

To the Senate Community Affairs Committees for inquiry into the provision of Palliative Care in Australia.

Anam Cara House Geelong & Anam Cara House Colac are pleased to submit the following information before The Senate enquiry into the provision of Palliative Care in Australia.

Anam Cara House Geelong, established in 2007 (see report in Hansard by David Koch MP) and Anam Cara House Colac, established in 2011 are innovative communities hospices, with social models of care, established by the community to support home care. The community identified a gap in service for respite and end-of-life care (as an alternative to acute or nursing home care) and established both these hospices to underpin home care – the acknowledged first choice for the large majority of people. As such Anam Cara House Geelong and Colac provide a cost effective choice in place of care, that closely replicates an home environment and provides local support to carers living in rural and regional Victoria. A steering committee is also currently looking at replicating this model of care in Warnambool at the south end of the region.

See www.anamcarahousegeelong.org.au and www.anamcarahousecolac.org.au

(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;

Anam Cara House – is an innovative community initiative established to provide regional care for people of all ages, cultures and denominations who have a chronic or life-limiting illness, including cancer related diseases, heart disease, diabetes, MND etc. Anam Cara House is a local service to the region so people remain supported within their own community. These “home-like” respite facilities provides short term care or support at end of life, thereby alleviating considerable imposte on carers.

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

Anam Cara House Geelong & Colac received initial Capital funding from the Federal Government however ongoing recurrent funding has currently not been made available. Anam Cara House, is staffed by Palliative Care experienced Div I Nurses, and supported by Volunteers trained to Palliative Care Australia Standards. The point of difference is a social model of care within a “home-like” environment, that encompasses excellence in palliative care alongside holistic care, including emotional, social and spiritual care for our guests and their carers. We estimate the cost of operating this facility is significantly less than providing care in a sub-acute facility or Palliative Care Unit, which is not always necessary or desirable.

To quote Yvonne Luxford CEO Palliative Care Australia: “ We are all acutely aware that our population is ageing and we are already bearing the burden of increasing levels of chronic disease ...[and] we all die and we all want to die well.... so why aren’t more Australians dying well? One reason is that doctors’ training is frequently restricted to treating and curing. We simply don’t teach the people who are going to care for us at end of life, to recognise when there is no longer a place for aggressive treatment, and that referral to palliative care is neither a failure nor abandonment of a patient.”

I would add further to Yvonne Luxford’s statement in that even within palliative care itself the model of care is at times “over medicalised” and positioned in an acute or sub-acute setting which again at times is both unnecessary and inappropriate. This fact can also at times add to the stress on the patient and their family and also add further imposte on our health system. (ie. Inappropriate admission to the acute and sub-acute system).

The community hospice model of care which is still very prominent in the UK, USA, Canada, New Zealand, Europe and parts of Asia, has in Australia been superseded by very sophisticated Palliative Care based on a strong medical model. While quality Palliative Care is undeniably important, it is of some concern that the hospice model of care, which can support and underpin home care has virtually been abandoned in Australia. With the strong “medicalisation” of palliative care in Australia, the concept of holistic and person centred end -of -life care has at times been compromised and people’s right to choice in place of care and type of care thereby discounted. This fact I would suggest, is in part represented in the low statistics of home deaths in Australia.

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

The invaluable inclusion of Volunteers in delivering care at Anam Cara House not only represents important cost savings but also brings both intangible and tangible benefits to carers and volunteers and thereby enhances social cohesion and the fabric of our community.

(d) including hospital care, residential or **community care** and aged care facilities;

Anam Cara House responds to Palliative Care Australia's priority that people who are dying have the right to be cared for in a setting of their choice. For many people this means the provision of care within their homes and communities. For government and service providers, this involves an understanding of the burdens that caring places on individuals and families. Anam Cara House is a community based service that addresses this burden of care and responds to the needs of our ageing population, frail aged carers we also provide carer's accommodation) and people living in single person households.

(e) the effectiveness of a range of palliative care arrangements

The service offered by both Anam Cara House Geelong & Colac, as a Community Hospice, includes:

- *much need respite for carers*
- *a choice in place of palliative care appropriate for persons of all ages*
- *holistic care within a "home-like" and very personalised setting*
- *costs savings to government and individuals*

All of the above, are principle tenets of the findings of numerous recent studies about the needs of people within our community requiring palliative care. Furthermore current recommendations from the Australian Government's Productivity Commission Inquiry Report: Caring for Older Australians [No. 53, 28.06.2011] also highlight the challenges facing palliative care providers in the future and especially the need for a choice in place of care and the importance of respite care for carers. An overview of the report highlights the reduced access to carers and family support, due to changes in social and economic circumstances. Anam Cara House Geelong and Colac respond to this need and the need for respite and end-of-life care, between home and hospital, to complement and support home care (the preferred choice in place of care) and yet a choice statistically less often realised.