

Position statement: The role of the nurse in end-of-life decisions and care for adults

I. Purpose

This position statement outlines the NZNO position on end-of-life decisions and care for adults, and the role of the nurse in providing that care.

II. Introduction

Aotearoa New Zealand's bicultural history is underpinned by the foundation document te Tiriti o Waitangi, cementing the relationship between Māori as tangata whenua and the Crown. In addition, Aotearoa is increasingly a multicultural society with people from various countries choosing to call it home. Tangata whenua and immigrants to New Zealand hold a range of different beliefs, customs and values that influence their ways of life, as well as their end-of-life care practices. Providing end-of-life care to culturally diverse patients, their families or whānau requires nurses to have an awareness and understanding of cultural differences about death and dying. Ensuring patients and their families or whānau receive culturally appropriate and safe end-of-life care must be a priority for Māori clients as well as those from other cultures.

The management of end-of-life decisions can be challenging and emotionally demanding for the dying individual and those close to them and/or involved in their care: health professionals, family, whānau. End-of-life care can occur at all life stages and in multiple settings. It is an umbrella term which includes multiple concepts concerning the end of life, of which advance care planning (ACP) is one. (ACP will be discussed later in this document). Decision-making about end-of-life care begins when an individual's clinical condition (through disease, trauma or ageing) changes and death becomes the expected outcome, for which treatment and care planning is required. During their careers, the majority of nurses will provide nursing care to people nearing the end of their lives.

III. Legislative and ethical frameworks

Nurses must adhere to legislative requirements and uphold ethical standards of nursing practice. To do this, nurses must be familiar with specific legislation related to information, choices, decision-making and privacy, and be familiar with a recognised code of ethics (eg. the *NZNO Code of Ethics*).

Because of the nature and complexity of end-of-life experiences, a number of ethical, legal and practical issues may arise. Decisions involving withdrawing or withholding treatments may involve the individual, their whānau, the health-care team, ethicists and ethics committees, and any legal team or adviser. Ethical dilemmas and differing views may arise around communicating the diagnosis/goals of care, options for withholding and/or withdrawing treatment, refusal of treatment, management of pain and other symptoms, organ donation, palliative sedation and requests for euthanasia or assisted suicide. Euthanasia and assisted suicide¹ are not legal in New Zealand, nor are they part of any formalised advance care planning. NZNO is working on further statements relevant to these areas.

Nurses are accountable for their professional conduct through statutory provisions that provide for the rights of people, in particular:

- > the Health Practitioners Competency Assurance Act 2003
- > the Health and Disability Commissioner Act 1994
- > the Code of Health and Disability Services Consumers' Rights 1996
- > the Mental Health (Compulsory Assessment and Treatment) Act 1992
- > the Privacy Act 1993
- > the Health Information Privacy Code 1994 (revised 2008)

IV. Communication

Effective communication between the person, whānau and the interdisciplinary team is essential in the development of an end-of-life plan.

The person

Nurses assisting individuals in end-of-life care need to consider the individual as a person in relationship with others, including their whānau. Good communication and care includes establishing the person's priorities, values and choices in all aspects of the management and provision of care to meet their te taha tinana (physical health), te taha wairua (spiritual health), te taha whānau (family health) and te taha hinengaro (mental health) needs. This may include their whakapapa, tīpuna and the wider whānau, hapū, and iwi.

¹ Assisted suicide is variously termed 'physician-assisted suicide', 'doctor-assisted suicide', 'medically assisted death', 'medically-assisted dying', 'medical aid in dying', or 'physician aid in dying', depending on which document one is referring to but all share the same meaning.

A person's wishes about sharing information need to be established and this information also needs to be readily accessible to all health professionals caring for the dying person. The nurse's advocacy can be pivotal in communicating and documenting the individual's goals and wishes. (See below for further information on advocacy). Where an end-of-life situation has arisen suddenly (and the person is still able to make decisions), the person may need significant support from whānau and/or members of the interdisciplinary team to clarify their thoughts and wishes regarding this new situation.

Nurses, along with other health care providers and decision makers, have a legal and ethical duty to respect the individual's wishes.

Whānau and cultural awareness

While the timing and delivery of information needs to be considered, the needs, developmental stage, cognitive status and readiness of the dying individual and their whānau must be assessed individually. Information may need to be repeated often or in different ways. In particular, children can have different levels of understanding of death and dying according to their developmental age and ability. Communication with whānau needs to be in partnership with the health professional.

Cultural differences can also have a significant bearing on how and when information is shared. Some cultures believe it is the whānau who should make a collective decision about care and treatments, while other cultures believe it is the individual's right to make all decisions themselves.

Inter-disciplinary teams

Good communication with and between health care professionals, individuals and whānau underpins the delivery of quality end-of-life care.

Nurses, doctors and allied health professionals are all part of the interdisciplinary team that liaises and consults with the person and their whānau.

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz

V. Informed choices

Choice is defined in clause 4 of the Health and Disability Commissioner's Code of Health and Disability Consumer Rights Regulations 1996 as being *"a decision to receive services, to refuse services or to withdraw consent to services. A person is able to change their mind and withdraw consent at anytime"*.

NZNO recognises a person's right to make informed choices about their care, in accordance with Rights 6 and 7 of the Health & Disability Commissioner Code of Health and Disability Services Consumer Rights Regulations 1996 and their own beliefs, values and culture.

For informed choice to be present a person and/or their legal guardian, must have a clear explanation and understanding of any underlying disease, a basic understanding of proposed treatment and care, and an appreciation of the likely outcome of this treatment. The whānau will often be an integral part of decision-making on treatment and care . Documentation of any conversation that occurs in relation to consent needs to be entered in the person's clinical notes.

The nursing role in ensuring informed consent may involve discussion about preferred place of death, choices relating to donation of organs following the person's death, and/or whether or not they would like initiation of life-sustaining treatments, if appropriate.

Refusal of treatment

Refusal of treatment (which is a person's legal right under the New Zealand Bill of Rights Act 1990) must be respected by nurses, even when this may conflict with their own beliefs and values. Where a conflict of interest or potential professional risk may exist, the nurse should seek advice from a professional or legal adviser (e.g. NZNO).

VI. Advocacy

Ensuring individuals' and their whānau views, wishes and best interests are central to discussions is a primary nursing function. The nurse's role is to work with the interdisciplinary team to understand all viewpoints, ensure all views are considered with respect, and work collaboratively with the person, whānau and interdisciplinary team towards a shared understanding and agreed approach. When a shared understanding and agreed approach cannot be reached and conflict arises, such as a difference between the individual's and whānau wishes, external ethical support may be required to help health professionals, families and whānau with how to

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz

proceed. Consultation with ethical committees and/or legal advice may be needed, if such a conflict cannot be resolved.

NZNO believes nurses should have the opportunity to consult, debrief and have access to peer review and supervision, when dealing with dilemmas or strong emotions surrounding care of those who are dying. See the NZNO guideline on supervision (2015) for further information.

VII. Advanced directives

The use of advance directives (also referred to as a living will) is becoming increasingly common in New Zealand. Right 7(5) of the Health & Disability Commissioner Code of Health and Disability Services Consumer Rights Regulations 1996 states that: *"Every consumer may use an advance directive in accordance with the common law". "Advance directive" is defined in the Code as meaning "a written or oral directive – (a) by which a consumer makes a choice about a possible future health care procedure. (b) that is intended to be effective only when he or she is not competent."*

The existence of an advance directive should be recorded in the dying individual's clinical notes and other health professionals must be informed of its existence. The nurse may also need to ensure whānau know of the dying person's advance directive, if they are not already aware of it, as long as this does not breach patient confidentiality or their wishes. Nurses, as part of a multi-disciplinary team, may be involved in discussions and, sometimes, decision-making surrounding the development of an advance directive.

While they are competent to do so, some individuals may give authority to another person to make decisions on their behalf once they are no longer able to do so for themselves (enduring power of attorney – see Glossary for definition). It is inappropriate for a nurse to hold power of attorney for a patient in their care.

If a nurse is present when a person is signing an advance directive, the nurse, who has an advocacy role, needs to be confident the dying person has been fully informed; has had adequate opportunity to receive advice on various health-care options pertaining to their current and possible future condition(s); understand the implications of the advance directive; and is acting voluntarily.

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz

VIII. Palliative care

Palliative care is:

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

- > *optimise an individual's quality of life until death by addressing the dying person's physical, psychosocial, spiritual and cultural needs;*
- > *support the individual's family, whānau, 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 aimed at improving quantity of life. It should be available wherever the person may be. It should be provided by all health 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 Māori, children and young people, immigrants, refugees and those in isolated communities.

(Palliative Care Subcommittee, New Zealand Cancer Treatment Working Party, 2007, p. 5, as cited in Ministry of Health 2015).

NZNO supports a palliative care approach which evidence shows is effective in improving the quality of life for people who are dying (Ministry of Health, 2001).

Palliative care is applicable at any stage after diagnosis of a life-threatening illness and NZNO supports the NZ Palliative Care Glossary (Ministry of Health, 2015) which has the New Zealand-specific definition of palliative care and also the World Health Organisation (2002) (<https://www.who.int/cancer/palliative/definition/en/>) definition of palliative care.

NZNO believes nurses should advocate for safe, compassionate, competent and ethical end-of-life care and equitable access to specialist palliative care services.

Pain and symptom management

Dying people may experience a range of symptoms including, but not limited to; pain, nausea, vomiting, constipation, excessive secretions, breathlessness, agitation and restlessness. It is the nurse's role to use their knowledge and skill to assess, plan, implement, monitor and reassess

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz

the patient and the effectiveness of interventions to relieve and control symptoms. Effective communication and patient advocacy are fundamental to achieving a sound symptom control treatment plan.

Some individuals who are dying fear they will experience pain and suffering, and some do. Cultural and belief systems may impact on the use of pain-relieving medicines and should be considered when assessing the person and planning their treatment. Just because pain can be relieved by medication it does not necessarily follow that it will be welcomed by a dying person. It is the nurse's responsibility to ensure the person has had and understood the relevant information. Individual choice is to be respected.

NZNO supports and advocates for access to the appropriate support systems to enable nurses to provide effective pain and symptom control.

This includes access to appropriate:

- > Policies and procedural guidelines;
- > Relevant education and training;
- > Resources to support care;
- > Specialist nursing advice and medical support; and
- > Access to palliative care services.

There are a range of local and international resources on pain and symptom management for nurses. *The NZ Palliative Care Handbook* (MacLeod, Vella-Brincat, & MacLeod, 6th edition, 2012) is a New Zealand reference guide on pain and symptom control in palliative care and may be helpful for nurses.

IX. Programmes and tools for planning and providing end-of-life care

Nurses will use a variety of approaches and tools to support end-of-life decisions and care. To achieve consistent, best practice care for the dying person in Aotearoa New Zealand, the following tools and documents may be helpful.

Te Ara Whakapiri – Principles and guidance for the last days of life

Te Ara Whakapiri (Ministry of Health, 2015a) evolved from a review of the Liverpool Care Pathway Framework. It outlines the essential components and considerations required to promote quality care at the end of life for all adults in New Zealand. It also provides examples of useful approaches and tools for the development of national and/or local resources as part of implementation. *Te Ara Whakapiri* is based on an extensive evaluation of the available literature and is informed by local research, ensuring it is applicable to the unique context of Aotearoa New Zealand. It has been endorsed by key health professional organisations in New Zealand and marks a major step towards ensuring all health-care services are focused

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz

on delivering the very best care for people who are dying and for their whānau, whatever the setting.

Advance Care Planning (ACP)

The document, *Advance Care Planning: A guide for the New Zealand health care workforce* (Ministry of Health, 2011) was prepared in response to greater health sector focus on the need for clear and accurate information and guidance regarding ACP. The intended audience encompasses providers, funders and planners in all areas of health care. The document is aimed at health practitioners and provides standardised information about ACP principles and legislation, with the aim of promoting consistency in practice. It will assist in the development of local policies, guidelines and education and training programmes in ACP. The ACP website contains multiple resources for health professionals and consumers (see reference list below).

X. Do-not-resuscitate orders

Organisations that employ nurses should have policies relating to resuscitation orders. Nurses must be familiar with these policies. Advanced care planning (see discussion below) allowing natural death is prevalent in many organisations, while others may require a do not resuscitate (DNR) status to be established for each patient.

End-of-life care discussion may include the futility of initiating active resuscitation and consideration of a DNR status. To avoid ambiguity, DNR decisions need to be clearly documented in the clinical record. Whānau and carers need to be reassured that a DNR decision does not mean other treatment and care will be denied. Individuals may also need to be reassured that they can change any DNR or advance care order at any time while they are still competent. Nurses must be aware DNR can have different meanings to people from differing cultures – extra time may be needed to support these people and their whānau facing DNR decisions.

XI. Definitions

DNR – A range of abbreviations and terminology is used to describe ‘donot-resuscitate’ orders. Any of the following acronyms may be used in differing settings and it is important terminology is consistent throughout agency policies:

DNR – Do not resuscitate

DNAR – Do not attempt resuscitation

NFR – Not for resuscitation

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz

AND – Allow natural death

Any DNR, DNAR, NFR or AND instruction needs to have a written definition so there is no misunderstanding. It is important also to note that DNR, DNAR, NFR or AND do not mean “do not treat”.

Enduring power of attorney (EPA) – an authority given by a person (known as appointing), while they are competent, to another person (known as the attorney) so that person can act for the patient, once the patient is mentally incompetent. Under the amendments to the Protection of Personal and Property Rights Act (PPPR Act) 2008, a medical certificate stating the patient is mentally incapable is required, before attorneys can act in respect of significant matters. There are EPAs for property and EPAs for care and welfare. (See the Ministry of Justice website for further detail ,as per reference list below).

Lineage – the members of a person's family who are directly related to that person and who lived a long time before him or her (Cambridge Dictionaries Online, Retrieved from <http://dictionary.cambridge.org>).

Tipuna - ancestors, grandparents - eastern dialect variation of tūpuna. Retrieved from <http://www.maoridictionary.co.nz/>

Whakapapa – (noun) genealogy, genealogical table, lineage, descent. He mea nui ki a tātau ō tātau whakapapa (HP wh1).Our genealogies are important to us. (Te Kākano Textbook (2nd ed.): 3;Te Māhuri Study Guide (1st ed.): 13-14;Te Kōhure Textbook (2nd ed.): 237-240). Retrieved from <http://www.maoridictionary.co.nz/>

Whānau – (noun) extended family, family group, a familiar term of address to a number of people. Retrieved from: <http://www.maoridictionary.co.nz/>

XII. References

MacLeod, R., Vella-Brincat, J., & MacLeod, A.D., (2012). The palliative care handbook. (6th ed.). Christchurch: Caxton Press.

Ministry of Health. (2011) Advance Care Planning: A guide for the NZ Healthcare workforce. Wellington: Ministry of Health.

Ministry of Health. (2015). *New Zealand Palliative care Glossary*. Wellington: Ministry of Health.

Ministry of Health. (2015a). Te Ara Whakapiri: Principles and guidance for the last days of life. Wellington: Ministry of Health.

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz
Page 9 of 10

XIII. Other useful reading and resources

Enduring Power of Attorney: <http://www.justice.govt.nz/family-justice/other-court-matters/power-to-act/enduring-power-of-attorney>

Johnstone, M. (2016). *Bioethics: a nursing perspective*. (6th ed). Sydney: Elsevier.

Ministry of Health, (2001). *The New Zealand palliative care strategy*. Wellington, New Zealand: Ministry of Health.

Muircroft, W., McKimm, J., William, L., & MacLeod, R. (2010). A New Zealand perspective on palliative care for Māori. *Journal of Palliative Care*, 26(1), 54-58.

New Zealand Nurses Organisation, (2010). *Code of ethics*. Wellington, New Zealand: New Zealand Nurses Organisation.

Palliative Care Nurses New Zealand, (2014). *A National Professional Framework for Palliative care Nursing in Aotearoa NZ*. Wellington. Ministry of Health.

Advanced care planning: <http://www.advancecareplanning.org.nz/>

Date adopted: 2011

Reviewed: 2016

Review date:

Correspondence to: nurses@nzno.org.nz

Principal author: Lorraine Ritchie, Professional nurse adviser

Mission statement

NZNO is committed to the representation of members and the promotion of nursing and midwifery. NZNO embraces Te Tiriti o Waitangi and works to improve the health status of all peoples of Aotearoa/ New Zealand through participation in health and social policy development.

© 2016 This material is copyright to the New Zealand Nurses Organisation.

Apart from any fair dealing for the purpose of private study, research, criticism or review, as permitted under the Copyright Act, no part of this publication may be reproduced by any process, stored in a retrieval system or transmitted in any form without the written permission of the Chief Executive of the New Zealand Nurses Organisation (NZNO), PO Box 2128, Wellington 6140.

ISBN: 978-1-877461-91-0

NZNO Practice position statement:

Position statement: The role of the nurse in end-of-life decisions and care for adults
New Zealand Nurses Organisation PO Box 2128, Wellington 6140. www.nzno.org.nz