

New Zealand Palliative Care: A Working Definition.

1. Preamble

The NZ Palliative Care Strategy (2001) aims to set in place a systematic and informed approach to the provision and funding of palliative care services. Furthermore, any approach must address inequalities in palliative care. Current inequalities include access for Māori, Pacific peoples, isolated communities, children, the very old, those with non malignant disease, as well as those with special needs: asylum seekers/refugees, people in prison, and those with mental illness.

Fundamental to the strategy's success will be clarity around palliative care definitions. Definitions form the basis upon which a comprehensive, cohesive and effective palliative care service can be built and sustained. They help clarify core service components, elucidate structure, and promote understanding. They are also key components for national palliative care service specifications.

As a starting point for defining palliative care in a NZ context we have used the 2002 WHO palliative care definitions:

Palliative care: World Health Organisation Definition, 2002

For adults:

Palliative care is 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 impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patients' care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness

- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

For Children:

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows (the principles also apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centres and even in children's homes

In applying the WHO definitions, New Zealand also needs to take into account the following :

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection. In addition, we must acknowledge and include He Korowai Oranga (the Māori Health Strategy (2002)). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Whā (four sided house) towards health/wellbeing is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau (family health).
2. Palliative care continues to evolve. Thus definitions need to be flexible enough to adapt to changes in society, disease and illness, and individual and society's expectations. Palliative care recognises and respects the rights of patients as detailed in the Code of Health and Disability Services Consumers' Rights.

3. Generalist Palliative Care will be available throughout the course of a life-limiting illness, with specialist palliative care provided on the basis of assessed need, rather than simply diagnosis or prognosis. Palliative care will also be available wherever the patient is – be that home, hospital, residential care, or hospice. Palliative care is centred on the patient and family / whānau. The level of palliative care support required for any individual, family or whānau is dynamic and varies during the course of illness (and into bereavement).
4. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whanau in contemporary New Zealand society.
5. Palliative care is best delivered through an integrated approach to care that recognises the roles and responsibilities of both palliative care generalists and specialists, in meeting palliative care need. This integrated model or framework of care delivery is essential for effective palliative care provision.
6. The patient's primary care team will continue to provide continuity of care through illness. Depending on need, the involvement of specialist palliative care may be episodic or continuous.
7. In the case of children and young people, palliative care will also be available on the basis of assessed need. Specialist palliative care will be provided in collaboration with formally trained or experienced paediatric healthcare professionals either community (eg GP, district nurse) or hospital based. In New Zealand, home is the preferred and usual location for palliative care for children and young people. It is recognised, however, that some children and young people spend long periods of time in tertiary hospitals far from the primary care team.

2. In Detail

Generalist palliative care is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. It is provided in the community by general practice teams, Maori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Some of the generalist providers, e.g. general practice teams, will have ongoing contact with a family throughout and following illness. Others, such as district nurses or ward nurses will have episodic contact, depending on the needs of the patient and family.

Providers of generalist palliative care will have defined links with (a) specialist palliative care team(s) for the purposes of support and advice or in order to refer patients with complex needs. They will also have access to palliative care education to support their practice.

Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways:

1. Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need.

Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.

2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.

Generalist/Specialist Integration

Generalist and specialist services need to be part of an integrated framework of care provision which may be facilitated through local and regional networks, with defined formal linkages to key services including community primary care, local acute hospitals, regional cancer centres, and other regional palliative providers.

Depending on the complexity of palliative care need, smaller specialist palliative care services will at times require input from a more comprehensive service with greater specialist resources which may be geographically distant. This must be readily available through defined linkages and processes.

Therefore, the New Zealand definition of Palliative Care is:

Care for people of all ages with a life-limiting illness which aims to:

- 1. optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.**
- 2. support the individual's family, whanau, and other caregivers where needed, through the illness and after death.**

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be.

It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities.