


Ratified by OTNZ-WNA Council State Date: 2012	Review date: 2016 Updated format: 22/11/2016	Version no. 2
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<p>Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa (OTNZ-WNA)</p> <p><b>End of Life/Palliative Care Position Statement</b></p>	 <p><b>OTNZ - WNA</b> Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa</p>
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## Purpose

The purpose of this statement is to describe the role of the occupational therapists /ngā kaiwhakaora ngangahau in providing services to people and their families/whānau who are living with a life limiting illness, and those who are in the terminal phase of life in Aotearoa New Zealand.

## Definition of Terms

- **Palliative care 1:**

“An approach that improves the quality of life of patients and their families facing the problems associated with life limiting of life threatening conditions 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 Organization, 2012).

- **Palliative care 2:**

Care for people of all ages with a life limiting or life threatening condition which aims to:

1. Optimise an individual’s quality of life until death by addressing the personal, physical psycho-social, spiritual and cultural needs.
2. Support the individual family, whānau and other care givers where needed through the illness and after death

(Palliative Care Subcommittee, N Z Cancer Treatment Working Party, 2007).

- **End of Life Care:**

“End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end of life

phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family” (Palliative Care Council, 2012, p. 5).

- **Primary Palliative Care:**

Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

(Palliative Care Council, 2012, p. 10)

- **Specialist Palliative Care:**

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.

(Palliative Care Council, 2012 p.10)

<b>Areas of practice in Palliative Care</b>
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**Occupational Therapists/ngā kaiwhakaora ngangahau work in both primary and specialist palliative care.**

## **Key Tasks**

Occupational therapy is primarily involved with enabling and improving quality of life experiences through participation in occupations. Occupational therapists/ngā kaiwhakaora ngangahau working in end of life/palliative care, focus on enabling clients’ participation and engagement in everyday occupations, across the lifespan - this includes living with death (Lala & Kinsella, 2011).

“Occupations” are groups of activities and tasks of everyday life, named, organised, and given value and meaning by individuals and a culture: occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic

fabric of their communities (productivity); (they are) the domain of concern and therapeutic medium of occupational therapy” (Townsend & Polatajko, 2007, p. 369).

**These interventions may include:**

**Self-care –**

- Activities of daily living - domestic and personal
- Energy conservation (Saarik & Hartley, 2010)
- Anxiety management
- Relaxation Techniques
- Managing breathlessness
- Seating and mobility
- Comfort and assistive equipment,
- Advice, education and support for family and carers
- Home assessments and complex discharge planning.
- Setting up home environment for end of life care in the home
- Falls prevention
- Pressure injury prevention and management
- Sexual wellbeing

**Leisure –**

- Legacy work, memory boxes, biography, digital story telling (La Cour, Josephsson & Luborsky, 2005; Hunter, 2008)
- Continuity of engagement in valued and meaningful activities
- Leading day units to provide specific programmes for palliative care patients (Strasser, et al., 2004)

**Productivity –**

- Enabling and maintaining independence in all areas of daily living, for as long as possible
- Cognitive assessments
- Work place assessments
- Work life balance and adaptation

(Canadian Association of Occupational Therapy, 2011; Burkhardt, et. al., 2011;; Pizzi, 1984; Pizzi & Briggs, 2004).

**Psychosocial –**

- Education, advice and support for carers and family members before, during and after end of life
- Enabling creative and expressive occupations

- Linking patients and family with family support teams, counseling services, kaiwhina and other cultural supports
- Linking patients and family with community supports and organisations

**The OTNZ-WNA Position supports Hospice New Zealand (2012) standards which include:**

- values based care
- ensuring equitable access
- coordinating care
- providing whole person assessment
- meeting the cultural needs of diverse family and whanau
- providing person centered care planning
- ensuring ongoing assessment and planning
- caring for patients who are dying
- caring for the carer/s
- providing bereavement care
- building community capacity
- quality and research
- professional development
- Reflective practice and self-care.

**OTNZ-WNA will help promote initiatives to enable occupational therapists/ngā kaiwhakaora ngangahau to deliver quality end of life palliative care which include:**

- Advocating for involvement of occupational therapists/ngā kaiwhakaora ngangahau in end of life/palliative care services.
- Collaborating with national groups e.g. Hospice New Zealand, Palliative Care Council, and Cancer Control New Zealand.
- Promoting and encouraging occupational therapy/whakaora ngangahau specific and interdisciplinary research studies and continuing professional development that expands and enhances the knowledge base for palliative care in New Zealand.

<b>Research and Evidence based practice</b>
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Research into the role of occupational therapists/ngā kaiwhakaora ngangahau in end of life/palliative care has been conducted since the 1970's (Burkhardt, et. al., 2011). It is acknowledged that to produce evidence based research can be difficult in this area; as patient function declines (Pearson, et al 2007).

Recently, phenomenological studies have been conducted into the engagement in occupation at the end of life. Results showed that participation in occupation allowed for: the reworking of everyday activities, preparing to say goodbye, being guided by one's body, living with death daily, giving priority to relationships and attending to the small things (Lala & Kinsella 2011; Benthall & Holmes, 2011). The clinical perspective of the occupational therapist/ngā kaiwhakaora ngangahau has also been studied, Bye (1998) discovered that therapists find ways to manage their practice and re-work their input based on patient deterioration and remain focused on occupation in practice.

Studies into the barriers present for occupational therapy/whakaora ngangahau have also been conducted. Boundaries include the under utilisation of the occupational therapists /ngā kaiwhakaora ngangahau skills, poor understanding of the role in the palliative care setting, limited funding and resources (Halkett, Ciccarelli, Keesing & Aoun, 2010) and minimal education provided to undergraduate therapists to enable them to work in this setting (Meredith, 2010).

**To ensure occupational therapists/ngā kaiwhakaora ngangahau have access to a robust evidence base to inform and support their work in end of life and palliative care, OTNZ-WNA recommends:**

- Promoting and advocating for increased resources to facilitate stakeholder research that will advance best practice in occupational therapy/whakaora ngangahau and end of life/palliative care.
- Promoting profession-specific and interprofessional research that expands the knowledge base for interprofessional practice
- Giving opportunities to share innovative practice and research in relation to occupational therapy/whakaora ngangahau in palliative care and interprofessional practice are developed and supports in occupational therapy/whakaora ngangahau and end of life/palliative care.
- Promoting opportunities for occupational therapists/ngā kaiwhakaora ngangahau to share innovative practice and research in relation to end of life/palliative care.
- Encouraging the practice of occupational therapy/whakaora ngangahau in current research and evidence based practice which supports the value and importance of occupation and occupational performance in palliative care.

<b>Education</b>
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**To ensure occupational therapists/ngā kaiwhakaora ngangahau receive relevant palliative care education, OTNZ-WNA recommends the following:**

- Interprofessional undergraduate education and teaching on palliative care and the role of occupational therapy.
- Supported personal development to include therapist self-care and the grief process.
- Advocate for professional development and post graduate learning opportunities that enhance, develop and promote occupational therapy/whakaora ngangahau and interprofessional practice in palliative care.

Position statements are statements on political, ethical, social, cultural and practice issues that influence client wellbeing, the role and practice of occupational therapy/whakaora ngangahau or that affect / Occupational Therapy New Zealand-Whakaora Ngangahau Aotearoa). Position statements are developed in consultation with ngā kaiwhakaora ngangahau/occupational therapists working in New Zealand, and reflect their current thinking. They are frequently time limited and persons wishing to use them more than two years after publication should confirm their current status with the executive director of OTNZ-WNA.

**Endorsed by OTNZ-WNA council June 2013**

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