

**Submission to the Senate Standing Committee
on Community Affairs**

Inquiry into Palliative Care in Australia

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The author claims no clinical expertise in palliative care provision and is not personally involved in the delivery of such services. However as a member of the ACT community I have had close acquaintance with some persons who have delivered such services and with patients who have benefitted from them. Recently a very long term friend died from cancer; she received excellent care delivered in the normal clinical setting. Every effort was made to give her the best quality of life over a period of many weeks though her illness gave her no hope of recovery. My friend's treatment appeared to meet the principles set out in a number of significant contributions to discussion of the underlying philosophy and basic principles of those involved in the practice and/or delivery of palliative care as evidenced in the following selection of material from organisations with expertise in this field.

World Health Organisation

The World Health Organisation (WHO) defines Palliative Care as an approach that improves the quality of life of patients 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. Significantly WHO recommends a team approach to address the needs of patients and their families, including bereavement counselling, if indicated. Also stressed is that palliative care is applicable early in the course of illness and in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO includes in its definition palliative care for children (WHO: 1998), recommending that such care should begin when illness is diagnosed, and continue regardless of whether or not a child receives treatment directed at the disease. Effective palliative care of children requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Palliative Care NSW (PCNSW) 2011 Discussion Paper

Particularly valuable is the Palliative Care NSW (PCNSW) 2011 Discussion paper. The PCNSW is the peak body for palliative care in NSW, representing the interests of health care professionals, people with life limiting illness and their carers and their families. PCNSW intends to release a Policy Statement by mid-2012, canvassing the significant challenges facing the palliative care sector (and therefore the health sector), and possible solutions to those challenges.

The Discussion paper points out that unfortunately there is often confusion and misunderstanding of what palliative care is, and what it means to be a palliative care patient. PCNSW instances that some patients or their families may resist

seeking access to these services as being relevant only in the last days or weeks of life. Such persons may also fear that seeking palliative care means that treatments to extend life will be withdrawn, or that measures will be taken to actively shorten the patient's life:

It is important to emphasise that Palliative Care intends neither to hasten nor postpone death. In fact, Palliative Care may be applicable early in the course of an illness in conjunction with other therapies that are intended to prolong life.
[from the Executive Summary]

PCNSW also points out it is unfortunate that primary service providers and clinicians in hospital and acute settings may view the care for the dying as a 'specialist area', rather than seeing care for the dying as a continuum of primary care. **While such referrals to specialist providers of palliative care may be appropriate, it is important that primary care providers are not deskilled, or discouraged, from dealing with the needs of the dying.**

Therefore PCNSW argues that all persons who suffer a life-limiting illness need appropriate assessment, management and review of pain and other distressing symptoms. The aim of palliative care provision is to assist these persons to live as actively as possible until death. This might include, for patients living in a home setting, access to equipment (such as oxygen, wheel chairs, walkers, ergonomic beds, commodes, hand rails and so on) as well as community support services, such as home help and access to community transport. It should also include access to services that support the patient's psychological, spiritual or cultural needs; and support to help the family cope during the patient's illness and in bereavement.

The PCNSW Discussion paper is a representative statement of the concerns of such peak bodies advocating an integration between primary care, aged care and specialist palliative care services, and the attendant need for increased awareness of palliative care amongst health professionals.

Productivity Commission Report, *Caring for Older Australians* (August 2011)

The Productivity Commission Report, *Caring for Older Australians* (August 2011) likewise recommended a single integrated and flexible system of entitlements to replace the current system of discrete care packages across community and residential care. Such a system would include palliative care.

The Report also recommends that the Australian Government should ensure that residential and community care providers receive appropriate payments for delivering palliative and end of life care. Such a flexible funding model would support individual choice and will help to ensure that people are assisted to die in the place of their choice, with the people they wish to be present.

The Commission has also identified the need to fund education for aged care staff and carers to increase knowledge, awareness and understanding of a palliative approach to

care of the elderly so that end of life care would be a basic competency for aged care workers.

Parliamentary Committee: *Palliative and Compassionate Care, Not to be Forgotten, Care of Vulnerable Canadians*. Canada, November 2011.

The Committee might be greatly assisted in considering the issues involved in their Inquiry by reference to the Canadian document, *Parliamentary Committee on Palliative and Compassionate Care, Not to be Forgotten, Care of Vulnerable Canadians*.

The Parliamentary Committee on Palliative and Compassionate Care (PCPCC) is an all party group of MPs, dedicated to improving care for elderly, dying and vulnerable Canadians. It is unique in the history of the Canadian Parliament as it was formed by the MPs on their personal initiative and funded out of their member office budgets. The committee grew out of MPs' personal concern for compassionate care for vulnerable people. The issues primarily dealt with were: 1) Palliative and end-of-life care, 2) Suicide Prevention, 3) Elder Abuse, 4) A disability perspective on health care and inclusive community living.

The Committee received testimony from hundreds of people at twenty four hearings, and local round tables, MPs were profoundly impressed by the dedication and depth of concern expressed by Canadians for issues surrounding the way palliative and compassionate care is practiced in their country.

The palliative care section of the report expanded as evidence increasingly indicated an urgent need for better pain treatment, including chronic pain, was also included; as was material on homecare and long term care. It also became clear that the issue of family caregiver support needed to be addressed, as family caregivers provided the great bulk of compassionate care of the sick and dying in Canada.

The contents of this extensive report would doubtless apply to conditions in Australia's health system. The Committee found that only 16-30% of those who need it received palliative care; and that even where palliative care is available quality and accessibility will vary based on place of residence with many parts of Canada having no palliative care services at all. It concluded that while the Canadian system was good at short term acute care it was less adapted to dealing with people with chronic conditions, with serious pain, with mental health concerns, or with the psycho-social and spiritual needs of patients and their families surrounding the dying process.

People with chronic conditions need holistic care that looks at them as a whole person. They require patient centered care that recognizes their individual needs and not those of the bureaucratic system, as most important. They require integrated continual care that does not allow them to become lost in a fragmented and confusing world of multiple siloed health systems with less than satisfactory inter-communication between them.

[from the Executive Summary]

Noting that the **palliative care philosophy** is person-centred, family-focused and community-based, the Committee concluded that palliative care is best delivered within a home and community-based integrated care system including: home care, small community hospices, and palliative care in nursing and long-term care homes. It should be delivered as close to a patient's home and community as possible. This principle is found generally to be more cost effective and care effective.

The common themes in these key documents is that palliative should be a part of integrated health care and available to all patients. It should be an essential part of the training of health care professionals so that they are equipped to offer such care in the course of treating patients suffering life limiting illness. Necessarily it should be delivered so far as possible where the patient wishes whether that be at home, in hospital, an aged or long term illness home, or a specialised facility such as a hospice.

Palliative Care and euthanasia

I ask the Committee's indulgence in alluding briefly to the matter of euthanasia in relation to the provision of palliative care, noting that such latitude has been granted to the submission (No.20) from the Health Care Consumers Association (see *Canberra Times*, 17 March 2012, page 13).

Clarity in the matter of relief of pain is essential in an appreciation of the role of palliative care services. Over the last few years we have seen an escalation in the number of people that pro-euthanasia advocates have 'presented' to the public. These people have been packaged as having a "terminal illness", suffering unrelievable pain and therefore wishing for death (with varying degrees of public exposure) with the assistance of others.. Early cases in point include infamously Nancy Crick whose death was exploited by Dr Philip Nitschke who on ABC *Lateline* argued that Ms Crick was suffering "unrelenting suffering" and that her case was proof that "palliative care does not work". In the event it was established that Ms Crick did not suffer from cancer, had not been properly diagnosed and was not a patient on a palliative care regime.

One critic of Dutch euthanasia practice, citing the Van der Maas survey has observed that palliative care training, knowledge, and research in the Netherlands lag behind comparable medical knowledge in other European states (see John Keown, *Euthanasia examined: ethical, clinical and legal perspectives* Cambridge University Press, 1995). He asserts that euthanasia is routinely used in the Netherlands as an alternative, rather than an infrequent supplement, to palliative care. Similarly, opponents of euthanasia assert that the legalization of euthanasia serves as a disincentive to the Dutch government investing adequately in palliative care education and may increase the risk of patients requesting euthanasia because of undue influence or duress (*The Dutch Story: Legalization of Euthanasia*, Christian Century, May 2, 2001).

It is also worrying that in discussions about palliative care there is a clearly demonstrated lack of understanding, not least among medical practitioners themselves, of the principle described by traditional philosophers/ethicists as 'double effect'. This is often derided as

a sort of ‘dodge’ in that, while opposition to euthanasia is expressed by the treating doctor, death might be brought nearer by treatment administered to relieve symptoms of pain or suffering. It is a principle of palliative care, as explained above, that the patient is entitled to relief from pain and that the proper application of palliative medicine is the improvement of the quality of life for those whose illness is life-limiting.

Intention is the bedrock of culpability in criminal law: it is critical whether my falling off a cliff path was accidental or intended by my companion. Likewise it is not an argument for euthanasia to misrepresent good medical practice where the intention is to apply the principles of palliative care and not deliberately hasten the death of the patient.

Summary

Palliative care practice does not include deliberate ending of life even if requested by the patient [Palliative Care Australia, Palliative Care Week 2004]. Rather it embraces a concept of care that provides coordinated medical and allied services to people facing life-limiting illness. Such services should be available to all patients whose illness is life-limiting and, as argued above, its principles should inform all medical staff and its delivery should be available as a regular part of patient care whether at home in a small regional hospital, a specialised unit, a hospice. It should be delivered wherever possible in an environment of the person’s own choice and include psychological, social, and emotional and spiritual support. It includes grief and bereavement counselling. To meet these goals palliative care needs adequate funding.