SUBMISSION TO THE SENATE COMMUNITY AFFAIRS COMMITTEES Inquiry into Palliative Care in Australia

March 2012

By Julie Roberts, who has an interest on palliative care, has worked in people's homes as a personal care worker, and as a palliative carer.

In this submission I would like to comment on the terms of reference (a) (i), (c). (d), (e) (i), with particular reference to conditions in the Bega Valley Shire in NSW. It is subjective in content. I am assuming the Committee is familiar with the history and definitions of palliative (terminal) care.

(a) (i): **People living in rural and regional areas**

The people in this region have been denied adequate palliative care for the past 20 years that I have been resident here. One part-time palliative care registered nurse (albeit incredibly competent) has been the only dedicated palliative care employee in the health care system covering Bega Valley Shire. There is a dedicated family palliative care room in Pambula hospital and a 2 'more private' rooms used for dying patients in Bega hospital. It is not clear why this situation of not addressing the need for palliative care has arisen.

This is an area of aging population of above average numbers. And, of course, as elsewhere, not all those who die are older.

Individuals have suffered in their last days without real support from the health care system simply because of inadequate palliative care staffing and facilities.

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

In this region it would appear that funding for palliative care either has not been sufficient, or funds have somehow not reached the target area.

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

It would be wonderful if we had a range of palliative care arrangements. Currently, the range consists of 'make-do' , and 'doing the best under the circumstances' approach. For example, general nursing staff in the local hospitals having to readjust their head-space walking into the 'palliative care' room in the hospital to support a dying person and their family. This is not palliative care.

Community nursing do their best to support people dying in their homes in the community, but without a dedicated palliative care team and easy consultation with a palliative specialist doctor for pain management, in particular, it is very difficult. People dying in their own homes in isolated areas produces its own legal problems not consistent with the palliative care ethos.

Palliative care ideally gives choice for the dying person and their family. Studies have shown that most people's preference is to die at home. If this is not possible a dedicated facility is next best. In Bega Valley there is no real choice.

It would be helpful for staff in aged and disability facilities to have access to palliative care training. These facilities are homes and the home is where the majority of people nominate as their preferred place of death.

(e) **The composition of the palliative care workforce, including**

(i) its ability to meet the needs of the ageing population

There is one part-time palliative care registered nurse in the Shire …..cannot meet the needs no matter how competent.

Many of the aged are in care facilities where palliative competence of staff is unknown.

I thank the Committee for this inquiry.