

2024-25

PCNSW Pre-Budget Submission 2024-25

*Palliative Care -
An essential strategy for a
critical moment in time*



Palliative Care
NEW SOUTH WALES

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PALLIATIVE CARE NSW

Palliative Care NSW Inc (PCNSW) is the peak body for palliative care in NSW. For over 40 years PCNSW has been representing the interests of health care professionals, people with life-limiting illness and their carers and families, and the community. We advocate for a future where all people in NSW, wherever they live, have access to quality palliative care support and services.

PCNSW is the trusted source of information and support for both health professionals and the community across NSW. Quality palliative care is realised when strong networks exist between specialist palliative care providers, primary generalists and specialists, allied health, support care providers and the community, enabling them to work together to promote an optimal quality of life, a good death, and grief and bereavement support.

WHAT IS PALLIATIVE CARE?

Palliative care aims to improve the quality of life for people living with a life-limiting illness by minimising illness-related suffering. A progressive or life-limiting illness means an illness that is going to get worse, and which will eventually shorten the person's life. There are many life-limiting illnesses such as cancer, motor neurone disease, end-stage heart failure, end-stage lung or kidney disease and dementia.

Palliative care is a holistic public health-based approach to individual needs that treats symptoms which are physical, emotional, spiritual, and social. A range of health professionals play their role, as well as members of the community. Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support.

EXECUTIVE SUMMARY

This Pre-Budget submission from PCNSW emphasises the critical need for enhanced funding, support and resources in palliative care services across New South Wales (NSW). Through engagement with stakeholders including patients, families, carers, and healthcare professionals, PCNSW highlights several key areas for consideration in the upcoming budget allocation:

1. INCREASE FUNDING TO SUPPORT DEDICATED INPATIENT PALLIATIVE CARE SERVICES ACROSS NSW:

As the population ages and chronic health conditions become more prevalent, the demand for specialist palliative care continues to increase. While there is a strong preference in the community for end-of-life care at home, a proportion of patients and families will prioritise a hospital setting for palliative care due to cultural, social and clinical needs. Current limitations in community-based palliative care services will also mean a hospital setting is the only viable option for many patients and families where at home care is not appropriate. The increasing number of people living alone, as well as elderly codependent couples necessitates the availability of inpatient palliative care services to be available, when staying at home is not possible.

PCNSW recommends the establishment and adequate ongoing funding of inpatient palliative care services such as dedicated units or wards in all Tertiary hospitals and expanding this to provide dedicated palliative care beds in hospitals in regional areas to ensure patients have access to high quality palliative care when and where they need it.

2. RECRUITMENT AND RETENTION OF PALLIATIVE CARE STAFF:

With demand for palliative care expected to increase by 50% by 2050, there is an urgent need to address staffing shortages. Funding and resources for increased palliative care clinicians continues to be inadequate. PCNSW advocates for expanding initiatives such as the Tertiary Health Study Subsidies program and introducing paid compulsory work placements as part of all undergraduate degrees in health to attract and retain healthcare workers in palliative care.

3. ENSURE ACCESSIBILITY OF PALLIATIVE CARE SUPPORT FOR THOSE UNDER THE AGE OF 65 WITH A DISABILITY ASSOCIATED WITH A LIFE-LIMITING ILLNESS (I.E. IMPROVE THE NDIS-PALLIATIVE CARE INTERFACE).

There is an immediate need to provide people under 65 living with a disability associated with a life-limiting illness access to appropriate non-clinical palliative care support to allow them to remain at home for as long as possible. PCNSW acknowledges the challenges in navigating the interface between disability, health, and aged care systems. Recommendations include clearer delineation of responsibilities between state and federal governments and improved funding of accessible support for this demographic.

4. ENHANCING THE HEALTH-AGED CARE INTERFACE:

PCNSW supports continued investment in shared funding models like the Comprehensive Palliative Care in Aged Care Measure to improve collaboration between health and aged care systems. Additionally, scalable programs focusing on hospital avoidance, such as specialist Palliative Care consultation services, the Geriatric Flying Squad, the GRACE program and virtual care resources, warrant further funding and expansion.

5. BOOSTING PALLIATIVE CARE VOLUNTEER SERVICES:

Palliative Care Volunteers play a crucial role in providing psychosocial support and respite care, yet funding and resources for volunteer services remain insufficient, especially in rural and regional areas. PCNSW calls for dedicated Palliative Care Volunteer Manager positions and additional funding to bridge existing gaps across Local Health Districts (LHDs).

Addressing these priorities aligns not only with the commitment to improving end-of-life care but also with economic and social imperatives. There is a need for immediate and continued investment in this area, both to meet the changing demographic profile and health needs of NSW residents, and because equitable access to timely palliative care is essential to a high-performing and cost-efficient health system. By investing in palliative care, NSW can enhance patient outcomes, alleviate pressure on healthcare systems, and ensure equitable access to quality care for all residents of NSW.

INTRODUCTION

This Pre-Budget submission follows engagement and consultation with PCNSW members, affiliated networks, services and other peak organisations who have supported patients, families and carers across multiple palliative care settings. Our members represent nurses, residential aged care workers, allied health workers, Palliative Care specialist nurses and doctors and General Practitioners, as well as consumers representing those with lived carer experience.

The current crises in healthcare and aged care have shone a light on where more work is needed to ensure everyone in NSW has access to high quality palliative care when and where they need it. Because palliative care focuses on the highest need and highest cost patient segment, specialist palliative care is particularly relevant as an essential strategy for population health management (Casarett DS, Teno J., 2016). The priority for palliative care in NSW is to ensure people are informed about their end-of-life care options, and that they can access appropriate care wherever they are and in a location that best meets their wishes and needs.

Investing in palliative care does not just have a positive impact on those with a life limiting illness, their families and carers, it also has a positive impact on the broader healthcare system and in particular can ease some of the pinch points in the acute care system currently being felt. There is now high-quality evidence that shows that people with life-limiting illnesses who receive palliative care at home and in the community have fewer hospital admissions, shorter stays in hospital when admitted, spend less time in Emergency Departments and Intensive Care Units, and use ambulance services less frequently. Every dollar invested in home and community based palliative care delivers a 100% return on investment (KPMG, 2020). **Continued investment in home and community based palliative care and staff must remain a priority.**

A systemic review of 14 current research studies currently being undertaken by the University of Melbourne demonstrates that palliative care can be highly cost-effective when compared to ‘usual care’ provided to patients with life-limiting illnesses. Lead Researcher, Associate Professor Chris Schilling concludes that “There is a misconception about the value of palliative care, yet the health economics of palliative care are strong”. PCNSW also shares this view and supports the current Special Commission of Inquiry into Healthcare Funding to improve how palliative care is delivered in public hospitals and community settings (The Special Commission of Inquiry into Healthcare Funding, 2024).

As our population ages and people live longer with more chronic health conditions, the demand for Palliative Care will likewise continue to grow. The Intergenerational Report 2023 (Commonwealth of Australia, 2023) showed that the number of Australians aged 65 and over will more than double and the number aged 85 and over will more than triple over the next 40 years. The number of centenarians is expected to increase six-fold. Aged care and specialist palliative care need to work cohesively together to provide our ageing population with choices and high-quality care.

PCNSW acknowledges that the NSW Government prioritised the recruitment and retention of nurses in general across the state, however, more must be done to ensure there are adequate numbers of tertiary educated specialist palliative care nurses to effectively meet the needs of the ageing population in NSW.

All residents of NSW should have access to the best possible end of life and palliative care – no matter where they live, their condition, age or who they are. (NSW Ministry of Health, 2019). This will require a solution that goes beyond staffing levels and addresses issues such as the intersections of aged care, disability care and death literacy within the broader community. Alternative care and funding models, that are flexible and ingenious will be required moving forward if palliative care is to be truly equitable.

Recently there have been reports of increasing numbers of people under 65 who have disabilities linked to a life-limiting illness that are unable to access the daily living supports they need to remain comfortably at home at the end of life (Palliative Care Australia, 2024). The lack of coordination between aged care, disability care and palliative care means people are often passed from one agency to another during one of the most stressful times of their lives. The dichotomy of State and Federal responsibilities in this space must be addressed, and PCNSW would like to see a more streamlined solution to accessing care for this group of people.

Palliative Care Volunteers serve as pillars of support within the palliative care landscape, offering invaluable psychosocial assistance and respite care to individuals navigating terminal illnesses and their carers. Despite the indispensable role these volunteers play, funding and resources allocated to bolster volunteer services remain insufficient, particularly in rural and regional areas where access to palliative care resources is already limited.

Addressing these challenges not only reflects a moral imperative but also promises substantial economic and social benefits for both current and future generations. By reducing reliance on emergency department services for end-of-life care, healthcare costs can be considerably mitigated, easing the strain on already overburdened healthcare systems. Moreover, by fostering a culture of community-based care and support with the ability to access inpatient specialist support if and when needed, individuals living with life-limiting-illnesses can experience enhanced quality of life and dignity while families receive the necessary support to navigate the complexities of caregiving.

November 2023 marked a significant change in NSW with the implementation of the Voluntary Assisted Dying (VAD) Legislation. Moving forward, it remains crucial that an individual's choice to explore VAD should never be a choice based on a lack of knowledge and access to specialist palliative care. Geographically equitable access to palliative care has yet to be achieved across NSW. As VAD is not part of palliative care or end-of-life care it is essential that Palliative Care and End-of-Life Care funding is always separate from VAD funding and be clearly delineated.

PCNSW hopes that supporting people and their families living with a life-limiting illness, healthcare professionals, volunteers, carers and communities will continue to be a priority for the NSW Government in this 2024-25 Budget.

KEY RECOMMENDATIONS

INCREASE FUNDING TO SUPPORT DEDICATED INPATIENT PALLIATIVE CARE SERVICES ACROSS NSW

PCNSW recognise the NSW Government's current commitment of the \$93 million World Class End of Life Care program to redevelop and enhance palliative care units across the state with five hospitals to benefit from an expansion of palliative care services and units. This commitment needs to expand to more hospitals across NSW to meet growing demand.

Despite around 70% of people, when asked, saying they would prefer to die at home, most of these deaths (51%) occur in hospital (Swerinsen, H and Duckett S, 2014). In the last week of life, preference for home care often can decrease due to complex palliative care needs and family preferences. Each person's care should be based on assessment and care plans that are regularly reviewed and updated as needs and preferences change (NSW Ministry of Health, End of Life and Palliative Care Framework 2019). When management of symptoms is complex, or patients and families decide they are unable to manage at home - access to specialist palliative care in an inpatient setting provides significant comfort and support. National PCOC data (Eagar, et.al, 2020) confirm this with 74% patients being admitted to hospital in the unstable or deteriorating phase. Without a significant increase in funding and resources, Community nursing cannot support patients 24/7, and in cases where people with a life-limiting illness are living alone, there are very few options other than to be cared for in a hospital setting. Australian Bureau of Statistics (2016-2041) data shows that by 2041 there will be approximately 1.2 million people living alone in NSW. This is a significant increase from 71,4419 NSW residents living alone in 2016. Models of care will need to adapt to this changing and increasing need.

Dedicated palliative care wards that carefully consider design can better align with best practice models of palliative care, in support of patient, family and staff well-being. Palliative care differs from other inpatient experiences owing to its distinct philosophy of care, longer lengths of stay, a greater presence of family members, and more frequent end-of-life events. In addition, data reveals a key relationship between staff well-being and the environments in which they work; environments that are unable to match the quality of care that staff aspire to deliver can engender frustration and distress (McLaughlan R, et.al, 2022). This feeling of frustration and distress has been reiterated by some Palliative Care NSW members trying to deliver palliative care services in the usual hospital setting, which is impacting their tenure and desire to remain working in palliative care.

PCNSW recommends the establishment and adequate ongoing funding of inpatient palliative care services such as dedicated units or wards in all Tertiary hospitals and expanding this to provide dedicated palliative care beds in hospitals in regional areas to ensure patients have access to high quality palliative care when and where they need it. This must be done in conjunction to ongoing support for high-quality community based palliative care to ensure palliative care is available equitably to everyone in NSW according to their needs and preferences at end of life.

FUNDING TO SUPPORT RECRUITMENT AND RETENTION OF PALLIATIVE CARE STAFF INCLUDING NURSES, ALLIED HEALTH WORKERS AND SPECIALISTS.

With the need for palliative care expected to double between 2020 and 2050 (KPMG, 2020) recruitment and retention of staff remains a challenge across all healthcare sectors including palliative care.

PCNSW acknowledges that the NSW Government previously committed to filling nursing shortages in last year's state budget, however more must be done to urgently increase the number of specialist palliative care nurses. As the NSW Nurses and Midwives Association has highlighted, specialised nurses practicing at an advanced practice level are key to the provision of high-quality care. Their roles include advocacy, mentorship, implementation of innovative models of care and improved access to high quality services to facilitate improved health outcomes. Additionally, these nurses can alleviate the burden on other health professionals in areas where they have shared competencies, resulting in more efficient and collaborative care (NSW Nurses and Midwives Association, 2023).

Palliative care is a highly skilled profession and it's important that this is recognised and that career pathways into palliative care are supported and encouraged. To advance in nursing practice further education is required, whether that be through skill acquisition like competencies, tertiary education, or specialist training such as training days (Jokiniemi, K. et al. 2023). Nurses who want to advance in their specialty area frequently fund the associated costs themselves. This is a barrier to skills and practice advancement for nurses who can't afford specialised training. (NSW Nurses and Midwives Association, 2023).

Previous reports and inquiries have time and time again acknowledged that these issues require more than one level of government to address them, and the problem is not just restricted to funding. There remains an ongoing need for an approach at state and federal levels to improve coordination and planning of nursing policy and workforce issues. Particularly in the context of aged care and palliative care as well as disability and palliative care – where state and federal funding models often intersect.

PCNSW recommends the NSW government continues and further expands the current Tertiary Health Study Subsidies program beyond the current 2000 students annually (NSW Health 2024). In addition to this PCNSW recommends that the NSW Government expand the undergraduate clinical placement grants. Currently, the amount of the grant is based on the distance between a student's home, University campus and the GPO of the clinical placement. PCNSW believes that cost of living pressures are significant for all students completing clinical placements, no matter their location in NSW. To encourage participation in the workforce and further study more support is needed. To support career progression and to advance clinical skills, PCNSW recommends that the parameters of the current post graduate scholarships are also reviewed including eligibility criteria that currently has timeframe restrictions and a requirement that they are only available for post graduate studies, thus not supporting financial support for training in advanced clinical skills.

ENSURE ACCESSIBILITY OF PALLIATIVE CARE SUPPORT FOR THOSE UNDER THE AGE OF 65 WITH A DISABILITY ASSOCIATED WITH A LIFE-LIMITING ILLNESS (I.E. IMPROVE THE NDIS-PALLIATIVE CARE INTERFACE).

There is an immediate need to provide people under 65 living with a disability associated with a life-limiting illness, access to appropriate services to avoid people in vulnerable situations bouncing between the disability and acute care systems during their final months and weeks of life.

This concerning situation is being faced by a growing cohort of NSW residents under 65 living with life-limiting conditions who require assistance with daily living, functional and other basic non-clinical supports to remain at home, but who cannot access this support from the NDIS and/or state funded support is not able to meet their specific non-clinical needs.

This issue has come to the fore recently for a range of reasons including:

- Well-intentioned efforts to divert people under 65 away from residential aged care (in response to the Royal Commission's recommendation that there should be no younger people living in residential aged care by January 2025).
- Recent changes in how the NDIA responds to access requests, which have made it harder for people with life-limiting conditions to get support from the NDIS.
- In the longer term, funding for programs which provided the kinds of services in question has been eroded. Collective decisions by governments about which systems are responsible where someone has disability support needs associated with a health condition have led to some people falling through the gaps between systems.

(Palliative Care Australia Federal Budget Submission 2024)

Specialist palliative care services provide holistic person-centered clinical care for people with life-limiting conditions, including at the end of life. However, these services are not resourced to provide the non-clinical daily living and functional supports that would support people to stay out of hospital where possible. At present no system – mainstream state health, or the NDIS – is adequately meeting the needs of this group.

PCNSW acknowledges the existence of the NSW Health ***Out of Hospital Care Program, Safe and Supported at Home (SASH) packages, and the End-of-Life packages***. However, accessing these packages can often be onerous and challenging for patients and carers at end-of-life. The support included in these packages is often inadequate for high needs care at end-of-life for many people – especially for those with a disability and with limited or no informal support network. In order to keep people at home, and out of hospitals and Emergency Departments, more must be done to support patients and carers.

PCNSW recommends the NSW Government work closely with the Australian Government to provide a clear resolution of the respective roles of different tiers of government and portfolios regarding responsibility of non-clinical support for people under 65 with life-limiting conditions. As well as significantly increasing the hours of accessible support for people receiving care in existing out of hospital programs and consideration of the barriers to accessing these programs.

ENHANCING THE HEALTH-AGED CARE INTERFACE

The Comprehensive Palliative Care in Aged Care (CPCiAC) Measure (the Measure) aimed to strengthen efforts to improve access to quality palliative care as a key component of an integrated health-aged care system. The Australian Government committed \$57.2 million to CPCiAC from July 2018 to July 2024. Current funding for the CPCiAC measure will end on 1 July 2024.

While waiting for the national evaluation of the Measure, the Mid-point report (Australian Department of Health and Aged Care, 2022) provides valuable insight into the benefits of continuing this shared funding model to improve palliative care in aged care.

The Measure has proven an effective mechanism to improve the interface of health-aged care in relation to palliative care. The Commonwealth contribution of funds was provided by NSW Health to each LHD in \$150,000 payments. The NSW contribution for the Measure was sourced from an existing state commitment to fund nursing positions, NSW also opted to only receive and match \$10 million from the Commonwealth, rather than the originally proposed \$17 million.

NSW Health is now in a better position to further develop the Measure and embed new models of care without the interruption and implementation challenges brought on by COVID-19 restrictions which the the initial funding round experienced.

PCNSW recommends the NSW Government continue with this shared funding model and commits to matching the full funding available to NSW, should the Measure continue, to improve the interface issues between health and aged care systems and to improve equitable access to high quality palliative care in aged care. To date this model has encouraged collaboration, strong relationships and shared responsibility between key players (Australian Department of Health and Aged Care, 2022). Palliative Care NSW and all palliative care peak bodies across Australia have also strongly advocated to the Department of Health and Aged Care for the continuation of this Measure.

There is great potential for cost savings through community-based prevention of hospital admissions. Innovative programs such as the Geriatric Flying Squad operating from South Eastern Sydney LHD that utilise a multidisciplinary team largely resourced by nursing staff is a good example of a service focused on hospital avoidance which could be rolled out across the state. Additionally, the Geriatric Rapid Acute Care Evaluation ('GRACE') program for assessing older people prior to hospital admission has proven equally successful. PCNSW would recommend adequately funding these effective and scalable programs so they may be adapted by all LHDs around NSW to reduce unnecessary hospital emergency department presentations from RACs.

INCREASE THE CAPACITY AND INSTANCES OF PALLIATIVE CARE VOLUNTEER SERVICES IN NSW

Palliative Care Volunteers provide much needed psychosocial support and carer respite to people diagnosed with a terminal illness, their family, and carers.

The *NSW Health End of Life and Palliative Care Framework 2019 – 2024* prioritises person-centred care and recognises the need to support families and carers.

The *Agency for Clinical Innovation Blueprint for Improvement* says well-supported community volunteer programs are an essential component towards ensuring that all NSW residents have equitable access to quality end of life care.

Despite these clear policies there is not enough funding being directed to palliative care volunteer services. Currently, there are not enough services in NSW to meet the demand, especially in rural and regional areas.

For Palliative Care Volunteering to thrive there needs to be people dedicated to supporting volunteers. Ensuring funding for dedicated Palliative Care Volunteer Manager positions across NSW is the best way to increase the capacity and instances of Palliative Care Volunteer Services.

The following table shows the gaps in funding per LHD. The suggested salary for a Volunteer Manager position is HSM1 starting at \$81 581 FTE. With this in mind, we recommend an additional \$2 million dollars in funding to support Palliative Care Volunteering in NSW.

Palliative Care NSW has all the resources, frameworks, and infrastructure to support palliative care volunteer services hosted by LHDs and community organisations. Through our NSW Network of Palliative Care Volunteer Managers, we can provide ongoing support for new and existing Volunteer Managers and collaborate with local stakeholders to build new services that reflect the culture and values of local communities.

(see Table on pg. 11)

Table: Palliative Care Volunteer Service and Management funding gaps in NSW

LHD	Number of Palliative Care Services operational*	Palliative Volunteer currently	Population**	Additional Number of FTE Palliative Care Volunteer Managers Required
Metro LHDs (6)				
Nepean Blue Mountains	2		384,742	1
Northern Sydney	4		985,708	0
South Eastern Sydney	1		979,370	2
South Western Sydney	3		1,038,534	1
Sydney	2		722,492	1
Western Sydney	1		1,144,280	3
Rural & Regional LHDs (9)				
Central Coast	1		350,000	1
Far West	2		30,000	0
Hunter New England	4		962,390	3
Illawarra Shoalhaven	2		404,000	1
Mid North Coast	0		226,422	3
Murrumbidgee	1		245,196	1
Northern NSW	2		290,270	2
Southern NSW	4		211,122	0
Western NSW	3		279,422	3
Other (3)				
Albury Wodonga Health	1		53,676	0
St Vincent's Health Network	1			1
Sydney Children's Hospital Network	2			1
TOTALS	36			24

*PCNSW (Services with volunteers providing psychosocial care)

**NSW Health: <https://www.health.nsw.gov.au/lhd/Pages/default.aspx>

ADDITIONAL CONSIDERATIONS

PCNSW acknowledges the ongoing support of the NSW Government in providing peak body funding that has allowed PCNSW to remain a trusted source of information and support for health professionals and the public. This funding also supports PCNSW to act as a conduit between frontline workers, subject matter experts, policy makers and government, enhancing how palliative care is delivered and funded across NSW. As the population ages and the workforce grows the demands on our organisation will increase significantly and PCNSW seeks an increase in peak body funding to support this. Recent benchmarking has shown that PCNSW receives the lowest level of state or territory palliative care peak body funding per capita across Australia.

By maintaining our strong membership base and stakeholder networks PCNSW is uniquely positioned to support health professionals, volunteers, volunteer managers, CALD populations and residential aged care to provide equitable and high-quality palliative care across the state in multiple settings.

Through our consultation process prior to this submission members and stakeholders also raised the following as areas of concern that must also remain front of mind for the NSW Government:

1. Reinstatement of any funding diverted from the \$743M enhanced funding announcement made by the previous government in 2022.
2. Ensuring equitable access to palliative care for vulnerable populations eg. People experiencing homelessness, culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people etc, people living with a mental health diagnosis.
3. Improving Community engagement and the understanding of palliative care and end-of-life care and improving death literacy.
4. The need to provide more after-hours Palliative Care Support across the state that meets the needs of patients, families and carers while also ensuring clinician safety. NSW Ambulance and paramedics are seen as a key partner in palliative care which needs to continue and expand as they can play a key role in addressing after-hours needs.
5. The development of new models of care to meet the needs of patients who have a life-limiting disease with a non-malignant cause requiring specialist palliative care and end-of-life care. This is a fast-growing need as diseases such as dementia will soon become the leading cause of death in NSW.

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