

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: New South Wales Nurses and Midwives' Association
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Submission to the NSW Legislative Council Standing Committee on Law and Justice inquiry into the provisions of the Voluntary Assisted Dying Bill 2021

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Recommendations

1. The NSWNMA recommends that the Voluntary Assisted Dying Bill 2021 be passed in its current form.

Foreword

The New South Wales Nurses and Midwives' Association (NSWNMA) is the registered union for all nurses and midwives in New South Wales. The membership of the NSWNMA comprises all those who perform nursing and midwifery work. This includes: registered nurses; enrolled nurses and midwives at all levels including management and education, and assistants in nursing and midwifery.

The NSWNMA has approximately 73,500 members and is affiliated to Unions NSW and the Australian Council of Trade Unions (ACTU). Eligible members of the NSWNMA are also deemed to be members of the New South Wales Branch of the Australian Nursing and Midwifery Federation.

NSWNMA strives to be innovative in our advocacy to promote a world class, well-funded, integrated health system by being a professional advocate for the health system and our members. We are committed to improving standards of patient care and the quality of services of all health and aged care services whilst protecting and advancing the interests of nurses and midwives and their professions.

We welcome the opportunity to provide a submission to this Inquiry.

This response is authorised by the elected officers of the New South Wales Nurses and Midwives' Association

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NSWNMA Position

The NSWNMA actively pursues our members' rights and supports member empowerment to influence decision makers for a fair and just society. It is the position of the NSWNMA that a fair and just society is one in which people with a terminal illness are afforded choice in the care and medical treatment they receive at the end of their life, including access to voluntary assisted dying (VAD).

The NSWNMA, as a branch of a national nurses' association, is required to develop position statements and guidelines that support human rights and ethical standards¹.

NSWNMA delegates, at our Annual Conference in 2017, first endorsed a position statement supporting the introduction of a legislative framework for access to voluntary assisted dying. This position statement supports the human rights of people to have liberty to make decisions with regard to their health care and treatment.

The NSWNMA supports legislative reform so that persons with a terminal or incurable illness that creates unrelieved, 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.²

A copy of the current NSWNMA position statement is **attached**.

As a member of the NSW VAD Alliance, the NSWNMA was grateful for the early opportunity to provide feedback in relation to a draft Bill. The NSWNMA wholly supports the passing of this Bill in its current form.

This Bill provides for a clear and robust process that enables access to VAD in appropriate circumstances, whilst maintaining the rights of people to conscientiously object to participation in the process. The NSWNMA is also comfortably satisfied with the range of legislative protections that are provided for nurses and other health care workers who may participate in the process or engage in discussions with patients regarding VAD.

VOLUNTARY ASSISTED DYING AND NURSING PRACTICE

Nurses and midwives exercise their right to a voice on professional issues, such as VAD, through the NSWNMA. Voluntary assisted dying is a professional issue for our members.

Members of the NSWNMA who provide palliative care are predominantly registered nurses and enrolled nurses. Registered nurses are required to be respectful of a person's dignity culture, values, beliefs and rights and must recognise that people are the experts in the experience of their life. Importantly,

¹ *The ICN code of ethics for nurses*, International Council of Nurses, 2012

² *Position Statement on Voluntary Assisted Dying*, New South Wales Nurses and Midwives Association, 2021

registered nurses must advocate on behalf of people in a manner that respects the person's autonomy and legal capacity.³

Enrolled nurses are required to practice in a way that ensures the rights, confidentiality, dignity and respect of people are upheld, must place people receiving care at the centre of care and support them to make informed choices.⁴

Registered nurses and enrolled nurses have a professional obligation to provide culturally appropriate end-of-life care and must understand the limits of healthcare in prolonging life, recognise when efforts to prolong life may not be in the best interest of the person; accept that the person has the right to refuse treatment, or to request withdrawal of treatment, while ensuring the person receives relief from distress and must respect diverse cultural practices and beliefs related to death and dying.⁵

SURVEY OF MEMBERS

In October 2021, the NSWNMA undertook a survey of members to seek feedback in relation to their experiences regarding caring for persons with a terminal illness. With over 4,000 responses it was clear that our members were keen to share their professional and personal experiences.

Over 85% of the members who responded to the survey agreed that people should have access to VAD and were in support of the NSW Government introducing VAD legislation.

The feedback received from our members was heartbreaking. Nurses, in their continued advocacy for their patients, have shared their stories of the experiences of those patients. Throughout this submission, our members' words (in blue) are provided to give an honest, first-hand picture of their experience caring for people with a terminal illness.

'Too many times I have watched people suffer to their death with pain medication no longer relieving their symptoms during palliation.'

'I have cared for many patients at "end of life", unfortunately even the expertise of palliative care is not always able to manage persistent pain, or intractable nausea. Dying while vomiting faecal fluid with distended painful abdomen from bowel cancer, with distressed family, watching faecal fluid ooze from their loved ones mouth. Fungating tumours oozing from abdomen, from obstructed ovarian cancer. The fear in people's eyes that even worse maybe yet to come. The distress for some patients, that they feel they do not wish their families to see them suffer.'

'I worked in community palliative care for two years and was asked many times to end suffering. I naively believed at the time that good palliative care negated any need for VAD. I remember one young man dying from stomach cancer that was

³ *Registered nurse standards for practice*, Nursing and Midwifery Board of Australia, 2016

⁴ *Enrolled nurse standards for practice*, Nursing and Midwifery Board of Australia, 2016

⁵ *Code of conduct for nurses*, Nursing and Midwifery Board of Australia, 2018

cachexic and really suffering. Good palliative care didn't alleviate his last miserable weeks. I also cared for my mother-in-law and my mother who both died of bowel cancer. My mother-in-law tried to commit suicide by an overdose and was unsuccessful. Following her surgery, her first words to me via a whiteboard were "kill me". It was tragic and heartbreaking for all the family and also for her nurses. That conversation still haunts me.'

The personal and professional experiences of nurses must be considered as an important and influential voice advocating for those terminally ill patients who have suffered and who no longer can advocate for option of having choice in relation to how and when they die.

'Palliative care can help manage symptoms but sometimes the symptoms are beyond the use of medicine or therapy. I have recently had a palliative patient in the last months of life attempt suicide as it was her last resort, she spent the remainder of her weeks in extreme emotional distress. If patients have a choice early in the journey, they may have a more peaceful death and they can control the circumstances of their death which is so important as they have a complete lack of control as their disease progresses'

'I've been a nurse for over 40 years - and even thought here have been great strides in palliative care, people still die in pain, distress, and without dignity. My father begged me to shoot him. It's cruel to leave people to suffer.'

Over 53% of members who responded said that they have been asked by terminally ill patients to assist them to end their life.

'I have laid on the hospital floor with a patient who was dying from a brain tumour. She was only 36 years old. A mother, a primary school teacher. I still see her face in my dreams, and I am still traumatised by this every day. I have held, comforted, and cried with countless family members as they watch their loved one suffer and slowly die! "Do something!" they will say. "I can't, sorry". This is so cruel; the committees, Government bureaucrats need to listen. I have nursed, nurtured, held the hand, and looked into the eyes of my patients suffering whilst they die. Gasping for air, grasping for that physical, warm human touch, looking- calling out, they cry, start to sing, turn blue, turn grey. I go home after my shift, must be strong for my family, pretend I am all good, but go to bed and cry all night. Then do it all again the next day.'

'Saddest day of my nursing career of 40 odd years was just recently when a terminal cancer patient said to me "I wouldn't put my dog through this, why do I have to go through it..." Why, indeed. It brought tears...'

Suicide by people with a terminal illness

The impact of suicide by people with a terminal illness must not be understated. It is a catastrophic trauma that reverberates from the person through to their family, friends, first responders and health care workers.

'I have cared for patients who have attempted to take their own lives in violent and horrific ways. These patients were not suffering from depression rather intractable suffering related to their terminal illness. These circumstances are so tragic.'

The trauma suffered in such circumstance creates an ongoing social cost which is directly associated with a lack of access to VAD.

'My brother-in-law committed suicide by hanging after a short battle with terminal lung cancer and was wanting the option of voluntary dying. My sister has long effects from finding his body and my brother-in-law was denied a peaceful death with loving relatives by his side. Please help to change the law.'

New data from the National Coronial Information System reveals one in five people over 40 who took their life in NSW in 2019 had a terminal illness.⁶

'It is sad that some feel it necessary to commit suicide so that they may die peacefully.'

Person-centred care

A fundamental principle of nursing care is that it must be person-centred. Person-centred care is defined as care that is respectful of, and responsive to, the preferences, needs and values of the individual patient.⁷

The current inability of nurses to provide care that is responsive to and reflective of the values and preferences of people with a terminal illness is a source of immense professional frustration.

The feedback from members expressed sadness and disbelief at the cruelty of suffering experienced by people with a terminal illness.

'I have cared for many terminally ill patients who have expressed a wish to have more choice in their treatment and the way they are going to die (including when they are going to die). They have led fulfilling lives and are deeply distressed by the suffering they have endured. I have had many requests to help them find a way to end their lives with dignity and in comfort. We do our best with the medical

⁶ *Intentional self-harm deaths of people with terminal or debilitating physical conditions in New South Wales 2019*, National Coronial Information System (prepared for Dying with Dignity NSW), July 2021

⁷ Australian Commission on Safety and Quality in Health Care [<https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care>]

interventions we have available and this is adequate in most cases, but there are always circumstances when the death comes slowly and painfully'

'How can we push person centred care in the healthcare model and then not honour someone's choice to die with dignity when they no longer want to suffer? My step-father lives a tortuous life day in, day out, waiting and wishing for it all to end. Society has advanced to a level where he could be assisted but instead he has no choice but to suffer. It is horrible for him and horrible for our family.'

'I find it unconscionable that an adult is not allowed to make the decision to end his or her life using assisted voluntary euthanasia. Just knowing that you can end your life if required puts people's minds at rest. Research has shown that people are highly unlikely to use this, but are greatly comforted by knowing it is available.'

'So many terminally ill people and their families become so distressed when their wishes to not go on are not met. It is incredibly distressing and frustrating to nursing staff and doctors when we have patients crying and begging to be assisted to die. Each individual has the right to make an informed decision'

'I have witnessed the suffering of patients and their loved ones - watching a loved one wasting away physically and mentally to someone barely recognisable is a truly cruel way to end one's life and if I had a dollar for every patient and person who have said that we treat our pets better at end of life than human beings I would be a millionaire.'

'People need to think of the ongoing pain and suffering that is endured by people with terminal illness when there is no more hope, there is no more treatment and they are just waiting out the days, and those days are spent suffering in unbearable pain, unbearable nausea and unbearable fatigue. If you are strong enough to make the decision to say enough is enough and you're happy to leave the world, then I think you have the right to end your life on your terms. It's an incredibly brave decision.'

Personal experiences of members

NSWNMA members, as members of the broader community, have also shared their personal experiences involving the care of family and friends with a terminal illness.

My husband has terminal cancer, and luckily has a slow bleed which means he will die in the next few days. I thank God he has the bleed so he and I do not have to endure months of slow death. We are one of the lucky few. If legislation was in place at least he could choose to end it. The thought of enduring more months of pain and suffering is horrendous, we are so lucky.

'I watched my dad choosing to end his life, and having to do it in a sneaky way, so people he loved could not be charged with assisting a suicide. It was so wrong. I think if there had been assisted dying, he would not have done it there and then, but would have pushed on, knowing that when it got too much...he would have a choice.'

'My daughter is dying of terminal, incurable stage 4 cancer. I fully agree [with VAD], when there is no chance of recovery for an individual to be able to make their choice on how and when they will pass on.'

'I have been a Registered Nurse for 43 years and have seen many patients who have suffered and died in extreme pain and agony over many months despite analgesia. My father died of septicaemia from a gangrenous leg, he was in a Nursing home, he was pleading and praying for God to take him because his pain and suffering was too much to bare, the Nurses and Dr gave him an inadequate, miniscule amount of Morphine (1mg) the day that he died, they feared that a further dose would stop him from breathing. My Father was in extreme pain until the moment he died. We were extremely upset as family members watching this tragic event.'

Concerns that religious beliefs will obstruct access to VAD

The survey responses demonstrated that among our membership there are palpable concerns that the religiosity of members of parliament was going to impede the ability for patients to exercise personal choice in relation to how they manage their terminal illness.

"People should not suffer because of someone else's religious beliefs".

'I believe religion and politics should remain separate. I am very concerned about how religious members of parliament have the potential to impact what should be the choice of the individual and of their own personal beliefs and their right to be treated with humanity and dignity.'

'This is a secular society, and all these religious people have no right to burden others with their beliefs ... if YOU don't want VAD don't have it, but do not enforce your ideas on those who do not agree and want it for themselves. I have worked in Community Palliative Care for 15 years. It is about time that the vast majority of people get their human rights listened to.'

I believe that religious beliefs should not be considered when determining legislation that is available to all. Religious beliefs have a part to play in the individuals' decision making when they reach the final stage of their own life. The

degree of suffering and acceptance of death should always be a personal choice. We all make peace with our final stage of life in very different ways. No one has the right to extend the suffering of others who have celebrated life and accepted dying.

'It is deeply disturbing to me the degree to which the religious beliefs of our leaders influence state policy decisions. The degree of extreme religious dogma upheld by key politicians does not reflect the views of the broad community as reported by census data.'

RIGHT TO CONSCIENTIOUS OBJECTION

A slim minority of respondents to the survey expressed a personal disagreement with the introduction of the Bill. Almost all dissent among respondents articulated that the basis for their position was due to their personal religious beliefs. Such responses were absent any acknowledgment that people who may wish to access voluntary assisted dying do not share their faith.

The NSWNMA Position Statement clearly supports the rights of our members to conscientiously object to participating in VAD.

The provisions of the draft Bill (s9) enshrine the protection of those members and their right not to participate.

RESPONSE TO CONCERNS REGARDING EXPLOITATION AND WEAKENING OF PROVISIONS

The introduction of voluntary assisted dying legislation would provide a framework for the regulation of VAD to relieve a person's suffering and provides protection to those health practitioners who are providing care.

The NSWNMA is supportive of the Bill and rejects any argument that the introduction of access to VAD for a defined cohort of people with a terminal illness will likely result in wider categories of people being eligible in the future. This assertion is not supported by evidence following the implementation of a legislated framework for VAD in the United States.

There is strong evidence⁸ from Oregon, where voluntary assisted dying has been regulated for over 20 years that does not support claims that this kind of legislation results in vulnerable people being manipulated or exploited. The Journal of the American Medical Association found that although physician assisted suicide was becoming increasingly legalised, it remained relatively rare and primarily involved patients with cancer. They also found that there was no indication of widespread abuse of the practice.

⁸ Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J., Journal of the American Medical Association, 2016 10.1001/jama.2016.8499

The draft Bill is rigorous in its requirements and would require a person with a terminal illness to go through significant steps with repeated requests to multiple health practitioners. The generation of fear about such laws being 'watered down' is also not reflected in the experience of all other Australian states.

'I previously was against VAD as a Palliative Care nurse. I thought people could be managed with good palliative care. But sometimes it's really hard to manage symptoms. As someone that works on the border and cares for Victorian patients - I have seen VAD happen and it has always been a good outcome.'

CURRENT END-OF-LIFE TREATMENT OPTIONS AND LIMITATIONS ON PALLIATIVE CARE

Our members provide high quality palliative care that, for the majority, is able to alleviate physical pain and provide adequate comfort. Unfortunately, palliative care is not effective for all patients and some experience unbearable pain and suffering for prolonged periods of time.

'30 years working in blood cancer field has brought few improvements in end of life care.'

'Being a palliative care nurse, I have seen persons with unrelieved symptoms associated with physical, emotional, psychological and spiritual distress.'

'I have nursed so many people who, at the end of their lives suffered more than they have ever suffered in their whole lives. I have seen people die in incredible pain, bleeding to death, drowning in their own secretions, climbing over bed rails due to terminal agitation.'

'Palliative care does the best it can within its legal parameters. The way most humans die is not dignified. It is a long, painful drawn out affair.'

As a palliative care nurse, I strongly support VAD - everyone should have the right to choose their death care if possible. While palliative care is important it is not always able to relieve suffering'

'When all other measures have been exhausted to manage the pain of someone who is terminal; the solution to put them on opioids or syringe drivers that knock them out anyway is not quality of life. As long as the person can make the decision with capacity and demonstrate an understanding, with the choice to change their mind right up until the end, this is the definition of 'patient-centred compassionate care.'

'There are occasions when a dying patient is suffering no matter how much care and analgesia you give them'

'I have witnessed some hideous deaths both in family and professionally. It is so wrong. For all those people who banter on about better palliative care, in my experience as it stands it doesn't work in giving people a pain free and comfortable death. Bring on voluntary assisted dying.'

Some of the feedback received by members advocated for broader medication options available for prescription by medical practitioners with regard to managing pain and anxiety in the context of palliative care. The NSWNMA supports people with a terminal illness having access to medicinal cannabis where, in consultation with their authorised prescriber, they receive some therapeutic benefit from it.⁹

Terminal sedation

At present, patients are having their deaths hastened by the use of terminal sedation and increasing doses of analgesia. This is not prohibited because the primary intention of the administration of this medication is to relieve suffering and not to hasten death, even if hastening death is a consequence. This means that assistance in dying is already occurring in an unregulated manner and often too late for a person to be aware that it is occurring.

'Permitting/assisting a person to pass with dignity should be legalised. Drs have been making this decision for decades as part of the Palliative care regime regardless of legality.'

'We euthanise patients quite regularly actually it would just be nice for them and family to have a framework around that'

'Assisted dying for those with a terminal illness is already practiced in hospitals, hospices and aged care facilities. It should be legalised to prevent misuse and the potential for the suing of all staff.'

It is important that any person with a terminal illness is afforded the choice of how and when they die and are able to request and consent to the administration of medication which has the consequence of ending their life.

IMPORTANCE OF PROPERLY FUNDED PALLIATIVE CARE SERVICES

High quality palliative care should be available to all people experiencing terminal illness and we will continue to lobby for adequate resourcing of palliative care regardless of the outcome of this Bill.

⁹ *Position Statement on Medicinal Cannabis*, New South Wales Nurses and Midwives Association, 2019

The NSWNMA 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.¹⁰

The NSWNMA continues to lobby for nurse to patient ratios across NSW, including in palliative care inpatient settings.

High quality palliative care and VAD are not mutually exclusive. It is the position of the NSWNMA that all people with a terminal illness are entitled to receive high quality, well-resourced palliative care as well as having the option to access VAD in the proposed regulated manner.

¹⁰ *Position Statement on Voluntary Assisted Dying*, New South Wales Nurses and Midwives Association, 2021



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POSITION STATEMENT ON VOLUNTARY ASSISTED DYING

Re-Endorsed by Annual Conference 2021

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Position Statement on Voluntary Assisted Dying

Note: This position statement has been adapted from the ANMF Position Statement on Assisted Dying.

For the purposes of this position statement voluntary assisted dying is defined as a regulated medical intervention by one person to end or to assist to end the life of another person, at that person's request, with the primary intent of ending pain and suffering.

Voluntary assisted dying is a complex social issue which causes debate in the community. Those contributing to the debate include: providers of health care, people seeking to end their lives due to pain and illness and their families, advocates for assisted dying, ethicists, disability advocates, religious organisations, and the broader community.

Presently, over 17 jurisdictions around the world have legalised or decriminalised some form of voluntary assisted dying

In 2017, the Victorian Parliament passed the *Voluntary Assisted Dying Act 2017* (Vic). This Act came into effect on 19 June 2019. This law gives terminally ill people in Victoria the ability to request assistance to die.

In December 2019, the Western Australian Government passed the *Voluntary Assisted Dying Act 2019* (WA). This Act will come into effect on 1 July 2021 and provide Western Australian residents with a terminal illness the ability to access voluntary assisted dying.

In Tasmania, the *End-of-Life Choices (Voluntary Assisted Dying) 2020 Bill* was passed in the House of Assembly on 4 December 2020. The Bill was passed through the Legislative Council on 23 March 2021.

On 4 June 2021, the South Australian Parliament passed the *Voluntary Assisted Dying Bill*. It is anticipated that voluntary assisted dying will be available in South Australia by mid-late 2022.

On 17 October 2020, the people of New Zealand voted in the *End of Life Choice Act* referendum to legalise voluntary assisted dying with 65.2% of votes in support of the Act. This will result in the law coming into effect sometime before 6 November 2021.

There have been nine unsuccessful attempts to introduce voluntary assisted dying legislation in New South Wales^{1,2}. It is anticipated that there will be future attempts to introduce this legislation in NSW.

IT IS THE POSITION OF THE NSW NURSES AND MIDWIVES' ASSOCIATION THAT:

1. People receiving end-of-life care have a right to maintain their dignity, comfort, and privacy, and to be cared for respectfully and with compassion⁴.

2. Nurses must provide culturally appropriate end-of-life care and recognise when efforts to prolong life may not be in the best interest of the person⁵.
3. Nurses must accept that a person has the right to refuse treatment⁶, or to request withdrawal of treatment, while ensuring the person receives relief from distress.
4. Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect⁷.
5. Our approach to voluntary assisted dying is informed by the moral and ethical dimensions of:
 - respect for self-determination;
 - primacy of quality of life; and,
 - compassion for those who suffer.
6. Currently, voluntary assisted dying is illegal in New South Wales. Nurses are required by both the law and their professional codes of conduct and ethics, to practice within the law.
7. Refusal of medical treatment is not voluntary assisted dying and is legal⁸. Adults with decision-making capacity have a common law right to consent to or refuse medical treatment which is prolonging their life.
8. Our membership comes from diverse cultural, religious, and ethnic backgrounds, and our members hold a range of ethical views on the subject of voluntary assisted dying. Nurses, midwives and assistants in nursing/midwifery have the right to hold their own opinion and for their opinion to be respected.
9. We support legislative reform so that persons with a terminal or incurable illness that creates unrelieved, 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.
10. 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 person.
11. Legislative reform must ensure that it shall not be an offence to confidentially advise a person regarding a voluntarily chosen death, assist or support such a death, or to be present at the time of that death.
12. In the event that voluntary assisted dying is legislated in New South Wales, nurses and assistants in nursing:
 - have the right to conscientiously object on moral, ethical or religious grounds to participate or have involvement in assistance with dying;
 - must be protected from civil liability and disciplinary proceedings when they are requested to assist with the process.
13. Where a person expresses a wish for assistance with dying, nurses should be educationally prepared to discuss the legal and medical parameters of this request and must consider what referrals need to be made in accordance with the nursing practice decision flowchart⁹.

14. We have a role in providing nurses, midwives and assistants in nursing/midwifery with information about issues related to voluntary assisted dying and providing a forum for members to debate those issues. Our role is also to participate in the broader debate as an appropriate organisation to ensure that the nursing and midwifery voice is heard in the public and political domains.
15. Irrespective of whether voluntary assisted dying is legislated in New South Wales, as a branch of the ANMF, the Association 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.

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