



## Caring for people with a life-limiting illness position statement

### 1. Purpose

This position statement sets out the rights of people with a life-limiting illness and the responsibilities the Australian Nursing and Midwifery Federation (ANMF) considers health services; employers; and nurses, midwives and assistants in nursing should meet when caring for them.<sup>1</sup> It should be read with the ANMF position statements: *Voluntary assisted dying* and *Conscientious objection*.

### 2. Definitions

In this position statement, **voluntary assisted dying** (VAD) is defined as a regulated intervention by an authorised health practitioner, either providing the person with the means to end their life or, if the person is unable to do so, ending the person's life with the primary intent of relieving pain or suffering, at the person's voluntary, repeated, and fully informed request.

### 3. Context

People in Australia with a life-limiting illness may choose to:

- access palliative care
- make an advance care directive about their wishes for treatment
- refuse treatment
- access VAD where it is available and they are eligible to do so.<sup>2</sup>

Nurse, midwives and assistants in nursing have a key role in providing care for people with a life-limiting illness and ensuring they exercise and realise their right to a dignified death. It is therefore important that the ANMF provide members with information about these choices and a forum to debate associated issues. The ANMF also advocates for increased resources for palliative care and appropriate protections in VAD legislation for both people with a life-limiting illness and their treating and assisting health professionals.

### Position

#### People with a life-limiting illness

1. People with a life-limiting illness, and where appropriate, their carers (including parents, family members, legal guardians, or medical decision makers) have the right to:<sup>3,4</sup>
  - have their privacy respected
  - be cared for respectfully and with compassion
  - be consulted and make informed decisions about their treatment options
  - a dignified death that takes place, where possible, in a place of their choosing.

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<sup>1</sup> Assistants in nursing refers to all care workers however titled.

<sup>2</sup> VAD laws have been passed in all states and have commenced operation in Victoria, Western Australia, Tasmania, Queensland, South Australia and New South Wales.

<sup>3</sup> From this point on in this document, parents, family members, legal guardians, or medical decision makers are referred to as carers.

<sup>4</sup> *National Consensus Statement: essential elements for safe and high-quality end-of-life care*, Australian Commission on Safety and Quality in Health Care, 2015, Sydney, Australia. Available at <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-consensus-statement-essential-elements-safe-and-high-quality-end-life-care>.



2. People with a life-limiting illness also have the right to:
  - refuse treatment when they have the mental capacity to do so or when they have made an advanced care directive
  - access specialist palliative care services – including services to help control pain, relieve other symptoms, and provide emotional and psychosocial support in preparation for death – irrespective of their location, age or financial means
  - access VAD in states and territories where it is legal and they are eligible to do so.
3. People with a documented advance care directive or their carers should make sure the treating health service or health practitioners are aware of their advance care directive and their wishes for treatment.

### **Health services and employers**

4. Health services and employers should:
  - ensure all people with a life-limiting illness can access early referral to palliative care services
  - ensure the outcomes of all discussions between a person with a life-limiting illness or their carer and treating health professionals are documented and available to all health professionals involved in their care – and updated at regular intervals as needed
  - have policies and procedures in place to ensure all treating health professionals are aware of any advance care directives and wishes for treatment
  - provide the necessary resources to support nurses and midwives to deal with the professional and emotional requirements of caring for a person with a life-limiting illness.<sup>5</sup>

### **Nurses, midwives and assistants in nursing**

5. Nurses, midwives and assistants in nursing must:
  - always comply with the existing legislative framework; the Nursing and Midwifery Board of Australia's (NMBA) *Professional practice framework* which includes the professions' codes of conduct and ethics; and organisational guidelines
  - develop and maintain a current understanding of their legal and ethical responsibilities in providing care for a person with a life-limiting illness
  - provide timely and adequate information to help a person with life-limiting illness exercise their rights in accordance with the law in their state or territory
  - provide culturally appropriate end-of-life care that is consistent with the person's beliefs, cultural expectations and choices
  - be aware of conditions which may impair a person's decision-making capacity such as depression, other mental illness, dementia, or the effects of mood-altering medicines
  - recognise when efforts to prolong life may not be in the best interest of the person.<sup>6</sup>

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<sup>5</sup> Such support should include access to employee assistance programs; clinical (reflective) supervision; debriefing; education; and continuing professional development.

<sup>6</sup> *Code of conduct for nurses*, Nursing and Midwifery Board of Australia, 2018, Melbourne, Australia. Available at <https://www.nursingmidwiferyboard.gov.au/codes-guidelines-statements/professional-standards.aspx>.



6. Nurses, midwives and assistants in nursing must:
  - familiarise themselves with any existing advance care directives and/or the person's wishes and expectations for their care and treatment
  - ensure the outcome of discussions with the person and/or their carers about an advance care directive and the initiation of cardio-pulmonary resuscitation and other life preserving measures are documented in the person's care/management plan<sup>7</sup>
  - make a report to their state or territory health ombudsman when they consider an advance care directive is not being followed according.
7. Nurses, midwives and assistants in nursing must:
  - understand the VAD legislation that applies in their state or territory and know their obligations and limitations
  - stay up to date and informed about the legal, ethical, professional, cultural and clinical implications of voluntary assisted dying
  - understand other available options and ensure appropriate referrals are made to other health practitioners when indicated or requested.
8. In any jurisdiction where voluntary assisted dying is, or becomes legal, nurses, midwives and assistants in nursing:
  - must have the right to conscientiously object on moral, ethical or religious grounds, to participation or involvement in assistance with dying
  - must be legislatively protected from litigation where they are asked and agree to assist with the VAD process.

#### 4. Position statement management

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