

PALLIATIVE CARE
V I C T O R I A

SUBMISSION TO

**SENATE COMMUNITY AFFAIRS
REFERENCES COMMITTEE**

INQUIRY INTO AGED CARE

JULY 2004

To the Senate Inquiry into AGED CARE,

Palliative Care Victoria is pleased to have the opportunity to provide the enclosed submission. This submission has been developed by:

Margaret Box
Executive Director,
Palliative Care Victoria,
Level 2, 182 Victoria Parade,
East Melbourne, Vic. 3002
Tel 03 9662 9644
Fax 03 9662 9722
Email: mbox@pallcarevic.asn.au
Web: www.pallcarevic.asn.au

for and on behalf of Palliative Care Victoria and its membership. If it is required, I would be available to make an oral presentation to the Inquiry.

Yours faithfully,



Margaret Box
EXECUTIVE DIRECTOR

INTRODUCTION

Palliative Care Victoria Inc. is an incorporated association whose membership comprises individuals and representatives of hospice and palliative care organisations. The Association's membership provides hospice and palliative care support via in-patient beds in acute hospitals, hospices and home care.

This submission will deal with some of the areas of concern to Palliative Care Victoria and its membership relevant to the Inquiry into Aged Care. Palliative Care Victoria has highlighted to its membership the terms of reference of the Inquiry and recommended they put individual submissions to the Inquiry as appropriate. The information contained in this submission has been provided for and on behalf of the membership.

BACKGROUND

This Senate Committee Inquiry is timely in that it provides an opportunity to highlight the issues regarding residential aged care and people living with MND, Multiple Sclerosis and other conditions that require care in residential aged care. This is a group that has often been highlighted by palliative care providers in Victoria. In particular, there are some in this situation who are younger people needing access to residential aged care facilities because of their deteriorating condition. They can have complex symptom management issues and longer-term requirement for care and support. A specific group is that of younger people with brain tumours whose management at home can be quite difficult and so the necessity for care outside of a hospital environment is often required.

Some of the issues that need to be addressed and/or considered by the Senate Committee Inquiry into Aged Care include:

- people of any age who are not demented being in nursing homes
- capacity of nursing homes to manage PEG feeding and/or ventilation
- the issue of when to cease PEG feeding and/or ventilation
- how can families and staff in residential aged care be supported when decisions are made to cease PEG feeding and/or ventilation
- capacity of nursing homes to invest time in communication issues with those who either have lost their capacity to communicate in the usual manner, or who never had that capacity
- capacity of nursing homes to meet the needs of people with Motor Neurone Disease, multiple sclerosis or other similar conditions
- capacity of nursing homes to meet the needs of younger people with brain tumours or other conditions requiring similar support
- risks of mixing people with these conditions and people with dementia
- adequacy of Home and Community Care in addressing needs
- services available if you are age 64 versus age 65
- skill mix of staff in residential aged care
- bereavement support for other residents, staff and families

There will be a number of other issues that might be identified as being appropriate in each State/Territory. This submission addresses only those highlighted by palliative care services in Victoria.

This is a great opportunity to highlight the needs of people requiring palliative care and a palliative approach during the course of their illness and to start some thinking around the acquisition of disability at a later age and what that means for services and service appropriateness. The barrier between age 64 and age 65 services needs to be reconsidered and perhaps replaced by one of service access based on needs.

YOUNGER PEOPLE IN RESIDENTIAL AGED CARE WITH A PRIMARY MALIGNANT BRAIN TUMOUR REQUIRING LONGER-TERM PALLIATIVE CARE

Background

The diagnosis of a primary malignant brain tumour is a catastrophic event as patients, carers, family and friends quickly become aware of the prognosis and outcome of the progressive cognitive and physical decline of the patient. It is an invasion of self[personality]. Patients often lose track of “ who they really are”.

Approximately 400 new malignant brain tumours are diagnosed every year in Victoria so this number would be significantly greater across Australia. The majority of these patients are under 65 years, frequently in their 30's and 40's. They have special needs specific to their progressive brain injury and include the following:

- Care and support of young children;
- Progressive cognitive impairment and loss of insight; inappropriate behaviour
- Progressive physical deficits; including increasing risk of skin tears – pressure sores due to side effects of medications
- Weight gain and increase in muscle weakness---side effects of medical management;
- For several months prior to death they are unable to be left alone. If the carer is unable to stop work for an indeterminable period of time due to financial constraints , i.e. mortgage, young families then care in a nursing home is often sought;
- Lack of availability of friends/ family to assist with respite due to their work commitments
- Carer obligations including employment and child-care, child-raising issues.

In home respite is often needed to maintain family integrity for as long as possible, however, whilst there has been some recent improvement in funding for in-home respite some young patients are physically too disabled and too heavy, cognitively too unreliable to remain alone at home. There are some patients who have no family at all. Each of these categories may need to spend several months in nursing homes with appropriate support, including palliative care, prior to their death.

One service reported to Palliative Care Victoria that of this group of patients admitted to their palliative care program in the past financial year, there were:

- difficulties in getting ACAS assessments because they were less than 65 years of age
- they had a high level of care needs
- they had complex social situations and young families

and because of many of the above they were never referred to aged care although they could have benefited from this type of care.

This service had 23 primary brain tumours with an average length of stay of 27 days, 15 died in their facility, with 12 of 22 staying between one and six months.

The service also reported that there often difficulties with families and patients accepting the need for transfer to a nursing home. This was because although the needs and prognosis of the patient were recognised, the patients and families felt they would not receive adequate care in a nursing home.

The Residential Aged Care Facilities needs:

- to be close in proximity to the family home to maintain as much as possible the family unit
- to have a friendly and safe environment to cope with young families and children;
- staff need to have understanding of grief and loss issues that are relevant to young patients, families and children [of all ages]
- supervision and support for staff;
- staff or resource expertise available;[due to the subtle differences in progressive cognitive decline of the brain tumour patient compared to aged/dementia patient,]- who can assess and direct the management of these young patients;
- to have appropriate skill mix in the staffing;
- knowledge and ability to provide and administer drug regimes appropriate to the disease/condition and symptoms of the patient/resident group;
- access to and knowledge of how to use appropriate equipment, e.g. syringe drivers
- experience, expertise to understand when specialist palliative care consultancy is required and capacity to access this expertise.

PATIENTS WITH MOTOR NEURONE DISEASE REQUIRING LONGER-TERM PALLIATIVE

The Calvary Health Care Bethlehem¹ service provided the following information for this submission to the Senate Inquiry:

“MND patients 2001 - 2003

15 patients commenced placement process. Eight of this group were successfully placed into residential care, the other seven patients died during the process. 80% of the group that were placed were over the age of 65 years, and the average time to placement was 120 days. The average timeframe for the group which died during the placement process was 105 days.

¹ Bethlehem Experience with Nursing Home Placement Retrospective Study – Calvary Health Care Bethlehem, 2004

MS and other Neurological diagnoses 2002 – 2004

Placement: four patients were over 65 and it took an average 81 days to placement.

Six patients were less than 65 years. Of the six, three were either waiting to be placed at 16th July 2004 or had died prior to discharge. They were waiting an average 568 days.

The three patients that were placed averaged 190 days to discharge.

Particular issues which relate to the less than 65 year group include:

- Admission to hospital due to pressure areas and inpatient respite care
- Community services not sufficient to meet need at home.
- Alternate accommodation set up for younger people not accessible easily.
- Majority of younger people with cognitive impairment.
- All younger people did not have personal funds to privately increase care.
- MS clients even with high disability needs may have lengthy prognoses.
- Younger people waiting to have quality of life issues met re: ability to maintain connection to community, contact with people of their own age.”

Grief, loss and bereavement needs to this particular client group are sometimes complex and require appropriately skilled interventions and support.

Some general comments provided to the Department of Human Services (Victoria) in response to a Public Consultation Paper² included comments on the issues of providing palliative care in residential aged care.

Following is a small selection of comments received:

- That DHS should enter into discussion with the Commonwealth to ensure that training and support in the palliative approach is an integral part of the service agreement expectations the Commonwealth has in relation to the delivery of Aged Care Services
- Aged Care Specialist Palliative Care. There is a need for someone to be appointed to look at the staff training and education in this area
- Need for some innovative models to address the needs of clients in residential facilities. Possible use of residential facilities to provide community palliative care patients with respite options. These clients should have on-going palliative care support from specialised community service consultancy provided on an inreach basis
- Implementation of the APRAC³ guidelines should be mandatory

² Department of Human Services *Strengthening Palliative Care: a policy framework for health and community services*. Public Consultation Paper, May 2004 (<http://www.palliativecare.gov.au/pubs/workforce/pallguide.htm>)

³ Australian Government Department of Health & Ageing, *Guidelines for a Palliative Approach in Residential Aged Care*, July 2004 (<http://www.palliativecare.gov.au/pubs/workforce/pallguide.htm>)

- Resources should be made available by the Australian Government to implement the new APRAC guidelines
- Nursing homes and hostels need to have access to regular education and access to extra support when they identify a need for extra guidance in meeting the needs of residents with complex needs
- The competence of all staff and GPs needs to be raised to support staff and residents in residential aged care facilities
- The issue of the cost prohibition of HACC services to residential aged care facilities should be addressed

The issue of the performance and effectiveness of the Aged Care Standards and Accreditation Agency in assessing and monitoring care with respect to residents with palliative care needs was limited. The ability to identifying best practice and provide information, education and training to residential aged care facilities was hampered by a lack of resources and a limitation on the skills and knowledge of many staff in these settings.

It was suggested that DHS and the Commonwealth work together to ensure that they incorporate evidence of the palliative approach in accreditation processes and the Aged Care Standards. The introduction of the new APRAC Guidelines will assist in improving quality of care but only if there is some degree of mandating their implementation.

CONCLUSION

This submission to the Senate Inquiry is limited. Many of the palliative care services in Victoria report to Palliative Care Victoria problems of access, inadequate skills, resources and capacity in their dealings with residential aged care facilities. Some also report very positive partnerships in providing appropriate care to their client group in these settings.

The issue of access to residential aged care facilities by younger people with complex needs that cannot be met at home but do not require hospital settings has long been an issue for this sector. The complex needs of those with conditions such as Motor Neurone Disease, Multiple Sclerosis and, particularly young people with brain tumours are often difficult to meet in residential aged care facilities. The waiting time for placement process as evidenced by the one example of 568 days reported by Calvary Health Care Bethlehem is untenable and places enormous strains upon the ill person, their family and other care settings.

It is hoped that the Senate Inquiry will set out some recommendations that takes these elements of the increasingly intertwined residential aged care and palliative care service systems into account.

Prepared by: Margaret Box
Executive Director