



Monday 2 July, 2012

Secretary
Senate Community Affairs Legislation Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

Re: Inquiry into Palliative Care in Australia

Dear Secretary,

Thank you for the opportunity to address the enquiry. Please find attached our Policy Statement: providing informed input into the development of palliative care in NSW.

Following is a summary of the recommendations appearing in our Policy Statement:

Recommendation 1:

That the review of the NSW Palliative Care Role Delineation Framework which is due in November 2012 revises the definitions of palliative care services in light of lessons learned from the Palliative Care Services Mapping Exercise.

Recommendation 2:

That PCNSW, work in collaboration with Alzheimer's Australia and the Australian Government Department of Health and Ageing to make 'The Dementia Journey' available at a national level.

Recommendation 3:

That the NSW Ministry of Health fund PCNSW to widely promote and distribute 'The Dementia Journey' to consumers, relevant health care professionals and aged care services across NSW.

Recommendation 4:

That the NSW Ministry of Health fund PCNSW to undertake a project to develop, in consultation with other relevant stakeholders, a generic Advance Care Planning Guidance Kit. The Guidelines would draw on lessons learned through the development of the 'The Dementia Journey'.

Recommendation 5:

That any state or national legislation for Advance Care Planning provide for flexibility given the reality that people may change their minds during the course of their illness. Further, that the NSW Ministry of Health work to prevent situations where the existence of an Advance Care Plan becomes a barrier to appropriate clinical assessment and care being provided in NSW facilities or by NSW services.

Recommendation 6:

That the NSW Ministry of Health fund PCNSW to provide a one-stop information point for the community about palliative care, referral pathways, advance care planning and directives.

Recommendation 7:

That the NSW Ministry of Health finalise as a matter of urgency its review of the Policy Directive "Assessment of the Extinction of Life and Certification of Death" (PD2005_488) and ensure that the revised requirements are clearly communicated to relevant health services, including the ambulance service.

Recommendation 8:

That a planned and negotiated process is undertaken by the NSW Ministry of Health to enable Specialist Palliative Care Services to provide 24/7 support in all NSW LHDs.

Recommendation 9:

That the NSW Ministry of Health ensures that there is adequate funding and support for a Volunteer Coordinator position in every palliative care service that recruits and trains volunteers or have identified the potential to do so.

Recommendation 10:

That PCNSW be funded by the NSW Ministry of Health to develop a state wide mandatory Palliative Care Volunteer training resource to support existing services, especially those in non-metropolitan areas and that annual volunteer training courses be conducted in rural and regional areas.

Recommendation 11:

That further research be undertaken into the cultural needs of Aboriginal people and Culturally And Linguistically Diverse communities, and the impact of different attitudes towards death and dying in the provision of palliative care to inform policy and service development.

Recommendation 12:

That Palliative Care Australia work in collaboration with the Australian Government Department of Health and Ageing to develop a national media campaign designed to raise community awareness about how to live with a life limiting illness, face death and cope with loss and bereavement.

Recommendation 13:

That death, dying and the role of palliative care be integrated into the personal development syllabus of all NSW schools and the development of the Australian Curriculum.

Recommendation 14:

That the NSW Ministry of Health and all Local Health Districts commit to the adoption of the National Standards for Providing Quality Palliative Care in all appropriate care settings in NSW.

Recommendation 15:

That following consultation with the broad spectrum of Specialist Palliative Care Services the NSW Ministry of Health determine a minimum Palliative Care data set and support its collection within all NSW Specialist Palliative Care Services;

That LHDs be held responsible for ensuring local capacity to collect and report this data.

Recommendation 16:

That PCOC consider adjustments to both its data set and processes to allow increased uptake in community and consultative palliative care services.

Recommendation 17:

That all Level 3 Specialist Palliative Care Services be supported to be centres of research excellence in palliative care. As a first step, the palliative care mapping exercise undertaken by the NSW Ministry of Health should include within its scope palliative care research capacity and activity in

order to assess progress in achieving the aim of transforming all Level 3 services into well-functioning research centres. This activity should include an assessment of the research activity and capacity of Level 2 services.

Recommendation 18:

That the NSW Ministry of Health review opportunities to improve resourcing for non-cancer palliative care research across all care settings. Areas of special concern include community care, coordination of care and the needs of culturally and linguistically diverse groups.

Recommendation 19:

That the State-wide Centre for Improvement in Palliative Care (SCIP) undertake an evaluation of the effectiveness of the dissemination of palliative care research findings through the Palliative Care Service Development Officer Network.

Recommendation 20:

That the NSW Ministry of Health clarify and confirm that the Treasury managed funds indemnity for investigator led research in palliative care covers all aspects of the health system where this care is delivered, including the community and residential aged care.

Recommendation 21:

That the Ministry of Health establish mechanisms to examine the palliative care service delivery possibilities of all eHealth developments and that systems to allow cross Specialist Palliative Care Service access to electronic medical records be facilitated where improvements in service access and provision can be demonstrated.

Recommendation 22:

That policies, processes and guidelines for the allocation and funding of “fly-in fly-out” palliative medicine support comprising a Specialist Palliative Care physician at minimum to regional and remote communities be reviewed and formalised on a state-wide basis.

Recommendation 23:

That the NSW Ministry of Health undertake a feasibility study for establishing a state wide Palliative care After Hours Advice Line, either through a single Level 3 Specialist Palliative Care Service, or on a regional basis through all Level 3 Specialist Palliative Care Services.

Recommendation 24:

That the Australian Government adopt the recommendations of the Productivity Commission with respect to aged care, and in particular:

- the replacement of the current system of discrete care packages across community and residential care with a single integrated and flexible system of entitlements. The System would cover services including palliative care;
- a flexible funding model that supports individual choice and ensures that people are assisted to die in the place of their choice, with the people they wish to be present;
- the Australian Government ensure that residential and community care providers receive appropriate payments for delivering palliative care;
- that Advance Care Directives form part of a person’s electronic health record; and
- that palliative care be a basic competency for aged care workers.

Recommendation 25:

That the NSW Ministry of Health:

- strongly engage with the Australian Department for Health and Ageing in the proposed review of barriers to the

- provision of short term intensive health care services in the aged care setting;
- facilitate consultation with PCNSW and Specialist Palliative Care Services as part of the review process;
- include in the scope of the review:
 - the ratio of Senior Registered Nurses to residents in Residential Aged Care Facilities;
 - access to and storage of medications needed to care for residents with life-limiting illness within the aged care setting;
 - access to specialist equipment, including oxygen, within aged care settings.

Recommendation 26:

That the NSW Ministry of Health prepare a “Palliative Care Workforce Strategy” based on supply and demand analyses arising from the current palliative care mapping exercise. The Strategy should:

- Identify workforce resources required across services (general, specialist and community);
- Address existing and anticipated workforce shortages in Specialist Palliative Medicine
- Address succession planning concerns amongst Rural Specialist Palliative Care Nurses
- Aim to ensure that palliative care is a basic competency for acute care workers, aged care workers and disability care workers.

Recommendation 27:

That the NSW Ministry of Health ensures, through their Service Level Agreements with Local Health Districts, that funding is provided to maintain effective access to Palliative Care Service Development Officer services in each Local Health District.

Recommendation 28:

That by 2015:

- revised and updated palliative care training curricula be in place in appropriate faculties of tertiary teaching institutions; and
- the Palliative Care Curriculum for Undergraduates (PCC4U – www.pcc4u.org) be in place in all appropriate faculties of tertiary teaching.

Recommendation 29:

Without pre-empting the outcomes of the NSW palliative care service mapping exercise, based on current estimates of the workforce shortage, PCNSW recommends:

- That the NSW Government provide an increase in recurrent funding for Specialist Palliative Care services to allow capacity to meet demand across all care settings (including hospital consultation teams).
- That the NSW Government review and adjust the existing funding arrangements to better meet costs of fly-in and telemedicine support from metropolitan level 3 services.

Recommendation 30:

In conjunction with the palliative care mapping exercise announced by the Minister in August 2011, the NSW Ministry of Health should:

- Ensure that the mapping accurately identifies not only the resources allocated to specialist, generalist and community services (as set out in the Role Delineation Framework), but also sets out the funding models underpinning the provision of each service;
- Review the current Specialist Palliative Care Service funding model to reflect the changing demand pattern for palliative care services and changing service role, (ie to reflect increased cancer related demand plus demand for palliative care service for people who have non-malignant life-limiting illness, and to better reflect the growing need specialist consultancy advice for generalist end of life care providers;
- Ensure that Specialist Palliative Care Hospital Consultations Teams are discreetly funded and available in all major rural, regional and metropolitan public hospitals’

- Formalise funding models and support structures for regional and remote access to Specialist Palliative Care Services (eg fly in/fly out programs, teleconferencing etc).

Recommendation 31:

That the NSW Ministry of Health ensure a suitable level of consultation with Palliative Care Services is undertaken to allow an informed determination to be made as to the future funding arrangements for Specialist Palliative Care provision across acute, sub-acute and community care settings under the healthcare reform agreements.

Recommendation 32:

That the Service Agreements between the Ministry of Health and Local Health Districts (LHDs) clearly specify:

- The minimum Specialist Palliative Care services to be funded or purchased, in all care settings;
- The strategies, targets and goals to be achieved in relation to palliative care services;
- Measures to be used to monitor the performance of services (including outcomes for consumers and carers) in relation to palliative care and these include that CEO performance is linked to palliative care standards achieved in their LHD.

Recommendation 33:

That the NSW Ministry of Health review current palliative care related consultative mechanisms in relation to Specialist and non-specialist Palliative Care and establish an on-going policy and strategic consultative/advisory body with a documented terms of reference covering palliative and life care issues, including Specialist Palliative Care, that is separate to the anticipated ACI Palliative Care Network. That the consultative arrangements ensure representation from peak bodies representing health service professionals in palliative, end of life and aged care services, health consumers, carers and disease-specific organisations.

Once again we are most grateful for the opportunity to appear before the Senate Committee. Should you require any further information please don't hesitate to contact me.

Yours sincerely,

Linda Hansen
Executive Officer