

Response to the *Voluntary Assisted Dying Bill NSW (2017)*

Submission from Palliative Care NSW

Palliative Care New South Wales Inc

Palliative Care NSW Inc (PCNSW) is the peak body for Palliative Care in NSW. We represent a membership that consists of a range of Palliative Care clinicians and allied health professionals. Our aim is to promote awareness of Palliative Care through education and networks for the health workforce and broader NSW community.

Introduction

This submission was prepared by the Management Committee of PCNSW on behalf of its membership. Our members represent a broad cross-section of Palliative Care specialists including nurses, physicians and allied health as well as volunteers and members of the general public with an interest in Palliative Care. Members are the target audience for conferences, education days and workshops.

During December 2016 and January 2017 Palliative Care NSW sought the views of members on euthanasia and voluntary assisted dying through an online survey.

The results of the survey indicated that some 65% of respondents were against Euthanasia and Physician Assisted Dying. When asked whether members supported the introduction of legislation the results were less clear with about 57% of members against the idea.

Following the results of the membership survey, PCNSW as a peak body, has a responsibility to its members and the broader Palliative Care community (including patients and carers) to ensure that as an organisation, it is part of any robust discussion, comment and critique of any proposed introduction of VAD in NSW.

This position reflects that of Palliative Care Australia whose position statement on Euthanasia and Physician Assisted Suicide can be found http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/08/20160823-Euthanasia-and-Physician-Assisted-Suicide-Final.pdf.

In summary that statement says:

Internationally, legislation of euthanasia and physician assisted suicide are two frequently debated issues that are seen as important matters for society to consider. These issues are highly complex and raise significant and ethical issues. PCA acknowledges that there is a broad spectrum of opinion and a level of support for reform within the Australian community which reflects diverse cultures, belief

systems and populations. PCA recognise that some competent people may elect to request euthanasia or physician assisted suicide.

Palliative Care Australia believes:

- *The practice of Palliative Care does not include euthanasia or physician assisted suicide.*
- *Palliative care does not intend to hasten or postpone death.*
- *Every Australian living with a life-limiting illness should have timely and equitable access to quality, evidence-based Palliative Care and end-of-life care based on needs.*
- *There is clear evidence of the benefits of timely access to Palliative Care and end-of-life care for persons, family carers and the health care system.*
- *The main goals of Palliative Care and end-of-life care are symptom relief, the prevention of suffering and improvement of quality of life. Palliative care and end-of-life care are person-centred and focused on individual and family needs.*
- *Compassion, dignity, respect and participation in decision-making are important to all and integral to delivery of high quality Palliative Care and end-of-life care. A request for euthanasia or physician assisted suicide requires a respectful and compassionate response.*
- *When aligned with a person's wishes, withdrawing or refusing life sustaining treatment, (including withholding artificial hydration) or providing medication to relieve suffering, do not constitute euthanasia.*

As a member of Palliative Care Australia, Palliative Care NSW supports this position statement.

This submission seeks to provide input on the specifics of the Bill as well as to pose some questions more generally about the implications for the Palliative Care sector, the health sector more generally for patients and families.

General comments

Overall we are concerned that the Bill is lacking in key patient safety domains including the qualification of Nominees and the competence to practice Voluntary Assisted Dying (VAD).

We are also concerned that there has been no consultation with the Palliative Care sector in the drafting of this Bill, practitioners who are recognised by the public for their specialist body of knowledge in end of life care.

Also of concern is the lack of consultation within the broader health sector, skilled practitioners, policy makers and managers who will be responsible for overseeing and administering this health system change.

There continues to be inadequate investment in Palliative Care even in light of the recently announced and very welcome boost to the sector by the NSW Government. These deficits are well documented. People cannot access specialist services by choice. There are waiting lists to access specialist Palliative Care in-patient beds. There is very poor health and death literacy within the community. Access to Palliative Care is neither universal nor equitable. Some 2 out of every 5 people in NSW die in residential aged care facilities but many residential aged care services lack access to Registered Nurses and GPs, much less to specialist trained Palliative Care practitioners. In community surveys many people don't know what Palliative Care is and even fewer people have completed

Advance Care Plans, yet the people of NSW will be expected to make informed choices about accessing VAD.

Accessible and equitable Palliative Care

There is a significant danger that the introduction of VAD may signal a reduced commitment to Palliative Care. The localised variations in Palliative Care service delivery, the need to improve access of Palliative Care to rural and remote communities, the need to develop and properly resource multi-disciplinary teams all impact on the experience of equitable access to Palliative Care in NSW. Improvements in the provision of Palliative Care is essential before a more advanced debate about VAD can be considered in the best interests of the people of NSW.

Improvements in the provision of Palliative Care, medical, mental health and other social and community support services for people at end of life, particularly in rural and regional areas need to be addressed before further debate on VAD is considered to ensure equitable access to quality end of life care.

There is likely to be inequitable access to VAD. In rural areas where there may be only one or two GPs, this may be problematic if either or both choose to object or not participate in VAD. In such cases – will infrastructure for Telehealth for instance be available and valid?

It seems to be a commonly held view amongst not only the general public, but the generalist health profession, that were euthanasia or assisted dying to be introduced, it would be the Palliative Care teams that would be responsible for implementing a VAD scheme. Palliative Care medical specialists by definition do not seek to hasten death and take great pride in their work in alleviating suffering, including pain and symptom management and the range of existential issues facing people as they approach and reach the end of their lives.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

World Health Organisation, Definition of Palliative Care

To assume then that these medical specialists would take on the role of administering Voluntary Assisted Dying is incorrect. Nevertheless, Palliative Care medical specialists have developed a significant body of knowledge about end of life care that is relevant to VAD. They utilise a systematic multi-disciplinary planned approach to the provision of care.

Through our submission we hope that the practice of VAD can be properly acknowledged as an area of speciality practice warranting a holistic 'systems-design' multi and inter-disciplinary approach rather than simply an 'occasion of service' approach.

Through intentional systems-design and the inclusion of proper safeguards consistent with contemporary legal health care practice the safety of NSW patients, their family and carers will be ensured.

Definition of terminal illness

We believe that the current definition of terminal illness should have a more deliberate focus on the last 6 months of life. We propose that the current definition:

***Terminal illness**, in relation to a patient, means an illness which will, in reasonable medical judgment, result in the death of the patient within 12 months. (Bill)*

be replaced with this definition from the Oregon Dying with Dignity Act:

***Terminal Disease** an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months (Oregon Dying with Dignity Act)*

The definition of Terminal Illness in the Bill should be altered to 6 months in accordance with the (Oregon Dying with Dignity Act).
--

Requirements for Nominees

We note that the role of the Nominee is to administer a substance, and that the Nominee may act or refuse to act as requested. We note that currently the Bill prescribes that the Nominee must be of minimum age (at least 18 years) but makes no other stipulations or qualifications of the Nominee.

Our concern is that this singular requirement (age) diminishes the gravity of decision-making within the process of VAD and does not adequately provide for the complicated intersection of trust, competence, legal capacity, liability and proof that we believe is warranted for public safety.

We are concerned about the disparity between the age of the Nominee specified in the Bill as a minimum of 18 years, and the minimum age of 25 years for the patient to access VAD. If the minimum age of 25 years relates to competence on the part of the patient then the same argument would be reasonably applied to the age of the Nominee which means that both should be a minimum of 18 years.

The Bill should review downwards the minimum age for the patient to be consistent with that of the Nominee and should be a minimum of 18 years.

In prescribing the requirements for Nominee we believe that proper account should be taken of the Nominee's relationship with the person and any conflict of interest that the Nominee may have in providing assistance and the possible pressure that might be exerted on them to administer the substance. In this we note the support provided by young carers in NSW and the problematic situation they might find themselves in if nominated to assist a mother or father.

Account should also be taken of the competence of the Nominee to understand the role required of them, that express definition be given to them being of sound mind and being willing and able to both administer and to refuse to administer the substance.

We also believe that there should be significant rigour applied to the way in which the Nominee is assessed and supported in terms of understanding VAD and their role in the VAD process including but not limited to the administration of the substance. This includes both when and how they can express consent or otherwise to assist, how they can access legal or emotional support in the performance or defence of their role, their rights or obligation to have witnesses in attendance, the qualifications of such witnesses, and the nature of proof that might be relied upon in legal proceedings in defence of their actions or unwillingness to act.

Given the likelihood that the Nominee will be present at the time of death, then we believe that the duty of the primary medical practitioner should include care for the Nominee by briefing them on the patient's likely physiological reaction after administration of the substance, the likely events and the experience of attending to the patient's death, responding to complications including what to do if the substance does not end the person's life, what to do and who to inform upon the person's death. This duty of care to the Nominee should be embodied in the Bill as an obligation upon the primary medical practitioner.

In summary the absence of safeguards for the Nominee in the Bill is concerning given the significant personal, relational and emotional investment that we imagine to be likely in the Nominee's relationship with the patient, the potential legal complications incumbent upon their role, and the potential physiological complications at the time of administration.

We also note that there is nothing in the Bill which would appear to prevent the primary medical practitioner, the secondary medical practitioner, an independent qualified psychiatrist, an independent qualified psychologist, or the person's health care provider from being a Nominee. We believe that such conflicts of interest would be unmanageable and therefore incompatible with the role of Nominee.

We note also the importance of investigating and clarifying the legal position of the Nominee in light of the role of a nominated Guardian and within the Person Responsible hierarchy for the Guardianship Act in light of possible role conflicts. We note that the Bill allows that guardians may not exercise any function of making or rescinding a request for assistance.

The Bill should install safeguards against abuse or corruption of the important advocacy role of Nominee, extend the duty of care of the primary medical practitioner to the Nominee and proscribe the possibility that the role of Nominee cannot be concurrently held by another of the patient's health practitioner (as defined by the Bill).

Requirements of primary medical practitioner

We note the requirement that the medical practitioner must not be a close relative to the patient or benefit financially from the provision of assisted dying. The definition of 'close relative' is restricted to parent, sibling or spouse. We believe this is too narrow and does not reflect the closeness in many families from a range of cultural backgrounds where cousins, aunts and uncles would be considered just as close. If this definition is designed to minimise the risk of close relatives seeking to hasten a death for financial reasons, it must be expanded to include those categories. The intent of this part must be for an absence of conflicts of interest, whether pecuniary or otherwise, on the part of all participating practitioners.

The definition of 'close relative' must be expanded to include cousins, aunts and uncles. Penalties must apply to practitioners with conflicts of interest who fail to remove themselves from participation, statutes of limitations must allow for future redress in such cases.

Even though the Bill doesn't specifically reference Palliative Care, the practice of end of life care by Palliative Care specialists is the medical field most relevant to patients at end of life and therefore those accessing assisted dying. For this reason, the Bill should more clearly define the attributes of medical practitioners, psychologists and psychiatrists assisting with the provision of assisted dying in terms of their end of life expertise.

In the interests of public safety, we believe that VAD practitioners should be able to demonstrate engagement with best Palliative Care knowledge and clinical practice, a commitment to professional development in end of life care along with a demonstrated level of competency in end of life discussions.

VAD practitioners must be able to demonstrate engagement with best Palliative Care knowledge and clinical practice, a commitment to professional development in end of life care along with a demonstrated level of competency in end of life discussions.

In overseas jurisdictions we note that some distress is incurred by patients with a terminal illness in situations where their usual medical practitioner informs them that they (the practitioner) are unable to offer assisted dying services. The patient must then establish a relationship with another medical practitioner at a stage in their life when they are understandably vulnerable.

We believe that this could be relieved by providing the public with information about which medical practitioners might be approached about the provision of assisted dying, such as by maintaining a publicly available register of self-identifying medical practitioners. Inclusion on the register need not be a guarantee that the practitioner will provide assistance as this would always be circumstantial on the patient's situation, as referenced in the Bill (clause 6). The maintenance of this register might be a function of the agency proposed in our later recommendation (see Assisted dying and public interest).

A register of medical practitioners interested in providing VAD should be available to the public.

Definition of Assist or Assistance

The definition of 'assist or assistance' (clause 3(1)) describes someone as 'physically incapable' of self-administering the substance. There must be a definition of what is meant by 'physically incapable'

and state very clearly the circumstances in which a medical practitioner could actively administer the VAD substance in compliance with the legislation. The definition would take into account a range of factors that can impede self-administration, such as: PEG feeding, inability to take or absorb oral medication, lack of physical capability to self-administer, etc.

The Bill should provide a more detailed definition of 'physically incapable' and state very clearly the circumstances in which a medical practitioner or Nominee could actively administer the VAD substance in compliance with the legislation.

Site of VAD process

We believe that the Bill should also provide safeguards around the location of the VAD procedure. Based on the experience in Oregon, it is likely that VAD would occur mostly in the patient's own home.

Patients requesting VAD may be living in residential aged care facilities, supported accommodation facilities, special residential services, prisons and other congregate living situations. If the 'facility' where the patient resides does not participate in VAD then arrangements would need to be made for the person to be transferred to one that does.

If the person is receiving care, either in a hospital or residential aged care setting then the Bill should clearly provide for the facility to refuse to allow for VAD on their premises if the organisation so chooses, and that this does not constitute any breach of another statute such as the Anti-Discrimination Act.

Where VAD is permitted then this should be done in a place that ensures the privacy of the patient (and of those they wish to be present) is respected. The medical practitioner and patient requesting VAD will need to consider the best arrangements for self-administration (or administration by the medical practitioner or nominee, where applicable) that will respect the privacy of the patient as far as possible and safeguard the safety and wellbeing of those living and working with patient.

Respect for the patient's autonomy and autonomous choices will need to be considered alongside the need to promote public safety and to protect the well-being of others (such as from adverse mental health and psychological impacts or fear of personal safety that may arise for vulnerable persons who become aware of VAD deaths occurring where they live).

The Bill should provide the right of facilities to veto the act of assisted dying by practitioners, and require that a consenting facility have a codified method of administration that respects patient privacy and safeguards the wellbeing of others in the facility.

Respecting VAD as a specialty area of practice

We note the preference of the authors of this Bill to model the NSW legislation around the default participation of medical practitioners as facilitators of assisted dying. In modelling the Bill around the active participation of doctors we believe that the authors have intuited the importance of offering specialised support to patients at this vulnerable time in their life.

Assistance in dying means different things in different countries. For example in Germany, Switzerland, Canada and Japan assisted dying operates largely outside of established medicine, or

provides for differentiated forms of involvement by physicians. Since June 2016 Canada has had two legal forms of medically assisted dying: the first involves a health practitioner injecting a drug, called voluntary euthanasia (VE); the second involves a health practitioner who provides or prescribes a drug that is self-administered to cause death, known as medical assistance in dying (MAID). Physicians, and where permitted by provincial legislation nurse practitioners, can provide medical assistance in dying.

In light of the NSW model of physician involvement, we believe that full consideration of the impact of the legislation on the health community generally, on recruitment to medical specialties (noting in particular Palliative Care and intensivist care) and on public confidence in health care should be assessed initially and further assessed during the life of the Bill.

In jurisdictions where practitioners are involved directly in the act of dying (noting Canada, Belgium, the Netherlands) the available studies and literature indicates a significant incidence of distress by association with VAD within the health professional community. This objection runs across health disciplines (medicine, nursing, pharmacy, social work), worldviews (religious, secular) and settings (rural, regional, metro).

Participation by VAD practitioners and their team (affiliated practitioners) in debriefing and access to proactive and reactive counselling should be mandated through the legislation.

The Bill should provide for mandated participation in proactive and reactive counselling and support structure to support VAD practitioners.
--

The practice of VAD should be informed by the end of life specialist body of knowledge held by Palliative Care. For example doctors who elect to specialise in Palliative Care undertake advanced training in end of life care including symptom assessment and management, communication about prognosis and treatment preferences, and treating depression in seriously ill patients. The demonstration of these skills through trainee pathways and professional registration has become an accepted means of enhancing public safety for people at end of life.

We are concerned that the Bill omits reference to how a specialised skill-base will be governed, measured and fostered in a way that best ensures public safety for those accessing VAD. Specifically, in the Bill we suggest an amendment to clause 14(3) and clause 17(a)(iii) to reference 'as verified by a VAD practitioner' and that a VAD practitioner be someone who can demonstrate engagement with best Palliative Care knowledge and clinical practice, a commitment to professional development in end of life care along with a demonstrated level of competency in end of life discussions.

We believe that public safety imperatives require minimum prescribed competencies for practitioners of VAD, who can demonstrate engagement with best Palliative Care knowledge and clinical practice, a commitment to professional development in end of life care along with a demonstrated level of competency in end of life discussions.
--

A referral to a VAD practitioner should require that the practitioner undertake a holistic end of life care assessment of the patient and consideration of any other assistance that may be available. If the person is not yet receiving specialist Palliative Care, a referral to specialist Palliative Care should be offered to them. As with any other treatment, the person would not be required to accept the referral or to receive specialist Palliative Care.

A Palliative Care specialist referral or consultation must be offered to a person who requests VAD, recognising that the person has the right to refuse the referral or consultation offered.

Monitoring the use of a lethal dose of medication

The issue of monitoring a prescribed lethal dose of medication is not dealt with under the Bill. Data shows that poisoning and hospitalisation due to the inappropriate ingestion of pharmaceuticals by children is a significant issue. Unlike many other pharmaceuticals, the VAD medication is fast-acting and lethal. Safety must be promoted by requiring appropriate storage of VAD medication and the return of any VAD medication no longer required to the dispensing pharmacy for disposal.

The Bill must provide for information about safe storage of the substance with particular concern over the home storage of the substance.

Effective monitoring of the use of VAD medication

A tracking system should be implemented for all VAD substance that would show the date of prescription, the date when the VAD substance was dispensed, the date when the VAD substance was ingested or the date when the VAD substance was returned to the dispensing pharmacist (if the patient died and did not ingest the VAD substance).

The Bill should oblige the VAD practitioner to be responsible for effective monitoring of the use of VAD medication. The requirements for effective monitoring of VAD prescriptions and the status of dispensed VAD substance should be included in the Bill, including an obligation on the VAD practitioner to review patient eligibility after 6 months of dispensation of substance.

The important safeguards of decision-making capacity and voluntariness must be enduring and not limited only to the time at which the request for VAD is assessed. Given that the intention is to limit VAD to people who are at the end of life (which we recommend be defined as a reasonable expectation of death within six months), it would be appropriate to renew the assessment of decision-making capacity and voluntariness 6 months from the date of VAD approval, if the person has not yet died from natural causes or ingested the VAD medication. Where possible, this could be undertaken by the same medical practitioners involved in the first assessment. The provision for a review of the person's situation after 6 months is also consistent with good clinical practice.

We are concerned that VAD substances could be retained (stored) for an extended period, during which the patient approved for VAD may lose their decision-making capacity. The risk is that they may no longer make an autonomous decision to ingest, or to request assistance to ingest, or to express an unwillingness to ingest the VAD substance. They may then be vulnerable to being given the VAD substance to ingest without their consent.

The Bill should include an obligation on the VAD practitioner to monitor the safe storage and use of VAD substance. In cases where 6 months has elapsed since dispensation the VAD practitioner must review the person's decision-making capacity and voluntariness.

Mode of death, data collection and dissemination

Data collected from Medical Certificate Cause of Death and subsequently issued death certificates are used for public research and planning purposes and contribute to important long-term data that

can be mined in ways that are beneficial for society. We believe that the Bill should provide for disclosure of VAD as a mode of death. The non-disclosure of VAD as the mode of death could distort survival data for a cohort of people with a particular diagnosis. Where data indicates that VAD is associated with a particular diagnosis, this may prompt further research to improve clinical care.

We note that clause 29 does not state whether VAD is to be recorded as cause of death along with the terminal illness of the patient. We suggest that in addition to the underlying cause of death recorded, the mode of death (ie VAD) be mandatorily recorded in a way accessible to researchers and policy makers. The monitoring and reporting on the status of dispensed VAD substances would also contribute to comprehensive data collection on deaths as a result of VAD.

Death certificates should not be the only means of communicating the mode and cause of a person's death to family members. There is a need to provide support to family members who find out that a loved one died as a result of VAD after the person's death. Non-disclosure of VAD as the mode of death is not the most appropriate way to deal with this issue.

The Bill should provide for the mandatory recording of VAD as a mode of death as well as the status of substances and the nature of the diagnosis in accessible records of death.

Assisted dying and public interest

Given that the provision of assisted dying transects several social interest domains (the provision of health care, end of life care, public health, public safety, patient advocacy and consumer empowerment) we believe that the Bill should provide for active monitoring of the usage and uptake of assisted dying services.

This would take the form of a responsibility on the Minister to ensure mandatory reporting of episodes of voluntary assisted dying by practitioners.

We note that the current provisions of the Bill require VAD practitioners to keep records. Our recommendation proposes a more proactive involvement with practitioners through mandatory reporting by VAD practitioners to an Agency.

The Agency would support an Advisory Board that would, on behalf of the Minister ensure safe clinical governance and appropriate reporting of VAD:

- data on service uptake is reported to the public in a way that allows transparency into the emergent practice of voluntary assisted dying;
- intentional review of service design, public information and patient advocacy in relation to voluntary assisted dying is effected through engagement with relevant groups representing health practitioners, community and public interest groups, legal advocates, consumer health representatives, peak bodies and interest groups;
- a body of knowledge about the provision of voluntary assisted dying to inform practitioners and consumers (including an interim research fund) is appropriately developed and promoted;
- guidance is provided for practitioners, consumers and nominees about assisted dying in NSW;
- how the practice of VAD and Palliative Care are each supported and developed; and
- other matters of service access and practice are attended to.

An agency or similar body should be established by the Minister for collecting mandated information from primary medical practitioners, developing a body of knowledge, and informing the public about the provision of voluntary assisted dying in NSW.

We believe that the mandated information required of VAD practitioners after death should include:

- Name and demographic information of the deceased;
- The names of the practitioners associated with the provision of voluntary assisted dying;
- If appropriate, the identity and age of the Nominee and their relationship with the deceased;
- A copy of the care plan from the primary medical practitioner;
- The medication used, the site of death and the role of those in participation; and
- Any complications associated with the administration of the medication.

Where the VAD practitioner declines to share the mandated information then, in addition to appropriate penalties, such refusal should effectively preclude them from further participation in assisted dying.

Mandated reporting from VAD practitioners should ensure that data on VAD usage is proactively sent to a central repository for analysis.

Mandated reporting would be ongoing obligation. The Agency would report at 6 months and then annually. This obligation is separate from and in addition to the proposed requirement that the Minister undertake a 5 yearly review of the Act with reporting obligation within the following 12 months.

The purpose of this recommendation is to ensure that a contemporary feedback mechanism is built-into the Bill to ensure practitioners and the public are better informed about the efficacy of the Bill and assisted dying services in NSW, to ensure the availability of data collected over the long term, and ultimately to assist in engendering public confidence in the practice of VAD.

Information on participation should be appropriately available to assist in engendering public confidence in the Act.

Voluntary Assisted Dying and publicly available information for the general public

The Bill should require the Agency to provide adequate information to family and carers and members of the public about VAD including:

- Information about choices and decisions about end of life care more generally:
 - About their right to refuse or withdraw unwanted treatment;
 - About the appointment of a Nominee and other substitute decision-makers;
 - About communicating wishes and preferences for end of life care and the right to have these respected; and
 - Links to information about the Office of the Public Advocate, Advance Care Planning, and the Health Complaints Commissioner.
- Information about care and support available:

- About specialist Palliative Care and how to access it – this should also clearly indicate that VAD is not part of Palliative Care;
- About care options for people with advanced illness and at end of life in different settings;
- Support for caregivers with information about pain and symptom management and the dying process; and
- Links to information & support.
- Information about VAD:
 - Emphasise the importance of a voluntary decision, free from pressure by others or a sense of duty or obligation to request VAD. Who to contact for help if they are feeling under pressure to request VAD;
 - About the VAD eligibility criteria;
 - About the VAD referral and assessment process and requirements, including practical steps and who to contact;
 - The prescribed information they must be given to make an informed decision about VAD;
 - Recommendation to discuss with or inform their caregivers and people close to them if they intend or decide to request VAD;
 - What happens when a request for VAD is granted, including: advance care directive and refusal of treatment (such as Not For Resuscitation (NFR) etc.); supply of VAD medication and its safe storage; no obligation to ingest the medication; requirement to self-administer and legal exceptions to this; who can be present when the medication is ingested; what should be done if they have an adverse reaction to the medication; completion of the death certificate, notification that medication has been ingested or return unused VAD medication;
 - Financial, insurance and superannuation implications;
 - Privacy arrangements in relation to VAD; and
 - Rights and responsibilities, including: their right to rescind a request for VAD or to decide not to proceed with VAD at any stage; respect for decisions by persons and organisations not to participate in VAD.

The information should be consumer tested to ensure that it is easy to read and appropriate for people with varying levels of literacy and health / death literacy. This easy to read information in English should ensure the needs of Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities to ensure the information takes account of cultural and linguistic considerations and that translation into community languages reflects these requirements. Adequate support should be provided through an information and referral phone line.

In the interests of public safety the Bill should mandate the availability of key information to patients, family, carers, members of the public with active support through an information and referral phone line.

Voluntary Assisted Dying and publicly available information for practitioners

Health professionals would need to be familiar with the information resources available to the public as outlined above. In addition, appropriate information resources would need to be developed for all health practitioners, health services and health organisations about VAD.

This would include information about:

- the VAD legislation and its operation
- conscientious objection and the opt-in arrangements
- VAD training
- the responsibilities of a VAD medical practitioner/ health service
- expectations regarding holistic care and continuity of care, including bereavement support for the family
- shared care arrangements with health professionals and health organisations who do not wish to participate in VAD and wish to otherwise continue to provide care to the patient and their family.

Resources to provide guidance for physicians and services participating in VAD would also complement relevant education to support VAD certification by participating medical practitioners.

In the interests of clinical safety the Bill should mandate information and access to information for reference by practitioners.

Questions outstanding

- As for access to Palliative Care, there is likely to be inequitable access to VAD. In rural areas where there may be only one or two GPs, this may be problematic if either or both choose to object or participate. In such cases – will infrastructure for Telehealth be available and valid?
- Has there been any consideration given to billing/cost of assessments under Medicare?

Concluding comments

We welcome the opportunity to contribute to this public consultation and the ongoing drafting process. In brief Palliative Care NSW believes that:

1. The time factor within the definition of Terminal Illness in the Bill should be altered to 6 months in accordance with the *(Oregon Dying with Dignity Act)*.
2. The Bill should review downwards the minimum age for the role of Nominee to be consistent with that of the patient and that is 18 years.
3. The Bill should install safeguards against abuse or corruption of the important advocacy role of Nominee, extend the duty of care of the primary medical practitioner to the Nominee and proscribe the possibility that the role of Nominee cannot be concurrently held by another of the patient's practitioner (as defined by the Bill).
4. The definition of 'close relative' must be expanded to include cousins, aunts and uncles. Penalties must apply to practitioners with conflicts of interest who fail to remove themselves from participation, statutes of limitations must allow for future redress in such cases.
5. VAD practitioners must be able to demonstrate engagement with best Palliative Care knowledge and clinical practice, a commitment to professional development in end of life care along with a demonstrated level of competency in end of life discussions.
6. A register of medical practitioners interested in providing end of life care should be available to the public.

7. The Bill should amend the provisions in relation to decision making capacity to require the person's capacity to be current at the time of ingestion or administration of the substance.
8. The Bill should provide the right of facilities to veto the act of assisted dying by practitioners, and require that a consenting facility have a codified method of administration that respects patient privacy and safeguards the wellbeing of others in the facility.
9. The Bill should provide for mandated participation in a proactive and reactive counselling and support structure to support VAD practitioners and all current members of the patient's multi-disciplinary health team.
10. We believe that public safety imperatives require minimum prescribed competencies for practitioners of VAD, who can demonstrate engagement with best Palliative Care knowledge and clinical practice, a commitment to professional development in end of life care along with a demonstrated level of competency in end of life discussions.
11. A Palliative Care specialist referral or consultation must be offered to a person who requests VAD, recognising that the person has the right to refuse the referral or consultation offered.
12. The Bill should include an obligation on the VAD practitioner to monitor the safe storage and use of VAD medication. In cases where 6 months has elapsed since dispensation the VAD practitioner must review the person's decision-making capacity and voluntariness.
13. The Bill should provide for the mandatory recording of VAD as a mode of death as well as the status of substances in accessible records of death.
14. An agency or similar body should be established by the Minister for collecting mandated information from primary medical practitioners, developing a body of knowledge, and informing the public about the provision of assisted dying in NSW.
15. Mandated reporting from VAD practitioners should ensure that data on VAD usage is proactively sent to a central repository for analysis.
16. Information on participation should be appropriately available to assist in engendering public confidence in the Act.
17. In the interests of public safety the Bill should mandate the availability of key information to family, carers, members of the public with active support through an information and referral phone line.
18. In the interests of clinical safety the Bill should mandate information and access to information for reference by practitioners.
19. Improvements in the provision of Palliative Care, medical, mental health and other social and community support services for people at end of life, particularly in rural and regional areas need to be addressed before further debate on VAD is considered to ensure equitable access to quality end of life care.