15 March 2012

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Sir

Re: Inquiry into Palliative Care in Australia

The committee of the Friends of Northern Hospice and Palliative Care Foundation, based in Northern Tasmania, is pleased to present the attached submission to the Inquiry. The submission outlines the challenges facing people in Northern Tasmania who require palliative care, including lack of access to dedicated palliative care beds, lack of appropriate palliative care options for Aboriginal people, people from culturally and linguistically diverse backgrounds, people living in rural areas and children.

Overall, it is our view that the current state of palliative care in Tasmania is grossly inadequate in terms of appropriateness of care options for the various sections of the community, and also because overall services are unable to cope with the increasing demand for such services. We therefore commend the Senate on undertaking this inquiry, and providing the community with the opportunity to highlight issues which have been of concern for several years.

Yours faithfully

Barb Baker
On behalf of the Friends of Northern Hospice and Palliative Care Foundation

Friends of Northern Hospice and Palliative Care

Submission to the Senate Inquiry into Palliative Care in Australia

Context

The last review of palliative care in Tasmania occurred eight years ago, and resulted in the report titled 'Palliative Care in Tasmania: current situation and future directions' which provided a comprehensive framework for the development of palliative care services across the State. The report included an analysis of existing palliative care services and considered a range of supply and demand factors, as well as proposing a model for the future planning of palliative care in Tasmania

The findings from this 2004 report included the assessment that Tasmania has 50% of the designated palliative care beds that are recommended by Palliative Care Australia (at the time), and these are unevenly distributed across the State. Other important observations made in the report were that:

- demand for palliative care in Tasmania is likely to grow more rapidly than in other States due to the highest overall incidence of cancer and a rapidly ageing population;
- Tasmania needs a staff ratio that is higher than the national average to be able to provide adequate palliative care services, because of Tasmania's low population density, the number of people living in rural areas, the high incidence of cancer and the high number of older people who live alone;
- during the period 2000 – 2003 there was a 22.4% increase in clients accessing Tasmanian palliative care services;
- Tasmania's ageing population and high numbers of people who live alone are significantly more likely to require hospice/inpatient care.

Since this report was compiled there has been no increase in the number of designated palliative care beds available in Tasmania. In Northern

Tasmania there are seven designated beds available in Launceston (4 public and 3 private) and there are none available elsewhere including on the North West Coast.

It is within this context we make the following comments in relation to the Committee's terms of reference, and make the overall comment that palliative care services in Tasmania do not meet the needs of the community.

1. Access to and choice of appropriate palliative care that meets the need of the community

In an overall sense there is a lack of options available for people requiring palliative care. There are insufficient palliative care beds in Northern Tasmania to meet patient demand, which has resulted in the following inappropriate practices taking place:

- people with palliative care needs are being treated in acute hospital beds, when the patient would be more appropriately treated in a dedicated palliative care facility.
- those patients who do access one of the seven palliative care beds at Calvary's St Lukes Hospital in Launceston can only stay a maximum of 35 days, regardless of whether they are a public or private patient. After that they must transfer, usually to a nursing home.

(a) People living in rural and regional areas

Whilst there are beds in regional hospitals which are available for palliative care patients, they are not designated palliative care beds, and therefore are only available if they are not occupied by other patients.

(b) Aboriginal

Existing hospice/palliative care facilities do not provide a culturally appropriate physical environment for members of the Aboriginal community, as they do not provide access to outside spaces.

(c) Culturally and linguistically diverse communities

Within the limited number of inpatient beds available for palliative care there is no capacity to develop palliative care services which address the needs of CALD communities. Northern Tasmania's CALD communities include those which have established in recent years through humanitarian entrant programs, and include significant numbers of people of all ages from Bhutan, Burma, Congo, Sudan and Liberia. At the same time there are long term established communities which include the Polish, Dutch, and Italian who are also ageing. There is no evidence of any existing services offering palliative care which addresses specific cultural needs.

(d) Other specific target groups

Overall, the specific needs of various groups within our community in relation to palliative care are going largely unmet. This includes people with disabilities, children, people with dementia, people with Motor Neurone Disease and people with HIV Aids. The lack of willingness to invest in palliative care, other than at the most basic level, means people with special needs are not receiving an appropriate service, and in many cases are only able to access at home/community based service options or services in a nursing home.

2. Funding

Our group has advocated over many years for upgrading of palliative care services across Tasmania, specifically through an increase in the number of publicly funded, designated palliative care beds. There has been no willingness within the Tasmanian health system to address this. The situation continues unchanged since 2004, even though at that time is was deemed inadequate and given it is eight years after the last review of data it would be reasonable to assume demand has continued to increase.

Indeed, since the closure of the dedicated hospice in Northern Tasmania, Philip Oakden House, in 2007 the number of designated palliative care beds has declined, as three beds were lost when this facility closed.

We therefore see the only viable option for people in Tasmania to be able to access appropriate palliative care services will be through a federally funded palliative care system.

3. *Other issues for the Committee to consider*

- With the number of people who need palliative care being placed in either acute care beds or in nursing home beds there is a need for a well resourced central resource centre, such as a Centre for Excellence in Palliative Care, to provide appropriate education and professional development to a wide range of health professionals, such as GPs, Nurses and aged care support staff. There are District Hospitals, aged care providers, the Launceston General Hospital and GPs in Northern Tasmania all playing a role in providing palliative care, however there is no ongoing professional development to ensure they have access to best practice developments in this area.

- Where palliative care patients are being treated in district hospitals there needs to be appropriate support services to enable adequate care to be provided, given these are not designated palliative care beds.

- In a region the size of Northern Tasmania, with our age and health profile, we believe a dedicated palliative care facility should be established, which incorporates hospice facilities and accommodates community care services and professional education for palliative care. Such a facility should, at a minimum have twelve designated palliative care beds available. It would enable strong community involvement to occur through volunteer support and fundraising, such as already occurs in Newcastle, NSW where the Little Company of Mary operate a similar facility.

- The Tasmanian Department of Health and Human Services has not made palliative care demand data publicly available since 2004, making it almost impossible for groups such as ours to plan and advocate for well researched, evidence based services.