

3 October 2012

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

Dear Committee Secretary

PALLIATIVE CARE IN AUSTRALIA

I write on behalf of the Avner Nahmani Pancreatic Cancer Foundation Limited ("Avner's" or "the Foundation") and provide this submission to the Senate Standing Committee for consideration as part of the Committee's inquiry into the provisions on palliative care in Australia.

1. Background on Avner's Foundation

The Avner Nahmani Pancreatic Cancer Foundation Limited is the only foundation in Australia dedicated exclusively to Pancreatic Cancer. The Avner Nahmani Pancreatic Cancer Research Fund was co-founded by Caroline Kelly and her late husband, Avner Nahmani in October 2008 and it became incorporated as the Avner Nahmani Pancreatic Cancer Foundation Limited in 2010. The foundation was granted full charitable status in 2010 (DGR).

Avner's Foundation has three main objectives:

- To support and promote research into pancreatic cancer;
- To build community awareness about pancreatic cancer; and
- To build capacity in support services provided to people personally afflicted by this illness which affects more than 2000 Australians each year.

The governance and management of Avner's Foundation appreciate that research is the means to improving outcomes for pancreatic cancer patients in the future, while support services are the way to help those living, and currently dying with pancreatic cancer.

In making this submission the Foundation wishes to underline that effective palliative care is critical to supporting those affected by pancreatic cancer.

2. Pancreatic Cancer

Pancreatic cancer is the eighth most common cause of cancer-related deaths worldwide¹. Pancreatic cancer is the most lethal of adult cancers and has a devastatingly poor prognosis.

Approximately 2,500 cases of pancreatic cancer are diagnosed in Australia each year, representing 2.3% of all cancers².

- In 2010 in Victoria, there were 681 recorded cases of pancreatic cancer with 620 deaths, representing 6% of all cancer deaths.
- In New South Wales, approximately 859 people are diagnosed annually with pancreatic cancer.

Relative to how many people are affected by pancreatic cancer, this cancer type results in more deaths than any other known cancer. These sobering statistics speak to the essential importance of excellent symptom management, psychosocial care and comprehensive care planning for all affected by a diagnosis of pancreatic cancer.

3. Palliative Care and Pancreatic Cancer

Effective palliative care is critical for pancreatic cancer sufferers but sadly current palliative care options available for pancreatic cancer sufferers are largely inadequate particularly for those in advanced stages of illness.

Many sufferers are left without the care and the support they need at end of life and the effects of this on patients and their supporters are devastating.

Nature of the pancreatic cancer

Patients with pancreatic cancer experience severe symptoms with faster onset than other cancers:

¹ <http://www.cancerresearchuk.org/cancer-info/cancerstats/world/the-global-picture/cancer-overall-world#source>

² <http://www.cancercouncil.com.au>: retrieved April 2012

- Symptoms include: severe neuropathic (nerve) pain in addition to depression, nausea, vomiting, weight loss, poor appetite, obstruction of liver drainage causing jaundice and painful fluid retention.
- Importantly, studies show increased intensity of symptoms and a sharp decline in quality of life in the 8 weeks before death in patients with advanced disease³.

The foundation notes the terms of reference for the Inquiry and requests the inquiry to consider the following terms in the context of pancreatic cancer, specifically:

- a) the factors influencing access to and choice of appropriate palliative care that meets the needs of the population
- 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 availability and funding of research, information and data about palliative care needs in Australia.

4. The Avner Nahmani Pan-Care Palliative Care Project - Peter MacCallum Cancer Centre



Avner's Foundation is pleased to inform the Committee of its July 2012 announcement of the development and testing of a comprehensive care planning service to facilitate care at home for patients with pancreatic cancer in Victoria.

Rationale for program

Despite many cancer patients articulating a wish to die at home surrounded by family and friends, an increasing number of deaths are occurring in hospitals and institutions⁴⁵.

³ Labori, KJ, Hjemstad, M.J., Wester, T., Buanes, T., Loge, J.H. Symptom profiles and palliative care in advanced pancreatic cancer – a Prospective study. Support. Care Cancer 2006 14:1126-33.

⁴ Brogaard T, Neergaard MA, Sokolowski I, Olesen F, Jensen AB. Congruence between preferred and actual place of care and death among Danish cancer patients. Palliative Medicine, 2012; Mar 14.

⁵ Yun YH, Lim MK, Choi KS, Rhee YS. Predictors associated with the place of death in a country with increasing hospital deaths. Palliative Medicine, 2006;20(4):455-61.

- This is both costly in terms of health service costs but importantly can be a significant source of distress for families who are left with feelings of guilt or inadequacy after the patient has died.
- Research indicates that anticipatory and comprehensive care planning early on in the illness and, the provision of adequate and expert support in the community particularly in the evenings and at night, allows for death to occur at home in up to 80% of palliative care patients⁶.

The program

The Avner Nahmani PANcare Home Nursing Project will involve patients with pancreatic cancer from major hospitals and community palliative care services in metropolitan Melbourne.

The Department of Pain and Palliative Care and the Department of Nursing and Supportive Care Research at the Peter MacCallum Cancer Centre, Australia's only comprehensive cancer centre, will lead the program.

- The Project will test an innovative new model of comprehensive care planning for patients with advanced pancreatic cancer to improve quality of care at the end of life.
- Central to this will be placing specially trained palliative care nurses in patients' homes during what is recognised as the most difficult stage of their illness – the night time hours of their final days.

Pain and other symptoms can worsen at night. International evidence shows that patients with cancer are more anxious (which worsens perceptions of symptoms, particularly pain) and feel more isolated during the night.

Family carers of patients with advanced cancer report that night time can be a particularly challenging and distressing time. Specialist nurses with expertise in end of life care and complex symptom management can improve quality of care, patient and family experiences, facilitate consultation with medical teams, coordination of hospital admissions if necessary and provision of much needed respite to the carer.

This project sets out to test a model of care that enables patients who express a wish to end their days in their own home to fulfil their wishes as a consequence of excellent care planning and symptom management.

- This model will be informed by long-established services in the United Kingdom (Marie Curie and Macmillan Nurses) and Ireland (Twilight Nurses), where trained nursing staff

⁶ Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ*, 2006;332(7540):515-21.

recruited from nursing pools, provide hands on nursing care to patients and respite to family/significant others.

- The Program will also incorporate national and international recommendations for enabling patients to be cared for and die in their preferred place.
- The study findings will be widely reported to all WCMICS hospital and palliative care teams; the Victorian Department of Health and key Palliative Care and Cancer Patient Advocacy groups across Victoria and Australia.

5. Other Avner's Foundation programs

PAN 1 Trial - Australian Gastrointestinal Trials Group

Pan 1 is an Australia-wide multi-centre cancer clinical trial and takes an innovative approach to research into understanding pancreatic cancer and individualising patient treatment.

It is hoped this trial will make it possible to identify ahead of time the patients whose cancers are more likely to respond to a particular treatment, so that alternative treatments can be considered for the patients in whom the treatment may be less efficacious.

Australian Pancreatic Cancer Genome Initiative – Garvan Institute of Medical Research

Researchers from more than 13 countries around the world have formed the International Cancer Genome Consortium with an aim of fully sequencing the genes of the most common cancers.

Today, more than 100 scientists and doctors at more than a dozen institutions across the country are collaborating on the Australian initiative, the APGI. Using innovative tools and technologies, they are working together in a coordinated, systematic manner to create a catalogue of genomic changes in pancreatic cancer.

6. Acknowledgements

In providing this submission we wish to make some important acknowledgements:

- The Australian Senate for this initiative.
- The Standing Committee for providing resources to undertake this important inquiry.
- The important activities currently carried out in association with Avner's Foundation by the Garvan Institute of Medical Research and partners, the Australian Gastrointestinal Trials Group and the Peter MacCallum Cancer Centre.

Conclusion

The Avner Nahmani Pancreatic Cancer Foundation Limited commends the Australian Senate for initiating this most important and over-due inquiry.

- We understand that the currently palliative care framework within an Australian Healthcare context is inadequate and sadly fails tens of thousands of seriously ill Australians each year.
- We understand palliative care delivers quality of life benefits.
- We seek to highlight that better use of limited health resources provides a strong case for increased funding of palliative care as an integral part of our health care services.
- We seek to impress upon the community the devastating number of Australians who die from pancreatic cancer and other illnesses each year.

Finally, we commend the efforts of the Standing Committee for providing resources to undertake this important inquiry. There is genuine hope this inquiry will provide the basis for desperately needed policy improvements in this critical aspect of the Australian Healthcare system.

Thank you for accepting our submission.

Yours sincerely

CAROLINE KELLY

CEO and Co-founder

AVNER NAHMANI PANCREATIC CANCER FOUNDATION LIMITED