The role of the nurse in end-of-life decisions and care, 2016

|  |
| --- |
| PRACTICE |
| position statement |

1. Purpose

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.

1. Introduction

The management of end-of-life decisions can be challenging and emotionally demanding for the dying person and those close to them and/or involved in his or her care: health professionals, family, whānau. End-of-life care occurs across the lifespan and in multiple settings. It is an umbrella term which includes multiple concepts on end-of-life of which Advance care Planning (ACP) is one (ACP will be discussed later in this document). 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 people nearing the end of their life during their careers.

1. 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 (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 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 formalized advance care planning. NZNO is currently 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)

1. Communication

Effective communication between the inter-disciplinary team, the person, and whānau is essential in the development of an end-of-life plan. A person’s wishes about the sharing of information needs 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.

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

Whānau

While the timing and delivery of information needs to be taken into consideration, the needs, developmental stage, cognitive status 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 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 the type of 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, allied health professionals and volunteers are all part of the inter-disciplinary team that liaises and consults with the person and their 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.

1. Advocacy

Ensuring that individuals and their 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, and work collaboratively toward a shared understanding and agreed approach.  When a shared understanding and agreed approach cannot be reached and conflict arises such as difference between the individual’s and whānau wishes, external ethical support may be required to assist health professionals and families with 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. See the NZNO guideline on supervision (2015) for further information.

1. 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 consumer 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 this decision-making. Documentation of any conversation that occurs in relation to consent needs to be entered in the person’s clinical notes.

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 life sustaining treatments if appropriate.

Nurses assisting individuals in this planning need to consider the individual as a person in relationship with others including their whānau. This may include acknowledging the person’s whakapapa or lineage.

1. 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 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 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.

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 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 – 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.

1. 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. 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).

1. Do not resuscitate orders

Employing organisations 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 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. 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.

1. 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.

1. Programmes and tools for planning and provide 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.

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. The documentoutlines 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 that will serve as aids 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 that is Aotearoa New Zealand. It has been endorsed by key professional health organisations in New Zealand and marks a major step towards ensuring that all health care services across the country are focused 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 an increasing sector focus on the need for clear and accurate information and guidance regarding ACP in the New Zealand context. The intended audienceencompasses providers, funders and planners in all areas of health care. The document is not aimed at the general public and provides standardised information about ACP principles and legislation in New Zealand with the aim of promoting consistency in practice. It willassist 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: <http://www.advancecareplanning.org.nz/>.

1. 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, and some do. 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;
* 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, 6th edition, 2012) is a New Zealand reference guide on pain and symptom control in palliative care that may be helpful for nurses.

1. Definitions

*DNR* – 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:

DNR – Do not resuscitate

DNAR – Do not attempt resuscitation

NFR – Not for resuscitation

AND – Allow natural death

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.

*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/>

1. 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.

1. Other useful reading and resources

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:** Month Year **Reviewed:** Month Year, Month Year  **Review date:** Month Year **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: ???