The role of the Nurse in the delivery of End-of-Life decisions and care

This position statement outlines the New Zealand Nurses Organisation (NZNO) position on end-of-life decisions and care, and the role of the nurse in providing that care.

Introduction

The management of end-of-life decisions and care can be challenging and emotionally demanding for health professionals, family, whānau and those who are close to and/or involved with care of the dying person. End-of-life care occurs across the lifespan and in multiple settings. Decision-making regarding end-of-life care begins when a person's clinical condition (through disease, trauma or aging) changes and death becomes the expected outcome for which treatment and care planning is required. The majority of nurses will provide nursing care to dying people during their careers.

NZNO Fundamental Values

NZNO believes the fundamental values underpinning the ethics of nursing practice are autonomy, beneficence, non maleficence, justice, confidentiality, veracity, fidelity, guardianship of the environment and its resources, and being professional (NZNO, 2010).

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 development. NZNO's vision for a fair and equitable Aotearoa New Zealand through strong bi-cultural partnerships can only be achieved if all New Zealanders are empowered to live to the fullest of their potential and die with dignity and support.

NZNO acknowledges that illness, dying, death and grieving are a central part of Māori life alongside health and healing dimensions. The Te Whare Tapa Whā model is a recognised Maori health framework which provides a holistic view of well-being. The framework consists of four concepts which are referred to as the four cornerstones of a house; if one is not aligned an imbalance is obvious (Durie 1998). NZNO believes the holistic and balanced Te Whare Tapa Whā model of health care (Durie 1998) should be embraced by all New Zealanders as a foundation for providing end-of-life experiences that bring peace to individuals, whānau and communities.

Legislative 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 (e.g. 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 the withdrawing or withholding of treatments may involve the individual, their family 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 suicide are not legal in New Zealand, nor are they part of any advance care planning.

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)

Communication

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

Family Whānau

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

While the timing and delivery of information needs to be taken into consideration, the needs, developmental stage and readiness of the dying person 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. This understanding will influence their capability to participate in decision-making in regard to the provision of care required. Communication with the child/young person and their family 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 family whānau who should make a collective decision about the type of care and treatments, while other cultures believe it is the individual's right to make all decisions themselves.

A person's wishes about the sharing of 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 role can be pivotal in the communication and documentation of the individual's goals and wishes.

Inter–disciplinary teams

NZNO believe good communication with and between health care professionals, individuals and families whānau underpins the delivery of quality end-of-life care.

Nurses, doctors, allied health professionals and volunteers are all part of the inter-disciplinary team that liaises and consults with the person and their family whānau. This includes establishing the person's priorities, values and choices in all aspects of the management and provision of care to meet their taha tinana (physical health), taha wairua (spiritual health), taha whānau (family health) and taha hinengaro (mental health) needs. This may include their whakapapa, tīpuna and the wider whānau, hapū, and iwi.

Advocacy

Ensuring that individuals and their family whānau views, wishes and best interests are central to discussions is a primary nursing function. The nurse's role is to understand all viewpoints, ensure all views are considered with respect, working collaboratively towards a shared understanding and agreed approach. When a shared understanding and agreed approach cannot be reached, external ethical support may be required to assist health professionals and families about how to proceed. Consultation with ethical committees and/or legal advice may be needed, if conflict resolution is unable to be achieved.

NZNO supports nurses being provided with the opportunity to debrief and to have access to peer review and supervision.

Where these opportunities are not available to nurses, research has demonstrated that discussion with trusted colleagues and acknowledgement they have done the best could for the person is appropriate. It is important to avoid self recrimination (Woods, 2006).

Informed choices

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.

Choice is defined in clause 4 of the Health and Disability Commissioner 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. Therefore a consumer is able to change their mind and withdraw consent.

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 family whānau will often be an integral part of this decision-making. Documentation that this conversation has occurred needs to be entered in the person's clinical notes.

NZNO believes the role of the nurse is pivotal in the delivery and planning of the dying person's care.

This may include instruction regarding preferred place of death, choices about whether to offer organs for use as donor organs following death, and/or whether or not they would like initiation of such life sustaining treatments as are appropriate.

Nurses assisting individuals in this planning need to consider the individual as a person in relationship with others, including their family whānau (Canadian Nurses Association, 2008), and in some traditions this may include acknowledging the person's whakapapa or lineage.

Advance 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 person's clinical notes and other health professionals need to be informed that the dying person has made an advance directive. The nurse may also need to ensure family whānau has been informed of the existence of the dying person's advance directive, if they are not already aware of this, as long as this is not breaching patient confidentiality or wishes.

While they are competent to do so, some people 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).

"In deciding the best interests of the patient, the team will respect valid advance refusals of treatment and will, as far as possible, interpret any statement of the patients values and wishes in terms of possible treatment decisions" (Randall & Downie, 2006, p.224).

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.

NZNO supports a person's right to refuse treatment. 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.

Nurses may be involved in discussions and sometimes decision-making processes surrounding the development of an advance directive as part of a multi-disciplinary team. While nurses should be aware of the legal aspects and potential risks of treatment refusal, they should not be expected to formally witness any associated documents. 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).

Do Not Resuscitate Orders

Employing organisations will have policies relating to resuscitation orders. Nurses should be familiar with these policies. Advanced care planning allowing natural death is prevalent in many organizations, while others may require a do not resuscitate (DNR) status to be established.

The heart inevitably stops at death. 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. Family 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 family whānau facing DNR decisions.

Palliative Orders

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).

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).

NZNO believes that palliative care is applicable at any stage after diagnosis of a life threatening illness and supports the Palliative Care Subcommittee, NZ Cancer Treatment Working Party (2007) and the World Health Organisation (2010) (https://www.who.int/cancer/palliative/definition/en/) definitions 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.

Programmes & 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. In order to achieve the goal of consistent, best practice care for the dying person in Aotearoa New Zealand, the following tools and documents may be helpful.

Liverpool Care Pathway for the Dying Patient (LCP)

LCP is an integrated care pathway/care planning document that empowers and enables health care professionals to deliver evidence-based, best practice care to the dying person and their family whānau in the last days and hours of life, irrespective of diagnosis or care setting. The LCP is not yet available in all care settings nor is it applicable for use with children, but it is the preferred last-days-of-life care programme supported by the Ministry of Health to improve the care of dying adults and their families whānau in Aotearoa New Zealand. Further information on the LCP can be found at http://www.lcpnz.org.nz

Preferred Priorities for Care (PPC)

The PPC is a tool to determine and record a person and their carers' wishes in relation to the dying person's care and preferred ultimate place of death. This tool has formed the basis for development of the Ministry of Health and Hospice

New Zealand Advance Care Planning document outlined below. Further information on the PPC tool can be found at: http://www.endoflifecare.nhs.uk/eolc/ppc.htm

Advance Care Planning: Overview (Ministry of Health & Hospice New Zealand, 2010 draft

This draft document provides standardised information and definitions about advance care planning (ACP) principles and legislation in New Zealand and has been developed to assist in the development of local policies, guidelines, education and training programmes in ACP in New Zealand. It is intended to be used as a reference. Well-implemented ACP policies and pathways will ensure that the end-of-life treatment and care that a person receives is in line with their preferences, values and cultural beliefs. http://www.moh.govt.nz/palliativecare

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 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 dying people fear they will experience pain and suffering. Cultural and belief systems may impact on the use of pain relieving medicines and should be considered in assessment of the person and planning 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 has understood the relevant information. Individual preference and choice is to be respected.

NZNO supports and advocates 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;**
- **A specialist nursing advice and medical support; and**
- **Access to palliative care services.**

There are a range of local and international resources available to provide guidance on pain and symptom management for nurses. The NZ Palliative Care Handbook (MacLeod, Vella-Brincat, & MacLeod, 2009) is a New Zealand reference guide on pain and symptom control in palliative care that may be helpful for nurses.

Professionalism

Nurses have a social contract with society (Chick 1993). This includes the expectation that nurses will act in the best interests of patients and advocate on their behalf at a health and policy level. In order to fulfil their obligations, registered and enrolled nurses and nurse practitioners are required to demonstrate compliance with the Nursing Council of New Zealand's determined scopes of practice, competencies and code of conduct.

The NZNO Code of Ethics (NZNO, 2010) provides a framework for ethical practice for nurses within Aotearoa New Zealand. Familiarity with these fundamental documents is a requirement.

Caring for dying people and their family whānau can be challenging professionally, physically and emotionally. Nurses need access to support from colleagues and employers. In particular, nurses have a role in supporting and nurturing students and newly qualified nurses in end-of-life care situations through role modeling and teaching. Access to, and engagement in, research, policy development, quality education and evidence-based guidelines is essential.

Professional growth and development are key nursing competencies. They require both reflection on self, and openness to advice and feedback from others, to identify knowledge and skill gaps and the instigation of some action to meet those identified needs. The National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand (Ministry of Health, 2009) and the National Framework for Professional Development and Recognition Programmes and Designated Role Titles (National Nursing Organisations, 2005) may be useful in professional development and career planning. Access to annual appraisals, peer review processes and professional supervision are also important opportunities for feedback and learning.

NZNO advocates for employer supported access to professional development opportunities.

Duty of Care

The phrase "duty of care" is different from "the duty to provide care". Nurses, as with other health professionals, have a legally imposed obligation or duty (as described in common law) to "take care". A duty of care is about ensuring our actions (or omissions) do not harm someone else. A nurse always has a duty of care to prevent harm to a person they are nursing, i.e. a duty to ensure they take care the actions carried out in relation to the person do no harm, and they do not carelessly omit to do anything that could have prevented harm to the person (NZNO, 2008). Professional standards, codes of conduct, scopes of practice and competencies are all taken into account to determine the standard of care expected. **As a nurse, it is expected you will take the same amount of care to prevent harm as any reasonable regulated nurse is expected to take in that specific situation. It is vital to understand that "duty of care" applies to both your professional and personal life.**

Definitions

A range of abbreviations and terminology is used to describe 'do not resuscitate' orders. Any of the following acronyms may be used in differing settings and it is important terminology is consistent throughout agency policies:

_Abbreviation	Definition
DNR	Do not resuscitate
DNAR	Do not attempt resuscitation
NFR	Not for resuscitation
AND	Allow natural health

Any DNR, DNAR, NFR or AND instruction needs to have its meaning available in writing 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) in order for that person to 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 that 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 (Ministry of Health and Hospice New Zealand, 2010).

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).

Tīpuna - 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/

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World Health Organization, (2010). Definition of palliative care. Geneva: World Health Organisation. Retrieved from: http://www.who.int/cancer/palliative/definition/en/

Relevant Legislation and Resource

A National Professional Development Framework for Palliative Care (2008)
http://www.anzspm.org.au/

Australian and New Zealand Society of Palliative Medicine - http://www.anzspm.org.au/

Cancer Control - http://www.moh.govt.nz/cancercontrol

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Health Practitioners Competency Assurance Act 2003 - http://www.moh.govt.nz/hpca

Health & Disability Commissioner (Code of Health and Disability Services Consumer Rights) Regulations 1996 -http://www.hdc.org.nz/theact/theact-thecode

Health & Disability Commissioners website including reference to the Health and Disability Commissioner Act - http://www.hdc.org.nz/

Human Rights Act 1993 - http://www.legislation.govt.nz/act/public/1993/
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Liverpool Care Pathway for the dying person - http://www.lcpnz.org.nz

Mental Health (Compulsory Assessment and Treatment) Act 1992 -
http://www.moh.govt.nz/moh.nsf/pagesmh/4584

New Zealand Legislation: Acts - http://www.legislation.govt.nz/act/searchquick.aspx

New Zealand Bill of Rights Act 1990 - http://www.legislation.govt.nz/act/public/1990/

New Zealand Palliative Care: A Working Definition - http://www.moh.govt.nz/moh.nsf/indexmh/palliativecare-definition

NZNO Cancer Nurses Section - http://www.nzno.org.nz/groups/sections/cancer_nurses
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Privacy Commissioner – the Health Information Privacy Code (revised edition 2008) - http://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/HIPC-1994-2008-revised-edition.pdf

Privacy Commissioner – the Privacy Act - http://www.privacy.org.nz/the-privacy-act/

National Framework for Nursing Professional Development & Recognition Programmes & Designated Role Titles (2005)
http://www.nzno.org.nz/LinkClick.aspx?fileticket=MkAd0SSFxZM%3d&tabid=130

Professional Development and Recognition Programme (PDRP): Evidential Requirements Working Party Report (2009)
http://www.nzno.org.nz/LinkClick.aspx?fileticket=YF-4S0z31ws%3d&tabid=130

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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.