LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT
Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA, Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

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Australian Nursing & Midwifery Federation
AUSTRALIAN CAPITAL TERRITORY

Australian Nursing and Midwifery Federation (ACT Branch)

A Submission to the Inquiry into End of Life Choices in the ACT

29 March 2018

About the ANMF ACT

The Australian Nursing and Midwifery Federation ACT Branch (ANMF) negotiates Enterprise Agreements which cover over 95% of the Nursing and Midwifery professionals practicing in the ACT. As such, the ANMF represents the industrial, professional and social justice interests of a majority of the Nursing and Midwifery workforce in the ACT, with the majority of the ANMF's members employed by the ACT Government or working in the ACT Public Service. Members of the ANMF, whether classified as Nurses, Midwives, or Assistants-in-Nursing, can be found across almost every part of the ACT Healthcare system including in public and private hospitals, aged care, mental health, community nursing, prisons, schools, the armed forces, community health and medical centres.

The ANMF nationally is Australia's largest union, with over 260,000 members, and regularly participates in the development and implementation of policy relating to Nursing and Midwifery practice, regulation, education, training, health and aged care, community services, work health and safety, industrial relations, social justice, human rights and law reform.

Introduction

The ANMF thanks the Select Committee on End of Life Choices in the ACT for inviting the ANMF to provide a submission to assist the Select Committee with their work.

The ANMF considers this Inquiry has significant relevance to the ANMF as a representative of a substantial proportion of the healthcare workforce operating throughout the ACT's health care services. As health policy researchers Hal Swerissen and Stephen Duckett have observed, 85% of Australians will die in an institution with about 50% of Australians dying in a hospital and about 35% dying in an aged care service[1]. This means nursing staff are often the chief care-providers for Australians at the end of their lives. Consequently, any decisions affecting the future direction of end-of-life Choices in the ACT will have considerable implications for the care provided by our members.

It should be recognised that ANMF membership is derived from a diverse array of cultural and religious backgrounds, with our members holding a range of ethical and moral views about end-of-life. As such, the ANMF is of the position that individual Nurses, Midwives and Assistants in Nursing have the right to hold their own views in respect of this matter.

Further, although the ANMF will reference the ANMF Position Statement on Assisted dying (Appendix A) in this submission, the ANMF recognises the distinction to be made between end-of-life choices and Assisted dying, and considers it reflected in the ANMF's policy position.

Applicable Terms of Reference

This submission considers matters relevant to, and aligning with, the following terms of reference of the Inquiry:

1. Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;

[1] Hal Swerissen and Stephen Duckett, *Dying Well*, Grattan Institute 2014, p. 20.

2. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT; and

3. Any other relevant matter.

Background for Discussion

Education

The ANMF considers that education programs for practitioners should not be limited to the legal parameters and framework for end-of-life matters and should encompass targeted education programs that include aspects such as how to initiate, and have, a therapeutic conversation with people considering their end-of-life choices.

These conversations can be difficult to have with people at this point in their life, and evidence-based approaches and frameworks in which to conduct these conversations are critical to ensuring that the person's wishes are at the forefront of end-of-life decision-making. These principles are fundamental to ensuring the person's dignity, at end-of-life, is preserved.

Further, the ANMF supports the continued roll-out of existing programs that support end-of-life matters (e.g. education regarding advanced care directives).

Symptom Management

The ANMF supports the right of every person to choose the circumstances of their end-of-life care, as much as is practicable, and urges the ACT Government to consider options that would allow residents of the ACT greater choice in their end-of-life care. One of the key barriers to a person receiving end of life care in their location of choice is the effectiveness of symptom management. An end-of-life care framework that produces timely and therapeutically effective symptom management can avoid the need for a person at the end-of-life being admitted to hospital.

Funding

In many circumstances, the hospital setting is not the most appropriate, cost-effective and preferred means of providing end-of-life palliative care. As the Grattan Institute has stated in its 2014 report, *Dying Well*, "seventy per cent of people want to die at home, yet only about 14 per cent do so.[2]"

Further, there is evidence that hospital-based palliative care is more expensive than community alternatives. The average admission for palliative care in a sub-acute hospital can cost almost $11,000[3]. In comparison, community-based palliative care initiatives have a mean average cost of about $8000 per patient[4]. Analysis conducted by the Silver Chain Group found that for each dollar invested in extending home-based palliative care services in New South Wales, up to $1.44 of expenditure on inpatient bed capacity at metropolitan hospitals[5] would be freed up.

[2] Hal Swerissen and Stephen Duckett, above n^1, p.2.
[3] Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Inquiry Report, 2018, 144.
[4] Ibid, 145.
[5] Ibid.

Expansion of existing services

The ANMF supports equitable access for every Australian to high quality and safe end-of-life palliative care services. Yet, as the Productivity Commission recently noted in its inquiry report, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*:

"…of the 160,000 people who die in Australia…many do not receive care that fully reflects their choices or meets their needs…[further] services are not available everywhere and to everyone who would benefit[6]".

Considering the potential to reduce costs, meet end of life decisions and provide a more suitable environment for end-of-life care, the ANMF considers that ACT Government home and community-based services should be expanded to meet community demand.

Recommendations

1. The ANMF recommends that legislative reform reflects the principles outlined in the ANMF Position Statement on Assisted Dying (see Appendix A).

2. The ANMF recommends that the service delivery and education principle outlined in the ANMF Position Statement (Appendix A) are adopted.

3. The ANMF recommends the expansion and promotion of existing home and community based end of life care services in the ACT.

Conclusion

The ANMF looks forward to working with the ACT Government to reform this important area of health care for the benefit of the ACT community. Consequently, the ANMF urges the Committee to endorse our proposed recommendations.

[6] Productivity Commission, above n^2, 109.

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References

Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Inquiry Report, 2018

Swerissen, Hal and Duckett, Stephen, *Dying Well*, Grattan Institute 2014.

This submission is authorised by ANMF ACT Branch Secretary, Matthew Daniel

The ANMF thanks the Committee for the opportunity to make this submission and acknowledges the work of Mr Michael Quincey O'Neill (Assistant Industrial Officer, ANMF ACT) and Mr Ron Cawthron (Organiser, ANMF ACT) in the preparation of this submission.

Assisted dying

Assisted dying is a complex social issue which continues to be debated by the community. Those contributing to the debate include: providers of medical, nursing and midwifery care; those seeking to end their lives due to pain and illness; advocates for assisted dying; ethicists; religious organisations; and the broader community.

It has become an issue for a range of reasons including: the advent of modern medical technology which makes it possible to artificially prolong life; cases which have arisen where existing laws have been challenged, such as the Northern Territory '*Rights of the Terminally Ill Act of 1996*', which was overturned by the Australian Government; and the growing population of older people and those with terminal illnesses.

For the purposes of this position statement assisted dying is defined as intervention by one person to end or to assist to end the life of another person with that person's informed consent and with the primary intent of relieving pain and suffering.

It is the position of the Australian Nursing and Midwifery Federation that:

1. Society's approach to assisted dying should be informed by the moral and ethical dimensions of:
    a) respect for self-determination;
    b) concern for quality of life; and
    c) compassion for those who suffer.

2. Currently assisted dying is illegal in Australia. Registered nurses, enrolled nurses and registered midwives are obliged by both the law and their professional codes of practice and ethics, to practice within the law.

3. Adult patients with decision-making capacity have a common law right to consent to or refuse medical treatment which is offered to them. Refusal of medical treatment is not assisted dying and is legal.

4. We support advance care planning whereby individuals consider end-of-life decisions while they have the capacity to do so, and to provide instructions about their wishes for future treatment as direction for their family and health professionals. This is legal and does not necessarily restrict itself to decisions that would end life.

5. Our membership comes from diverse cultural, religious, and ethnic backgrounds, and our members hold a range of ethical views on the subject of assisted dying. Nurses, midwives and assistants in nursing have the right to hold their own opinion and for their opinion to be respected.

6. Registered nurses, enrolled nurses and midwives have a professional responsibility to stay reliably informed about the ethical, legal, professional, cultural and clinical implications of assisted dying.

7. Where a person expresses a wish for assistance to die, nurses should be educationally prepared to discuss the legal and medical parameters of this request as well as other options available to the person or seek the assistance of knowledgeable health care professionals.

8. We have a role in providing nurses, midwives and assistants in nursing with information about issues related to assisted dying and providing a forum for members to debate those issues. Our role is also to participate in the broader public debate as an appropriate organisation to ensure that the nursing and midwifery voice is heard.

9. We will continue to participate in the debate and will ensure a critical nursing and midwifery voice is represented in the public and political domains.

10. In the event that assisted dying becomes legalised, nurses, midwives and assistants in nursing:

    a) have the right to conscientiously object on moral, ethical or religious grounds, to participation or involvement in assistance with dying;
    b) are protected from litigation where they are requested to assist with the process.

11. Irrespective of whether assisted dying is legalised, the ANMF will continue to lobby for adequate resourcing of palliative care (including suitably qualified and adequate numbers of nurses and midwives) for those requesting and/or requiring palliation.

12. We support legislative reform so that persons who have an incurable physical illness that creates unrelieved, unbearable and profound suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes.

13. Legislative reform must ensure that no individual, group or organisation shall be compelled against their will to either participate or not participate in an assisted or supported death of a sufferer.

14. Legislative reform must ensure that it shall not be an offence to confidentially advise a sufferer regarding a voluntarily chosen death, assist or support such a death, or to be present at the time of that death.

15. Should legislative reform be introduced, specific criteria would provide safeguards for both the individual and those nurses and midwives involved in their care.

    For people who have an incurable physical illness that creates unrelieved, unbearable and profound suffering to obtain and use prescriptions from their treating doctor for the self-administration of lethal medication ending one's life in accordance with any state or territory law which does not constitute suicide, the following criteria must be met:

    The person must:

    a) be a resident of the state or territory where the request is made;
    b) be 18 years or older;
    c) be deemed 'capable' of making decisions:-
        - have the ability to make and communicate healthcare decisions.
        - have the appreciation of the relevant facts including medical diagnosis and prognosis.
        - be aware of the risks involved in taking the lethal medication.
        - be aware of any feasible treatment alternatives; and
    d) have made a voluntary, well considered request.

    The process must include a reporting regime (pharmacist and doctor).

endorsed December 2007
endorsed February 2009
reviewed and re-endorsed May 2012
reviewed and re-endorsed August 2015
reviewed and re-endorsed November 2016