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HCCA Submission to the Senate Inquiry into Palliative Care in Australia

March, 2012

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Senate Inquiry Terms of Reference

The provision of palliative care in Australia, including:

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:
(i) people living in rural and regional areas,
(ii) Indigenous people,
(iii) people from culturally and linguistically diverse backgrounds,
(iv) people with disabilities, and
(v) children and adolescents;

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

(c) the efficient use of palliative, health and aged care resources;

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

(e) the composition of the palliative care workforce, including:
(i) its ability to meet the needs of the ageing population, and
(ii) the adequacy of workforce education and training arrangements;

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians;

(g) advance care planning, including:

(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,
(ii) national consistency in law and policy supporting advance care plans, and
(iii) scope for including advance care plans in personal electronic health records; and

(h) the availability and funding of research, information and data about palliative care needs in Australia.

Background

The **Health Care Consumers' Association (HCCA) of the ACT** was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.
We have drawn on our experiences in the ACT in preparing this submission but are confident that our examples are consistent with the experiences of consumers and their families more broadly.

Consumer-Centred Care

We recognised that our health system is under pressure and cannot cope if policies and planning continue to focus on diseases rather than consumers. The key to changing our health system lies in involving individual consumers, to empower us to understand our conditions, treatments and options. It is through understanding that we adhere to treatments, make behavioural changes and self-manage. HCCA considers that consumer-centred health care is the most cost-effective way to improve health outcomes for our community.

The essence of consumer-centred health care is that the health care system is designed and delivered to address the health care needs and preferences of consumers so that health care is appropriate and cost-effective. By promoting greater consumer responsibility and optimal usage, consumer-centred health care leads to improved health outcomes, quality of life and optimal value for health care investment.

We support the common priorities that the International Association of Patient Organisations have identified as critical to achieve consumer-centred health care at every level in every community.

To achieve consumer-centred health care we believe that health care must be based on the following Five Principles:

1. **Respect**
2. **Choice and empowerment**
3. **Consumer involvement in health policy**
4. **Access and support**
5. **Information**

All health strategies should as a bare minimum have the Australian Charter of Heath Care Rights as their first point of reference. We have considered these rights in preparing our submission.

(a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population

The palliative care approach is highly valued as a response to end-of-life care in the community. However, not all consumers are adequately served because of limited resource availability. Cancer patients are mostly well cared for, but some people with other end of life conditions, such as motor neurone disease, or those living in Residential Aged Care Facilities (RACF), there are difficulties in the accessing palliative care. It is also worthwhile noting that the provision of Palliative Care is often focused on the Aged whereas we need to consider the access needs of all age groups, including children and adolescents.

In 2009 the ACT Government consulted the community on the potential sale of our only hospice, Clare Holland House, to the Little Company of Mary. During this time HCCA held extensive consultations with our members and the broader community and garnered a strong understanding on the value our community places on palliative care. A strong view emerged that Canberra needed a second, secular hospice. A concern was expressed that the only hospice in the ACT is run by a religious organisation, which has moral and spiritual principles which, for some consumers and their families, felt were inappropriate to their needs. We need to consider those consumers with conflicting spiritual / religious beliefs, different cultural backgrounds (eg, Aboriginal and Torres Strait Island Australians), and those who may have had negative experiences with religious organisations in their past (eg, Forgotten Australian).

There is also a view that palliative care should be provided by either the government or a not for profit organisation. There was concern that the competing interests of shareholders and service users was too sensitive when people were in such a vulnerable state.

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

We need a qualified and well trained workforce providing holistic, multidisciplinary, coordinated and patient centred care, inclusive of the support needed for family and other care givers. This is also reflected in Palliative Care Australia submission[i] to the Treasurer on Priorities for the 2012 Federal Budget (January 2012) which stated:

> *"Supporting the needs of people living with a life limiting illness, their carers and families, requires a well resourced and well integrated service delivery model that supports specialist palliative care services, and enhances in-home support through better integration of community care with specialist palliative care services. Such a system minimises unnecessary demand for, and expenditure on, hospital beds."*

We are very aware of the difficulties of providing adequate and effective Palliative Care services to those in Residential Aged Care Facilities. In the ACT the chronic GP shortage in addition to the inadequate staffing in these facilities often results in the transferring to hospital of Palliative Care patients against theirs and their families wishes. Anecdotally we have heard that some General Practitioners (GP) are fearful of litigation because of the lack of trained nursing staff in these facilities that can safely and professionally administer the palliative care treatment under the GP's management. Often the GP visits are limited to once a week leaving the Carers with inadequate support. The high staff turnover in RACFs and adequate resident/ carer and resident/nurse ratios need to be remedied before it is possible to add extra duties to these overburdened staff. An example of a this is a training system adopted in ACT residential aged care facilities is the program for advanced care planning – Respecting Patients Choices (RPC). Residential aged care staff agreed to participate in this program and a number of staff were trained as Respecting Patients Choices consultants which provided them with the skills and authority to assist their patients in creating an advanced care plan and register it with the RPC program so that the patient's wishes were recorded on their personal electronic health record in the ACT health system. But after a few years, there were no longer any staff from RACFs participating in this program. Recently, RPC began again working with RACF to again restore their participation in RPC program. This history of RPC in ACT RACF demonstrates the need but also the difficulties of adding extra unfunded tasks on to RACF. The feedback seems to be that the staff are often too busy with their core business to manage these extra responsibilities.

Only a small number of GPs are prepared to work in RACF in the ACT. To address this gap, the ACT Government created the mobile locum GP Aged Day Care Service to provide GP services between 9am -5pm, Monday to Friday. This is a welcome initiative but it remains to be seen whether it will reduce the transfer of Palliative Care patients to hospital or increase the safe and effective provision of Palliative Care. Another welcomed initiative is that of the Palliative Care Nurse Practitioner and the Aged Care Nurse Practitioner. It appears however that many more of these professionals are needed.

(e) the composition of the palliative care workforce

While there have been some improvements in resources for palliative care in the past few years, people wanting and/or needing palliative care services have been unable to access them in the community, hospitals and in RACFs. The bulk of palliative care services are provided in the community and this has been the area of most rapid growth of demand which has been unable to be met. While the bulk of people who access home based palliative community care receive a very good service, there are others who have been very poorly served because of inadequate resources.

The ACT Palliative Care service began as part of the ACT Community Nursing Service and provided a full range of services. The service was sub-contracted to Calvary Health Care in the 1990s, and after some time, the service model was changed to a consultative model, in which the Palliative Care staff act as advisors and referral for other services and the actual nursing of palliative care patients returned to the Community Nursing service of ACT Health. It has been suggested that this may have been due to the inadequacy of the funding of Calvary's Palliative Care service to cater to the growing demand. However, for patients in the community palliative care service, this model is less than satisfactory. It would be much better if all services are provided by the one organisation providing a seamless service for consumer and carers. This would alleviate the burden of negotiating to get the additional services we require from other organisations (such as the nursing care). There has been a reduction in the number of palliative care nurses. In 2009 there were 8 nurses, a reduction from 15 nurses in the 1990s.

Volunteers can play a crucial role in residential aged care facilities but it is imperative they receive appropriate training and support to successfully carry out their roles.

(g) advance care planning

We consider *advance care planning to be a key component of consumer choice and patient centred care.*

The Productivity Commission[ii] made reference to this and advised:

> *'Given that advance care planning can result in a win-win situation, there is a case for assisting care recipients, their families and health professionals and care workers to be better informed about advance care planning and the common law rights of people to make decisions about their medical treatment (including the right to decline treatment).'*

Health Care Consumers Association supports a national system for the recognition of advanced care plans and was disappointed in the final national report (http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf) that only recognised an aspirational goal in relation to a national system for recognising advanced care plans. A nationally consistent and recognised system of advanced care planning is particularly important as we ACT residents are frequently in other jurisdictions holidaying, visiting family or with work commitments.
We support a national system where advance care plans are included in personal electronic health records. Already, ACT residents have the ability to register their advance care plans in their ACT Health personal electronic health records thru the Respecting Patient Choices program. Under this system, an alert comes up when a patient is admitted to the Emergency Department at the Canberra Hospital when a patient has registered their advanced care plan thru the Respecting Patient Choices

program. The emergency staff can then access an electronic version of that patient's advanced care plan.
We support this type of system being extended Australia wide. Given that the Respecting Patient Choices is a national program, it would be well worth investigating where else in Australia this is occurring and exploring the potential for using this program as a base for having national advance care plans in personal electronic health records.

(c) the efficient use of palliative, health and aged care resources;

Older people need to have available a range of options available both in aged care and palliative care but under the presently under-resourced system, this is not possible. Ideally, residents of RACFs should not need to be transferred to another setting for palliative care which is often inappropriate. The facility is their home and many find the disruption of relocating disorienting and not conducive to good quality of life.

The perennial question of inadequate funding remains. A solution occurred in those countries/ jurisdictions (such as Belgium and Oregon) that have introduced voluntary euthanasia which was tied to significantly increased funding for palliative care. A story from Ken Hillman about his sister-in-law who is dying in Oregon demonstrates how good palliative care can be co-ordinated at home and centred around the patient's wishes.

In November 2011 Ken Hillman wrote an article[iii] entitled: *End of the Care Conveyor Belt: Death in Intensive Care Units* in which he looks at why so many people end their lives in Intensive Care Units. He says that around 70% of Australians would like to die at home but over half will eventually die undignified and painful deaths in hospitals. He also comments that almost half of the cost of health care is spent in the last six months of life. This is a huge and increasing burden for our ageing society. Ken Hillman includes examples of different approaches to end of life care that provides alternatives to hospital admission.
He tells the story of his sister-in-law who lives in Oregon and is in the terminal stages of Motor Neurone Disease

As part of medical care in the United States, you can opt for what is known as hospice care. The word hospice refers to a program, not a site of care. The government-funded Medicare program covers all costs. Ken Hillman considers the hospice care that his sister-in-law is now receiving must be one of the more appropriate ways of managing people at the end of their life.

> *"She remains under the care of her general practitioner. Since her wish is to remain at home, a palliative care nurse co-ordinates care and is on call and available 24 hours a day. A social worker, physiotherapist, occupational therapist initially assessed her and now visit as needed."*

Those consumers and their families that receive palliative care through the home based or hospice service have much better experience at the end of life than those families who experience this through the hospital system.

Home based palliative care

There is a need for increased funding for home based palliative care, as well as integration with local community health services, which are also accessed by many people requiring palliative care.

There is a need to ensure that those people who are accessing treatment in private hospitals can also receive home based palliative care. We have anecdotal evidence of the disconnect between private hospitals and home based palliative care that put extreme pressure on the family and compromised the quality of life for the last few months.

Palliative care in aged care facilities

There is support for training in palliative care for aged care staff and volunteers; however because of issues with staff turnover and staffing levels in aged care facilities there is some concern that training by itself will not result in a satisfactory improved outcome.

We would like to stress that only 7% of older people live in RACFs. There are also many older people living in the community and the majority of whom live on their own towards the end of their life. Consumers need to be in the centre of the strategy so that regardless of where we live we have equitable access to palliative care.

Finally, the Australian community has a great deal to say on the subject of voluntary euthanasia. Consideration of the subject is required if there is a consumer centred palliative care strategy. It is not mentioned in the terms of reference but voluntary euthanasia is supported by a majority of Australians as many polls show. Also the current medical practice of increasing pain medication as a palliative care measure needs to be addressed. This increased medication often leads to an earlier death. This practice needs to be addressed openly in a palliative care strategy. We think that voluntary euthanasia needs to be considered in this inquiry.

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[i] Palliative Care Australia Submission to the Treasurer on Priorities for the 2012 Federal Budget (January 2012) http://www.palliativecare.org.au/Portals/46/PCA%20submission%20-%20Federal%20Budget%202012%20-%20FINAL.pdf Retrieved 22 February 2012

[ii] Productivity Commission, 2011, Caring for Older Australians, Inquiry Report, Canberra

[iii] Ken Hilman http://theconversation.edu.au/end-of-the-care-conveyor-belt-death-in-intensive-care-units-249