions such as Director of Care, Care Manager or Village Manager in residential aged care facilities throughout the ACT. Follow up visits to collect information and conduct interviews occurred across a three week period in November/December 2005. In the introductory letter facility staff were given background to the project and assured that information they provided would not be identified specifically with their organization.

In order to maximize the potential response rate to the questionnaire the number of questions was limited to 12, that is, the number that could be formatted onto both sides of one page. Statistical

---

information was requested on the basis of knowledge of figures that facilities are required to submit monthly to the Commonwealth as opposed to information that would require staff to access individual residents notes. Follow up interviews were brief, taking approximately 15 minutes of people’s time, although most gave more than this.

A 100% response rate was achieved. Questionnaires were returned from all facilities and interviews were conducted with 21 management staff across all 23 facilities. In one instance a Director of Care spoke on behalf of both the nursing home and hostel components of her facility, in another the Care Manager spoke on behalf of the specialized dementia unit and the hostel component of her organization.

While Appendix A provides full details of the questionnaire and interview questions, the following lists those relevant to the scoping section of this report, that is the transfer of patients for the purposes of receiving palliative care:

**How many residents died in your facility during the 2004-2005 financial year?**

**How many residents died away from your facility (ie in hospital) during this same period?**

**How many residents had leave from your facility to hospital during the 2004-2005 financial year?**

**In your experience what are the main reasons aged palliative care patients end up dying in hospital rather than returning to their facility? (tick more than one)**

- Family wishes
- Resident wishes
- Care needs beyond the capacity of the organization
- Rapid deterioration
- Acute care episode
- No high care beds available if resident low care or independent living

Other reasons?

Figures 14 and 15 show the number deaths of aged care patients within and outside aged care facilities. 258 of the 289 deaths in nursing homes occurred within their facility, which translates to facility staff providing some form of palliative care to approximately 89% of those residents who died during July 2004 – June 2005. The corresponding figure for hostels is 117 of the 157 deaths or approximately 75% of deaths of hostel patients occurring on site with some form of palliative care being provided.

Data collected in South Australia found comparable results with 89% of deaths in high care and dual care facilities occurring on site and 11% occurring elsewhere. For low care facilities however, 64% of deaths occurred away from the facility with only 36% taking place on site – a virtual reversal of the situation in hostels in the ACT.14

![Figure 14](image)

**Figure 14**

Number of residents who died in nursing homes in the ACT July 2004 – June 2005

![Figure 15](image)

**Figure 15**

Number of residents who died in hostels in the ACT July 2004 – June 2005

---

The total number of deaths, 446, differed from the 419 identified in the Commonwealth data described previously. This is a 6% discrepancy. It is likely that the Commonwealth data is more accurate as it is presented by facilities on a monthly basis for funding purposes, while the questionnaire figures required staff to add up totals across the 2004-2005 financial year. Nevertheless the questionnaire figures allow investigation beyond that of Commonwealth data as they provide detail on the number of deaths away from facilities along with corresponding comments and opinion from management staff.

Nursing homes reported 159 of their 632 residents spent at least 24 hours away from their facility on hospital leave during 2004-2005, while of the 13 hostels that provided this information 197 out of a total resident population of 730 spent at least 24 hours away on hospital leave. The exact relationship of these hospital transfers to the provision of palliative care is unknown. However, as detailed below, transfer for palliative care is considered to be low by the aged care directors. An opinion supported by the ACT health data described previously.

As asked to name the main reasons why aged palliative care patients end up dying in hospital (the total figure being 71 deaths away from facilities for 2004-2005) rather than returning ‘home’ to their facility the responses were as follows;

Table 1

In your experience what are the main reasons aged palliative care patients end up dying in hospital rather than returning to their facility? (Question 7 Questionnaire Appendix A)

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Nursing Home n = 7</th>
<th>Hostel n = 16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family wishes</td>
<td>71%</td>
<td>37%</td>
</tr>
<tr>
<td>Residents wishes</td>
<td>28%</td>
<td>12%</td>
</tr>
<tr>
<td>Care needs beyond the capacity of the organization</td>
<td>14%</td>
<td>75%</td>
</tr>
<tr>
<td>Rapid deterioration</td>
<td>28%</td>
<td>44%</td>
</tr>
<tr>
<td>Acute care episode</td>
<td>86%</td>
<td>81%</td>
</tr>
<tr>
<td>No high care beds available if resident low care or independent living</td>
<td>37%</td>
<td></td>
</tr>
</tbody>
</table>

One facility also mentioned that they had incidents of residents transferring to hospital for scheduled surgery, investigations and or procedures and then not returning having died in hospital.

Finally a brief telephone survey was conducted in March 2006 in which staff were re-contacted and asked to respond to the following question.

You stated in your questionnaire response that x number of residents died in your facility during the 2004 – 2005 financial year, and y away from your facility. Was it necessary to transfer any of these residents for the purposes of receiving palliative care, that is they had palliative care needs beyond the capacity of your organization?

Staff were not given the time nor were they expected to provide an answer based on a search of resident notes but rather to give a generalized response on the basis of their memory and their working knowledge of procedures in this area.

Five responses from Directors of Care in nursing homes were collected along with 14 responses from Care Managers/Directors of Care in hostels.

The responses from nursing homes are as follows;

- On the whole we do not transfer residents for whom there is a clinical intent for palliative care. We have however had one resident transfer to Calvary Hospital for an acute episode and then transfer to the hospice.
- We have had no transfers for palliative care – if this was necessary it would be negotiated through the Home Based Palliative Care team
- We have had an incident where a patient was being managed for palliative care and subsequently had an acute episode for which the family members requested a transfer to hospital. The resident was subsequently transferred to the hospice. This however is not a common event.
- The remaining two Directors of Care simply stated they have had no transfers for the provision of palliative care.

The responses from hostels are as follows;

- We have had an incident where we transferred a resident for an acute episode who subsequently became palliative but could not be returned to the facility as she had mobility needs beyond the capacity of the organization.
Residents with palliative care needs tend to be transferred to the nursing home part of the organization to enable them to be managed within the facility rather than being transferred elsewhere.

Once a clinical intent for palliative care has been acknowledged by the family and GP residents are not transferred.

We have had residents transferring back from the hospital for the provision of palliative care by us. We draw on the Home Based Palliative Care team for support if we need it. Residents would not be transferred to the hospice as it is acknowledged that we can provide palliative care here. Generally residents are not transferred once the clinical intent for palliative care is accepted by the family and GP.

Sometimes patients who could be defined as for palliative care are transferred to hospital if they have a subsequent acute episode that cannot be managed within the facility.

There are no transfers for palliative care – we bring in palliative care doctors if we feel that the GP is reluctant to start palliative care but this is occurring less than it did in the past.

Families are routinely given the option to transfer to hospital when there is a change in medical condition but this is usually for the purposes of more active medical interventions. Once palliative care has been agreed upon by the family and GP transfers do not occur.

Families are given the option to transfer but this is usually discussed in relation to an acute episode. Generally we do not transfer palliative residents.

There were no transfers for palliative care.

One individual was transferred to hospital for an acute episode and subsequently went to the hospice, the other 23 residents who died were managed in the facility.

This facility is dependent upon GPs referring to the Home Based Palliative Care team for support with the provision of palliative care. If a family insists that a resident is transferred for the provision of care then the resident may be sent to Emergency for assessment and then admission.

We have had no transfers for the purpose of receiving palliative care. However we had one incident of a resident transferred to hospital for an acute episode who then went on to the hospice for the management of complex palliative care needs.

We have had no transfers for palliative care – we usually bring in the support we need. We have however had two people returned from hospital for the provision of palliative care.

We have had an incident when a GP requested a resident who was receiving palliative care be transferred to hospital via the Emergency department as he was not confident that facility staff could manage. When the resident arrived in Emergency we were contacted by the hospital who wanted to know what they were expected to do with the resident. We suggested that hospital staff speak further with the family. The resident was then returned to the facility without being admitted and was managed for palliative care for one week before dying. The GP’s attitude towards the facility’s capability was changed through this experience.

Home based palliative care team

The Home Based Palliative Care team operating out of Clare Holland House provides specialist palliative care support to staff in residential aged care facilities and to residents’ GPs. Their goal is to enable facility staff and GPs to manage residents with complex needs that are beyond the expertise of the primary care providers – and to manage those residents in the facility which is their home. During 2004-2005 the Home Based Palliative Care team conducted 37 consultations to residents across 16 facilities (see figures 16 and 17) in the ACT with 107 corresponding follow up visits (see figure 18).

---

Data was requested from and released by the CNC, Home Based Palliative Care team Clare Holland House September 2005
Alzheimer’s Australia ACT
Palliative Care Provision in ACT Residential Aged Care Facilities

Figure 16
Number of Home Based Palliative Care Consultations to Nursing Homes July 2004 – June 2005

Figure 17
Number of Home Based Palliative Care Consultations to Hostels July 2004 – June 2005

Figure 18
Visits to aged care facilities 2004 – 2005
General summary and conclusion of data

There are currently 23 residential aged care facilities in Canberra, which in August 2005 provided 1565 aged care beds. 632 beds were in 7 nursing homes and 933 beds in 16 hostels.

The provision of palliative care is core business for aged care facilities. Residential aged care facilities reported (via questionnaire) 446 deaths for the 2004-2005 financial year. 289 of these occurred in nursing homes and 157 in hostels.

All Directors of Care articulated a commitment to looking after residents to the end of their lives, whenever possible within their facility. This commitment is evidenced by the fact that of the 289 deaths in nursing homes, only 31 occurred away from the facility, in other words nursing homes looked after 89% of those residents that died, within their facility as opposed to transferring them elsewhere. The corresponding figure for hostels is 40 deaths out of 157, which equates to hostels looking after 75% of those residents that died, on site.

Six hostels had less than five deaths for the year while the largest number of deaths occurred in a nursing home with 55 (information from the Commonwealth data). From this it can be assumed that staff experience in the provision of palliative care is diverse across the sector.

With regards to transfers to hospital, the number of hospital leave days across all facilities was 7,283. Collected data and anecdotal evidence from both hospital staff and facilities indicate that this group of people was transferred primarily for the purposes of receiving acute care; for investigations, the management of infections and fractures. No data currently exists on the exact number of residents transferred for palliative reasons; however, such transfers are a rare event and only constitute a small fraction of the aged care residents within the hospital system.

One reason why the number of transfers from aged care facilities for palliative care is low is that the facilities accessed the services of the Home Based Palliative Care Team, for support with the management of residents with complex needs that were beyond the expertise of staff and GPs. Those residents that received palliative care away from their facility were most likely to have been originally transferred for acute care. These people either died during the acute episode or did not return to their facility because of, family wishes or they had care needs that were beyond the capacity of the organization.

Of all the patients assessed for palliative care needs, within the Canberra hospital system, less than 10% were aged care residents, and 37% of these were returned to their aged care facility. Only six residents from aged care facilities were transferred to Clare Holland House (during July 2004 – June 2005).

With regards to the process of transferring people for the purposes of receiving palliative care, the direction of these transfers is primarily from hospital back to the residential aged care facilities.

Patients are not transferred to hospital or Clare Holland House for palliative care, except in rare circumstances. The low frequency and varied nature of these transfers are such that they are best dealt with on a case by case basis. There is not the need for standardized procedures or protocols for the transfer of residents from aged care facilities to hospitals for palliative care.
Outcome One
Protocols and Procedures on decision making

The issue of decision making originated with a concern expressed by the Palliative Care Partnership Team that the wishes of residents’ in aged care facilities within the ACT, with regards to their end of life care were not being systematically canvassed or documented prior to a crisis occurring. This section reports findings on what is actually happening in the ACT. It also links the canvassing of residents’ wishes with the process of advanced care planning, identifies the regulatory and legislative framework in which advanced care planning occurs, presents relevant Australian research on the use of advanced care planning in residential aged care facilities and identifies the Respecting Patient Choices program as a methodology for the systematic implementation of advanced care planning. The section also includes a series of recommendations on protocols and procedures for use at key moments in the decision making process for the provision of palliative care.

Key decision points
There are three key points at which residential aged care facilities in the ACT can have a role in the process of decision making for the provision of palliative care. These are;
1. prior to admission when they are approached by individuals wishing to go on their waiting list;
2. during the admission interview and initial stages of care; and
3. at the time of an acute episode.

1 Pre-admission
   (the raising awareness stage)
During pre admission contact, facilities have the opportunity to raise awareness of the importance of medical decision making. In particular encouraging individuals and their families to consider the level of medical intervention they may wish at the end of their life, with decisions needing to be made about the possible withholding of medical treatment, and the appointment of an attorney that can act on their behalf should they lose capacity to give consent. Given the increasing levels of dementia within aged care facilities (in Australia, in 1998, 65% of permanent residents of residential aged care were identified as being possibly or probably affected by dementia, whereas this proportion increased to 80% in 2002.16), it seems reasonable to assume that many people admitted to facilities are already diagnosed with dementia. Thus their wishes regarding palliative care would need to be canvassed prior to admission. Another concern is that under ACT legislation there is no automatic right for a doctor or relative to make substitute medical decisions when a person is unable to give consent for treatment. Once someone becomes unable to give consent, the rights of such people are protected by the Guardianship and Management of Property Act 1991 or the Powers of Attorney Act 195617.

At such times as when people inquire about joining residential care waiting lists, or when a doctor first diagnoses dementia, it is important that information provided includes planning for future medical decision making. Recommended resources include:

17 Office of the Public Advocate August 2004
Legal Planning and Dementia which can be downloaded from www.alzheimers.org.au or ordered in hard copy by phone from the National Dementia Helpline 1800 100 500. This document speaks directly to someone who has recently been diagnosed with dementia. As well as providing general information on topics such as why planning ahead is important, it also provides information specific to the legislation in the ACT.

Information on substitute decision making, Guardianship and Management Orders and Enduring Power of Attorney can be obtained from the Office of the Public Advocate. They also have information sheets entitled Informed Consent for Health Care Treatment and Guardianship and the Management of Property. Information can be downloaded from www.oca.act.gov.au or requested by phone on 6207 0707

Appendix B provides an example of a form on advanced care planning developed by the Respecting Patient Choices program in Victoria and that has been adapted for use in the ACT. This form may be included in a pre-admission pack.

2 Advanced Care Planning – documenting patients wishes at the time of admission.

Advance care planning is the term used to describe the process of planning care for the end of a person’s life before death is imminent. The Guidelines for a Palliative Approach in Residential Aged Care state

‘An advanced care plan is an interactive process of communication between a competent resident and the aged care team. The purpose of the advanced care plan is to elicit the resident’s wishes regarding treatment decisions, which will often include decisions related to their impending death; to extend their autonomy, and to guide decision-making when the resident may be rendered incompetent of doing so. Advance care planning does not have to be a legalized formal process. It should revolve around ongoing communication with the resident and/or family, as communication is the fundamental principle of advanced care planning’

Residential aged care facilities in the ACT, as with facilities throughout Australia operate within a regulatory and legislative environment. Commonwealth government funding for facilities is tied to an accreditation process. Accreditation Standard 2.9 speaks directly to the provision of palliative care and assumes the development by facilities of policies and practices. The expected outcome of Accreditation Standard 2.9 is that the comfort and dignity of terminally ill residents is maintained. The key aspects are:

• residents wishes are identified, respected and where possible acted upon in relation to their terminal care; and
• individual palliative care programs are provided that enable family involvement, accommodate religious and cultural beliefs and recognize an individuals right to die with dignity.

The Medical Treatment Act 1994 (ACT) and The Powers of Attorney Act 1956 (ACT) provide the legislative framework for advanced care planning in the ACT. The Medical Treatment Act 1994 enables a competent adult, or an attorney acting on behalf of an incapacitated adult, to make a direction to refuse medical treatment either generally or of a particular kind. The Act also provides protection from liability for health professionals who withhold or withdraw medical treatment in good faith and in compliance with the Act. Under the Act an attorney can be appointed by a competent adult (‘the grantor’) but only exercises power once a medical practitioner has declared the grantor to be incapacitated. A direction to withhold treatment by either the patient or their attorney can only be complied with after the person has been informed about the nature of the illness, any alternative forms of treatment available, the consequences of those forms of treatment and the consequences of remaining untreated18. An attorney can also be appointed under The Powers of Attorney Act 1956. The Enduring Power of Attorney document associated with this legislation is more versatile and all-encompassing enabling the appointment of a substitute decision maker for financial, medical and personal decisions, in the event of incapacity. This document is the one that is more commonly used19.

In summary, advanced care planning is a funding expectation and within the ACT is enabled by legislation. This legislation also places medical practitioners in key roles.

19 Personal communication with staff, Office of the Public Advocate, October 2005
Adoption of Advanced Care Planning in residential aged care facilities in Australia

Australian research that provides evidence on end of life decision making in residential aged care facilities is not extensive, there are however two significant articles published within the last five years that provide descriptive data. Nair et al. investigated the relative use of formal and informal methods of advanced care planning in 88 aged care facilities in the Hunter region of NSW. Directors of Care were surveyed to establish how many residents had a formal directive, no cardio-pulmonary resuscitation orders or an enduring power of attorney appointed either by the resident or Guardianship Tribunal. Less formal unwritten processes for decision making were also identified. These included the availability of a person who could make health care decisions for the resident if the resident was unable to make decisions for him or herself or general consensus formed by the staff as to the appropriate medical management of the resident. The results found that formal methods of advanced care planning had very low levels of prevalence. 0.2% of residents had an advanced directive, 1.1% of residents had no CPR orders documented in their medical records, 5.6% had a formal guardian and 2.8% had an enduring guardian. In contrast informal processes were much more common. 65% of residents had a ‘person responsible’ recorded to make decisions while in 13% of cases there was ‘staff consensus’ as to the optimal care for the patient. For 10.6% of residents however there was no clear process for medical decision making identified.

Brown et al. conducted a study investigating the use of advanced directives and advanced care planning in residential aged care facilities in South Australia. This research was part of a larger project looking at the provision of palliative care for residents with non-cancer diagnoses. The study was carried out in two stages. Stage one involved a survey of 90 randomly selected residential aged care facilities in rural and metropolitan South Australia. Stage two involved the prospective case studies of 69 residents, appropriate for palliative care, from 17 facilities and interviews with 15 directors of care. The results of the research found that almost three quarters of the facilities had a policy on palliative care but there was little consistency in the language used or in the process of documenting advanced directives or advanced care planning. Most facilities had developed their own specific forms to record residents’ wishes with regards to their end of life care in keeping with their responsibilities under Accreditation Standard.

2.9. There was however little consistency in the content of information collected by these forms, the terminology used or the use of the appropriate legal instruments.

Advance Care Planning in the ACT

To find out how facilities in the ACT are currently interpreting their responsibilities with regards to canvassing patient wishes a questionnaire and semi-structured interview of Directors of Care was undertaken. (Refer to Appendix A, questions 10, 11 and 12 on the questionnaire and questions 1 and 2 from the interview) The results are as follows.

All facilities in the ACT indicated that they are currently having conversations with residents and or their significant others attempting to ascertain what the residents’ wishes are with regards to their end of life care.

Asked to indicate when these conversations were taking place, 17 (74%) indicated routinely during admissions, 6 (26%) indicated routinely within a set time frame after admission, and 11 (48%) indicated when the need arises. While asked to give only one response 10 (43%) facilities ticked more than one box suggesting that they consider these conversations to be ongoing. Additionally 10 (43%) facilities mentioned their use of case conferencing and/or annual reviews, both circumstances being identified as situations in which end of life wishes were raised and discussed.

While there was no question related directly to the content of these conversations, Directors of Care mentioned that conversations included the following;

- 7 spoke of open ended questions about special requirements/ needs
- 6 spoke of pastoral care and spiritual needs
- 3 spoke of arrangements for patient transfer to hospital
- 2 spoke of treatment options in relation to prognosis
- 8 spoke of funeral arrangements
- 5 spoke of the possibility of a GP presence during these conversations

The following quantifies responses in relation to the question; The term advanced care directive means giving directions about one’s care in advance of incompetence. Does your facility recommend or require any of the following?

---


The most common form both recommended and required was the Enduring Power of Attorney.

All facilities indicated an interest in accessing more information on tools for collecting and documenting patients' wishes. A number of facilities indicated however that they were part of broader networks and that the work of developing specific forms currently used by their facility occurred within the context of these networks. Some of these facilities also indicated that they did not have the autonomy to simply adopt new procedures without reference to and the approval of, the network organization.

To make a brief summary at this point, evidence from facilities in the ACT indicates a broad commitment to, and ongoing interest in the process of advanced care planning. However, the more detailed analysis of Nair et al indicates preferences for the use of informal procedures and the study by Brown et al reveals that there is a lack of clarity at the policy level and a lack of consistency at the procedural level in the area of advanced care planning within the aged care sector. While The Guidelines for a Palliative Approach in Residential Aged Care referred to earlier have identified and analyzed research evidence and distilled principles to support the use of advanced care planning, it appears that facilities may be uncertain of how to proceed with their clinical application.

### Options for advanced care planning

The Respecting Patient Choices Program is a Commonwealth and Victorian governments funded advanced care planning program. It was piloted by Austin Health in 17 residential aged care facilities in northeast Melbourne. Respecting Patients Choices provides a methodology for

- the systematic implementation of advanced care planning within organizations
- staff training and
- the evaluation of patient outcomes, that is the evaluation of the extent to which the wishes expressed by residents were acted upon by facilities.

---

**Table 2**

The term advanced care directive means giving directions about one's care in advance of incompetence. Does your facility recommend or require any of the following? (Question 12 Questionnaire Appendix A)

<table>
<thead>
<tr>
<th>Type of Advance Directive</th>
<th>Recommend* by Hostels (n=15)</th>
<th>Recommended by Nursing Homes (n=7)</th>
<th>Required* by Hostels (n=15)</th>
<th>Required by Nursing Homes (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enduring Power of Attorney</td>
<td>12</td>
<td>2</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Financial Management Order</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Guardianship Order</td>
<td>9</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Written Direction Under the Medical Treatment Act 1994</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Good Palliative Care Order Form</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>A specific form designed by your facility</td>
<td>6</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

* A number of facilities ticked both recommended and required

The results of the pilot were provided to the Commonwealth in February 2006 and on the strength of the evidence to date the Commonwealth has committed funding for a national roll out of the program. The Canberra Hospital is the chosen pilot site for the ACT. Implementation requires the adaptation of the program to the ACT legislative framework and organizational preparation. The development of a procedure for documenting an individual’s statement of choices using legal instruments specific to the ACT is also part of the preparation process. The pilot will begin in 2006 with a 12 month running time. It is envisaged that the Canberra Hospital will then assume the role as the lead organization for rolling out the program to interested facilities in Canberra. What this means for aged care facilities within the ACT is that potentially from 2007 onwards they will have access to a program that will provide them with a methodology for implementing advanced care planning that is in keeping with The Guidelines for a Palliative Approach in Residential Aged Care Facilities. That is a program adapted to local legislation that can be systematically implemented, involves the education of staff, residents and their families, and allows for ongoing assessment.

**Interim recommendations for Advanced Care Planning**

Under current arrangements the locus of control for the development and implementation of palliative care policies within aged care facilities rests with the facilities themselves. While the Commonwealth government has identified a broad network of 44 standards against which facilities are assessed to determine their suitability for accreditation, facilities themselves are expected to interpret these standards within their organizational structures and to develop quality systems to support their provision of care. Statements of policy and procedure in the area of palliative care form part of these quality systems and are documents that express a facility’s understanding of and commitment to palliation. In this sense policies and procedures cannot be proscribed from outside an organization. Grbich et al\(^\text{24}\) have however identified a number of features that would be included in a comprehensive palliative care policy. They are;

1. A definition of key terms relating to palliative care
2. The naming of indicators that trigger the referral of residents to other palliative care service providers.
3. Reference to the relevant Accreditation Standards and legislation.
4. A tool for advanced care planning

On the basis of this best practice Palliative Care Policies in facilities in the ACT would include the following.

**1. Definitions**

Palliative care as defined by the World Health Organization\(^\text{25}\) is;

An approach that improves the quality of life of individuals and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care,

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers support to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance the quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation

\(^\text{23}\) Correspondence with Project Officer Respecting Patient Choices Program Austin Health 14\textsuperscript{th} July 2005 and conversations in February 2006 Project Officer ACT Health.


therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The identification and definition of the three forms of palliative care provided to residents within the aged care context as outlined in the Guidelines for a Palliative Approach in Residential Aged Care26.

- **A palliative approach**
  This form of palliative care is implemented when a resident’s condition is not amenable to cure and the symptoms of their disease require effective symptom management. Providing active treatment for the resident’s disease may also still be important and may be provided concurrently with a palliative approach. However, the primary goal of a palliative approach is to improve the resident’s level of comfort and function, and to address their psychological, spiritual and social needs.

- **Specialized palliative service provision**
  This form of palliative care involves the referral to a specialized palliative team or health care practitioner. Specialized palliative care augments the palliative approach with focused, intermittent and specific input as required. The goals of this type of care are:
  - Assessing and treating complex symptoms experienced by a resident; and
  - Providing information and advice on complex issues (e.g. ethical dilemmas, family issues, or psychological or existential distress) to the aged care team.

- **End-of-life (terminal) care**
  This form of palliative care is implemented when a resident is in the final days or weeks of life and care decisions may need to be reviewed more frequently. The goals of care at this stage are more sharply focused on the resident’s physical, emotional and spiritual comfort, and support for the family.

2. **Referral to other palliative care service providers**

A good policy statement would include acknowledgement of the facility’s role as a primary care provider whose staff work as part of a multidisciplinary team which includes other primary care providers such as GPs. The role of staff in assessment and when necessary referral to specialist palliative care providers would also be stated. Complex and resource intensive needs that are beyond the expertise or exceed the capacity of primary care providers would be a key indicator triggering the referral of a resident to specialist palliative care service providers. In the ACT general practitioners have referring rights to the Home Based Palliative Care team, who in turn can draw on the expertise of Palliative Care Medical Specialists.

3. **Accreditation Standards and Legislation**

A good policy statement would acknowledge that palliative care was provided in the context of the Accreditation Standards in particular Standard 2.9. This standard states

‘Policies and practices provide;
That residents’ wishes are identified, respected and where possible, acted upon in relation to their terminal care; and

Individual palliative care programs that enable family involvement accommodate religious and cultural beliefs and recognize an individual’s right to die with dignity.

A copy of these standards would be available on site and a commitment to educate staff in their responsibilities to provide palliative care in accordance with these standards would be documented.

In the ACT The Medical Treatment Act 1994 and The Powers of Attorney Act 1956 provide the legislative framework for advanced care planning. A policy statement should include references to this legislation and an acknowledgement that facility staff are informed and act within their legal responsibilities under this legislation.

4. **Advanced care planning**

Finally a good palliative care policy would state that advance care planning is offered to all residents and their families in accordance with Standard 2.9 and The Guidelines for a Palliative Approach in Residential Aged Care.

Following on from this a statement of best practice in procedures for advanced care planning may include the following.

---

• That discussion with residents regarding their end of life care routinely occurs and is documented.

• That these discussions are either
  ◦ Initiated during the admissions process and followed up within a 4-6 week settling period, or
  ◦ Initiated and completed during the admissions process

• That residents are informed of their rights to change their documented wishes, and that advanced care plans are reviewed annually or when there is a change of medical condition.

• That conversations on end of life care provide for
  ◦ Family involvement and information on family notification at the time of a change in medical condition
  ◦ Identification of religious and cultural beliefs
  ◦ And reference to and discussion of Part C of the Enduring Power of Attorney document or Schedule 1 of the Medical Treatment Act.

• That documentation of these conversations is held within the residents’ notes and transferred with the resident if it becomes necessary for them to be treated away from the facility.

3 Decision-making at the time of an acute episode

Decision making is an integral part of the role of staff in residential aged care facilities at times when residents have a significant change in their medical status or experience an acute episode. The primary responsibilities of staff during this time are monitoring and assessment and where necessary referral of residents to appropriate medical treatment. The probability of a resident remaining within the facility for treatment in the case of an acute episode will be impacted on by the qualifications and confidence of the facility staff, the availability of resources in terms of nursing and personal care hours, equipment needs and access to the resident’s GP. If the resident’s condition is managed within the facility the decision making processes will occur on site. In these circumstances facility staff will be involved in discussions with the resident, family members and the general practitioner about the benefit and burdens of various treatment options and the residents’ wishes regarding care. Ultimately decisions may need to be made about the transition of the goals of care from curative to palliative.

From data collected in this study the seven nursing homes in the ACT reported that for the 2004-2005 financial period approximately 25% of their residents spent more than 24 hours away from their facility in hospital. The corresponding figure for the thirteen hostels that provided this information was approximately 27%. According to anecdotal evidence provided by the Directors of Care the majority of these transfers were for acute care as opposed to end of life care. This evidence is further corroborated by the numbers of residents who transferred from hospital back to their facilities. 81% of residents from nursing homes who transferred to hospital returned home to their facility with the corresponding figure for hostels (n=13) being 84%. Finally all Directors of Care in the ACT articulated a commitment to looking after residents to the end of their lives, wherever possible within their facility.

While it is beyond the scope of this study to develop protocols and procedures for the management of acute episodes in aged care facilities, The NSW Department of Health Guidelines for end-of-life care and decision making is a recommended resource in this area. Of particular value is the cyclic feedback model outlined in Section 5 (see Appendix C) which acknowledges the continuous nature of the decision making process. The model identifies and clarifies the various stages for the development of a management plan which may be initiated when there is a clinical deterioration of a resident, when they do not appear to be responding to treatment and or when they have expressed a desire to limit or withhold treatment.

The subsequent steps outlined are;
• assessment of the resident both medically and in terms of their expressed preferences and values,
• disclosure of information regarding prognosis,
• discussion of the benefits and burdens of the different courses of action,
• concluding with the detailed documentation of a consensus decision.

This resource can be downloaded from www.health.nsw.gov.au or ordered in hardcopy from the Better Health Centre – Publications Warehouse on (02) 9816 0452.

 Outcome Two
 Assessment of Hospital in the Home arrangements

 The issue of outside hours assistance was identified by the Palliative Care Partnership Team as an area of interest. Of concern was that overnight staffing levels in residential aged care facilities impact on the ability of facilities to provide appropriate palliative care. The Hospital in the Home service was put forward as a possible response to these concerns, potentially providing after hours ‘fly in’ support and reducing the number of resident transfers. This section reports findings on the availability of registered nurses overnight in facilities in the ACT and presents comments made by the Directors of Care on the impact of current arrangements on the provision of palliative care. Information is detailed on the current service provision of Hospital in the Home in the ACT, which could not, in its current form be considered an appropriate service provider for after hours palliative care. The section concludes with comments by the Directors of Care on the kinds of characteristics that would make an after hours ‘fly in squad’ for support in the provision of palliative care attractive to their organization, and the recommendation that further investigation be undertaken to ascertain the feasibility of establishing such a service.

 Staffing arrangements in residential aged care facilities are not specifically addressed in the Aged Care Act 1997. The Accreditation Standards however require facilities to employ staff with skills and in appropriate numbers to meet residents’ needs. Under these arrangements there are no stipulated staff patient ratios, and facilities have discretion to make their own staffing arrangements. Registered nurses play a significant role in the provision of palliative care in facilities, both in terms of their skills in clinical assessment and their ability to administer medication. In the questionnaire (refer to Appendix A question 9) Directors of Care were asked,

 With regards to after hours care, does your facility have a registered nurse available;
 • On the premises?
 • On call?
 • On the premises some nights and on call at other times?

 Responses are as follows;
Table 3
After hours care

<table>
<thead>
<tr>
<th></th>
<th>Nursing Homes* (n=7)</th>
<th>Hostels# (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered nurse on premises after hours</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Registered nurse on call after hours</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Registered nurse on the premises some nights and on call at other times.</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

* One facility ticked both on premises and on call
# One facility ticked both on call and on the premises some nights and on call at other times.

Comments by the Directors of Care, from hostels, included the following:

- 9 spoke of their use of the Home Based Palliative Care team and its integral role in their provision of palliative care
- 8 spoke of their use of syringe drivers
- 2 spoke of accessing medications training for their enrolled nurses
- 2 spoke of staff accessing the Palliative Experience of the Palliative Approach program with one detailing the flow on effect of this training within their facility

Other strategies mentioned were:

- Directors of Care being available for telephone support overnight
- The availability of access to specialist palliative care physicians through GP referral
- The transfer of residents from the hostel to the nursing home part of the facility when medium to long term palliation is required.

Gaining an objective measure of the after hours palliative care needs of residents in aged care facilities in the ACT is difficult. A report has just been released by the ACT Division of General Practice on the after hours care and emergency hospital transfers for those in aged care28.

Information was collected from seven facilities over a seven month period and indicates something of the patterns of after hours medical care and transfers to hospital. Of interest to this project are the reasons documented by staff for requesting after hours medical support. Data from 54 call outs was recorded and the reasons for the call outs were listed as follows:

- 11 for falls
- 3 for high BP
- 3 for unresponsiveness
- 4 for pain
- 4 for chest pain
- 4 for hypoxia
- 3 for assessment
- 2 for seizure
- 5 for chest infection
- 3 for fracture

28 Baynes A, Andrew G. After Hours Care and Emergency Hospital Transfers for Residents of Aged Care Facilities in the ACT. Evaluation of the 2005 data. ACT Division of General Practice. 2006
12 for other, which included rectal haemorrhage, abdominal ultrasound and abdominal pain

While a number of these reasons could be indicative of after hours palliative care need the exact relationship between these reasons for call out and palliative care is unclear.

Turning now to the Hospital in the Home service. There are two arms of this service operating out of The Canberra Hospital, both providing acute care. One focuses primarily on the provision of intravenous therapy for patients requiring the treatment of conditions such as cellulitis and pneumonia, the other arm is oncology based for patients diagnosed with leukemia and lymphoma. The following are summaries of conversations with the clinical nurse consultants from each of the services. These conversations took place in December 2005.

Hospital in the Home service – intravenous therapy section

- What services does your program provide and to whom?

Hospital in the Home program is available to patients who have been admitted to The Canberra Hospital and are under the care of a clinical consultant.

The program is involved with the provision of acute care rather than palliative care.

Patients continue to be considered Inpatients of the hospital when they are returned home under the care of HITH and their treatment is managed by the hospital consultant rather than their GP.

Nurses visit patients in their home between the hours of 7.30am and 10.00pm and patients must return to hospital for review prior to the cessation of their treatment.

- Do you currently have staff that are skilled in the provision of palliative care?

No. Palliative care is not the focus of this program and in recent times nurses from HITH have worked with clients from the oncology section with palliative care needs staff have drawn on the expertise of the Link team to compliment their skill base.

- Do you have established relationships of service provision to residents in aged care facilities here in the ACT?

HITH is a service provided to clients through the hospital system rather than directly to aged care facilities. All clients have been admitted to hospital under the care of a clinical consultant. The service sees on average around one client per month from a residential aged care facility, with the main treatment procedures being the provision of IV antibiotics for cellulitis and pneumonia.

- What are the hours within which your services are currently provided?

Operating hours are from 7.30am to 10.00pm with an on call phone number for crisis situations. Responses to a crisis may include telephone assessment, recommendation that a patient is returned to hospital via ambulance and or staff going out to a client’s home to respond to equipment problems.

Hospital in the Home service – oncology section

- What does your program provide?

This service provides acute care primarily to patients diagnosed with deep vein thrombosis, leukemia and lymphoma. If a patient does not respond to treatment and subsequently requires palliative care the Hospital in the Home service may share care this individual with palliative care service providers and or community nursing for a short transition period before referring the patient on to be managed exclusively for palliative care.

- Do you currently have staff that are skilled in the provision of palliative care?

As oncology nurses staff have some training in the area of palliative care, this is not however the dominant component of their skill base.

- Do you have established relationships of service provision to residents in aged care facilities here in the ACT?

While there is a history of service provision to residents in aged care facilities the number is currently around one person per year in this category.

---

29 Personal conversation CNC, Hospital in the Home, Intravenous Therapy Section
30 Personal conversation, CNC, Hospital in the Home, Oncology Section
• **What are the hours within which your services are currently provided?**

Staff currently work between the hours of 8.30am and 5.00pm. If clients have need for staff attention outside these hours they can call The Canberra Hospital, Ward 14B for advice on the telephone. Staff are not available however to go to clients homes after hours and clients must present to the ward if the situation requires.

On the basis of this information it would appear that the Hospital in the Home service in its current form could not be considered appropriate for the provision of after hours palliative care in residential aged care facilities. Hospital in the Home is an acute care service and consequently its staff does not have a palliative care skill base, it does not provide after hours care to clients beyond telephone support, and its relationship of service provision to clients in aged care facilities is limited.

To conclude Directors of Care were asked to consider what kind of characteristics would make an after hours ‘fly in squad’ for support with the provision of palliative care attractive to their organization (Appendix A interview question 4). The following is a summary of the responses obtained from twenty Directors of Care across all 23 aged care facilities in the ACT during the period of November to December 2005 (full details of these responses can be viewed in Appendix E).

A number of Directors of Care across both nursing homes and hostels perceived the Home Based Palliative Care team currently in operation as a form of ‘fly in squad’. Two nursing homes reported that they did not consider access to a ‘fly in’ service appropriate to the needs of their facility given the availability of Registered Nurses on site overnight. The remaining five nursing home directors identified the following characteristics that would make a ‘fly in squad’ attractive to their organisation; assistance with clinical assessment, the ability to set up syringe drivers, a capacity for phone order medication, assistance with after hours pain management and a role in the education and building of staff confidence.

Directors from hostels emphasized characteristics in a ‘fly in squad’ that involved being available to; come out to the facility after hours, provide clinical assessment, proscribe medication as well as accessing and administering it, provide care to residents regardless of their RCS classification, work towards creating an atmosphere of cooperation and support with facility staff, and to have an educative role.

In the light of evidence collected further investigation is warranted to ascertain the feasibility of establishing an after hours ‘fly in’ service to residents in aged care facilities – particularly hostels where there is no registered nurse available on site overnight.

### Outcome Three

**Mechanisms to facilitate the return of aged palliative care patients**

Identification of mechanisms to facilitate the return of aged palliative care patients to a residential aged care facility following an acute episode requiring specialist palliative care.

Specialist palliative care is provided to those patients whose needs exceed the capacity and resources of the primary care provider. Specialist palliative care within the ACT is provided by transfer to Clare Holland House or through consultation based advice from the Home Based Palliative Care (HBPC) team, which is delivered within a primary care facility.

---

The HBPC team is the principle provider and first port of call for specialist palliative care. The team goes out to facilities and assesses residents on site, providing advice to staff and GPs on management strategies for palliative care. The most common reason for referral is symptom management with pain management being the most common symptom. The team aims to provide support to enable facility staff and GPs to manage residents in their ‘home’. It is rare that a resident would be recommended to transfer to the hospice. In such circumstances the purpose of the transfer would be to provide a period of intensive symptom management, with the resident returning to their facility once stabilised³².

The HPBC team is multidisciplinary. It includes palliative care medical consultants to whom the specialist HBPC nurses can consult for clinical advice. GPs also have referral capabilities to this team of three specialists that are based at Clare Holland House³³.

The team may be contacted either directly by facility staff or by a resident’s GP. However if contacted directly by facility staff the expectation of GP involvement remains, and GPs retain their role as prescribers of medication³⁴.

During 2004-2005 the Home Based Palliative Care team³⁵ conducted 37 consultations to residents across 16 facilities (see figures 16 and 17) in the ACT with 107 corresponding follow up visits (see figure 18). Only six aged care residents were transferred to Clare Holland House during this period, and some of these transfers were from the hospital system, of aged care residents who originally were transferred to the hospital for acute treatment³⁶.

All of the aged care residents transferred to Clare Holland House died there. Of the six residents transferred three were for end of life care and spent less than five days in the hospice. The other three were transferred for complex symptom management and support and spent 33, 101 or 113 days in the hospice. The length of stay of these three residents suggests that they would have been able to return to their aged care facility with support from the HBPC team, but in each of these instances beds were no longer available to them in their original facility³⁷.

The Department of Health and Aging³⁸ advised that residents can take unlimited days of leave for the purposes of receiving hospital treatment. After a period of thirty continuous days away from the facility the resident is however considered to be on extended hospital leave and while a facility continues to receive funding from the Commonwealth for this resident’s place, it is at a reduced rate.

A decision to discharge a resident from a facility would be made primarily on the basis that it was not expected that the resident was going to return to the facility. Family members would be consulted and would need to be in agreement with this discharge assessment³⁹.

Given the small number of people that did not return to their facilities after receiving specialist palliative care, there does not seem to be a need to establish and implement standard mechanisms for returning individuals. Negotiation on a case by case basis seems to be a more appropriate mode of operation.

Department of Health and Aging⁴⁰ note that methods to identify survival time for patients in palliative care have limitations in accuracy and precision, while treatment for acute illness has uncertain outcomes and treatment times. Thus it is to be expected that there will always be a level of uncertainty about whether a patient transferred to hospital or the hospice will return. The unpredictable nature associated with patient outcomes also re-enforces that while numbers of transfers remain low, a case by case approach is the most appropriate.

The arrangements for specialist palliative care seem to be working well and there is no reason to change the existing procedures. It is very evident that most residents are receiving specialist palliative care within their facilities, as required.

³² Personal communication, CNC, Home Based Palliative Care team, Clare Holland House, March 2006
³³ As above
³⁴ As above
³⁵ Data was requested from and released by CNC, Home Based Palliative Care team, Clare Holland House September 2005
³⁶ Data requested from and released by the Manager, Clare Holland House, February 2006
³⁷ Data requested from and released by the Manager, Clare Holland House, February 2006
³⁸ Personal communication, Department of Health and Aging, Health and Aged Care, Australian Capital Territory Office, March 2006
³⁹ Personal communication, Department of Health and Aging as above and with Executive Director Alzheimer’s Australia ACT, March 2006
Outcome Four
Improved continuity of care

The development for implementation of new resources to improve the continuity of care for aged persons who as a result in the change of their condition are required to transfer between facilities to receive palliative care.

The data presented and analysed in the scoping study section of this report clearly demonstrates that the large majority of transfers of aged care residents is for acute treatment in hospital. Most of the patients transferred for acute care return to their facility following treatment, some die during treatment and some following treatment are assessed for palliative care. This chapter investigates and provides guidance on the continuity of care of the last group of people.

During the financial year 2004/2005, twenty aged care facilities reported that 356 residents spent at least 24 hours away from their facility on hospital leave. Across all the 23 facilities, 71 residents died away from their facilities, all others returned. Hospital data available to this project is insufficient to trace the exact treatment outcomes of these 71 patients. However, when Directors of Care were asked to name the main reasons why aged palliative care patients end up dying in hospital rather than returning ‘home’, their responses were as shown in Table 1. In summary, both nursing homes and hostels acknowledge that an acute care episode was the primary reason why a resident would not return. Nursing homes also reported that family wishes played a significant role in the prevention of residents returning, while hostels reported that care needs beyond the capacity of the organization was a significant factor.

A similar question was asked of South Australian directors and in accordance with the ACT acute care episodes were acknowledged as the primary reason why a resident may be transferred from a facility prior to death. Increased care needs were also identified as a major reason for transfer from low care facilities.

Canberra Hospital Palliative Care Service Data
Data provided by the Canberra Hospital Palliative Care Service gives further insight into the fate of transferred aged care residents assessed for palliative care. Between January 2005 to March 2006 the service provided consultations to 62 patients from aged care facilities, 34 from nursing homes and 28 from hostels. All of these patients would have been initially assessed and admitted to hospital for an acute episode. As shown in figures 12 and 13 and the table below the outcomes of the assessment where that roughly one third of patients returned to their aged care facility, another third died in hospital, 10% were assessed as not for palliative care and 14% went on to the hospice.

<table>
<thead>
<tr>
<th>Location of Care</th>
<th>Nursing Home</th>
<th>Hostel</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Returned to aged care facility</td>
<td>18</td>
<td>5</td>
<td>37%</td>
</tr>
<tr>
<td>Died in hospital</td>
<td>14</td>
<td>10</td>
<td>39%</td>
</tr>
<tr>
<td>Assessed not in need of palliative care</td>
<td>2</td>
<td>4</td>
<td>10%</td>
</tr>
<tr>
<td>Transferred to hospice</td>
<td>0</td>
<td>9</td>
<td>14%</td>
</tr>
</tbody>
</table>

A much smaller percentage of hostel residents (18%) were able to return to their facility than residents from nursing homes (53%), while only hostel residents were referred on to the hospice. The figures confirm that the inability to provide the required level of care is a key issue for hostels.

Advice from Directors of Care on how the return of aged care residents from hospital could be facilitated

Directors of Care were asked to think about that group of residents who had been transferred to hospital and had subsequently died in hospital and to consider the question “Do you have any ideas on what more could be done to assist aged palliative patients to return ‘home’ from hospital to die?”

Comments were obtained from twenty Directors of Care across all 23 aged care facilities in the ACT during the period of November to December 2005. In one instance a Director of Care spoke on behalf of both the nursing home and the hostel components of her facility, in another the Care Manager spoke on behalf of the specialized dementia unit and the hostel component of her organization. Full details of these comments can be viewed in Appendix F. The following is a summary of the ideas and issues raised by management staff.

Facilities, and in particular nursing homes, do receive the majority of their patients back, for the provision of palliative care. The two key things that would improve the rate of return of nursing home patients are the supply of appropriate medication for these patients and that patient families become more informed and supportive of the capabilities of nursing homes.

For hostels key issues were the need to build informed trust between the acute and aged care sectors, with hospital staff coming out to facilities to gain a clearer picture of the resources available and a greater understanding of the practical meaning of “aging in place”. Facility staff also wish to be involved in case conferencing. Hostels require residents be returned with more information, with advanced warning of residents return and no weekend discharges. Medications in Webster pack formats and written up medication orders would also be of great assistance. Finally, return would be aided if there was a process for negotiated referral to the Home Based Palliative Care Team prior to discharge from hospital.

Advice from Directors of Care on how continuity of care for patients transferred could be improved

Directors of Care were asked ‘Do you have any suggestions on what could be done to improve the continuity of care for patients who have to transfer between your facility and hospital? What is working well and what could be improved?’ The full details of their responses can be viewed in Appendix G. The following is a summary of key ideas and issues raised.

Involving aged care facilities in discharge planning and consistently recognizing their needs and resources is a common concern. When residents return from hospital aged care staff need access to information that is clear, legible and details; prognosis, treatment options, decision making discussions that have occurred with families, and vital information such as when residents have received their last pain relief or insulin. This is particularly important as there is currently no identified person/s within The Canberra Hospital or Calvary whom facilities can contact to gain further information if required about a resident’s needs on return from hospital.

Suggestions were also made regarding staff attending resident’s case reviews at the hospitals and for hospital staff to be invited to information sessions to become more informed about aged care facilities capabilities. The need for a better working relationship is particularly pertinent for hospital areas other than Ward 11A at the Canberra Hospital.

The return of patients at an appropriate time and with sufficient notice was another key issue. The return of residents on Friday afternoons, weekends or at night with little warning has a significant negative impact on patient care. Such practices compound the lack of adequate information exchange and don’t recognize the problems of facilities in administering medication and gaining access to GPs and/or registered nurses over the weekend.

The removal of access to support services such as the wound clinic, continence clinic and the gastroscopy clinic have also impacted negatively on the continuity of care, increasing a burden of cost on the aged facilities and the likelihood of residents being returned to hospital for the provision of these services.

Information collected from the Directors of Care is also supported by data recently released by the ACT Division of General Practice. The patterns of after hours care and emergency hospital transfers were monitored in seven aged care facilities within the ACT over a seven month period during 2005^{42}. The results highlighted that when residents were

---

^{42} Baynes A, Andrew G. After Hours Care and Emergency Hospital Transfers for Residents of Aged Care Facilities in the ACT. Evaluation of the 2005 data. ACT Division of General Practice. 2006
transferred back to their aged care facility in 50% of cases they were not transferred with a medication sheet and in 31% of cases they did not have a discharge form. In 14% of cases aged care facilities were not notified by the hospital that a resident was returning to them. The report also acknowledged the difficulty for aged facilities accessing GP services. Data from the ‘MBS Item Summary Report for Divisions of General Practice’ state that the number of GP services provided to residents of aged care facilities in the ACT decreased from 12,269 in 2002-03, to 11,306 in 2003-04 and a further decline to 10,257 in 2004-05, this was a decline of 7.8% and 9.3% respectively for the ACT, compared to an increase nationally of 5% and 3.7%.43

To conclude, the issues and ideas for improving continuity of care have much in common with those enunciated for the ‘home’ return of residents. Thus recommendations and guidelines to address these issues are best considered together.

**Recommendations for improving continuity of care and the return of hospitalized palliative patients to aged care facilities**

Continuity of care and the return of palliative patients from hospital will not be greatly assisted by the provision of written resources to facilities or hospitals. What is required is a better working relationship between the two sectors and particularly for hostels greater and more consistent provision of practical support. Within this framework the following recommendations are made.

**Transfer arrangements**

1. Aged care facilities are given 24 hours notice of discharge of palliative care patients, unless negotiated otherwise with a director of care.

2. Palliative care patients should not be returned on Friday afternoon, at night or on the weekend.

**Improved information exchange**

3. Aged care facilities are given the opportunity to be involved in case conferencing of residents in hospital with palliative care needs.

4. Hospital staff involved in discharge planning should gain an understanding of the capabilities of individual nursing homes and hostels or at least consult the expertise available in Ward 11A.

5. Hospital staff should provide a completed and legible discharge summary and medication chart when a patient is discharged from hospital back to their aged care facility.

6. Consideration should be given to the appointment of a discharge planner within both The Canberra Hospital and Calvary, dedicated solely to residents from aged care facilities.

**Family education**

7. Repeated and timely opportunities for patients and their families to undertake advance care planning, should occur as recommended in the section ‘Protocols and Procedures on Decision-Making’.

8. Advanced care plans should accompany residents to hospital and back.

**Required resources**

9. Hospital staff need to ensure a supply of discharge medications and appropriate scripts. If required by the facility this medication should be presented in a Webster pack.

10. That where appropriate a referral to the Home Based Palliative Care team be organized prior to a resident being discharged from hospital.

11. If support services are not going to be re-instated then consideration should be given to the provision of costly bandages to aged care facilities accepting a patient with complex wound management.

---

Appendix A

Questionnaire

1. No of licensed high care beds

2. No of licensed low care beds

3. What is the number of residents in each RCS category (as of your last return)?
   1  2  3  4  5  6  7  8

4. How many residents died in your facility during the 2004-2005 financial year?

5. How many residents had leave from your facility to hospital during the 2004–2005 financial year?

6. How many residents died away from your facility (i.e., in hospital) during this same period?

7. In your experience what are the main reasons aged palliative care patients end up dying in hospital rather than returning to their facility? (tick more than one)?
   - Family wishes
   - Resident wishes
   - Care needs beyond the capacity of the organization
   - Rapid deterioration
   - Acute care episode
   - No high care beds available if resident low care or independent living
   - Other reasons?

8. How many residents in your facility do you currently consider palliative?

9. With regards to after hours care, does your facility have a registered nurse available; (tick one)
   - On the premises?
   - On call?
   - On the premises some nights and on call at other times?
10 How do you find out what residents wishes are with regards to their end of life care?

11 When is this information collected? (tick one);
- [ ] Routinely during the admissions process
- [ ] Routinely within a set timeframe after admission
- [ ] When the need arises

12 The term advance directive means giving directions about one's care in advance of incompetence. Does your facility recommend or require any of the following?

<table>
<thead>
<tr>
<th>Advance directive</th>
<th>Recommend</th>
<th>Require</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enduring Power of Attorney</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Management Order</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guardianship Order</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Written Direction Under the Medical Treatment Act 1994</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good Palliative Care Order (Palliative Care Council)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A specific form designed by your facility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thankyou for your assistance
Interview questions

1. Do you currently use a form/tool to collect information on residents’ wishes with regards to their end of life?

2. In your opinion how useful would it be to you to have access to a standardized resource to be used in the admissions process to assist with the collection of information on residents wishes?

3. Do you think your current overnight staffing levels impact on the provision of palliative care in your facility? In what way?

4. What is your opinion of a ‘fly in squad’?

5. Do you have any ideas on what more could be done to assist aged palliative patients to return ‘home’ from hospital to die?

6. Do you have any suggestions on what could be done to improve the continuity of care for patients who have to transfer between their facility and hospital? What is currently working well and what could be improved?
Appendix B

What is advanced care planning?

Advanced care planning is an opportunity for you to have a say in your current and future health care. It can help you to discuss, reflect upon, decide and communicate your future health care decisions. It also ensures that these decisions can be communicated to the health care workers who will provide your care in the future.

Advances in medical technology, such as being on a life support machine in an intensive care unit, have given us the ability to prolong life where previously it was impossible. What these advances have brought with them is the dilemma for doctors and family of deciding when to withhold or withdraw life-sustaining treatments which may be of limited or no benefit. Advance care planning enables individuals to take part in the discussion and decision-making process about their future care.

Individuals have the right to make decisions about their health care, now and for the future. Decision-making about medical treatment should involve being fully informed and, after being informed, choosing to accept or refuse treatment. An advanced care plan offers you the opportunity to say now what life-prolonging medical treatment you would and would not want in the future. If in the future you are unable to express your wishes about treatment, your doctor and family will know what you would have wanted or how you would have liked the choices to be made.

How do I make an Advance Care Plan?

Step 1 Think about your beliefs and values and your goals for what is important in your life.

Step 2 Think about your current health and possible future health problems.

Step 3 Think about what you would want from future medical care.

Step 4 Talk to your family/next of kin/important others about these issues.

Step 5 Talk to your doctor about these issues.

Step 6 Choose an attorney who will make your medical decisions if you are unable to make them for yourself.

In the ACT, you may appoint an attorney under the Enduring Power of Attorney legislation. To find out more about appointing an attorney visit the website of the Office of the Public Advocate (ACT) www.oca.act.gov.au and download the information on the Enduring Power of Attorney.

Or telephone the Office of the Public Advocate on ph 6207 0707 and ask them to send you a copy of the Enduring Power of Attorney form.

Step 7 Meet with your attorney and your doctor and discuss what is important to you, your current health and your future medical choices.

Step 8 Complete the form as required by the legislation ensuring that it is signed by you in the presence of two witnesses who are not related to the attorney. The attorney must also sign the document.

Step 9 Give copies of your Enduring Power of Attorney form to your family/partner, your attorney, local doctor and anyone else whom you feel is appropriate.
Planning end-of-life care is an iterative or cyclic process based on assessment, disclosure, discussion and consensus building with the patient and/or their family and the treatment team. This process can take place over a short period, such as hours, where the patient suddenly or unexpectedly deteriorates, but it can also extend over weeks or months. The key points in each step of this process (section 5.1) are discussed in the following sections.

5.1 Process of end-of-life decision-making

Clinical deterioration/ non-response to treatment or patient's desire to limit treatment

Assessment

Consensus

Discussion

Disclosure

Options
- Time and repeat discussion
- Second medical opinion
- Facilitation
- Guardianship Tribunal
- Transfer of care – physician or institution
- Legal intervention.

Conflict

5.2 Assessment

A sudden or unexpected deterioration, or uncertainty about prognosis, usually requires efforts to stabilise the patient so that a complete assessment can be undertaken and potential reversibility of the condition be established. The treating team should undertake this assessment at the earliest appropriate time. Life-sustaining treatment already commenced may be subsequently withdrawn if deemed appropriate upon assessment of the patient's wishes or clinical condition.

Where there is reasonable doubt about the medical assessment in the treating team, advice should be sought from other senior clinicians with experience in the condition if possible. Second opinions should be documented.

Assessment should also include evidence of the patient's preferences and values where available from the patient, or his or her family if the patient has no capacity to express those wishes. Patients' preferences for life sustaining treatment are not static over time and should be regularly reviewed by the treating team.

A patient's desire regarding direct communication and information must be respected. The patient also has a choice to nominate someone to receive information on his or her behalf, or to exclude family members from discussions and decision-making processes.

The desire for autonomous-style decision-making or the preference for a collective or delegated approach to end-of-life decisions may vary among patients from different cultural or religious backgrounds. This aspect should be explored on an individual basis to avoid inappropriate clinical decisions and poor interaction with patients and families. The informal use of untrained interpreters such as other family members should be avoided where possible to prevent role confusion and misinterpretation of clinical information.

Failure to demonstrate any improvement in clinical condition over an extended period appropriately generates questions about further initiation or continuation of treatment. The patient, the treating team or the family may initiate such discussions.
Developing a management plan

5.3 Disclosure

Honest information in non-technical language should be provided to patients and their families for them to participate meaningfully in decisions about end-of-life care. Uncertainty about prognosis or likely response to treatment should be communicated to patients and their families. Prognostic information is ideally given by a health professional who is respected as an expert.

Patients and families may be caught off guard when conversations about the goals of care and possible treatment cessation occur suddenly, very late, without preparation, or when they have not received a balanced picture of the patient’s prognosis. Patients and their families should be engaged in open communication about possible outcomes early in treatment, especially where the patient is seriously or critically ill, in order to prevent unrealistic expectations about what can be achieved with treatment. Early, honest and regular communication can also help create the trust needed for shared decision-making and to defuse tension.

5.4 Discussion

Discussions with patients and their families about treatment limitation should ideally occur in stages over a period of time, preferably while the patient can determine the appropriateness of treatment or its cessation. The presence of nursing staff, or other key members of the treating team, at these discussions is recommended to support and facilitate communication between the treating team and the family.

Strategic opportunities for the treating team to initiate or revisit discussion about end-of-life care may include recent hospitalisation with severe, progressive illness or repeated recent admissions, inquiries from the patient or family about palliative or hospice care or an expression by the patient of a wish to die.

Having the same person’s communicate with the patient or family on behalf of the treating team throughout this process can be useful, as minor differences in explanation of the patient’s condition or progress can seem to patients and families like major disagreements or discord in the team. Ideally, this health professional should be experienced in conducting such discussions, have earned trust before treatment limitation is discussed, and be able to discuss prognostic information.

The phrases ‘do everything’ or ‘do nothing’ are unproductive and should be avoided: neither term is ever strictly enacted and such terminology is a barrier to informed discussion regarding the benefits and burdens of certain courses of action. The ongoing care with the goal of providing comfort to the dying patient should be emphasised with the patient and his or her family where limitation of life-sustaining treatment is planned.

5.5 Documenting a consensus decision

The agreed management plan for end-of-life care, and decisions about the use of life-sustaining treatment within that plan, should be documented and conveyed to all members of the treating team. Such communication may be difficult where many staff care for the patient but adequate documentation may assist in this regard. The senior treating clinician is responsible for summarising discussions held with the patient, family and treating team in the patient notes. These notes must clearly state:

- medical facts leading to the decision, including prognosis
- persons involved in the discussion
- statement of the patient’s wishes, where known
- goals of treatment
- details about medical treatments to be provided, timeframe before review, or details about treatments to be withdrawn/withheld.

Management plans may cover a shorter or longer period of time, depending on the clinical situation of the patient. Decisions that involve withholding treatment such as CPR should be regularly reviewed in accordance with fluctuations in the patient’s condition. A change in the appropriateness of withholding treatment such as CPR needs to be re-documented. (See also 7.5).

Other appropriate treating team members should continue to document other aspects of care that will be maintained or enhanced, such as comfort measures. Thorough documentation of decision-making processes and subsequent care enables greater transparency and accountability in the care provided and ensures that all health professionals fulfil their professional and legal obligations.
Appendix D

The following comments were obtained from twenty Directors of Care across all 23 aged care facilities in the ACT during the period of November to December 2005. In one instance a Director of Care spoke on behalf of both the nursing home and the hostel components of her facility, in another the Care Manager spoke on behalf of the specialized dementia unit and the hostel component of her organization.

Directors of Care were asked to respond to the question ‘Do you think your current overnight staffing levels impact on the provision of palliative care in your facility? In what way?’

Directors of Care from nursing homes responded with the following comments.

• We have one RN, one EN and six other staff rostered on across our facility overnight. In my opinion we are adequately staffed to meet the palliative care needs of our residents overnight. We do not own a syringe driver but prefer to hire one if necessary.

• We currently have access to an RN on the premises and an RN on call overnight. Two of our RN’s have palliative care training certificates and three have participated in the PEPA program. We also have a mechanism for calling in extra staff for the provision of palliative care if necessary.

• We currently have seven staff on overnight one of whom is a RN. We also have had two staff participate in the PEPA program.

• I am satisfied that our current levels of overnight staffing are adequate to meet the palliative care needs of our residents.

• We currently have five staff on overnight. We have an RN on roster seven nights on and seven nights off. On the nights when the RN is off duty there is an EN on site who has an advanced medication certificate. We also have an RN available on call.

• We currently have one RN on site overnight across both the nursing home and the hostel. At times this staff member can have a high work load.

We have purchased a syringe driver which has helped the situation, however clinical assessment is difficult with this level of staffing. PCA’s do not have adequate training and or skills for clinical assessment.

• We have RN’s on site 24/7 and have staff that have undergone the PEPA training. We are in the process of buying syringe drivers and access the Home Based Palliative Care team when necessary. We also use music and aromatherapy during the provision of palliative care.

Directors of Care from hostels responded with the following comments.

• In our facility we have a RN available on site from 8am to 10pm, with a PCA and a staff member on sleep-over. The Director of Care is also available on call overnight. In two of the most recent deaths in our facility we drew on the services of the Home Based Palliative Care team. The team made arrangements for the prescription and supply of medication; they also set up the syringe driver. The team made two after hour visits to our site.

• In this facility we have an RN available for 38 hours between Monday-Friday and for 4 hours on Saturday and Sunday. Overnight the facility is staffed by two PCA’s who have access to an RN (who is the Director of Care) on call. We have enough staff cover to run a syringe driver although we do not have one on site. We rely on the support of the Home Based Palliative Care team for the provision of palliative care and we need that support to continue. The administration of S8 medications is a difficulty as two RN’s need to be available for the checking procedure.

• We have an RN on the premises some nights and on call at other times. We are currently restructuring our staffing arrangements in response to the increasing levels of high care need amongst our residents. Our aim is to relieve the Registered Nurse of her role in the distribution of medications and to allocate this task to an appropriately trained EN. The RN will then become available for more clinical assessment responsibilities.

• We have two staff on overnight an EN and a PCA. We use syringe drivers in the provision of palliative care. Current difficulties include; the
management of breakthrough pain at night that requires the administration of an S8 medication, and the low level of clinical assessment skills that staff have. I would like to see the development of a decision making flow chart for palliative care. A chart that staff could use to help them with basic assessment decisions.

- We have two PCA's on overnight with the Director of Care available on call. While we have a history of managing patients to the end of their life, we make assessment of a residents needs against the resources of the facility in terms of the staff and the needs of other residents. This is done on a case by case basis.

- In my experience over the past five years as a Care Manager it has only been necessary for me to come back to the facility at night on three occasions. During this time I have received numerous phone calls at night from staff but have found that a lot of support can be given over the phone and with appropriate forward planning crises can be avoided. We try to keep residents in our facility for palliation. We have three staff on overnight with an RN available on call. Two of our staff have attended the PEPA program and we have purchased two syringe drivers. We rely on the Home Based Palliative Care team for backup but sense that they want to decrease their support. We have also had issues with GP's who are reluctant to initiate palliative care, either delaying or providing insufficient pain relief. This situation is however improving.

- Overnight staffing in our facility consists of one EN and one PCA with an RN available on call overnight. We also have one syringe driver and an RN who has had palliative care training. We currently liaise with GP's and the community nurses for the provision of palliative care and use the community nurses and the Home Based Palliative Care team over the weekend and at night. The Home Based Palliative Care team is integral to the provision of palliative care in our facility. We rely on them for setting up the syringe drivers, for clinical advice on the management of breakthrough pain and for telephone and on site support.

- We have an RN available on site 24/7 and are happy with the current levels of staffing in relation to the provision of palliative care. We have palliative care packs made up in advance; we have staff who are trained and confident in the use of syringe drivers; we currently have an EN attending the CIT course to increase her skills and enable her to check S8 medications. We do however have problems at times with the management of breakthrough pain at night, as one RN does not have access to a second RN for the checking and administration of S8 medication.

- Currently we have one PCA and one EN on overnight with the Director of Care available on call. We also have the flexibility to put on extra staff if need be. When providing palliative care we liaise with the resident’s GP first and foremost. We also use the Home Based Palliative Care team for the provision of a syringe driver. Of the two people that died in the facility this year neither required palliative care.

- In our facility we are able to provide high level personal care but not high level nursing care. We transfer to hospital residents who require acute care, but are happy to receive them back for palliative care. We currently have a six night roster with an RN on site for three nights and an EN on site for the alternate 3 nights. With regards to having an RN on call overnight, if that person is called to the site they must be paid for 4 hours worth of work, this is a very expensive option, and essentially not cost effective. With regards to palliative care we rely on the Home Based Palliative Care team for support and to set up the syringe drivers. While our staff have been educated to observe and assess syringe drivers in situ they need support if there are problems or breakthrough pain. We have had two RN’s and one EN attend the PEPA training. They are now taking responsibility in educating other staff, and being part of a palliative care working group that is looking at the development of a Palliative Care Plan.

- In our facility we have one PCA on overnight. While there is also an RN available on call it is not possible for her to go to the site at night. We rely on the Home Based Palliative Care team to keep our residents at the facility for palliation; to set up syringe drivers and to be available after hours for the management of breakthrough pain. Residents requiring long term palliation can be transferred to the nursing home section of our organization.

- We have a RN on the premises on some nights and always have an RN available on call overnight. We draw on the Home Based Palliative Care team for support and at times a resident’s GP may refer
them to the specialist palliative care clinicians. Our residents also have access to a chaplain for their spiritual care.

- Our facility is staffed by PCA’s overnight who have access to an RN on call. The main issues that make the current overnight situation difficult are; adequate pain management, the inadequate skill base of the staff and clinical assessment. Despite this however, residents have been managed for palliative care on site for the first time this year, which is a real milestone for our staff.

- We have an RN on the premises on some nights and on call at other times. We have used the Home Based Palliative Care team for support with Schedule 8 medication, symptom management and consultations with resident’s families. An ongoing issue with the provision of palliative care is the lack of skills and experience that new staff bring to the job.

Appendix E

The following comments were obtained from twenty Directors of Care across all 23 aged care facilities in the ACT during the period of November to December 2005. In one instance a Director of Care spoke on behalf of both the nursing home and the hostel components of her facility, in another the Care Manager spoke on behalf of the specialized dementia unit and the hostel component of her organization.

Directors of Care were asked to respond to the question ‘What is your opinion of a fly in squad?’

In the broader context Directors of Care were asked to consider what kind of characteristics would make an after hours ‘fly in squad’ for support with the provision of palliative care attractive to their organization.

Directors of Care from Nursing Homes reported the following;

- We currently access the Home Based Palliative Care team during the day for support and the provision of equipment

- We currently access the Home Based Palliative Care team for the setting up of syringe drivers if they have been ordered and for staff assistance. We have occasionally used this service during the weekend or at night.

- We currently access information and support from Sue Woods the project officer with the PEPA program.

- A ‘fly in squad’ would not be of specific interest to this facility given our current access to RN’s on site, 24/7

- In my opinion a ‘fly in squad’ would be useful for the following; assistance with clinical assessment, the setting up of a syringe driver, increasing staff confidence and education by osmosis. Under the current circumstances if it is necessary for staff to call in an RN overnight it is a requirement that she be paid for four hours which is cost prohibitive.
A ‘fly in squad’ would be useful in circumstances when a patient is not responding to the current pain regime and is experiencing breakthrough pain. Currently we have access to the CALMS service but they can have a wait time of up to four hours, alternatively there is hospitalization, but we try to avoid this for palliative patients. A phone service could be desirable allowing staff the opportunity to clarify actions and assessment. Phone order medications would also allow the RN on duty more flexibility in terms of treatment options for pain relief.

This service would not really be appropriate to the needs of this facility given the current access we have to registered nurses.

Directors of Care from Hostels reported the following:

- The characteristics of a ‘fly in squad’ that would make it attractive to this organization are; the ability to both access and administer medication, and access to equipment such as syringe drivers.

- A ‘fly in squad’ that could provide backup for clinical assessment and set up syringe drivers would be useful.

- In my opinion a ‘fly in squad’ would need to be professional, approachable for all staff, available 24/7 and have a prescribing capacity such as that enabled by nurse practitioners. We currently notice that there is a lag time between when a GP refers a resident to the Home Based Palliative Care team, consultation by the team and subsequent ratification by the GP.

- Currently some community services can only be accessed by residents with a low care RCS classification. Of interest to us would be the availability of a ‘fly in squad’ to all residents irrespective of their RCS classification. Any cost to be borne by either the facility or the resident would also impact on our potential use of such a service.

- A service that provides back up phone support for night staff could be useful although staff in our facility already have this type of support provided for them by the Director of Care. An availability to come to the site at night to provide assistance with the management of breakthrough pain would also be useful.

- We would be interested in a service in which staff were competent in the provision of palliative care, available at short notice and were prepared to provide follow up afterwards to enable facility staff the opportunity to gain feedback and improve their confidence and skills.

- We currently liaise with both GP’s and the Home Based Palliative Care team to meet the palliative care needs of our residents. Having access to the Home Based Palliative Care team on the weekend would be useful.

- We currently use the Home Based Palliative Care team as a type of ‘fly in squad’ due to the lack of availability of registered nurses. Our facility is trying to develop some more medium term approaches to the management of residents with palliative care needs, with the aim of decreasing the staff experience of crisis during the night.

- The characteristics of a ‘fly in squad’ that would make it attractive to our facility include; access for all residents regardless of their RCS classification, the provision of phone support for staff who are alone at the facility overnight, the ability to come to the site for the provision of breakthrough pain relief, and the ability to liaise with GP’s and residents’ families (to provide an objective outside point of view).

- From my point of view the characteristics that would make a ‘fly in squad’ attractive are; they would have a medical knowledge to make assessment and changes to medication orders when necessary, they would have access to medication and equipment such as syringe drivers, they would have the power to authorize medication changes, and they would have people skills that would enable them to empathize with facility staff creating an atmosphere of support.

- The requirements for an effective ‘fly in squad’ would be access to a palliative care trained registered nurse who could make clinical assessments, administer medication and be available to come to the site.

- Currently our night staff have little contact with professionals such as GP’s, the availability of an after hours service would assist to educate night staff within their working hours and environment. A ‘fly in squad’ would need to have an availability to come to the site and to supplement current staff skills in area such as the use of syringe drivers.
Appendix F

The following comments were obtained from twenty Directors of Care across all 23 aged care facilities in the ACT during the period of November to December 2005. In one instance a Director of Care spoke on behalf of both the nursing home and the hostel components of her facility, in another the Care Manager spoke on behalf of the specialized dementia unit and the hostel component of her organization.

Directors of Care were asked to think about that group of residents who had been transferred to hospital and had subsequently died in hospital and to consider the question “Do you have any ideas on what more could be done to assist aged palliative patients to return ‘home’ from hospital to die?”

For Directors of Care from Nursing Homes this population consisted of 31 patients and was approximately 11% of the total population of patients that died from their facilities in the 2004–2005 financial year.

• We feel that we are keen to receive patients back yet we have on occasions been given a response from the hospital that a resident is too close to death to be moved.
• The hospital is quick to return patients with dementia who have challenging behaviours.
• Our facility is proactive in liaising with the hospital staff for the return of residents however sometimes there is a delay in accepting a resident back if they have come from a low care part of the organization and subsequently need high care.
• We have had experience of residents returning for palliative care with either inappropriate or no medication.
• In our experience those individuals who died away from the facility did so because of families’ wishes. More education of families is needed.
• Of those who died away from the facility one died from pneumonia and two did not return due to the families’ wishes.
• We are supportive and pro-active in encouraging residents to stay in our facility to receive palliative care.
• Of those who died away from the facility it was primarily because of the wishes of the family and the resident themselves that these individual did not return.
• Family wishes were the main reason that patients were transferred to hospital in the palliative stage of their care. Families were in denial of the immanent death of their relative.

For Directors of Care from Hostels this population consisted of 40 patients and was approximately 25% of the total population of patients that died from their facilities in the 2004–2005 financial year.

• We believe that more liaising with families giving them reassurance that appropriate palliative care can be provided in hostel setting would improve the return rate of residents.
• The situation could also be improved by residents being able to access a referral to the Home Based Palliative Care team while they are in hospital, prior to their return.
• Facilities need to be able to assess the needs of their residents against the resources they have available and make a decision on a case by case basis.
• Hospital staff need to come and visit facilities and gain a clearer picture of the resources facilities have available to them.
• There needs to be an acknowledgement from hospital that facilities can manage with the limited resources available to them.
• The current barriers to the return of palliative care patients are staffing levels and equipment needs.
• Of the two residents from this facility that died in hospital both had needs that were beyond the resources of the organization.

• In our experience lack of adequate pain management for people with dementia was a primary reason for transferring patients in the palliative stage.

• At the moment our organization which consists of three hostels and an outreach program is exploring the development of a community nursing project. The idea would be to employ two registered nurses who would have an availability 24/7, to meet amongst other things the palliative care needs of our client population. The current difficulty for the project is sourcing registered nurses.

• The factors that impact on the decision to accept patients returning for palliative care include the level of care required, the layout of the facility itself, and the level of family support available.

• All four deaths that occurred away from the facility involved crisis situations in which there was an acute episode, the patient was transferred to hospital and died shortly afterwards, usually spending less than a week in hospital.

• All four residents who died in hospital had acute episodes and died quickly after transferring to hospital.

• The four deaths that occurred in hospital were all initiated by an acute incident, two were medical cases and two were surgical. None of these residents could have been accepted back to the facility.

• Having access to the Home Based Palliative Care team on the weekend would assist in the return of palliative patients to the facility.

• Our facility is already proactive in wanting to assist patients to return from hospital to die ‘at home’, but we accept that we must operate within the limits of our resources. We cannot assist anyone whose care requires access to a registered nurse 24 hours per day. We also cannot accept residents with complex wound management as the cost of dressings must be borne by the facility. Quoted the example of a resident whose dressings cost $900 per week.

• More information from the hospital needs to be given along with advanced warning of the return of a resident so that residents with high care needs can be appropriately placed.

• There seems to be a misunderstanding within the hospital sector of what Aging In Place means and hospital staff need to be more accurately informed in this area.

• Patients need to be returned with medications in Webster pack format so that staff can administer them. Orders for medications also need to be written up and returned with the resident.

• No weekend discharges. 11A tends to be good in this area but other wards are not so sensitive.

• The Director of Care cited the case of a resident with complex needs who had multiple hospital admissions. Eventually this individual was assessed as palliative with care needs beyond the capability of the organization. She was transferred to the hospice where her condition was stabilized and her symptoms managed more satisfactorily. The facility was subsequently asked to re admit this resident, but as she had been discharged this was not possible. This situation was a source of anxiety and disruption for the resident and her family and also for the staff of the facility, the hospital and the hospice.

• This facility has the capacity to absorb the palliative care needs of residents when death is immanent and predictable, consequently low care residents who become palliative can remain in the facility. Residents who deteriorate and need to be managed in the medium term are however reassessed by ACAT and the family is asked to put their relative’s name on the waiting list for a nursing home placement. This is always a difficult process.

• Case conferencing at the hospital should include facility staff and the sustainability of care that the hostel can provide needs to be raised and discussed in these forums.

• The Director of Care cited the example of a large patient who was immobile and unconscious with care needs beyond the capacity of the organization. The facility received a lot of pressure to accept the resident back for palliative care. A team decision was made to refuse this request after the care manager and three staff visited the hospital to sight the resident for themselves. The resident’s family had hoped that the resident would be able to return to the facility.
and so discussions were had with them explaining why this would not be possible. Agreement was reached with the hospital that when a high care place became available in another part of the organization the resident would be returned. The resident died in hospital before a place became available.

• In our experience palliative patients are routinely returned from hospital to die ‘at home’ in the facility. This is in keeping with the wishes of most families who feel uncomfortable with the hospital situation and prefer their relative to be returned to the hostel.

Appendix G

The following comments were obtained from twenty Directors of Care across all 23 aged care facilities in the ACT during the period of November to December 2005. In one instance a Director of Care spoke on behalf of both the nursing home and the hostel components of her facility, in another the Care Manager spoke on behalf of the specialized dementia unit and the hostel component of her organization.

Directors of Care were asked ‘Do you have any suggestions on what could be done to improve the continuity of care for patients who have to transfer between your facility and hospital? What is working well and what could be improved?’

Directors of Care from nursing homes gave the following responses:

• If all residents from aged care facilities could be cared for in 11A there would be an improvement in continuity of care. In our experience it is when residents are cared for in other parts of the hospital that continuity of care and communication with the facility is poorer.

• Residents from aged care should by pass the Emergency Department triage process and have an alternate stream for assessment and admission.

• We have had incidents of residents returning from hospital with pressure sores and on one occasion staff from the facility were informed by hospital staff that if a resident presented to the emergency department they would not be given any food or water overnight.

• For our part we send residents to hospital with a transfer form, and continue to keep communication channels open with follow up phone calls and visits to the hospital.

• Hospital staff need to become more informed about aged care facilities. Would like to have information sessions with the discharge planners from each of the wards where residents may receive care.
• Facility staff should be invited to case reviews at the hospital, provided with more information and given prior warning of a resident’s return.

• An increasing number of patients are being returned to the facility with pressure sores that require extensive and expensive dressings for which the nursing home must bear the cost.

• Information sharing and the facilitation of trust between the sectors are essential. For our part we have initiated consultation with the discharge planner at Calvary Hospital. However the information that we receive back from the hospital is often carbon copied and not legible and we are not given an accurate picture of a returning resident’s prognosis, treatment options, the decision making discussions that have occurred with families or the families preferences. The decision by the facility to return a resident to hospital is often due to the fact that inadequate information has been provided for their care.

• Patients returning from hospital with medication scripts written for up to a two week period would alleviate a lot of frustration.

• Our facility is committed to maintaining a good rapport with the Canberra Hospital and Calvary. We maintain phone contact with the hospital; if a resident has been transferred for an acute episode we ring twice per day, however if they are in a non acute phase we ring every second day. We routinely ask to have residents returned to the facility for palliative care.

• I believe there is a lack of respect for older people within the acute care sector.

• We have recently revamped our transfer sheet for residents transferring to hospital. We are happy with the information we are sending and are prepared to give further information if it is requested of us. We experience the need to maintain constant follow up for any of our residents who are transferred to hospital. There is however a lack of consistency in the information that is given back to us when residents return.

• We have experienced residents being returned without details on vital information such as when they received their last insulin injection or dose of pain relief.

• We have had experiences of patients being inappropriately transferred, returned from the Emergency Department via taxi in the middle of the night during winter.

Directors of Care from the hostels gave the following responses to the above question.

• When transferring a resident to hospital we try to weigh that decision in terms of the cost and benefit to the resident themselves.

• Lack of appropriate access to a resident’s General Practitioner increases the likelihood of a resident being transferred to hospital. Sometimes GP’s may be delayed by days before they are able to come to the facility.

• We experience a good relationship in terms of discharge planning with ward 11A.

• The National Capital Private Hospital has approached our facility offering to take residents with private insurance who have after hours medical needs but they are not able to assess and treat residents with suspected fractures.

• The arrangements for the provision of medication for residents returning from hospital are an issue for us.

• When a resident leaves hospital and returns to the facility the medical registrar at the hospital has no ongoing responsibility for that individual. On returning to the facility they return to the care of their GP. If medications have been altered while in hospital the patient needs to be seen by their GP.
within a three day time frame to be reviewed. This arrangement is very difficult for low care facilities, particularly if a resident is returned on Friday.

- In my opinion things could be improved if the discharge planner at the hospital made direct contact with a resident’s GP, faxing them a medication pro-forma and a request for a review. That way the GP could then issue a script as necessary.

- Hospital staff need to know that staff in low care facilities who are not RN’s can only dispense medication from a Webster Pack. If for example a resident is returned to the facility on Friday and some of their medications from their Webster Pack need to be removed and others added, the EN’s and or PCA’s employed over the weekend will not be able to do this, medications can only be administered by them if they have been repacked by the pharmacy.

- Discharge planners need to contact the facility 48 hours in advance of the resident returning.

- We find that we need to be proactive in our relationship with the hospitals. Our facility has recently allocated one staff member to the role of dialoguing with the discharge planners at both The Canberra Hospital and Calvary and to making contact with resident’s GP’s. This has led to increased dialogue and an improvement in continuity of care.

- In my opinion continuity of care would be improved by increased information exchange. We often find that there is a lack of information given to us on a residents return from hospital and that the information that is given is poorly written.

- A strategy for dealing with the issue of Friday afternoon returns would be for information regarding medication changes to be faxed directly from the hospital to the resident’s GP for his/her authorization. The RN on duty at the facility at that time could then dosette out the three day supply of medication provided by the hospital to be administered by the weekend staff (who are not registered nurses).

- The problems that currently impact on the continuity of care are; medication changes in which residents are returned to the facility with no accompanying paper work or in some cases no medications, Friday afternoon returns (approximately 25% of residents would be returned at this time) and late afternoon returns where not enough information on medication changes and or diagnosis has been provided and facility staff then try to make contact with the hospital to gain access to this information.

- Things that could be done to improve the continuity of care include the electronic transfer of information and the standardization of medication charts and transfer forms.
• Continuity of care could be improved by clearer guidelines and instructions for facilities accompanying a resident’s discharge and for medications to be returned in a Webster Pack format.

• Continuity of care could be improved by a commitment to more honest relationships on the part of the hospitals regarding the reporting of a patient’s condition. Currently it is necessary for us to sight our residents in hospital due to the history of inaccurate information being given. Hospital staff seem to be unaware that hostels have a duty of care to both their staff and residents. The legal and safety obligations of hostels need to be respected.

• It is not possible for our facility to accept back patients who are on medications that may be administered as required as a registered nurse must be available to make that assessment. We do not have a registered nurse available on site at all times to make that decision when needed.

• Our relationship with John James Hospital is working well and this is in part due to the fact that they return residents with medications in Webster Pack format.

• In the past facilities received greater support from the hospital in terms of free access for residents to the services of the wound clinic, the continence clinic and the gastroscopy clinic. In my opinion access to these services led to a lower rate of re-admission for residents. Continuity of care could be improved by the reintroduction of these support services from the hospital.

• In terms of what is working well; our facility has developed a comprehensive transfer form that details the residents usual care needs, their medication profile and the reason for transfer. We also have an established relationship with the discharge planner at 11A who is well informed of the capabilities of low care facilities. In terms of what could be improved we are often given little warning of a resident’s return, we have had more difficulties with patients returning from private hospitals after elective surgery and discharge planners from wards apart from 11A not being informed of the capabilities of low care facilities.

• In our experience there is no communication from the hospital, we must initiate contact. When staff do ring the hospital they are often find themselves speaking with a different person each time. It may be the discharge planner, the nurse currently on shift looking after the resident, the CNC, the physiotherapist … There is also an issue of lack of consistency in the information given. Having access to student nurse practitioners is having a significant impact on reducing the need to transfer residents and on the provision of support for staff within the facility.

• We currently keep in touch on a daily basis with the nursing staff when we have a resident in hospital. The hospital usually rings regarding the return of a resident; however this is usually at short notice. Continuity of care could be improved by the provision of more detailed information from the hospital.