



PALLIATIVE CARE AUSTRALIA

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SUBMISSION TO HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON AGEING

"PROVISION OF PALLIATIVE CARE IN AGED CARE FACILITIES"

INTRODUCTION

This submission aims to explore the area of palliative care in aged care facilities at a national level.

It provides information on some of the issues found to date in work undertaken and/or discussions held between aged care facilities and palliative care services. The list of issues is neither exhaustive nor exclusive. It does not take account of the results of two current Commonwealth Government projects which are yet to be completed. These studies and future discussions will elicit more issues and will assist in prioritising areas for further examination, policy and service development in palliative care within aged care areas.

The proposed set of principles for consideration found below is, likewise, not complete. A firm set of principles will require extensive consultation with palliative care services and aged care providers. Each group will have their own ideas of principles which should be incorporated and an opportunity to explore, consult and aggregate ideas is necessary in this process.

Palliative Care Australia (PCA) presents this submission for your consideration and anticipates proceeding with further collaborative work to ensure that any resident of an aged care facility will be able to access adequate palliative care if there is a need.

BACKGROUND

Studies on palliative care in aged care facilities have previously been undertaken in both Victoria and South Australia. These studies found that an increasing number of residents in aged care facilities receive care during a terminal illness. Although the current Commonwealth Standards for Aged Care Facilities (1997) include standards for pain control and for terminal care, it appears that access to palliative care of an acceptable standard varies greatly between States and Territories and between aged care facilities.

PCA Members

ACT Hospice Palliative
Care Society Inc

Northern Territory Hospice
and Palliative Care Association

Palliative Care Association
of New South Wales

Palliative Care
Queensland Inc

Tasmanian Association for
Hospice and Palliative Care Inc

Palliative Care Victoria

Palliative Care WA Inc

Palliative Care Council
of South Australia Inc



Time to Reflect
Adelaide
September 9-12
2003

There is a need to develop and implement strategies, principles and protocols to ensure residents in aged care facilities can access good quality palliative care when necessary and desired.

Knowing that palliative care services exist and can be accessed by people in aged care facilities may improve quality of life. The additional support these services can provide to staff in aged care facilities can further assist the quality of life of resident and their family.

A small workshop to discuss this area of service delivery was organised by PCA in Hobart in March 1999. Since that time much discussion of issues surrounding palliative care in aged care facilities has taken place. It is pleasing to see that the Commonwealth Department of Health & Ageing has a current project to 'develop guidelines for palliative care in residential aged care and an education program on palliative care for staff working in aged care facilities'. Guidelines of this type and the skill and knowledge of staff working in aged care were two of the areas highlighted as an urgent needs to improve access to good quality palliative care for those in aged care facilities.

It is assumed that the Standing Committee on Ageing will use the results of the work currently being undertaken to assist in the formation of some of the long-term strategies to address ageing of the Australian population over the next 40 years.

ISSUES

There have been several issues identified in work undertaken to date and further investigation may indicate that these vary from state and territory and from facility to facility. PCA wishes to work with the coordinating bodies and their members in the aged care area to facilitate this process.

Standards

PCA acknowledges that aged care facilities are governed by specific standards and suggests that some collaboration to bring about common ground with palliative care standards is required for the benefit of people living in aged care facilities.

It is important when considering ways to implement change that there is an understanding of the different sets of standards for both palliative care services and aged care facilities. Any work in developing, modifying and implementing standards appropriate to palliative care in aged care facilities needs to ensure their relevance to the care setting.

It is assumed that the current work being undertaken by the current Commonwealth project on the development of guidelines for palliative care in aged care facilities will be considered in this context. Those involved in the project have extensive experience in either/both aged care and palliative care.

Values and Principles

Palliative care standards¹ are based on the following values and principles:

- Upholding the dignity of the patient and family;
- Compassionate care of the patient and family;
- Equity in access to palliative care services;
- Respect for the patient and family and carers;
- Advocacy on behalf of the expressed wishes of patients, families and communities;
- Pursuit of excellence in the provision of care and support; and
- Accountability to patients, families and the wider community.

Many aged care facilities strive to or would like to operate in this manner, but may be hampered due to a range of factors, which include funding, knowledge, desire and/or experience.

PCA will continue to work toward a palliative approach being fundamental to the delivery of health care services and wishes to work with those involved in the delivery of aged care services to achieve this outcome for our ageing population.

To this end, PCA hopes that the stakeholders in both the palliative care and the aged care sectors and other interested parties will agree to a number of principles that will enhance those services already being provided and create support for those areas where palliative care could be improved.

Access and Equity

Australians are encouraged to see palliative care as a service that is available to everyone regardless of their age, gender, religion or culture, or principal diagnosis, there are increasing numbers of people in aged care facilities in Australia who may be receiving less than they could.

PCA is committed to enhancing access and equity in the provision of palliative care to all Australians. This means that people have knowledge of, and access to, palliative care if, and when, it is required.

A key element of this fundamental principle of access is that palliative care should be available no matter where a person lives. PCA suggests that this is consistent with the Commonwealth Government's policy of "ageing in place", which aims to provide aged care without the necessity to relocate to a different care setting if that is the desire of the patient/family. It appears, therefore, there is an implicit agreement by those planning and delivering services to the aged on the one hand, and palliative care services on the other, that access to palliative care should be available no matter where the person lives and where the individual chooses. PCA is keen to see further policy development which builds upon these complimentary concepts.

¹ Palliative Care Australia: Standards for Palliative Care Provision October 1999 3rd Edition

Information

One of the most important strategies for addressing the needs of the ageing population is to ensure that they have knowledge of palliative care. For those in aged care facilities, it is necessary that

- providers can identify if palliative care is required for their residents
- providers understand how and when referrals should be made to specialist palliative care services if their knowledge or capacity to deliver palliative care is limited
- there is appropriate support and information for family, friends, other residents and staff if required.

Aged Australians in the Community

PCA does not wish to limit the discussion to those in aged care facilities but views this as a starting point. Studies show that there is an increasing number of older persons in our community living in households where the person who is terminally ill is, in addition, a carer for another ageing person or a person with a disability (of any age). This phenomena must be taken into account when issues of access to palliative care for ageing Australians are considered. In particular, it presents a challenge to the palliative care sector in helping people to understand the palliative care options available to them and a further challenge to a range of service providers to ensure surviving household members continue to receive appropriate support after their primary carer has died. Aged care facilities are frequently called upon to provide this support in both the short and long term.

DETERMINING FACTORS

In PCA's experience, some of the key elements that prevent or inhibit the provision of adequate palliative care in aged care facilities include:

1. Funding

- requirements for accreditation and compliance with standards;
- the additional staffing responsibilities/stress and workload required as death approaches and the inadequacy of current funding arrangements to allow for extra staff hours;
- the capacity to pay the necessary skilled staff;
- the availability and cost of equipment; and
- the level of general practitioner rebate from Medicare for provision of palliative care support to residents in aged care facilities.

2. Education

- the skills mix of nursing and other care staff recruited to aged care facilities;

- education and professional development for staff at all levels in aged care facilities, which may require change to ensure a palliative approach becomes part of the culture of service delivery;
- the lack of skilled and authorised staff to administer appropriate drug regimes to residents;
- the availability and level of skill of care available in low care facilities (hostels); and
- the lack of professional development in palliative care for general practitioners.

3. Access and Equity

- the restricted availability of designated palliative care beds in the acute care setting for residents of aged care facilities to assist with the management of difficult symptoms;
- the restricted availability of interpreting services and advice and education regarding culturally specific issues surrounding death and dying;
- the lack of choice of general practitioner;
- the resistance of some general practitioners to provide palliative care in aged care facilities;
- the sometimes restricted availability of pharmaceutical supplies particularly those listed on the PBS;
- inequity of access between and within states/territories.

PRINCIPLES FOR CONSIDERATION

There are many facets to the issues in all of the above, each meriting considerable study and discussion. PCA would request that when the Standing Committee on Ageing is developing the long-term strategies to address the ageing of the Australian population over the next 40 years, to consider the following broad principles:

- that all residents of Australia have a right to access palliative care services if required;
- that place of abode should not determine eligibility for the provision of palliative care services;
- that the Guidelines currently being developed by the APAC Project for palliative care in residential aged care and the education program on palliative care for staff working in aged care facilities, be adopted;
- that a strategy be developed for these Guidelines to be incorporated into the Standards for inclusion in the accreditation process for aged care facilities;
- most importantly, that a requirement for policy and service planning and development for current and future access to palliative care by residents in aged care facilities, be included in the Government's overall health and aged care strategies and budgetary deliberations.

PCA's newly released policy on service provision and planning should be taken into consideration ²; and

- that government consults with all stakeholders in the community, as it has done until now, when proposing and implementing new policies, practices and structures.

It is also acknowledged that some palliative care providers feel unable to provide the longer-term support sometimes required by patients from the aged care sector. This is a matter of particular concern for ageing Australians. PCA suggests that this should be dealt with in the broader context of issues for service planning and development for the aged sector.

STRATEGY DEVELOPMENT

PCA considers that any long-term strategies to address ageing of the Australian population over the next 40 years must include a strategy for the provision of Palliative Care in Aged Care Facilities which takes into account:

- the previous work undertaken to ascertain the gaps in palliative care service provision and why these gaps exist;
- the results of the current Commonwealth Department of Health & Aging Project for the development of Guidelines for palliative care in residential aged care and an education program on palliative care for staff working in aged care facilities (APAC Project);
- the relevant results of the current Commonwealth Department of Health & Aged Care National Scoping Study;
- the demographics and statistics of cancer deaths;
- the demographics and statistics for age-related and non-malignant conditions whose patients could benefit from the provision of palliative care;
- the development of services sensitive to the needs of our diverse population; and
- changing technology and advances in medication and treatment for those with a life-threatening illness;

and makes recommendations as to:

- how service gaps can be addressed and by whom, and
- how future service policy, planning and development should proceed.

² Palliative Care Service Provision in Australia: A Planning Guide released in December 2002

PCA recognises that there are broader issues for the provision of palliative care to the ageing population but considers that, as a starting point, access to quality palliative care for people in aged care facilities must be improved.

In summary, Palliative Care Australia's vision is that with appropriate policy, service planning and development for the future, the provision of palliative care for those who would benefit, will be automatic for Australians in aged care facilities.

Palliative Care Australia
January 2003