

Submission to The University of Tasmania's Independent Review of the *End-of-Life Choices (Voluntary Assisted Dying) Bill 2020* (referred to hereafter as the VAD Bill).

My name is Karen Dickson and I welcome the opportunity to address the VAD Bill on behalf of not only myself but my nursing colleagues of Tasmania. I give permission for any part of this submission to be referenced by the Independent Review Panel and included in reports.

INTRODUCTION:

My interest in the VAD Bill comes from my 30 year career as a Registered Nurse /Midwife during which time I have cared for people in all stages of the lifespan, particularly in the context of the Emergency Department. As the Emergency Department is the coal face of acute care in our health care system, I have had much experience of humanity at its best and equally at its worst.

It may be perceived that end of life care would not feature in the acute care setting. On the contrary, the Emergency Department is the first port of call for anyone and everyone with any kind of medical related concern, which has routinely included end of life care, not only for the ill person, but for their family and carers.

Caring for a person in a holistic way is complex and cannot be fully appreciated by capturing snapshots of information in medical reports. Each person who finds themselves dependent on others for care becomes vulnerable to the influences of health care professionals, carers, family members, treatment therapists and the health 'system' itself. For so many people, the idea of relying on and hence becoming a burden to loved ones or even healthcare professionals whom they perceive should be focused on others who are more deserving or in need, can be overwhelming. While it is true that many families will invest whatever time and energy is required to care for a loved one who is ill, it is equally true that many suffer more from the pressure from families not to be a burden that they do from their medical condition.

It is the harsh reality of the selfishness of humanity, that not everyone, when faced with a chronic illness which may or may not be imminently terminal, will receive unconditional support from those around them. Those with chronic or terminal illness are vulnerable and need keen advocates to guarantee their needs are met in a timely and comprehensive way that does not rob them of dignity but rather empowers them to live with hope.

Having routinely observed the interactions between family members and carers around those with chronic and terminal illness, I have grave concerns about the impact the VAD Bill will have on those in our state who are affected by illness, are dependent on others for long term intimate high level care and hence are vulnerable.

I am addressing my concerns to you based on my nursing experience and my interactions with those who care for the vulnerable. It is my determination to protect ordinary Tasmanians from being influenced by what superficially appears to be a choice around end of life care, but what will ultimately become a treatment option when caring for people becomes too taxing for individuals or for us as a society. It is also my determination that as assisting someone to end their life is a completely inconsistent with the practice of nursing, nursing professionals should not be compromised by the VAD Bill.

SPECIFIC CONCERNS:

Clauses taken directly from the End-of-Life Choices (Voluntary Assisted Dying) Bill 2020.

1) Part 1. Objectives and principles (2) (e)

a therapeutic relationship between a person and the person's registered health practitioner should, wherever possible, be supported and maintained;

A therapeutic relationship between a person and a health care practitioner / clinician is one that develops over time and involves the person being 'known' by the clinician on a level that gives the clinician insights about the person relevant to their illness, life situation and care. It is imperative that every person needing

care for chronic or potentially terminal illness has a therapeutic relationship with their Health Care Practitioner to ensure that the person is known and has opportunity to receive appropriate and timely care. What has been evidenced in Victoria however challenges this model.

As only a small percentage of medical practitioners have made themselves available to facilitate voluntary assisted dying, persons wishing to access the process are drawn to one of a small number of practitioners. This makes the development of a therapeutic relationship difficult, if not impossible, as persons are only seeking a relationship with a practitioner for the purposes of accessing voluntary assisted dying.

While this clause of the bill purports to promote a therapeutic relationship, it is impossible to measure the quality of such a relationship and as the clause itself states, the relationship should be supported 'wherever possible'. This is an obvious escape clause. Even where it is not possible to maintain a therapeutic relationship, the VAD process is not effected. There is no obligation on the part of the person or the practitioner to maintain a therapeutic relationship. The relationship is thus reduced to a transaction of supply and demand for a service. This is not the way medicine is practiced. The safety of vulnerable persons is thus significantly compromised where a therapeutic relationship does not exist.

2) Part 1. Objectives and principles (3)

(j) there is a need to protect persons who may be subject to abuse or coercion;

Abuse and coercion exists where the behaviour of one adversely effects the welfare of another. These are very difficult to detect and even harder to demonstrate. Interpersonal interactions between family members are complex and are routinely manipulated or disguised during health practitioner interviews. It is impossible for a clinician to rule out the often very subtle coercive behaviours endured by chronically ill persons.

This clause cannot be considered a safeguard as it is impossible for a clinician to rule whether or not coercion or abuse exists for a person outside the clinical setting.

3) Part 2 Interpretation Provisions (6)(1)

(c) *except if the person is exempted from this requirement under subsection (3), is expected to cause the death of the person –*

(i) *within 6 months; or*

(ii) *if the disease is neurodegenerative – within 12 months.*

Prognosis is a safeguard many consider the most important in the VAD process. It gives legislators the comfort they need that the people accessing VAD are those who are 'going to die soon anyway'. Prognosis is a determination made by a clinician based on data around a person's diagnosis. Clinicians are human and can only offer a prognosis based on statistical data. It is unreasonable to expect a clinician to always know with enough certainty to satisfy the VAD Act, that a person will die within a certain time frame. Many clinicians have been proven wrong when ill persons long outlive their initial prognosis and in fact enjoy rewarding lives despite their diagnosis of a terminal illness. Prognosis is influenced by clinical data as well as a person's support networks, belief systems and general wellbeing.

Prognosis gives legislators a false sense of security and is not an adequate or definitive safeguard.

4) Part 2 Interpretation Provisions (9)(b) and (c)

(b) *the person –*

(i) *is a vocationally registered general practitioner; or*

(ii) *holds a fellowship with a specialist medical college; and*

(c) *the person has relevant experience in treating or managing the medical condition expected to cause the death of the person; and*

This clause places General Practitioners in a very difficult position, While they are likely best placed to know the person seeking to access VAD, assuming that a therapeutic relationship has been established

over time, they do not have the extensive experience required to make accurate prognosis. General Practitioners should only be considered for consultation with or referral to Consultant Practitioners.

5) Part 2 Interpretation Provisions (10)(1)

(e) the person is suffering intolerably in relation to a relevant medical condition.

I question whose determination it is that someone is suffering intolerably. How is intolerable suffering measured? Palliative Care and the existence of specialised Pain Clinics have made significant contributions to those suffering chronic pain. In my experience, it is often a family member who despairs at seeing a loved one in pain, who requests that "something be done to end their suffering". Often times those who are suffering significantly, have not utilised the services that are available to them for support and for pain management. This is a casualty of the sense that a person is a burden and doesn't want to ask for more care services.

When family members are not coping with the chronic illness of a loved one or they anticipate that they will not cope with the progression of illness, they are more likely to focus on this fear and hence negatively influence the cognition of the ill person. This is normal human behaviour. One of the roles nurses play in the care of any person is providing information and care to the family members and carers who often feel overwhelmed by the progression of illness. There are resources, often delivered by experienced nurses, available to persons and families affected by chronic / terminal illness, to relieve what is feared to be intolerable suffering. Assisting someone to end their life is not the only answer to relieving what is perceived as intolerable suffering. We are deceived if we believe VAD is a treatment modality.

6) Part 2 Interpretation Provisions (10)

(2) For the purposes of this Act, a person is not eligible to access voluntary assisted dying by reason only that the person –

(a) has a mental illness, within the meaning of the Mental Health Act 2013; or

(b) has a disability, within the meaning of the Disability Services Act 2011.

While this clause prevents those who have a Mental Health diagnosis or Disability diagnosis from accessing VAD on that basis alone, it does not prevent those who have a terminal medical condition but who are also affected by a mental health concern or disability from accessing VAD. The existence of a Mental Health or Disability diagnosis raises concerns about decision making capacity .

It is also to be noted that those suffering chronic/terminal illness are very likely to also be affected by mental health concerns, notably depression. This can have a significant bearing on the person's ability to actively engage in treatment or accept support.

The existence of a Mental Health or Disability diagnosis in conjunction with a medical condition makes a person increasingly vulnerable due to carer fatigue and already taxed support structures.

7) Part (3) When Person May access Voluntary Assisted Dying(2)

For the purposes of subsection (1) –

(a) a person is to be taken to have decision- making capacity in relation to a decision unless there is evidence to the contrary; and

Nowhere in this Bill is there detailed a means by which decision making capacity can be assessed. It appears to be a subjective decision by a clinician who may or may not have an established therapeutic relationship with the person. What evidence is required to substantiate the existence or non existence of decision making capacity?

My experience of giving medical information to the general population is that there is a significant level of health illiteracy in our society. I have observed many a clinician give what they considered to be comprehensive information around a diagnosis and treatment, only to discover that the person understood only a small part of the discussion and the implications for their life going forward.

The existence of decision making capacity appears to be a safeguard, but in essence can be very difficult to ascertain with certainty. It is a subjective assessment and the consequences of misjudging decision making capacity in a person in the context of VAD will result in untimely deaths.

8) Part (3) When Person May access Voluntary Assisted Dying

13. When person is acting voluntarily

For the purposes of this Act, a person is acting voluntarily if the person is not acting under duress, coercion or because of a threat of punishment or unfavourable treatment, or a promise to give a reward or benefit, to the person or another person.

As mentioned previously, it is impossible to rule the existence on non existence of coercion. Coercive tactics and behaviours by family members or carers may not be covert or intentional, but still impact the person with chronic/terminal illness such that they perceive themselves to be a burden.

The perception that a person is a burden to loved ones may well be the only impetus for seeking to access VAD. This type of duress is not externally imposed but rather is self imposed. The existence of chronic/terminal illness makes a person vulnerable to this type of thinking.

This clause does not offer a safeguard to guarantee that a person is acting voluntarily or prevent decision making under duress.

9) Part (3) When Person May access Voluntary Assisted Dying (14)(b)

(ii) anticipation of the suffering, or expectation, based on medical advice, of the suffering, that may arise from the relevant medical condition or from the relevant medical condition together with the person's other medical conditions;

This clause and its use of the word 'anticipates' appears to be in contradiction to the clause that refers to prognosis and its associate time frames for predicted death. It also relies heavily on Clinicians knowing with certainty exactly what a person will experience as a result of their medical condition, such that they can inform them of their future. While clinicians can to a point offer some insight into how particular medical conditions can affect a person, they are not able to determine with confidence how an individual in the context of their extended family and support structures will respond to the illness and its treatment. This knowledge is further challenged by the absence of a therapeutic relationship due to the limited number of clinicians who will be available to facilitate the VAD process.

This clause appears to offer assistance to a person who has great fear around their anticipated experience of death, but rather it increases the number of people who become vulnerable to a pattern of thinking that death is to be feared and the experience of that fear avoided at all costs. It robs persons and their loved ones of the opportunity for invaluable life experiences.

10) Part (3) When Person May access Voluntary Assisted Dying(15)(2)

A relevant communication that may be made or given by a person (the VAD person) to a relevant practitioner under this Act may, if –

(a) the VAD person is unable to communicate to a person who is unfamiliar with the VAD person's method of communication; and

(b) the VAD person's means of communication is comprehensible to another person who is familiar with the VAD person or the method of communication –

be made to the relevant practitioner by the other person, if the relevant practitioner is satisfied as to the relevant matters in relation to the VAD person and the other person.

This clause appears to protect those for whom communication is challenged either by illness, disability or cultural and language barriers. I have witnessed and been party to innumerable consultations with people and their families around health concerns, when the person cannot communicate to the clinician themselves. The process of using interpreters or others who are familiar with a person's means of communication is fraught with opportunity for misunderstanding. It is very difficult to ascertain with certainty that a person has understood and appreciated the significance of information about their chronic/terminal medical condition when the person and the clinician are communicating using the same method eg spoken English. It is impossible to ascertain the same level of understanding when a third party is required to deliver/interpret information. This magnifies the person's vulnerability immeasurably.

This clause cannot offer a safeguard to those whose means of communication for whatever reason is not the same as the clinician, and relies on a third party.

11) Part 5 – First Request (24)(2)

(c) the prognosis in relation to –

(i) the relevant medical condition or the relevant medical condition together with other medical conditions of the person; and

Again the concept of a prognosis gives legislators security that a person accessing VAD is going to die within the allotted timeframe. Prognosis is not definitive, is to a degree subjective and is open to be misjudged by even the most experienced clinician.

12) Part 5 First Request(27)(4)

If a person's PMP determines under section 26 a first request by the person by determining under section 26(a) that the person is eligible to access voluntary assisted dying, the PMP must, if the person consents –

(a) provide to a member of the family of the person, if any, the relevant facts in relation to accessing voluntary assisted dying; and

The inclusion of family members in a process as definitive and life altering as VAD is vital not only for the person but for the family who will have to live with the outcome of the process. While I understand the need for a person with decision making capacity to give consent for any procedure or intervention that effects them, I am concerned that a person may not give consent for family to be involved or notified and as such the VAD process can be undertaken without any family/carer knowledge.

This clause appears to protect the rights of the person, but it has long term immeasurable implications for harm for the person's family.

13) Part 6(Second Request (30) (2)

A person must not make a second request to the person's PMP within 48 hours of the person having made a first request to the PMP, unless, in the opinion of the PMP –

(a) the person is likely to die within 7 days; or

(b) the person is likely to cease to have decision-making capacity within 48 hours.

If a person is expected to die within 7 days or is expected to lose decision making capacity within 48 hrs, I wonder at the need for the VAD process to be accessed at all or whether the VAD process can be completed safely and effectively in such a short time frame.

Not only is the assessment around timeframes subjective and difficult to deliver with any real accuracy, the timeframes themselves require haste which challenges the safety of 'due process' being followed.

Haste is the enemy of safety and should not be employed particularly in the context of VAD.

14) Part 11 Health Practitioner Who is to Supply VAD Substance to Person (60)

(b) the PMP does not intend to be the person's AHP and intends to request the Commission to appoint an AHP in relation to the person.

If for whatever reason the PMP does not intend to be the person's AHP, and the commission appoints an AHP, the therapeutic relationship that has theoretically been established and maintained between the person and the PMP becomes disrupted. This introduces a clinician not known to the person and further hampers the accuracy of assessment of decision making capacity and existence of coercion/duress.

15) Part 11 Health Practitioner Who is to Supply VAD Substance to Person

(62) Appointment of AHP

This clause does not preclude a staff member from a care facility that a person is a resident of, being appointed as the person's AHP.

When staff members of care facilities are known as AHP's, it increases vulnerability and fear for residents of said facilities, knowing that a particular staff member is involved in a process such as VAD. There is likely to be an increase in fear experienced by the general community if it becomes known that a particular care facility facilitates VAD. Persons being enrolled for care in such a facility would have reason to fear that they might become victim to the VAD process.

A discussion with any elderly person who is likely to be accessing care in a residential facility will bring this type of fear to light.

16) Part 13 Final Administrative Requirements

78. Final determination by AHP of decision-making capacity and voluntariness

A person's AHP must, within 48 hours before the AHP receives a final permission from the person, determine whether the person has decision-making capacity and is acting voluntarily.

This clause requires the AHP to determine decision making capacity and voluntariness within 48 hrs of the final permission of the person. Surely the person's decision making capacity and voluntariness needs to be valid at the time of final permission, not just with the previous 48hours. Capacity will be influenced by the progress of the disease process. As the administration of the VAD substance is dependent on the final permission from the person, capacity needs to be intact at the time of final permission and most definitely at the time of administration of the VAD.

If at any time during the VAD application process, decision making capacity or voluntariness is in doubt, the process should be stopped.

17) Part 13 Final Administrative Requirements (82)(3) (d)

(ii) take action that it is reasonable for the person's AHP to take to preserve the person's life.

This clause highlights that there is potential uncertainty around the outcome of the administration of the VAD substance. In the event of a failed termination of life, and the initiation of life saving measures, significant distress will be experienced by the person and whoever is present. There is significant pressure placed on the AHP to have in their possession not just the equipment but the skills to initiate life saving measures.

It needs to be highlighted to all who have contact with the VAD bill,(legislators, health care professionals, chronically ill persons and the community at large) that a peaceful death for the person is not guaranteed. It is a misconception that VAD guarantees a peaceful death at the time of a persons choosing. It is a misconception that this is a better option than dying at the end of life.

18) Part 14 Provision of Assistance to Die (93)(2)

(b) if the Coroner has no cause to believe the death occurred otherwise than in accordance with this Act, is to record under that Act the cause of death as being a voluntary death in accordance with this Act and to record the relevant medical condition in relation to the person.

It is imperative that where VAD has been employed, that it be recorded as such. At no stage should VAD be excluded from records relating to the death of a person.

When clinicians are making decisions about prognosis and outcomes for a person, they rely on data recorded around disease outcomes. If for example, persons with a particular type of cancer or neurodegenerative disease access VAD and their death is only recorded against their medical condition and does not reflect the use of VAD, the data around life expectancy and outcomes will be distorted and effect information available to persons in the future. It is vital for tracking health data as well as tracking the use of VAD, for causes of death to include VAD where it has been utilised.

19) Voluntary Assisted Dying Commission(117)(2)

The Commission may request the Secretary to authorise, under section 25B of the Poisons Act 1971 –

(a) a nurse practitioner who is a registered nurse and who is specified in the request; or

(b) each member, of a class, of nurse practitioners who are registered nurses, that is specified in the request –

to possess and supply a VAD substance for the purposes of use under this Act, if the nurse practitioner or member of the class of nurse practitioners who are registered nurses is supplied with the VAD substance as the AHP in relation to a person.

This clause appears to nullify some clauses of the Poisons Act which require 2 Registered Nurses to check the storage and supervise the administration of a controlled substance.

20) Part 20 – Miscellaneous

145. Administration of Act

Until provision is made in relation to this Act by order under section 4 of the Administrative Arrangements Act 1990 –

(a) the administration of this Act is assigned to the Minister for Health; and

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(b) the department responsible to that Minister in relation to the administration of this Act is the Department of Health.

When a person becomes a Medical Practitioner, Nurse or Allied Health Professional, one does so with the intention of joining a sector of the community that cares for, seeks to improve the welfare of and positively impacts the lives of the community in which they live. They work under the banner of the Department of Health. The VAD legislation and process contravenes the principles under which Health professionals practice, and indeed represents a behaviour that formerly practitioners were prosecuted for, that being involvement in the untimely death of a person.

It is inconsistent with the health care ethos for its members to be involved in untimely death, or to assist a person to end their own life. To involve health care professionals in intentionally ending a person's life is incongruent with health care goals and practices. Tasmanian health care professionals do not want to be involved in intentionally ending lives of fellow Tasmanians. Tasmanian lives are valuable.

CONCLUSION:

This legislation is not advantageous to the welfare of all Tasmanians. The legislated availability of VAD, which may be better described as medically assisted suicide, will adversely impact the framework of thinking that governs health care in Tasmania, will directly result in poorer health outcomes for all Tasmanians, compromise the wellbeing of the practitioners involved and create an increasingly large group of people who are vulnerable to mistreatment or inappropriate care.

Tasmanians deserve better.

I welcome any approach for clarification of my statements.

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