ANZSPM

The Australian and New Zealand Society of Palliative Medicine Incorporated

ABN 54 931 717 498

Submission to

THE SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE INQUIRY INTO

Palliative Care in Australia

Authorised by Dr Frank Brennan, President, ANZSPM and the ANZSPM Council

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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 that there are several principal areas of Commonwealth capacity and responsibility in the area of Palliative Medicine. They include support and funding for:

1. The four aspects of the National Palliative Care Program;
2. The provision of Palliative Care in Residential Aged Care Facilities;
3. The Medical Specialist Outreach Assistance Program (MSOAP);
4. Funding of Chronic Disease service improvement;
5. Leadership role of the Commonwealth in pursuing legislative uniformity in Advance Care Planning legislation – persuasive capacity of the Commonwealth in the promotion and drafting of uniform laws across all jurisdictions;
6. The Specialist Training Program (STP); and
7. The National Partnership Agreement.

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

Recommendation 1. That the Commonwealth continues to fund all elements of the National Palliative Care Program.

Recommendation 2. That the Commonwealth continues to fund the Chronic Disease Service improvement programs with recognition of the importance of the care of organ failure and neurodegenerative diseases throughout the trajectory of illness until death.

Recommendation 3. That the Commonwealth continues to fund the MSOAP and STP programs.

Recommendation 4. That the Commonwealth supports the development of telehealth services to link remote communities to specialist palliative care services.

Recommendation 5. That the Commonwealth supports doctors working in Aboriginal Medical Services in all ways relevant to Palliative Medicine including professional development and, through the PEPA program, the opportunity to observe the work of Palliative Medicine specialists and services.

Recommendation 6. That the Commonwealth ensures that funding for the National Partnership Agreement (NPA) for subacute care:

- is allocated according to population-based needs;
- has its distribution linked to a clear improvement in the quality of service; and
- is transparent, and that details of allocation/distribution are made publicly available to

ensure that State and Territory governments and LHHN (Local Health and Hospital Networks) are accountable for the use of this funding stream.

Recommendation 7. Any new funding models should recognise the need to fund Consultation Liaison services in hospitals.

Recommendation 8. 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 9. That the Commonwealth funds a Community Nurse Practitioner, Palliative Care in every Specialist Palliative Care Service, classified as Level 3 by Palliative Care Australia, to be devoted to the provision of Palliative Care in RACFs, the teaching of palliative care practice to staff of RACFs (urban and rural) and for liaising with General Practitioners, Geriatricians and other Medical Specialists.

Recommendation 10. That Commonwealth policies support the ANZSPM position of having a *minimum* of 1.0 FTE Palliative Medicine Specialists per 100,000 population.

Recommendation 11. That the Commonwealth funds the teaching of Palliative Care in all Medical Schools in Australia.

Recommendation 12. That the Commonwealth continues to fund the PEPA program around Australia.

Recommendation 13. That the Commonwealth Government provides funding for accredited positions for training in Palliative Medicine.

Recommendation 14. That the Commonwealth Government instigates and promotes a national framework of legislation for Advance Care Planning that is consistent across all State and Territory jurisdictions.

Recommendation 15. That the Commonwealth does all within its capacity to facilitate the inclusion of Advance Care Plans in personally controlled electronic health records.

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 Commonwealth of Australia 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 things be improved?
- To what extent is access to Palliative care services inequitable?
- Could more be done to support education, professional development and research?

In summary the Commonwealth Government currently contributes to Palliative Care through:

The National Palliative Care Program which consists of:

a. Support for patients and families through local grants to health and aged care providers;
b. Access to Palliative Care medicines – through the Palliative Care Clinical Studies Collaborative (PACCSC program);
c. Education, training and support – through the Program of Experience in the Palliative Approach (PEPA program);
d. Research and quality improvement – through the Palliative Care Research Program, CareSearch, NSAP (National Standards Assessment Program) and PCOC (Palliative Care Outcomes Collaboration) programs.

The MSOAP Program – Medical Specialist Outreach Assistance Program which funds multiple specialties, including Palliative Medicine Specialists, to do regular clinical and teaching visits to rural and remote centres.

The Chronic Disease Prevention and Service Improvement Flexible Fund – an initiative of the Commonwealth Department of Health and Ageing designed to support service improvement in the area of chronic diseases including its management from diagnosis until end of life.

The Specialist Training Program (STP) - The Specialist Training Program provides support to enable medical specialist trainees to rotate through an expanded range of settings beyond traditional public teaching hospitals.

The National Partnership Agreement (NPA) – Subacute care funding.

Recommendation 1. *That the Commonwealth continues to fund all elements of the National Palliative Care Program.*

Recommendation 2. *That the Commonwealth continues to fund the Chronic Disease Service improvement programs with recognition of the importance of the care of organ failure and neurodegenerative diseases throughout the trajectory of illness until death.*

Response to the Terms of Reference

ANZSPM provides the following in response to the Terms of Reference of the Inquiry:

a. The factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including

(i) People living in rural and remote areas

There is a major paucity of Palliative Medicine Consultants working in rural and remote Australia. The vast majority of doctors working in Palliative Medicine, work either in the cities or the major regional centres. The Australian Commonwealth Government, in an attempt to alleviate this lack of presence of this specialty, in addition to myriad other medical and surgical specialties, funds the MSOAP program. This allows the regular visiting by metropolitan-based Palliative Care Consultants to rural and remote centres. Many areas of Australia are not covered. Nevertheless, those that are visited benefit considerably in supporting local Palliative Care nurses, assessing and advising on the management of difficult clinical presentations, raising the importance of meticulous symptom control and end of life care with the local medical and nursing communities and educating doctors - formally or informally- in this area. Generations of doctors have graduated both in Australia and overseas without any training in the basics of symptom control and the care of the dying. This teaching, guiding, advising and mentoring is vital.

The MSOAP program has some limitations in supporting palliative care in rural and remote areas because the program is one of recurrent service provision and requires sufficient patient numbers to be available at each visit, therefore the smaller the community the less likely it is that MSOAP will succeed.

As well the Commonwealth Government also funds the STP, which supports trainees in positions outside public hospitals. Whilst early grant rounds enabled an increase in Palliative Medicine training positions, there have been very few (if any – unknown as there has been no publication of positions) funded positions in recent grant rounds.

Recommendation 3. *That the Commonwealth continues to fund the MSOAP and STP programs.*

The Federal government is currently encouraging the development of telehealth services with a focus on clinical support through Telehealth MBS items since July 2011. Additionally education and support can be provided to extensive regions via videoconferencing. The NBN network should also facilitate the use of videoconferencing when it is complete. Such programs may provide an alternative. They would require the development of a hub-and-spoke model linking remote communities to specialist palliative care services.

Recommendation 4. *That the Commonwealth supports the development of telehealth services to link remote communities to specialist palliative care services.*

(ii) People from indigenous backgrounds

There is a major gap in the life expectancy of indigenous and non-indigenous Australians. Premature deaths, grief, loss and bereavement are major issues within indigenous communities. There is a disproportionate prevalence of chronic heart and kidney diseases and diabetes with its increased rate of vascular complications. End stage renal disease is epidemic across Aboriginal Australia.

In terms of the on-going care of patients with these diseases up to and including death and the bereavement support of families and entire communities after death, the Commonwealth plays a crucial role in supporting Aboriginal Medical Services. ANZSPM would especially encourage the Commonwealth to support doctors working in Aboriginal Medical Services throughout the country in all practical ways – funding of positions, adequate wages, and professional development and, through the PEPA (Program of Experience in the Palliative Approach) program, the opportunity to spend time observing the work of Palliative Medicine specialists and services.

The development of a palliative approach for Indigenous patients with non-malignant conditions requires active collaboration between Aboriginal health providers, primary care providers servicing Aboriginal communities and specialist physician groups. The Commonwealth through the various peak bodies could facilitate the development of such models of care. Pilot programs have already been developed in some jurisdictions e.g. The Northern Territory Renal Palliative Care Program.

Many Aboriginal Medical Services are already overburdened with the demands of acute care. The development, training for and rolling out of such programs with adequate local input and discussion would need additional resources. This includes up-skilling Aboriginal Health Workers in the principles of the palliative approach to care.

Grief and bereavement are very prevalent in Aboriginal communities because of high morbidity and early mortality, as well as the current increase in suicide and self-harm. There is little additional professional capacity for assisting the bereaved. Moreover it needs to be provided in a culturally appropriate manner for the communities concerned. This is an area requiring the development of new programs.

Recommendation 5. *That the Commonwealth supports doctors working in Aboriginal Medical Services in all ways relevant to Palliative Medicine including professional development and, through the PEPA program, the opportunity to observe the work of Palliative Medicine specialists and services.*

(iii) People from culturally and linguistically diverse backgrounds

Australia is a nation of widespread diversity in its population. That diversity extends to language, culture and religion. Each of these components of diversity is relevant to the care of patients with serious life-limiting illnesses. Examples include the disclosure to the patient of progression of the disease (for some cultures truth telling about serious illness is seen as a harm), the use of pain medications (some cultures and backgrounds view opioid medications including morphine as automatically harmful and worry that the use of these opioid medication is tantamount to euthanasia) and the preparation for and immediate aftermath of the death of a loved one. Sensitivity to these issues is paramount.

Programs that might improve access to palliative care services for people of culturally and linguistically diverse backgrounds include:

- using the media (including ethnic television, radio and newspapers) to improve public awareness;
- making available translated materials about palliative care at doctors surgeries and community facilities; and
- training community workers in the palliative approach to care through workshops or as integrated modules within existing educational programs.

There is some material already available in a variety of languages but its use is not widespread. Palliative Care Program funding would be useful to resource this issue.

Lower socio-economic areas – access to Palliative Care services

Other populations with limited access to palliative care that require special programs include homeless people and long term incarcerated individuals.

(iv) People with disabilities

Much of the work to be done in the area of palliative care for people with intellectual and/or physical disabilities is around:

- information giving;
- the training of care workers; and
- ethical decision making.

This is an area where specialist palliative care community input would be invaluable.

(v) Children and Adolescents

Very few doctors have trained in Paediatric and adolescent Palliative Care.

Many doctors working in Palliative Medicine have not had any training in paediatric and or adolescent Palliative Care. In practice, colleagues with such expertise are called upon to provide advice and support.

ANZSPM wishes to endorse the submission made to this Inquiry by the *Australian Paediatric Palliative Care Reference Group*.

b. The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

An important initiative of the Commonwealth Department of Health and Ageing has been the Chronic Disease Prevention and Service Improvement Flexible Fund. It was designed to support service improvement in the area of chronic diseases including its management from diagnosis until end of life.

A major source of funding over the last few years has been the NPA 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 difficulty with the way in which the money has been distributed, is that our members have experienced frustration, firstly at the lack of actual distribution of money, and secondly at what is seen as distribution according to political motives rather than the needs of patients. Many members have complained at the lack of benefit from this money for palliative care provision across Australia.

Recommendation 6. *That the Commonwealth ensures that funding for the National Partnership Agreement (NPA) for subacute care:*

- *is allocated according to population-based needs;*
- *has its distribution linked to a clear improvement in the quality of service; and*
- *is transparent, and that details of allocation/distribution are made publicly available to ensure that State and Territory governments and LHHN (Local Health and Hospital Networks) are accountable for the use of this funding stream.*

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.

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

For non-hospital care to be effective, 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 changing the culture within aged care facilities and reducing inappropriate hospital admissions, investigations and treatments.

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.

There is concern that the consultation liaison services in acute hospitals will not be funded under the proposed ABF model.

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

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 so that GPs and patients can also have access to specialist palliative care and allied health practitioners, including social workers, occupational therapists, physiotherapists and pharmacists.

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.

Recommendation 8. *New funding models should recognise the need to fund adequate 24 hour Community Palliative Care access to support increased home care and home deaths.*

Aged Care facilities

There are two incontrovertible facts pertinent to this section. The first is demographic; the second jurisdictional. Firstly, the rising numbers of older Australians entering Residential Aged Care Facilities (RACF) and the expectation that those numbers will continue to rise. The second is the fact that the Commonwealth has jurisdiction over Residential Aged Care Facilities throughout Australia; it is therefore a core responsibility of health care for the Commonwealth.

A critical issue is the sporadic and uncoordinated nature of the involvement of four relevant disciplines in the medical care of residents of RACF around Australia. The four disciplines are – General Practice, Geriatrics, Psycho-Geriatrics and Palliative Care. Currently none of these disciplines has a large or consistent presence in RACF throughout the nation.

There are two priorities:

i. The importance of the co-ordination of medical care as it pertains to RACF across the four disciplines and across the nation;

   and, from the perspective of this Inquiry,

ii. To adequately fund the provision of Palliative Care for the residents of RACF. An extremely valuable measure would be for the Commonwealth to fund a Community Palliative Care Nurse Practitioner in each Palliative Care Service in Australia to be devoted to the provision of Palliative care in RACF and the teaching of the staff of RACF.

Recommendation 9. *That the Commonwealth funds a Community Nurse Practitioner, Palliative Care in every Specialist Palliative Care Service, classified as Level 3 by Palliative Care Australia, to be devoted to the provision of Palliative Care in RACFs, the teaching of palliative care practice to staff of RACFs (urban and rural) and for liaising with General Practitioners, Geriatricians and other Medical Specialists.*

e. The composition of the palliative care workforce, including:

(i) Its ability to meet the needs of the ageing population

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.[1] 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.[2] That figure is in accord with Royal College of Physicians (UK) recommendation of 2 FTE per 250,000 population.[3]

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. 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 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. 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 Palliative Care doctors, it is important to also recognise the importance of multidisciplinary teams, and to develop these in a balanced manner as resource centres.

Recommendation 10. *That Commonwealth policies support the ANZSPM position of having a minimum of 1.0 FTE Palliative Medicine Specialists per 100,000 population.*

(ii) The adequacy of workforce education and training requirements

A critical issue in the provision of Palliative Care is the historic fact that generations of doctors have received little or no education in Palliative Care and the care of the dying. It is only in the modern era that this has been begun to be addressed. This means that many doctors are inadequately equipped to deal with these issues. Education, therefore, at all levels from undergraduate to post-graduate is crucial to the provision of Palliative care in this country.

[1] 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.

[2] *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

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

e. The composition of the palliative care workforce, including:

(i) Its ability to meet the needs of the ageing population

Undergraduate

The amount of time allocated to Palliative Care in the undergraduate curriculum in Medical Faculties around Australia varies substantially. From negligible beginnings, there has been a slow increase in the number of hours allocated, but there is no uniform national standard. Prescribing such a standard presents difficulties in the local exercise of the autonomy of the development of medical curricula.

One important development in the quality of this education has been the development of an undergraduate curriculum in Palliative Care by the University of Queensland. They have developed high quality material to aid and educate medical and nursing students.

Recommendation 11. *That the Commonwealth funds the teaching of Palliative Care in all Medical Schools in Australia.*

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.

The consensus of doctors working in Palliative Medicine in Australia has been highly favourable to both the concept and the practicality of the PEPA program.

ANZSPM is delighted that the Commonwealth has committed to fund the PEPA program for the 2011-2014 period.

Recommendation 12. *That the Commonwealth continues to fund the PEPA program around Australia.*

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.

Accreditation of training positions is performed independently by the RACP (Royal Australasian College of Physicians) Palliative Medicine Education Committee. As such, there are more accredited positions than there are trainees. 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.

There is a need to support the development of a CALD (Culturally and Linguistically Diverse) training module for registrars training in Palliative Care Medicine.

Recommendation 13. *That the Commonwealth Government provides funding for accredited positions for training in Palliative Medicine.*

f. The adequacy of standards that apply to the provision of Palliative Care and application of the Standards for Providing Quality Care to All Australians.

ANZSPM endorses the standards in *Palliative Care Australia's* document: *Standards for Providing Quality Palliative Care for all Australians (4th edition)*[4].

g. Advance care planning, including…

(i) Avenues for individuals and carers to communicate with health care professionals about end-of-life care

For this term of reference, ANZSPM endorses *Palliative Care Australia's* submission to this inquiry.

(ii) National consistency in law and policy supporting advance care plans

Currently there is no uniform national legislation on Advance Care Planning. Each of the eight State and Territory jurisdictions has its own iteration – many have a statutory scheme, some do not have a relevant statute and the common law applies. The Commonwealth Government has the critical role in promoting a national legislative framework.

Recommendation 14. *That the Commonwealth Government instigates and promotes a national framework of legislation for Advance Care Planning that is consistent across all State and Territory jurisdictions.*

(iii) Scope for including advance care plans in personal electronic health records

Amongst others, there are two critical effects of the lack of uniformity in national advance care planning legislation. The first is the confusion that may lie within medical and hospital staff when people move across jurisdictional boundaries as to whether and to what extent Advance Care Plans apply. Also the reality is that an Advance Care Plan made in one location may never follow that person to another

[4] Accessible at www.palliativecare.org.au

location. For both of these reasons the idea of including Advance Care Plans in personally controlled electronic health records is sensible.

Whilst Advance Care planning does involve a multidisciplinary approach, doctors play a critical role. General practitioners or medical specialists are often involved in the initiation and completion of Advance Care Plans.

Recommendation 15. *That the Commonwealth does all within its capacity to facilitate the inclusion of Advance Care Plans in personally controlled electronic health records.*

h. The availability and funding of research, information and data about palliative care needs in Australia

ANZSPM supports the continued funding of the National Palliative Care Plan as it relates to research, information and data collection about palliative care in Australia.

See **Recommendation 1**.