Australian College of Nursing

Australian College of Nursing (ACN) submission to the ACT Legislative Assembly on the *Inquiry into End of Life Choices in the ACT (February 2018)*

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General comments

The Australian College of Nursing (ACN) strongly believes that an individual's dignity and choice are vital for end of life (EOL) care. Quality nursing care provided during EOL profoundly influences a person's quality of life, comfort and dignity during this vulnerable time. Care should be delivered in partnership with health professionals, individuals and their families and be responsive to changing needs and circumstances, whilst maintaining a person centred focus. EOL is one of four inaugural Policy Chapters endorsed by ACN. ACN's National Policy Summit held in April 2017, called for governments to invest in initiatives supporting individuals' choice regarding EOL care. This also echoes the nursing profession's health policy priorities. Specifically, ACN is in favour of changes to health policy reflecting community preferences in terms of both *when* and *where* terminally ill individuals prefer to die with dignity.

ACT law currently recognises an individual's right to refuse treatment, which may have a life-limiting effect, however, does not allow a person with a terminal illness to voluntarily end their own life at a time they choose to end suffering and preserve their dignity. ACN supports legislation that protects individuals and health professionals and ensures all necessary safeguards are in place that address issues of competence, conscientious objection and abuse of process. It is timely that the ACT government pass a Voluntary Assisted Dying Bill as seen in Victoria (effective from 2019) should terminally ill individuals choose this end of life pathway. More so, in Australia it is reported that while 70% of terminally ill individuals wish to die in their own home, only approximately 14% get that opportunity.[1,2] This is despite home-based palliative care programs demonstrating emotional benefits for individuals and families, as well as workload and financial benefits for hospitals and the health system more broadly. ACN supports the option of home-based palliative care services being increasingly available to the community.

Nurses play a pivotal role in EOL care and commonly receive requests for assisted dying (up to 18%), placing them in difficult professional, moral and legal positions.[3] This is either through providing or prescribing medication that could speed up an individual's death. Nurses must therefore be protected by policies outlining clear roles and responsibilities on EOL care and an individual's options. It would be appropriate to develop a well-defined scope of practice to improve respectful care decisions surrounding an individual's choice during all stages of care. Education at a state and territory level is necessary to ensure a skilled nursing workforce in supporting individual options for EOL care. In particular, nurses and other health care professionals require an improved understanding of EOL laws and Advance Care Plans (ACP) with wider community engagement regarding these. In addition, ACN believes the role of the Nurse Practitioner in the community setting can be better utilised within EOL care.

[1] Swerisson H and Duckett S, 'Dying Well' (2014). Accessed from: https://www.grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf.
[2] Broad J, Gott M, Hongsoo K, Chen H, and Connolly M, 'Where do people die? An international comparison of the percentage of deaths occuring in hospital and residential care settings in 45 populations, using published and available statistics' (2013). International Journal of Public Health, 58, p 257-267.
[3] Health Times, 'Dignity and choice vital for end-of-life care' (2017). Accessed from: https://healthtimes.com.au/hub/palliative-care/69/news/nc1/dignity-and-choice-vital-for-endoflife-care/3067/.

Reported Terms of reference:

(A) 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.

EOL care received by most Australians is costly[4] and does not reflect their values, goals or preferences.[5] From a national nursing perspective, Advance Care Planning (ACP) is considered essential in assisting people in exercising their EOL preferences and ensuring these are respected by family and health care professionals. ACN members have expressed that whilst ACP is considered best practice, many individuals enter palliative care without any documented wishes and there is a general lack of community awareness or uptake of ACP. In addition, whilst there is a National Palliative Care Program, palliative care service provision generally occurs through state and territory jurisdictions. As a result, there are differences in terms of available EOL options, particularly around the option to die at home. Individuals in Tasmania are fortunate to have the 'hospice@HOME' model of care, which involves the delivery of in-home, community based EOL services and enables individuals who wish to die at home to do so with the support of a multidisciplinary team of health professionals. Amongst the nursing profession and community, ACN would like to see greater promotion of EOL programs such as the ACT's 'Respecting Patient Choices Program', 'Dignity Therapy workshops' as run in Western Australia by Palliative Care Australia, and EOL resources such as 'Death over Dinner' promoting conversations about EOL preferences within the home.

The international literature shows that EOL care preferences utilised in the medical community are largely governed by the law. In a cross-national population-level study in 14 countries, the place of death (hospital or home) of people was largely influenced by the countries' palliative and EOL care policies rather than sociodemographic characteristics.[6] In addition, whilst most developed countries have appropriate palliative care services to ease symptoms, provide comfort and promote quality of life[7] either within a hospital, outpatient clinic service, home, residential care facility or inpatient hospice service,[8,9] not all provide a legalised option for voluntary euthanasia (health provider controlled) or assisted dying (patient controlled). Whilst assisted dying is generally restricted to terminally ill adult patients who are deemed mentally competent, the Netherlands and Belgium have extended euthanasia to infants with disabilities and children respectively.[10,11,12] ACN understands that although these options are exercised abroad, these choices may cause ethical concerns for members within the nursing profession of Australia. Nurses play a crucial role in providing care and services to individuals nearing the end of their life. ACN would advocate for, and would like to see an increase in, nurses being more actively invited to participate in discussions related to EOL care.

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[4] Bartel, R. (2016) 'Conversations: Creating Choice in End of Life Care', Melbourne: Australian Centre for Health Research (ACHR). Accessed from: http://www.achr.org.au/wp-content/uploads/2016/02/Conversations-Choice-in-End-of-Life-Care-ACHR-20161.pdf.
[5] Jones A, and Silk K, 'Improving end-of-life care in Australia' (2016), Deeble Institute issues brief. Accessed from:
[6] Pivodic L et al., 'Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries' (2016). Epidemiol Community Health. 70:17–24.
[7] Alliance Hospice, 'Palliative Care' (2018). Accessed from: http://alliancehospice.com/services/palliative-care/.
[8] Cancer Council ACT, 'Palliative and Hospice Care', (2018). Accessed from: http://www.actcancer.org/information-and-support/publications/cancer-services-directory/palliative-hospice-respite-care-and-holiday-break-services/.
[9] Alliance Hospice (2018).
[10] Verhagen AAE, and Sauer PJJ, 'End-of-life decisions in newborns: an approach from the Netherlands' (2005) Pediatrics 116.3:736-739.
[11] Siegel AM, Sisti DA and Caplan AL, 'Pediatric euthanasia in Belgium: disturbing developments' (2014). JAMA 311.19:1963-1964.
[12] Carter BS, 'Why Palliative Care for Children is Preferable to Euthanasia' (2014). American Journal of Hospice and Palliative Medicine.

It is evident that improving EOL care is not only a key issue in Australia but also internationally as countries face increasing health care demands brought on by an ageing population and increasing proportions of people suffering from multiple co-morbidities and chronic disease.[13] ACN believes the quality of EOL care can be improved by encouraging conversations and promoting public awareness around EOL preferences and ACP; integrating ACP documents within My Health Record; developing a nationally consistent framework around EOL decision making; and improving access to EOL care in different settings including preferred settings.[14] ACN advocates for enhancing the role of primary care services in managing EOL care; and providing appropriate training to the EOL and palliative care workforce.[15]

(B) ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

Community views expressed on this topic are varied. There are those who strongly support national legislation of voluntary assisted dying based on alleviating any pain or suffering experienced by terminally ill patients with suicidal thoughts. Alternatively, others oppose legislation due to moral or religious objections, or beliefs that palliative care services are satisfactory in terms of care, pain relief and grief counselling. In addition, some believe palliative care services should be strengthened prior to considering any assisted dying legislation, and that more individuals articulate their desire for adequate pain relief rather than assisted dying.

EOL care options are becoming increasingly important to the ACT community as palliative care services are reported to be overstretched. In particular, there have been delays in commencing home-based palliative care services due to overwhelming workloads. Palliative Care Australia has also noted that only one palliative medicine specialist exists for every 704 deaths nationally, which affects a patient's EOL journey.[16] ACN supports people's right to choice and nurses have a clear role in advocating, educating and informing patients, their families and carers of their EOL options and rights. There should be a focus on the provision of EOL care services in the setting most suitable for the individual (home, aged care facility, hospice). ACN advocates for services to provide round-the-clock care and support, and be adequately resourced by suitably qualified staff including registered nurses and Nurse Practitioners. This would assist in reducing delays in access to services and promote meaningful and respectful experiences for patients, families and staff.

(C) Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.

There are various potential risks to both the *individuals* involved and the *community* that need to be discussed and addressed before considering legalisation of voluntary assisted dying in the ACT. Much can be learnt from countries in Europe where assisted dying has been legalised and in operation for many

[13] Australian Institute of Health and Welfare, 'Australia's Health 2016' (2016). Australia's Health Series no.15. Cat. No. AUS 199. Canberra: AIHW
[14] Australian Institute of Health and Welfare, 'Australia's Health 2016' (2016). Australia's Health Series no.15. Cat. No. AUS 199. Canberra: AIHW
[15] Parliament of Victoria, 'Inquiry into end of life choices Final Report' (2016). Accessed from: https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf.
[16] Canberra Times, 'Not the way they wanted to die: Final wishes of thousands of Australians go unmet' (2018). Accessed from: http://www.canberratimes.com.au/federal-politics/by/Anne-Davies-gh5roe.

years.[17] Complications such as spasm, gasping for breath, cyanosis, nausea or vomiting, longer-than-expected time to death, failure to induce coma, or re-awakening of the individual have been reported in the Netherlands, resulting in subsequent euthanasia rather than requested assisted dying.[18] Similarly the risk of intentional life ending without consent or underreporting of euthanasia has been reported in Belgium, and this is most likely to occur under nurses' care.[19,20,21]

Acknowledging these risks, ACN strongly believes there should be a focus on providing quality nursing care that promotes quality of life, dignity, respect of choices and comfort during any stage of a person's EOL care. To ensure this occurs there should be a focus on providing nurses and other health care professionals with nationally consistent education on scope of practice, EOL laws and ACP. ACN also believes that mechanisms need to be in place to address specific risks that may arise in relation to the *individual* and *community* (detailed below).

Specific and potential risks to the *individual* include:

1) Misdiagnosis of terminal illness, prognosis and/or life expectancy. ACN believes individuals should be able to seek alternative clinical opinions without judgement if they choose to do so. This may assist individuals in making an informed decision they are ultimately comfortable with when it comes to accessing assisted dying or other EOL care options.
2) Unsuccessful attempts at assisted dying with a lethal dose of medication not being effective. ACN believes clear guidelines must be provided by government/health authorities for use by health care professionals in these situations to address any potential physical and emotional impact on the individual and their family.
3) Religious or moral dilemmas and uncertainty about what happens in death. ACN supports the need for clear guidelines detailing how health care professionals can address the potential mental and emotional impact on these individuals and their family.
4) Vulnerable individuals (e.g. those suffering from depression, the elderly, persons who see themselves as a burden) may be influenced or pressured into accessing assisted dying by family members or carers who wish to benefit financially from the individuals' assets. ACN believes health care professionals should be provided with clear guidelines aimed at identifying these scenarios, as well as protecting and maintaining the dignity of vulnerable individuals.
5) Liability of health professionals performing assisted dying incorrectly or outside the span of complex EOL laws. ACN believes health care professionals must be protected by providing them with education around EOL laws, ACPs and nationally consistent scope of practice guidelines outlined through the Australian Health Practitioner Regulation Agency (AHPRA).

[17] The Guardian, 'Euthanasia and assisted suicide laws around the world' (2014). Accessed from: https://www.theguardian.com/society/2014/jul/17/euthanasia-assisted-suicide-laws-world.
[18] Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD, Willems DL, van der Maas PJ, and van der Wal G, 'Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands' (2000). New England Journal of Medicine, 342(8), 551-556.
[19] Cohen-Almagor R, 'First do no harm: intentionally shortening lives of patients without their explicit request in Belgium' (2015) Journal of Medical Ethics.
[20] Smets, Tinne, et al, 'Reporting of euthanasia in medical practice in Flanders Belgium: cross sectional analysis of reported and unreported cases' (2010). British Medical Journal 341: 5174.
[21] Inghelbrecht, Els, et al., 'The role of nurses in physician-assisted deaths in Belgium' (2010). Canadian Medical Association Journal. 905-910.

Specific and potential risks relating to the *community* include:

1) Perceived stigma amongst people from Aboriginal and Torres Strait Islander (ATSI) or Culturally and Linguistically Diverse (CALD) communities concerning voluntary assisted dying. ACN believes the values and wishes of these people must be considered by providing more culturally appropriate and responsive EOL care options for people from diverse backgrounds. ACN advocates that health care professionals be prepared to explore what is culturally appropriate as part of their EOL care.
2) Inability to access services due to disadvantaged circumstances (e.g. homeless) or lack of available services in a particular area (e.g. rural or remote areas). There is the potential for people to move across states and territories to access assisted dying if it is not legalised within their area. ACN advocates for consistent national legislation for voluntary assisted dying.
3) The erosion of existing palliative care services and ACP services which have been effective for many years in providing quality care at a person's end of life.
4) The impact of grief, fear and misunderstanding for people in the community and family members. ACN believes mechanisms must be in place to address these concerns.
5) Complicated laws may affect community understanding of their responsibility and the criteria for accessing assisted dying. ACN recommends appropriate referral pathways for addressing complex laws around EOL, which may differ between states and territories. For example, the Queensland University of Technology (QUT) have a dedicated website named "End of Life Law in Australia" which aims to assist individuals, families, health professionals and others in navigating legal issues that can arise around EOL decision-making.[22] ACN believes there should be greater public awareness about accessing useful legal information and health care professionals should be informed and aware of appropriate resources.

(D) The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme.

ACN believes the Victorian scheme may be used to inform applicability of voluntary assisted dying schemes in the ACT. However, given that it has not yet been operationalised in Victoria it may also be appropriate to look at other countries such as Belgium and the Netherlands, where such schemes have been effective for many years, to assess risks, benefits, processes, and procedures that could be effective in the ACT.

In the Victorian scheme, eligibility for access to voluntary assisted dying is grounded on having a terminal disease from which an individual will die within six months.[23] This timeframe is often uncertain and predicted with variability in estimations between doctors. The applicability of this may be challenged amongst the ACT community.

[22] Queensland University of Technology (QUT), 'End of Life Law in Australia' (2018). Accessed from: https://end-of-life.qut.edu.au

[23] Parliament of Victoria, 'Inquiry into end of life choices' (2016). Accessed from: https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

(E) The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change.

Whilst the Australian Government (federal legislation) does not have the power to overturn legislation in the states of Australia, which are considered sovereign entities, it can do so in self-governing territories as these have no legislative power. Given that the ACT is not a state, and as seen in the Northern Territory (NT), laws can be changed within territories. The Parliament of the NT legalised euthanasia in 1995 under the Rights of the Terminally Ill Act 1995, following a majority of the territory in support of assisted dying. However, the Federal Parliament overturned this when it passed the Euthanasia Laws Act 1997. Many of our ACN members believe that the rights, responsibilities and clearly expressed requirements of those residing in Territories should not be seen as less than those living in a state of Australia.

In saying that, ACN believes that legislation should be based on best practice situations that are accountable to the Australian public and based on the needs of the Australian population. Consistent legislation across Australia and informed by the Victorian trial should be considered to ensure a cohesive understanding and operational model around this complex topic.

(F) Any other relevant matter. Other relevant matters include:

1) ACN believes there is significant capacity and capability in the autonomous role of the community Nurse Practitioner in improving an individual's access to high quality palliative and end of life care. In 2016 there were 52 palliative care Nurse Practitioners[24] working clinically in Australia; ACN would like to see this number increase.
2) ACN believes it would be beneficial for society to have a deeper understanding of issues around death, the end of life journey, the delivery of palliative and end of life care services and the role of nurses in the health care team.
3) Eligibility for voluntary assisted dying reflects opinion among health professionals on estimated time of dying from a terminal illness. Discussion is required about the applicability of individuals who suffer from a non-terminal illness or disability for voluntary assisted dying. There are many individuals experiencing mental suffering due to loss of control, chronic depression or early dementia that may wish to access such services, and ACN believes their views should be included in discussions.[25]

[24] Australian Government Department of Health (2016) 'Nurse Practitioners NHWDS 2016 Fact Sheet'.
[25] Kouwenhoven PSC, et al. 'Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach' (2013). Palliative medicine 27.3: 273-280