

23<sup>rd</sup> March 2012

Dear Sir/Madam

Thank you for the opportunity to contribute to the senate inquiry into palliative care. Our submission focuses on promoting investment in research funding and training which are urgently needed to underpin end of life care.

### **The Centre for Palliative Care**

Palliative care focuses on supporting patients diagnosed with advanced, incurable disease; it is 'family centered', with the patient and their family (the unit of care) being core to all its functions.<sup>1</sup>

The Centre for Palliative Care is part of St. Vincent's Hospital (Melbourne) and is a Collaborative Centre of The University of Melbourne, Australia. The Centre has a state-wide role in palliative care education and research in Victoria, with networks and collaborative projects extending nationally and internationally. The Centre plays a pivotal role in the development and implementation of training and education programs for health professionals from a variety of disciplines, while undertaking cutting-edge research to set benchmarks and improve practices in palliative care.

### **Issues related to research and education in palliative care**

Disease focused cancer care in the last weeks of life can be futile and have a negative impact on patients' and family quality of life. Vast amounts are spent on caring for cancer patients in their last weeks of life yet there is an extraordinarily small proportion of research funding allocated to the study of palliative and end-of-life care. Data on UK research funding in 2010 show that, of the 508 million pounds awarded for research into cancer, just 0.24% was allocated to palliative and end of- life care research. Similarly, in the USA, of the National Cancer Institute's total appropriation for 2010 of US\$5 billion, only 1% was allocated to palliative care research.<sup>2</sup> We are unable to access similar data within Australia, however our experience of more than a decade in this field reveals a significant shortage of palliative research investment (both grants and positions) in comparison to cancer disease control. This is inequitable; particularly given the fact that approximately 40-50% of cancer patients will die within five years of diagnosis. In addition, most cancer patients are inadequately palliated at the end of life, with basic symptom control such as pain relief unmet. Early palliative care interventions have been shown to reduce symptoms, improve quality of life, and reduce the use of anti-cancer therapy while improving

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<sup>1</sup> World Health Organisation. National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva (Switzerland): WHO, 2002.

<sup>2</sup> Sleeman K, Gomes B, Higginson I. Research into end-of-life cancer care-investment is needed. *The Lancet* 2012;379(9815):519.

survival. A substantial investment in research into palliative and end-of-life care is urgently required to inform the transition from disease-directed to palliative care, to improve symptom control.<sup>2</sup>

In addition to the need for research investment for patient care, evidence to underpin family care is also required. According to a recent review<sup>3</sup> resources and research investment to improve family carer support is urgently required, because family carers:

- Should receive evidence based support from health professionals as per national and international policies and standards.
- Are receiving support which is ad hoc and based on minimal evidence.
- Are prone to physical and psychological morbidity.
- Are responsible for numerous tasks, such as symptom management.
- Are financially disadvantaged.
- Become socially isolated.
- Report unmet needs.
- Have needs equal to and/or greater than the needs of patients.
- Have very limited first hand exposure to death and dying.
- Are pivotal to achieving 'successful' palliative care at home (where most people prefer to die).
- Make a remarkable economic contribution to health care.
- May significantly enhance the well-being of patients when they are well supported.

It is also apparent that there is a need for workforce growth and investment in resources and structures to support palliative care training<sup>4</sup>. Unless this occurs, end of life care will commonly be provided by health care professionals who lack fundamental skills and knowledge, resulting in suboptimal care.

### **Recommendations for education and training**

All health professionals should be appropriately qualified to provide palliative care. This should be achieved by:

1. Developing a national competency framework for all health professions involved in specialist palliative care.
2. Ensuring sufficient numbers of training positions to meet current and future needs of the specialist palliative care workforce.

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<sup>3</sup> Hudson P, Payne S. Family caregivers and palliative care: current status and agenda for the future. *J. Palliat. Med.* 2011;14(7):864-9.

<sup>4</sup> Mitchell, G., Johnson, C., Thomas, K. & Murray, S. (2010). Palliative care beyond that for cancer in Australia. *Medical Journal of Australia* 193(2): 124-126.

3. Funding to develop training programs and scholarships.
4. Enhancement of strategies to provide training to generalist health care providers.

**Recommendations for research**

Develop a nationally funded framework for palliative care research that:

1. Provides funding for the development of research programs specifically addressing symptom management, psychosocial support (including family carers and bereavement), and health service evaluation.
2. Invests in capacity building by developing a critical mass of palliative care researchers.
3. Creates a “whole of health” approach to palliative care research that incorporates cancer care and non malignant diseases.
4. Focuses on strategies to translate research into practice in specialist and generalist settings.

Thank you for considering these recommendations and please contact me if you require additional information.

Yours faithfully

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