

**CANCER VOICES NSW END OF LIFE AND PALLIATIVE CARE
POSITION STATEMENT
August 2021**

BACKGROUND

Efforts to improve the provision of end of life and palliative care services (see definitions below) are vital to both cancer patients and their carers/families, to help ensure that these services are both timely, targeted, equitable, clearly understood and readily available to all people.

Cancer Voices NSW continues to be concerned in relation to the allocation of a sufficient and trained workforce, and in particular in relation to the allocation of workforce resources, and the variable levels of these resources across the state and between, and within, metropolitan and rural/regional locations. Accessing appropriate end of life and palliative care for many people remains a difficulty creating inequities. This includes our First Nations community, people from culturally and linguistically diverse backgrounds and those from lower socio-economic backgrounds.

AIM

To contribute to the improvement of end of life and palliative care services across the whole of NSW to ensure they are readily available and understood by all people with cancer at the time that they need them.

OBJECTIVES

- I. influence decision making by the NSW Government about improving integrated end of life and palliative care in an equitable manner across the state
- II. advocate for improved health literacy in patient centred care in the delivery and communications of services to ensure choices and care are clearly understood and discussed with patients and carers
- III. influence the education, training, and access to information, of end of life and palliative care providers
- IV. advocate for all people to have equitable access to quality end of life and palliative care services that are culturally safe and provided in a co-ordinated way
- V. where appropriate, facilitate consumer participation in research about end of life and palliative care service provision and the development and review of NSW end of life and palliative care-related information resources
- VI. work with, and support the work of, other end of life and palliative care advocates in the improvement of and equity of end of life and palliative care services
- VII. advocate for consistent use of Patient Reported Outcomes Measures across all end of life and palliative care service providers
- VIII. monitor the allocation of end of life and palliative care funding in each year's NSW State Budget to ensure that it is directed to the areas intended.

ACTIONS

- provide input to NSW Government policy development and decision making regarding end of life and palliative care, managed by the [NSW Agency for Clinical Innovation End of Life and Palliative Care Network](#)
- track progress of recommendations in the [NSW Health End of Life and Palliative Care Framework 2019-2024](#) and the [Blueprint for Improvement 2016](#).
- meet regularly with decision makers and influencers within government and the health bureaucracy to present specific issues regarding cancer-related end of life and palliative care services
- advocate for consumer representation on all decision making committees / groups
- identify areas for improvement in the initial education and ongoing training of palliative care providers

- identify opportunities to include a cancer consumer perspective in research about the need for end of life and palliative care
- meet on a regular basis with palliative care-related organisations, and other palliative care advocates, to support their work in improving services on a statewide and local basis
- monitor changes in the provision of end of life and palliative care services by public and private providers.

KEY RELATIONSHIPS

- Minister for Health; Shadow Minister for Health
- Ministry of Health/Health and Social Policy Branch
- The NSW Agency for Clinical Innovation Palliative Care Network
- Palliative Care NSW
- Cancer Council NSW (Palliative Care campaign)
- Push for Palliative (Yvonne McMaster)
- palliative care education and training accrediting institutions
- palliative care providers' professional bodies
- voluntary palliative care provider networks

Definitions

Palliative Care

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

End of life care

The care delivered to improve the quality of life for people who have a life limiting illness, as well as their families and carers. End of life care ensures the appropriate support and palliative needs are provided to the person, so they live as well as possible until their death. It recognises end of life care is the responsibility of everybody.

(Extract from The NSW Health End of Life and Palliative Care Framework 2019-2024, Page 34)

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