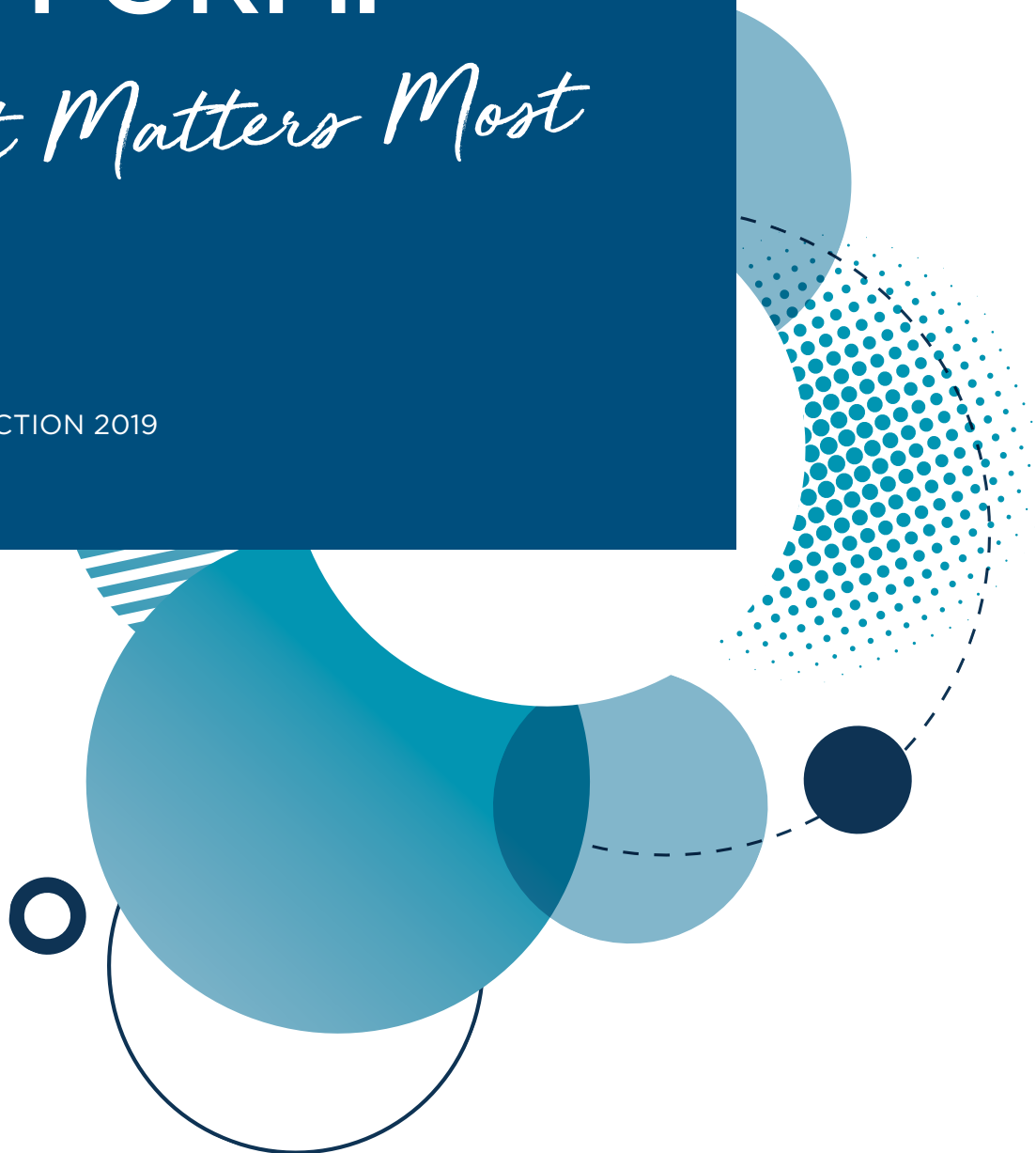


ELECTION PLATFORM:

What Matters Most

NSW STATE ELECTION 2019



Palliative Care
NEW SOUTH WALES

MESSAGE FROM THE PRESIDENT

What Matters Most

When we talk about 'What Matters Most' in Palliative Care, we are talking about one of the most important times in a person's life. What Matters Most to a person as they approach and reach the end of their life? What Matters Most to the family and friends of that person? What Matters Most to the people providing care to that person and their family?

What Matters Most is the knowledge that their needs and concerns will be addressed by a system built to support them. How do we make sure that everyone involved in a dying person's life is an active participant in that supportive system?

We need to build a **Palliative Care 'Culture'** in New South Wales.

The NSW Government has taken very welcome steps to ensuring that the people of NSW have access to quality care as they approach and reach the end of their lives. We welcome the injection of funds and the focus of NSW Health on palliative care in this state.

There is more to be done. The focus on dying at home means that there is a renewed need to ensure community support for carers and family members through education, online portals and volunteers. With centralised expertise and support to Local Health Districts through the Palliative Care Volunteer Support Programme, volunteering in palliative care has greatly improved support for patients and carers, particularly in the community setting. Grief and bereavement support in palliative care is an area with potential for state-wide system improvement, including better equity and access to services providing practical support and counselling to bereaved carers. Improvements are required in providing quality end of life care in NSW hospitals, with a large number of people still dying in hospitals, or others preferring not to die in their homes. Access to quality end of life care should be available regardless of a person's preferred place of death. Capital funding for improved infrastructure such as dedicated palliative care units, dedicated beds and non-acute 'environments' are also a priority. Data in end of life care often lacks socialised context but the social dimension of an individual's life is a predictor of their end of life experience and this suggests the need for a public health approach to palliative care to supplement the primary and secondary approaches.

What Matters Most is that the people of NSW are able to access quality palliative and end of life care and support: the right care at the right time in the right place.

Palliative Care NSW is well positioned to take a lead role, in partnership with Government and health providers, to develop systems that will build a Palliative Care culture that meets the needs of the people of NSW.



Professor Deb Parker

President, Palliative Care NSW

INTRODUCTION

Palliative Care NSW (PCNSW) is a 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 life-limiting illness, and their carers. We are the peak body for Palliative Care in NSW.

Palliative Care NSW members and community

PCNSW is part of a professional and compassionate health community. We support our professional community and the general community with events and educational opportunities:

- National Palliative Care Week events
- Professional Education Day
- Community Forums around the state
- Information and support through online portals and communications
- Biennial state conference
- Palliative Care Volunteer Services Support Programme.

Our vision

To be the peak body and leading voice in NSW promoting quality Palliative Care for all.

Quality palliative care

Quality palliative care is realised when strong networks exist between specialist Palliative Care providers, primary generalists and primary specialists, support services and the community, enabling them to work together to promote optimal quality of life and good end of life care.

Our mission

Promote awareness of palliative care through leadership and through education and networks for the health workforce and broader NSW community

WHY IMPROVING PALLIATIVE CARE IS IMPORTANT:

To the people of NSW:

- Improvements in health care over recent decades have resulted in people living longer. However, they are living longer with more complex and chronic health issues e.g. dementia, diabetes, cancer, cardiovascular, respiratory, musculoskeletal and progressive neurological conditions. Caring for this growing number of older people with complex healthcare needs is becoming increasingly costly.
- In 2016, the number of people aged over 65 in NSW was 1,217,261 (16%) out of a total population of 7,739,274. By 2036, this is estimated to grow to 2,085,078 (21%) out of 9,925,548.
- 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.
- Almost 54,000 NSW citizens died in 2015 – 34% of the total number of deaths in Australia. Of these, the vast majority died from ischaemic heart disease and dementia, yet palliative care remains very focused on people with a cancer diagnosis, with death from lung cancer rated as the only the 4th leading cause of death.
- Community members are becoming increasingly aware of their rights as health care consumers, and justly, of their right to be able to access palliative care services. Palliative Care services need to be able to grow in line with community expectations for quality palliative and end of life care regardless of diagnosis, location or setting, including bereavement support.

To the Health System:

- The national costs of hospital and residential aged care services in the last year of life have been estimated to be in the order of \$2.4 billion and \$2.3 billion respectively, which translates to \$768M worth of hospital care alone in NSW. (Swerissen H & Duckett S (2014) 'Dying Well').
- Funds for increased specialist palliative care services will help meet the increasing demands, needs and community expectations especially in the area of specialist consultancy and advice for primary care providers across all settings. Improved access to specialist 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.
- Adopting innovative, sustainable and outcome-focused models of care across all settings, using specialist palliative care expertise, helps to build capacity in generalist and primary health care settings.
- Ensuring that regardless of a person's palliative care diagnosis, location, setting or preferred place of death, they can access safe and quality palliative and end of life care is fundamental to building a strong palliative care culture within the health sector.

WHAT IS NEEDED TO:

Build a Palliative Care Culture within the health sector

- All providers should have the capacity to implement a palliative approach to care for people with a life-limiting illness.
- Good linkages and referral pathways within and between service providers in relation to palliative care.
- Awareness of the palliative care services available to people in their community.
- Community networks that support each other to understand and deal with loss, ageing, death and grief as part of life.
- Access to specialist palliative care consultation teams across all NSW health facilities through hub and spoke models of service delivery.

Increase “death literacy” within the community

- Enhance community understanding of dying, death, grief, bereavement and loss whilst building community capacity to support a compassionate public health approach to death and bereavement.
- Initiate programs to encourage early conversations about advance care planning and death.

Educate: Patients, families and carers

- Better inform consumers about how, what, where and when they can access palliative care services and resources.
- Provide a ‘How to’ navigate the system of palliative care referrals and the network of services.
- Increased multidisciplinary support for carers providing care for a person at home.


Integrate Palliative Care across all settings

- Support for Palliative Care NSW to assist palliative care providers, specialists and generalists, RACFs allied health, Aboriginal Health, CALD communities, volunteers and other services to provide better integrated palliative care.
- Ensure equity of access to services across social/cultural/geographical barriers.
- Address state-wide workforce challenges of lack of skilled specialist medical and nursing palliative care health professionals
- Ensure palliative care health professionals are adequately supported and represented professionally and ethically .

All providers should have the capacity to implement a palliative approach to care for people with a life-limiting illness.

OUTCOMES:

- People will have access to palliative care services regardless of diagnosis, location, or setting.
- Primary care health professionals will have capacity to provide quality end-of-life care, and have prompts and referral pathways to specialist Palliative Care as required.
- Patients will be supported in their choice to be cared for and die in their preferred place, and will be able to receive quality palliative care regardless of setting.
- Numbers of expected deaths in acute hospitals will decrease as staff are educated in “identifying dying”, with patients transferred to their preferred place of care and supported in the community and generalist settings e.g. RACFs.
- Carers are better supported with improved access to community services, after-hours services, respite and advice services.
- Volunteers and Volunteer Managers across the state are fully supported and educated to provide essential support to palliative care patients and carers.
- Improved access to palliative care by vulnerable groups including but not limited to, CALD groups, Aboriginal and Torres Strait Islander people, people with disabilities, homeless people and people in Justice Health.
- Specialist Palliative Care Services will be resourced with adequate numbers of well-trained staff to enable them to respond to the growing number of patients and increasingly complex management needs across settings.
- More efficient and less costly delivery of health services through provision of care in the community setting.



People will have access to palliative care services regardless of diagnosis, location, or setting.

RECOMMENDATIONS:

Our recommendations to help build a Palliative Care Culture in NSW are based on the Guiding Principles of the National Palliative Care Strategy:

- Palliative Care is person-centred care
- Death is a part of life
- Carers are valued and receive the care they need
- Care is accessible
- Everyone has a role to play in Palliative Care
- Care is high quality and evidence-based.

We also take into account the NSW Auditor General's report and the work currently underway within the Ministry of Health to develop a Framework for Palliative Care in NSW.

1 Recommendation 1

That palliative care bereavement services in each LHD receive recurrent funding. Recent funding for a Psychologist/Social worker for each LHD is time limited to a three year funding round. The need for dedicated palliative care bereavement services is only going to increase with predicted growth in patient numbers, and with increased medical, social and family complexities. Estimated cost \$120,000 pa per service.

2 Recommendation 2

That Palliative Care NSW be funded to develop a state-wide Palliative Care PallCare Navigator online service for NSW in order to improve access for carers to education, information and support. People will receive guidance and navigation through the health system from the point of referral to accessing resources for caring in the home. \$130,000 pa.

3 Recommendation 3

That Palliative Care NSW be funded to develop a state-wide community engagement programme to raise awareness about palliative care and end of life issues. This programme will increase community awareness about palliative care and service availability, build community capacity in dealing with issues of dying, death, bereavement and to encourage people to discuss, clarify and document their advance care wishes. \$400,000 pa.

3 Recommendation 4

As most people in NSW with a life limiting illness or with an expected death currently die in an acute public hospital, PCNSW calls for a commitment to improve the quality and safety of dying in these facilities. That a hub and spoke model be developed and funded whereby all hospitals in NSW can access Specialist Palliative Care consultations and advice 7 days per week and after hours for complex end of life management, utilising a range of communication modalities (face to face or virtual). Cost is dependent on staff mix required and telehealth options. Estimated cost: \$20m pa.

5 Recommendation 5

That Palliative Care NSW be funded to work with NSW Primary Health Networks (PHNs) to establish State-wide referral prompts and palliative care information for integration into electronic Health Pathways. Estimated cost \$200,000 over three years.

6 Recommendation 6

That NSW Health continue to fund the Volunteer Services Support Program (managed by Palliative Care NSW) to ensure that Palliative Care Volunteers and Volunteer Managers across the state are fully supported and educated. Volunteers improve the palliative care experience of all patients and carers, while community-based volunteers are pivotal in supporting patients and carers in the home. Cost \$400,000 pa.

7 Recommendation 7

That NSW Health, along with key partners, investigate and develop models of care for implementation in RACFs that support residents remaining 'at home' to die by providing high quality end of life care. This will reduce unnecessary hospital transfers for futile interventions at end of life.

8 Recommendation 8

That NSW Health continue to support, and broaden education initiatives for health professionals through LHDs and Palliative Care NSW. Education to specialist and generalists related to palliative care, communication, advance care planning conversations and bereavement will help build a skilled workforce to deal with increasing demands.

MORE INFORMATION:

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