



ANZSPM

The Australian and New Zealand Society of Palliative Medicine Incorporated

ABN 54 931 717 498

Submission to

The Queensland Parliament
Health and Community Services Committee's

Palliative Care Services and Home and Community Care Services Inquiry

August 2012

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About ANZSPM

The Australian & New Zealand Society of Palliative Medicine (ANZSPM) is a not-for-profit specialty medical society for medical practitioners who provide care for people with a life threatening illness.

ANZSPM facilitates professional development and support for its members, promotes the practice of Palliative Medicine and advocates for those who work in the field of palliative medicine.

ANZSPM is managed by a Council of members, which includes representation from New Zealand and also from the Australasian Chapter of Palliative Medicine. ANZSPM's day to day operations are managed by a part-time Executive Officer.

Our members are medical practitioners involved in caring for people with a life threatening illness – palliative medicine specialists, palliative medicine trainees, and other doctors such as, but not limited to, general practitioners, oncologists, haematologists, psychiatrists and geriatricians.

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Executive Summary

ANZSPM sees adequate funding for Palliative Care as essential for an efficient and humanistic health care system. Patients at the end of their life are amongst the most vulnerable members of our society. Quality End-of-Life Care (last 12 months of life) and a ‘good death’ for people should be the aim of every health care system.

Queensland has a very good health care system, but currently lags behind the other states of Australia in both resourcing and state wide planning for the provision of Palliative Care. ANZSPM applauds this inquiry, from which it is hoped Queensland will use the opportunity to become a leader in Palliative Care provision across Australia over the next five years.

ANZSPM believes that the funding necessary for high quality Palliative Care service provision is already absorbed by inappropriate ‘curative’ based treatments in the acute care sector, largely in-hospital; because there are few other alternatives available for many patients and their families.

Below is a list of the recommendations included in this submission:

Recommendation 1. That the Queensland government ensures that funding for the National Partnership Agreement (NPA) for subacute care, and future funding for Palliative Care:

- is allocated according to population-based needs;
- is specifically allocated for Palliative Care (at least 25% of any future sub-acute care funds allocation until sufficient funds are allocated to Palliative Care to provide all Queenslanders with access to high quality Palliative Care in their setting of choice, when they need it)
- has its distribution linked to a clear improvement in the quality of service, using validated measures; and is transparent, and that details of allocation/distribution are made publicly available.

Recommendation 2. That the Queensland government supports the ANZSPM position of having a minimum of 1.0 FTE Palliative Medicine Specialists per 100,000 population, as well as ensuring sustainable on-call arrangements are in place to support Palliative Medicine Physicians.

Recommendation 3. Any new funding models should recognise the need to fund Consultation Liaison services in hospitals.

Recommendation 4. New funding models should recognise the need to fund adequate 24 hour Community Palliative Care access to support increased home care and home deaths.

Recommendation 5. New funding models recognise that 25% of a Palliative Medicine Physician’s time is spent educating, training and up skilling junior doctors, Non-Pall Medicine Specialists and Generalists in providing a skilled and evidence based palliative approach to End-of-Life care (last 12 months of life).

Introduction

The Australian and New Zealand Society of Palliative Medicine Incorporated (ANZSPM), represents doctors working in Palliative Medicine in Australia and New Zealand.

Palliative Care is the broad discipline of care undertaken by a wide variety of health professionals. Palliative Medicine is the practice of medicine by doctors in the care of patients with life-limiting illnesses and their families. That practice is critical to the care of patients at multiple levels. The central expertise of doctors working in Palliative Medicine is the physical – the control of difficult symptoms such as pain, nausea and shortness of breath. But the practice of medicine from its antecedence in antiquity has been always more than the physical. It includes the need to listen to the spirit of a patient facing an illness, and attending to the multiple fears, concerns and regrets that proximity to mortality entails.

In an era where society can be infatuated by developments of medical research and long-anticipated breakthroughs, doctors working in Palliative Medicine remind both medicine and society of a simple truth: we are all mortal. And if that is so, how are people cared for through this period and what level of symptom control and spiritual equanimity is reached? Is the death comfortable, loving and dignified or is it one of tumult, agony and heartache?

The Queensland government currently contributes significantly to Palliative Care at several levels. That contribution should be seen as the foundation to this Inquiry, and the Terms of Reference as the signposts for the future.

- How can significant improvements be achieved?
- To what extent is access to high quality Palliative Care services inequitable?

Response to the Terms of Reference

Term of Reference 1: Capacity and future needs

A major source of growth funding for Palliative Care in Australia over the last few years has been the National Partnership Agreement (NPA) on subacute care funding. This money has been distributed to States and Territories, and covers four areas of subacute care – Palliative Care, Geriatric Evaluation and Management, Psychogeriatrics and Rehabilitation. In the initial funding round all States and Territories were required to publish their implementation plans; these were available to the public. The detail of these plans varied from having no breakdown of monetary allocation, to detailed distribution of funds between the different subacute care areas. Unfortunately, in the second round of funding, there has been no publication of the allocations.

The lack of transparency and rationale evident in the distribution of NPA funds has resulted in our members experiencing severe frustration and “burnout” for some. This response was generated by the relative paucity of NPA funds distributed to Palliative

Care, and secondly at what is seen as distribution determined by political motives rather than the needs of patients. Many members have complained at the lack of benefit from this money for palliative care service provision in Queensland.

Recommendation 1. *That the Queensland government ensures that funding for the National Partnership Agreement (NPA) for subacute care, and future funding for Palliative Care:*

- *is allocated according to population-based needs;*
- *is specifically allocated for Palliative Care (at least 25% of any future sub-acute care funds allocation until sufficient funds are allocated to Palliative Care to provide all Queenslanders with access to high quality Palliative Care in their setting of choice, when they need it)*
- *has its distribution linked to a clear improvement in the quality of service, using validated measures; and*
- *is transparent, and that details of allocation/distribution are made publicly available*

Developing a Public Health approach to Palliative Care means that existing resources are wisely and fairly allocated. This means not only equitable access to Specialist Palliative Care but also the use of a palliative approach to care¹ to make better use of acute care services.

For non-hospital care to be effective, specialist community resources need to be extended. Programs which can facilitate a palliative care approach to aged care include Link Nurses based in aged care facilities. Link Nurses develop expertise in palliative care and are supported to provide in-house expertise as well as to work together with specialist palliative care services. These are currently mostly local initiatives with little funding support but could be cost effective in terms of being ‘champions’ of supporting a palliative approach which will change the culture within aged care facilities and reduce inappropriate hospital admissions, investigations and treatments.

In terms of the Palliative Medicine workforce there is significant gap between the current and ideal workforce numbers. According to the Australasian Chapter of Palliative Medicine Workforce Report of 2007 there are 0.5 FTE Palliative Medicine Specialists per 100,000 population in Australia.² ANZSPM’s position is that the minimum number of specialists for a reasonable provision of service is 1.0 FTE Palliative Medicine Specialists per 100,000 population.³ That figure is in accord with Royal College of Physicians (UK) recommendation of 2 FTE per 250,000

¹ ANZSPM Clinical Indicators Working Group – 5 major domains for addressing evidence-to-practice gaps in EoL Care (last 12 months of life: symptom management, advance care planning, carer support, continuity of care across settings & time, diagnosing dying and providing terminal care (last few days to week of life) <http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1320265764&sid=> .

² Australasian Chapter of Palliative Medicine (2007) Survey of the Palliative Medicine Specialist Workforce. See details of statistics in: *ANZSPM Position Statement – Benchmark Number of Specialists in Palliative Medicine*. 2009. Accessible at www.anzspm.org.au.

³ *ANZSPM Workforce Strategy – Meeting the Palliative Care Needs of Patients in Australia 2011-2015 and beyond*. July 15 2011. Accessible at www.anzspm.org.au

population.⁴ and is less than that recommended by PCA of 1.5FTE per 100,000 population.⁵

It is important to note that the figure of 1.0 FTE is based on traditional referral patterns to Palliative Care services where 80-90 % of patients have a malignancy and largely only in the last 2-3 months of life. This situation has evolved significantly over the past 5-10 years where, increasingly, Palliative Care Services are asked to advise on aspects of the care of patients in the last 6-12 months of life and also now include many more patients with other life-limiting illnesses, including end stage heart disease, lung disease, renal disease, Motor Neurone Disease and end stage dementia. For many services, 30-40 % of their work will have this focus on non-malignant diseases. Many of those diseases are associated with increasing age. The needs of Palliative Care Services, including Palliative Medicine Specialists will increase with time as both the population ages and the scope of Palliative Medicine expands to include earlier referrals and significant numbers of patients with non-cancer diagnoses. Of course it would be impossible for Palliative Care Services to be the sole discipline involved in all patients with these illnesses but most of those patients would benefit from the advice and guidance of Palliative Care services, including that of doctors working in Palliative Medicine.

While ANZSPM is an association of Specialist Palliative Care doctors and doctors with a special interest in Palliative Care, it is important to also recognise the importance of multidisciplinary teams, and to develop these in a balanced manner operating from Regionalised Centres that cover identified populations across Qld.

Recommendation 2. *That the Queensland government supports the ANZSPM position of having a minimum of 1.0 FTE Palliative Medicine Specialists per 100,000 population as well as ensuring sustainable on-call arrangements are in place to support Palliative Medicine Physicians.*

The factors influencing access to and choice of appropriate palliative care that meets the need of the population include:

- rural and remote populations;
- indigenous populations; and
- culturally and linguistically diverse populations

A critical issue in the provision of Palliative Care is the historic fact that generations of doctors and other healthcare professionals have received little or no education in Palliative Care and Terminal Care - the care of the dying. There is a lack of teaching around the signs and symptoms of dying and the prognostic recognition that a person is in the final 12 months of life. It is only in the modern era that this has started to be addressed. This means that many doctors and other healthcare professionals are inadequately equipped to deal with many End-of-Life Care issues (last 12 months of life) in an evidence based manner. Hence, the health care system and the public are used to continuing to focus on inappropriate and often costly "curative care" rather than more rational and cost efficient "subacute, end-of-life and palliative care"

⁴ Royal College of Physicians. Consultant Physicians Working for Patients. 2008, 4th edition.

⁵ PCA Guidelines for Service Planning 2003

paradigms. Education and re-education, therefore, at all levels from undergraduate to post-graduate is crucial to the provision of Palliative care in this country.

Regionalised interdisciplinary teams of health care professionals (doctors, nurses, allied health professionals) **skilled in Palliative Care** need to be developed to manage complex patients and families, build capacity amongst the generalist and non-palliative care specialist workforce and educate the public if we are to have a rational and efficient way of managing the population health issues around End-of-Life Care (last 12 months of life).

General Practice

A practical step forward in the provision of Palliative Medicine around Australia is in the relevant training of General Practitioners. All General Practice training should include a component of some time spent in Palliative Care.

Once doctors have completed their training in General Practice their education should not stop. A vital and highly successful Commonwealth program for the education of all health professionals, including doctors has been the PEPA program. It funds health professionals, including doctors, to spend a period of time working alongside a specialist Palliative Care health professional. For many participants that experience has been revelatory. The PEPA program also funds education sessions in rural and remote Australia on all aspects of Palliative Care.

Many GP Trainees have been able to use Special Skills posts (6 months) to train up in using a skilled Palliative Approach to Care at the End-of-Life (last 12 months). Many ANZSPM members have been supervising GP Trainees to do this and many of these Trainees have also been able to obtain a Diploma in Palliative Medicine through the RACP during this 6 months of Advanced Training.

Specialty training

To meet the future workforce need it is imperative that more doctors are trained in the specialty of Palliative Medicine. Currently a major rate limiting step is the funding of positions by State and Territory governments. A minority of positions are funded through the STP. There continues to be (although this is under review by Australasian Chapter Palliative Medicine) a requisite that all trainees complete a mandatory term with an Oncology service. The number of positions available to satisfy demand in Queensland is insufficient. This situation threatens the success of the newly implemented integrated pathway of training.

Accreditation of training positions is performed independently by the RACP (Royal Australasian College of Physicians) Palliative Medicine Education Committee. Many accredited positions are unfunded such that there are relatively few trainees. So as to increase the number of Palliative Medicine Specialists for the future, ANZSPM proposes that funding is provided according to numbers of accredited positions, rather than on the basis of historical allocations, usually to public hospitals.

As with General Practice, there are now a number of Specialist trained doctors of other disciplines who have obtained or are in the process of obtaining a Diploma

Palliative Medicine, including from General Physician, Emergency Medicine and Intensive Care pathways. This ‘strengthening’ through other disciplines extends and ‘champions’ the Palliative approach.

Term of Reference 2: The effectiveness, efficiency and adequacy of palliative, frail and chronic care services.

Hospital Care

Currently, not all hospitals have consultation liaison services, and ANZSPM believes that it is essential that all major hospitals should have an adequately staffed palliative care consultation service. This will encourage a culture of increased and earlier referrals of both cancer and non-cancer patients with advanced disease to Palliative Care services. This has been shown to:^{6,7}

- increase patient and family satisfaction
- increase advance care planning and
- lead to more efficient and cost effective health care in more appropriate settings and decrease futile care in acute care settings

There is concern that the consultation liaison services in acute hospitals will not be funded under the proposed ABF (Activity Based Funding) model, although there is strong evidence that they greatly help with improving patient flow, decreasing average length of stay (ALOS) in acute care beds and integrating care from hospital to community.

In terms of hospitals in rural and remote settings, since it is unlikely there will be a substantial increase in the numbers of Palliative Medicine doctors working in rural and remote areas, there are three important prerequisites:

- a. Undergraduate teaching of the principles of palliative care; this varies considerably across the country;
- b. General Practice training – teaching Palliative Medicine as part of their training;
- c. MSOAP/PEPA funding – teaching of GPs, especially with the increasing number of overseas doctors working in rural and remote settings without the chance of undergraduate or post graduate exposure to Palliative Medicine.

Recommendation 3. *Any new funding models should recognise the need to fund Consultation Liaison services in hospitals.*

⁶ American Society of Clinical Oncology Post April 2012: <http://www.ascopost.com/issues/april-15-2012/asco-releases-palliative-care-provisional-clinical-opinion.aspx>

⁷ Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 363:733-742, 2010: <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

Residential/Community Palliative Care

The role of Palliative Medicine doctors in the community setting is crucial. Many people prefer, if at all possible, to die at home. Unfortunately that coverage varies considerably around the country. General Practitioners have always and will continue to provide care of the deteriorating and dying patient in the community. However, there needs to be adequate funding of specialist palliative medicine to provide both an education service for primary care up-skilling and a consultancy service for all general practitioners. This service needs to be multidisciplinary in nature and elements of these regionalized Palliative Care services will need to be available 24 hours per day, so that GPs and patients can also have access to specialist palliative care and allied health practitioners, including social workers, occupational therapists, physiotherapists, pharmacists and pastoral care.

A critical issue here is the advent of the consolidation of General Practices and a trend away from committing to do home visits leading to a reduction in the numbers of General Practitioners available to visit patients in their homes.

Most patients and families (60%-90%) would prefer to be managed at home rather than in hospital, however they are not being given this choice. For example “Home Death Rates” in Qld. for even Palliative Care Registered patients are low (16%) where community care is not readily available. However, where Specialist Community Palliative Care access is provided round-the-clock the Home Death Rate for Palliative Care Registered patients is 50-60%.^{8,9}

Recommendation 4. *New funding models should recognise the need to fund adequate 24 hour Community Palliative Care access to support increased home care and home deaths.*

Up-skilling and capacity building at a **Regional Level** of the generalist, non-palliative medicine/care specialist workforce, junior staff and medical, nursing and allied health students in high quality EoL Care needs to be a standard feature of any Specialist Palliative Care Service. The time (approximately 25%) needs to be put aside for every discipline in the Specialist Palliative Care Service, including Palliative Medicine Physicians.¹⁰

Recommendation 5. *New funding models recognise that 25% of a Palliative Medicine Physician's time is spent educating, training and up-skilling junior doctors, Non-Pall Medicine Specialists and Generalists in providing a skilled and evidence based palliative approach to End-of-Life care (last 12 months of life).*

⁸ Silver Chain W.A. submission to Health & Hospitals Reform Commission 2009

⁹ St. Vincent's Brisbane: conversation about current data from Home Care Team 2012

¹⁰ Royal College of Physicians Report on working in Palliative Care 2008

<http://bookshop.rcplondon.ac.uk/contents/7920ccc4-1b69-40ff-ab2a-3bbb383023a7.pdf>