Palliative Care New South Wales

Palliative Care NSW (PCNSW) is a small, not-for-profit NGO representing the interests of healthcare professionals who work in Palliative Care (in either a specialist or primary care capacity), people with a terminal illness and their carers.

**Our mission:**

To promote the delivery of high quality palliative care for all.

Quality palliative care is realised when strong networks exist between specialist palliative care providers, primary generalist and primary specialist and support care providers and the community, enabling them to work together to promote an optimal quality of life and a good death.

**Our role:**

- We provide informed input into the development of policy
- We provide information and education to our members
- We provide a range of information services to patients, their families and/or carers
- We raise awareness of palliative care and the Association within:
  - The community;
  - The health sector; and
  - Government
- We promote excellence in the provision of Palliative and End of Life Care in NSW.
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Executive Summary

Palliative Care NSW welcomes this opportunity to provide a submission to help inform the NSW State Budget in relation to Palliative Care.

Over the past 15 years Palliative Care has been moving from being only a cancer related service to becoming an appropriate service option for all non-cancer life-limiting illnesses. Specialist Palliative Care services are now required to provide stronger patient and service advocacy, consultancy to primary health care colleagues (in-patient and community) and significantly more skill enhancement and training. In addition services are now required to consult on patients with life-limiting illnesses such as Dementia, Renal Failure, Heart Failure, End Stage Respiratory Disease and many others.

These changes have made it more difficult for Palliative Care to fit neatly into one single funding model. It’s not just Aged Care. It’s not just Cancer Care. It’s not just sub-acute care. A Palliative Care approach should be available to anyone who is dying from any illness or disease in any setting.

Despite these expectations of Specialist Palliative Care services, the historical cancer based funding model has not been reviewed and amended to meet these increased and increasing demands. Modern Cancer treatments have seen an increase in the symptom burden during the palliative phase. More people are dying from end stage organ failure and dementia and management of these disease trajectories are significantly more complex. This necessitates more coordination of multi-disciplinary care – a role that falls to specialist Palliative Care services and the existing workforce does not meet the minimum requirements or specifications as recommended by Palliative Care Australia guidelines.

In rural and regional areas a significant number of services operate without formal agreements for specialist medical support: this is most often provided on a good will basis by fly-in/fly-out Palliative Care medical specialists from metropolitan services. This is not a sustainable model and needs to be reviewed.

Palliative Care NSW recommends that NSW Health moves to a new model of funding for Specialist Palliative Care services which encapsulates the changing demand pattern and changing service role, especially in the area of specialist consultancy advice for other care providers.

Palliative Care NSW has a number of other recommendations and these are summarised below. These will serve to deliver the intent of the NSW Palliative Care Strategic Framework (PD2010_003). We look forward to the opportunity to discuss these with government with a view to improving outcomes for all people in NSW who are dying and their families.

Linda Hansen
Executive Officer
Summary of Recommendations

1. **Improve equity of access to Specialist Palliative Care services throughout NSW**
   
   a. People in regional and remote areas of NSW do not have equal access to Palliative Care services
   
   b. People in metropolitan areas of NSW have variable access to Palliative Care Services
   
   c. People dying from cancer have better access to Palliative Care services than people dying from other illnesses

2. **Enhance the quality of life for people living with and dying from a terminal illness**
   
   a. Most people want to die at home
   
   b. Most people in NSW die in public hospitals

3. **Improve support for families and carers**
   
   a. Improve access to up-to-date information on supporting a person who needs palliative care - One Stop Information Point
   
   b. Improve access to grief and bereavement support

4. **Develop workforce capacity**
   
   a. Further develop the capacity of Specialist Palliative Care services
   
   b. Increase the availability of scholarships for the rural Specialist Palliative Care workforce
   
   c. Further develop capacity in the palliative approach in disability and aged care services
   
   d. Improve access to palliative care volunteers
Introduction

What is Palliative Care?

Palliative Care is an approach that improves the quality of life of patients and their families facing the challenges associated with life limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation).

Palliative Care is interdisciplinary care, delivered by coordinated medical, nursing, allied health and social services and integrating the physical, psychological, social and spiritual aspects of care. It recognises the patient and family as the unit of care, and respects the right of each patient to make informed choices about the care they receive. It offers, through a mixture of specialist and primary care providers, as well as community partnerships, a support system to help people live as actively and well as possible until death.

Palliative Care also plays an important role in helping the family cope during the patient’s illness and in their own bereavement.

The NSW Health Palliative Care Role Delineation Framework (GL2007_022) makes clear that palliative and end of life care can be provided by a range of health care professionals, with Specialist Palliative Care services playing an essential provider and supportive role. Palliative Care Services have been at the forefront of symptom management, supportive care, advance care planning and excellence in end of life care, focussing on quality of life and quality of death for some time in NSW, and PCNSW has seen a growing demand for the provision of services, and for information about Palliative Care.

Who can benefit from Palliative Care?

Palliative care is provided on a needs basis to people living with a life limiting illness, including children. It can be an adjunct to ongoing treatment and can be delivered from diagnosis to bereavement. There is no need to necessarily cease ongoing treatment for a life-limiting illness just because a person is accessing Palliative Care e.g. a cancer patient receiving Palliative Care may still be receiving treatment to extend their life through chemotherapy.

“We judge our worth by how we treat our sick and dying.”
Why improving the provision of Palliative Care is important to:

The people of NSW:

- The number of people aged 85+ is expected to increase by more than 56% between 2006 and 2016. Improvements in health care over recent decades have resulted in people living longer. However, they are living longer with more complex health issues e.g. dementia, diabetes, cardiovascular, respiratory and musculoskeletal problems. Caring for this greater number of older people with increasingly complex healthcare needs is becoming increasingly costly;
- The World Health Organisation predicts that by 2020 chronic disease (i.e. an illness that is long-lasting or recurrent such as diabetes, arthritis, some types of heart disease or cancer) will account for almost 75% of all deaths; this trend is reflected in Australia;
- The demand for Palliative Care services is expected to increase by at least 4.6% annually in NSW.
- Over 70,000 NSW citizens die each year

Palliative Care enhances quality of life for people dying of a terminal illness and their families:

- Physically, by relieving pain and discomfort and by controlling other symptoms such as nausea, constipation and lethargy which can be associated with a life-limiting illness, or a side effect of the treatment thereof;
- Mentally, by helping to alleviate the fear associated with death and dying, and by treating people with dignity and respect during these difficult times, patients, carers and their families can arrive at a sense of acceptance, confident that they will live well until they die;
- Spiritually – people’s needs vary widely as death approaches, but they commonly include the need to understand what is happening, resolve issues with family and friends, achieve a sense of completion emotionally and spiritually, and come to terms with significant life changes;
- Socially, by reducing feelings of isolation through the engagement of volunteers and local support networks.

The Health System:

Through ensuring Palliative Care provision receives a valid share of Commonwealth sub-acute monies together with an improved share of state funds, pressure on the acute care system can be supported in three ways:

- Provision of sub-acute beds for Palliative Care enables transfer of appropriate patients away from acute beds;
- improved resources for community palliative care increases community (non-hospital) stays;
- Acute inpatient Palliative Care hospital consultation teams facilitate discharge or transfer out of the acute care system where possible, as well as reducing the use of clinically futile treatments.
Improved access to palliative care services has the potential to improve both the effectiveness and the efficiency of healthcare services for the dying, and the healthcare system as a whole:

**Efficiency** – by avoiding inappropriate and preventable admissions to emergency and acute services, thus, a more cost-effective use of health resources. Further, by minimising or avoiding investigations, treatments and procedures that offer no improvement in quality of life.

**Effectiveness** – by providing better outcomes for patients and their families.

A conservative analysis of available data indicates that the cost of palliative care services can be between 50% and 300% less expensive than care in an acute bed or intensive care bed. The estimated costs of this can be broken down as follows:

- An ICU Bed costs around $4000 per patient, per day, or $1.5M per bed per year, according to Professor Ken Hillman, who says “at least half of my ICU patients shouldn’t be there...Dying in ICU is a very cruel, awful way to die.” (Hillman, K. “Address at Launch of National Palliative Care Week 2010.” Palliative Care Australia, Parliament House, 26 May 2010);
- An Acute Hospital Bed costs >$1100 per day on average;
- Ambulance callouts cost between $300 and $5000;
- The cost of Palliative Care varies depending on where it is provided and the particular needs of the patient, but it has been broadly estimated at between $200 per day (for a patient in an Aged Care Facility) and $600 per day (for an Inpatient Palliative Care Facility).

Palliative Care can play a pivotal role in the broader health system in achieving the goals of the NSW Health State Plan and ‘Caring Together’ – The Health Action Plan for NSW. A greater awareness of, and investment in Palliative Care would help address several of the key strategies in both of these documents, including:

- *Make prevention everybody’s business* – Palliative Care can help prevent the types of distressing, often lengthy, costly and unnecessary acute hospital admissions at the end of a patient’s life;

- *Create better experiences for people using health services* – One of the principal aims of Palliative Care is to enhance quality of life, and create better experiences for patients and their families. Studies in the US have shown that families of patients who have undergone Palliative Care and have received bereavement counselling have much better experiences during the terminal phase of their loved one’s illness, have an acceptance of death and lower rates of depression 6 months after the death. A further study of patients receiving treatment for metastatic lung cancer who also received early palliative care support may live longer and with better quality of life, including decreased depression; *(NEMJ 363(8):733-42)*

- *Make smart choices about the costs and benefits of health services* – Investing more in Palliative Care Services has the double benefit of achieving significant financial savings, and freeing up acute hospital beds.

The value adding, cost beneficial nature of Palliative Care Services has only recently been recognised overseas. In Oregon, where Palliative Care (or Hospice Care) is much better resourced and utilised than in other US states, palliative care patients in the last two years of life have, when compared to patients across the USA:
• Approximately half the number of days in ICU;
• Less than half the number of Medical Specialist visits;
• Nearly 25% (or over $US10,000) less spent on their care in terms of Medicare reimbursements (Dartmouth Atlas of Healthcare).

The economic benefits of Palliative Care have been further supported by a study of 90,826 US cancer patients enrolled in a Hospice (palliative care) program, comparing those who “disenrolled” with those who remained enrolled. It was found that those who left the Hospice program:

• more frequently died in the hospital;
• were more likely to be admitted to the hospital as an inpatient and spent almost three times as many days in the hospital once admitted;
• were hospitalized within 48 hours of hospice disenrollment in twenty five percent of cases. (J Clin Oncol 28:4371-4375)

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**Case Study – Saving Acute Care Resources**

Andrea is 79 and has metastasised breast cancer in her bones. She is being treated with chemotherapy in an attempt to extend her life, but the cancer has spread so far it is not curable.

Andrea is also a Palliative Care patient, as her illness is terminal. Her symptoms are becoming more complex, particularly as an elderly person with other health issues.

Andrea has just been released from hospital following a bad bleed in her stomach. That night, at home, she feels dizzy and nauseous. Her daughter Jill calls the Palliative Care team, rather than an ambulance, which would otherwise have been her only option. Andrea is too frail and ill for Jill to take her to hospital.

A Palliative Care nurse arrives within an hour, and identifies that Andrea is still on high blood pressure medication, even though (with her significant weight loss) she now has low blood pressure.

The Nurse calls Andrea’s GP on the “after hours” call line and they agree that Andrea should immediately be taken off her blood pressure medication. The nurse settles Andrea, reassures her daughter but notes that they should call again if the symptoms worsen.

Andrea’s symptoms ease and she stays at home and recovers well from the stomach bleed.

The support of the Palliative care system:

• Provided extraordinary reassurance to Andrea and her daughter;
• Allowed Andrea to stay at home, comfortable in her own bed;
• Prevented the unnecessary use and cost of an ambulance;
• Prevented the unnecessary use and cost of acute services at Accident and Emergency;
• Allowed Andrea’s medical files at home to be kept up to date.
Palliative Care New South Wales Recommendations

An additional $10M per year to:

1. Improve equity of access to Specialist Palliative Care services throughout NSW

   a. People in regional and remote areas of NSW do not have equal access to Palliative Care Services

   b. People in metropolitan areas of NSW have variable access to Palliative Care Services

      Whether or not a person has access to Specialist Palliative Care services depends on their location and their disease. People in some parts of NSW have no access to Specialist Palliative Care services. Outside of the Greater Sydney Metropolitan Area (encompassing Newcastle and Wollongong) there is only one Specialist Palliative Care doctor in NSW. That Specialist works in Lismore.

      To address this inequity, pathways for appropriate access to Specialist Palliative Care services need to be identified and resourced. This can be achieved by creating common referral criteria to adequately staffed multidisciplinary teams.

      Action Increase in recurrent funding of $6.25 million for Specialist Palliative Care services to allow capacity to meet demand across all care settings (including hospital consultation teams).

      For rural and regional areas without Specialist Palliative Care doctors, fly-in and telemedicine specialist support needs to be made more readily available. The funding of this type of service needs to be reviewed to meet real demand.

      Action Review and adjust the existing funding arrangements to better meet costs of fly-in and telemedicine support from metropolitan level 3 services - up to $1.5 million.

   c. People dying from Cancer have better access to Palliative Care Services than people dying from other illnesses

      It is recognised that people with end stage diseases other than cancer have palliative and end of life care needs that are appropriate for referral to Specialist Palliative Care services. However, palliative care service funding models are historically based only people dying from cancer. Specialist Palliative Care services require real growth in capacity to meet the existing and future demand from people with other life-limiting conditions such as heart disease, respiratory illnesses and dementia.
2. **Enhance the quality of life for people living with and dying from a terminal illness**

Quality symptom management and supportive care delivered in an individualised manner contributes substantially to overall quality of life. Additional supports, especially volunteer services, provide further contributions to quality of life outcomes. Respect for individual care preferences, including place of care, further add to perceived quality of life.

**a. Most people want to die at home**

Community Palliative Care teams can provide support for patients to die at home and for their families. Having this support can make the experience of dying less distressing for the patient and their loved ones, while also relieving some of the pressure on the acute healthcare system. However, this in-home service is not universally available and after-hours access to specialist advice is a challenge for many services. For Cancer related deaths in NSW 63% occur in public hospitals while 15%-20% occur at home (NSW Cancer Institute).

There are important regulatory reforms that can facilitate a person dying at home, with little or no cost to the health care system. NSW Health’s Policy Directive, “Assessment of the Extinction of Life and Certification of Death” (Circular 99/92) is in urgent need of review to address confusion around legal obligations around the issuing of a death certificate when people die at home.

NSW Health policy aims to support the choice of palliative care patients and their families to stay in their homes (where practicable) during the final stages of life. Unfortunately, palliative care professionals are encountering confusion about the legal obligations of medical staff to report a death to the police. This is particularly the case where a doctor is not immediately available to attend to certify death. In these circumstances, rather than arranging for the body to be transferred to a holding area or mortuary for later certification of death, some staff believe it is their obligation to report the death to the police.

The attendance of the police, and the potential for the home to become a “crime scene”, creates significant distress for families and carers. Palliative Care NSW understands that the practice of calling police to attend the death of a terminally ill patient may be frustrating NSW Health’s broader policy objective of facilitating the care of people, where appropriate, in non-institutional settings.

Palliative Care NSW has produced a Discussion Paper outlining these issues.

**Action**

Commitment by NSW Health to review and reissue the revised policies to enable people to choose to die at home, such as Assessment of Extinction of Life.
b. Most people in NSW die in public hospitals

Even if PCNSW’s vision for increased community-based palliative care is realised, the majority of deaths will continue to occur in NSW public hospitals for the foreseeable future. The need for Palliative Care Hospital Consultation teams in all major NSW public hospitals is well established but not consistently addressed or executed. NSW public hospitals require ready access to these teams on a regular and ongoing basis. This will support NSW public hospitals to become more “Dying Friendly” for those whose end of life occurs in these facilities.

Action

Commitment by NSW Health to ensuring all NSW Public Hospitals without Specialist Palliative Care services onsite have high level access to Palliative Care Hospital Consultation Teams with the goal of a multidisciplinary Palliative Care Consultation Team in every major hospital in metropolitan and regional NSW by 2013.

3. Improve support for families and carers

a. Improve access to up-to-date information on supporting a person who needs palliative care - One Stop Information Point

Like death and dying, Palliative Care can be a mysterious and confronting realm for many people, who do not give much thought to these matters until they are sprung upon them. By this point, they are often in a state of distress.

Caring for someone in the end stage of life is a task that many in our community ideally would like to undertake, but there are many impediments and challenges in doing so. There is a need to grow capacity at both the community and individual carer level to maximise support for carers in an end of life context. PCNSW believes that a state-wide series of carer-centred materials needs to be developed and made available to the NSW community.

Action

Development of a state-wide Palliative Care training resource for carers in NSW. Estimated cost $120,000.

PCNSW believes that a central contact that can assist individuals, their carers and families with information about accessing palliative care, building local networks of support, preparing Advance Care Directives, and other end of life planning, will ease this burden for NSW citizens. This is a natural extension of the current role of Palliative Care NSW.

Action

Recurrent funding of $400,000 per annum to establish and operate a state-wide Palliative Care Information Service.
b. **Improve access to grief and bereavement support**

Many palliative care services do not have a bereavement counselling service to support patients and their families through the inevitable grief and bereavement that comes with the end of life experience. This support should be provided to all who need to prepare for the realities of grief and loss, along with further counselling to grieving relatives after their loved one has died. Appropriate support for bereaved family members has been shown to reduce the possibility of poor health outcomes, such as depression.

**Action**  
PCNSW would undertake a review of existing grief and bereavement support services with a view to establishing a more structured approach to bereavement services, as well as improving public awareness of, and access to, bereavement care. Estimated cost $50,000.

4. **Develop workforce capacity**

Across NSW there are gaps in Specialist Palliative Care Medical, Nursing and Allied Health personnel workforce capacity. Applying the NSW Palliative Care Role delineation framework (GL2007_022) across all Local Health Networks (LHNs), each metropolitan LHN requires a level 3 Specialist Palliative Care Service, each regional LHN requires a minimum level 2 service with linkages to a level 3, and each rural LHN requires a minimum level 1 service.

a. **Further develop the capacity of Specialist Palliative Care services**

Existing shortages in the Specialist Palliative Care workforce require a coordinated response from NSW and Commonwealth fund holders. Funding is sought for both training and employment of Palliative Medicine Staff Specialists, Palliative Care Nurse Practitioners, and Allied Health Practitioners, for both Hospital and Community sectors.

**Action**  
Specific and recurrent funding of $1.5 million to encourage post graduate training in Palliative Medicine and Palliative Care for nurses and allied health workers linked to funded new specialist Palliative Care positions.

b. **Increase the availability of scholarships for the rural specialist palliative care workforce**

Specialist workforce shortages in rural and regional areas of NSW are the significant contributor to inequity of access to specialist palliative care for these populations. Rural / regional targeted training scholarships are a strategy to address this problem.

**Action**  
Establishment of Rural Palliative Care Scholarships for specialist training in the fields of Medicine, Nursing, Social Work and other Allied Health disciplines.
c. **Further develop capacity in the Palliative Approach in disability and aged care services**

Palliative Care should be everyone’s business. Health professionals throughout the community and the hospital sector should be able to apply the Palliative Approach to their patients with life-limiting illnesses, with referral to Specialist Palliative Care services as required.

Adequately resourced Palliative Care services will have capacity to support the development of primary palliative care capability in disability and aged care sectors. Prevention of inappropriate acute hospital presentations are one of the intended outcomes of this strategy.

**Action**  
Inclusion of a substantial Palliative Care component in all undergraduate health professionals training.

**Action**  
Specific and recurrent funding of $150,000 per annum for a Palliative Care Educator to provide education and training to staff in aged care services and other primary health care providers throughout NSW.

d. **Improve access to palliative care volunteers**

Palliative Care Volunteers offer compassionate, ‘neutral’ support to those living with a terminal illness. They complement and enhance the care being provided by professional staff both in the Hospital and in the Community. Voluntary work is integral to the provision of Palliative Care.

Over recent years, paid Volunteer Coordinator positions for palliative care have been cut by NSW Health, resulting in additional challenges in training and managing volunteers for many services. Funding for the development of a core training package for Palliative Care Volunteers will help to reduce the burden on stretched services. PCNSW presents as an agency capable of developing this material and overseeing its’ implementation and maintenance in NSW.

**Action**  
Development of a state wide Palliative Care Volunteer training resource to support existing services, especially those in non-metropolitan areas. Estimated cost $100,000.

**Action**  
Conducting of annual volunteer training courses in rural and regional areas. Estimated cost $80,000 per annum.
Conclusion

Palliative Care NSW would like to thank the NSW Government for the opportunity to make this submission for the 2011-12 Budget. Palliative Care NSW believes that 2011-12 presents an opportunity to improve and increase support and services to people in NSW who are living with a life-limiting illness, their families and carers.

Palliative Care NSW looks forward to achieving equal access to Palliative Care for all people in NSW who are dying and enabling them to more frequently die in the place of their choosing.