

Palliative Care NSW: Draft Policy Statement 2014 Revision

Submission by Cancer Voices NSW

Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard.

Cancer is now the greatest cause of death of Australians (ABS), and with earlier detection and improved treatment, many are living much longer with their cancer. Added to the known ageing of the population, the need for palliative care for cancer patients will increase rather than diminish.

Background

Cancer Voices NSW activated and has participated in and the successful campaign for better palliative care services across NSW over the last three years. We did this in response to our members having identified that palliative care experiences of people affected by cancer – a majority of people seeking palliative care – have been underfunded, were often sub-optimal, were hard to access and in some cases, very distressing. Cancer Voices had also become aware that there are geographical gaps (within metro as well as rural area) in the availability and quality of palliative care services.

This year Cancer Voices successfully sought the public release of the Palliative Care Expert Advisory Group (PCEAG) Report, having participated on the PCEAG during 2011 and 2012 as consumer representatives for people affected by cancer.

We have closely worked with a number of palliative care professional during this period of advocacy and acknowledge that such collaboration is the best path in the interests of both cancer patients and their professional advisors and care givers. **We suggest that consultation with relevant health consumer groups be part of the Statement's recommendations.**

Cancer patients, their families and carers are becoming more aware of options to ensure a dignified and comfortable death although we stress that access to them needs more attention.

Cancer Voices welcomed the Minister for Health's 12 September confirmation that the \$35million promised for palliative care in NSW had been approved for allocation to suite of identified services.

Cancer Voices members attended PCNSW's Parliamentary Forum on **Palliative Care – Where to from here?** held on 30 October, and issues raised then and by our own members have shaped our response to the Draft Policy Statement.

General Comment

Cancer Voices NSW commends Palliative Care NSW's commitment to developing Policy Statements, and is pleased to again contribute the views of people affected by cancer – who will remain the largest "client group".

CVN draws attention to the following specific issues which we believe should be highlighted in the 2014 recommendations:

- access to information about local palliative care services for patients and GPs, with special emphasis on how to access those services if they wish to die at home
- funding and provision of dedicated palliative care beds/wards/hospices to meet demand, separate to medical or critical care wards for those who do not wish to die at home, or are unable to
- guidelines re roles and their coordination for all involved in providing PC services, at all levels
- coordination of services – something no one seems to be really focussing on
- better and compulsory undergraduate palliative care education of GPs AND nurses
- regular palliative care nurse access at all aged care facilities, and access to palliative care specialists as needed
- recurrent funding levels which enable the above to be provided

Addressing PCEAG Recommendations

Cancer Voices reconfirms that it has at last secured release of the important report **Improving Palliative Care in for People in NSW** via a request under the GIPA Act 2009. This is full of valuable data, as requested by the Minister following the Parliamentary Debate in August 2011, on which to base decisions. We recommend that the Policy Statement include in its recommendations the need to address the ten “Community Concerns” identified by the Report (pages 45-46), most of which remain outstanding. We recommend a review of this under a specific heading, as well as cross-references to the Statement’s content, where relevant.

Addressing PCNSW Statement’s 33 recommendations

Firstly, we recommend that all those recommendations which have been partly addressed be retained and flagged for easy monitoring.

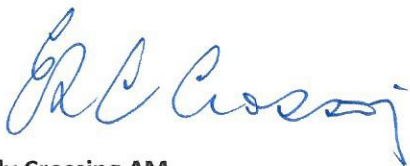
Cancer Voices supports and endorses all recommendations, with special interest in:

Recommendation 6: regarding provision of a one-stop shop information point for the community about palliative care *itself, services available, referral pathways, advance care planning and directives* (those in italics are to us essential additions to Recommendation 6)

Recommendation 14: regarding the adoption of National Standards for providing quality palliative care in all appropriate care settings in NSW. If these were formally adopted by the NSW Ministry of Health and all Local Health Districts *and Medicare Locals* (many of which are showing interest in palliative care), we imagine most of the other recommendations would become requirements. We will be inquiring as to their adoption status as part of our own advocacy.

We trust these comments; coming as they do from people affected by cancer, find fertile ground in your consultation process. Thanks again for the opportunity.

Yours sincerely



Sally Crossing AM
Secretary & Deputy Chair

9 December 2013