

Supplementary Questions

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Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021

Friday, 10th December 2021

Parliament House, Sydney

Questions directed to Professor Leeroy William, Immediate Past President, The Australian and New Zealand Society of Palliative Medicine:

In response to these questions, I have used de-identified cases to highlight pertinent issues with the VAD legislation in Victoria. In my recent position as President of the Australian and New Zealand Society of Palliative Medicine, I was fortunate to hear the concerns of many palliative care clinicians across Victoria who were unable to discuss their experiences. My responses are therefore aimed to respect the confidentiality of the patients, families, clinicians, and healthcare organizations across Victoria. I hope that the issues raised can inform the VAD discussions in New South Wales and lead to positive outcomes for the people we serve and those that care for them.

1. In evidence provided to the inquiry hearing on 13th December, Dr. Danielle McMullen, President, Australian Medical Association (NSW) said:

“We would undertake that the requirement for two separate doctors to both consult with the patient about their reasoning, intent and illness and to discuss with them all options available to them for their care, including voluntary assisted dying... ” (Hansard, page 5)

In evidence to the inquiry hearing on the same day Dr. Cameron McLaren, appearing as a private individual from Victoria said:

“I underwent the training [Voluntary Assisted Dying training] for two reasons: I did not want a patient for whom I had cared throughout their journey with cancer to have to seek external providers that they chose to pursue this option [Voluntary Assisted Dying]; secondly having been educated in medicine with a strong focus on patient-centred care, I felt that my opinion... ” (Hansard, page 67)

In evidence to the inquiry hearing on the same day Dr. Greg Mewett, Palliative Care Physician, Grampians Regional Palliative Care Team, Ballarat Health Services, Victoria said:

“My final comments would be that I find this [Voluntary Assisted Dying], as a palliative care doctor, patient-centred care... .”

and

“Palliative care is a style of care which, near the end of life, VAD is one type of choice in that care – they are not mutually exclusive.” (Hansard, page 69)

In evidence to the inquiry hearing on the same day Associate Professor Charlie Corke, Acting Chair, Voluntary Assisted Dying Board, Victoria said:

“I note that Dr. McLaren and Dr. Mewett both talked of patient-centred care. Really, the way in which we deliver health care can be considered as patient-centred care or medical-centred care or perhaps as legally-centred care or religious-centred care. There is a whole load of different ways we look at the way we deliver care. But, fundamentally, I think patients are wanting patient-centred care rather than any of those other options.” (Hansard, page 71)

Can you please comment on the implications for the professions of medicine and nursing and the overall medical, health and aged/residential care ecology of New South Wales by describing Voluntary Assisted Dying, as provided for in the Voluntary Assisted Dying Bill 2021, as “care” or “patient-centred care”?

Response to Question 1

A dictionary definition of care is:

“The provision of what is necessary for the health, welfare, maintenance, and protection of someone or something.”

Patient-centred care (PCC) is defined as:¹

“a concept that involves meeting the multidimensional needs and preferences of [older] people dependent on care, by acknowledging the carers as well as the family — taking into account each individual’s needs, goals, and abilities. PCC focuses on the whole person and involves shared decision-making as well as better communication between health care professionals and patients. PCC reflects principles of philosophy and ethics, based on mutuality and respect.”

¹ Ebrahimi Z, Patel H, Wijk H, Ekman I, Olaya-Contreras P. A systematic review on implementation of person-centered care interventions for older people in out-of-hospital settings. *Geriatric Nursing*. 2021 Jan 1;42(1):213-24.)

From the above definitions, we can see that patient-centred care is complex and holistic. It involves a collaboration between non-professional and professional carers to meet the physical, psychological, social, and existential needs of the individual. One person cannot deliver this care alone.

End-of-life care requires this holistic and collaborative approach. The modern hospice movement emanated from a decision by Cicely Saunders to attend to the suffering of people and their families at the end-of-life – not to hasten their death via euthanasia. An excerpt from Siddhartha Mukherjee’s book describes the situation encountered in the 1950s:²

As Saunders entered and explored the forsaken cancer wards of London’s East End in the fifties, she began to decipher that cryptic request in a more visceral sense: she encountered terminally ill patients denied dignity, pain relief, and often even basic medical care—their lives confined, sometimes literally, to rooms without windows. These “hopeless” cases, Saunders found, had become the pariahs of oncology, unable to find any place in its rhetoric of battle and victory, and thus pushed, like useless, wounded soldiers, out of sight and mind.

Saunders responded to this by inventing, or rather resurrecting, a counterdiscipline—palliative medicine...If oncologists could not bring themselves to provide care for their terminally ill patients, she would leverage other specialists—psychiatrists, anesthesiologists, geriatricians, physical therapists, and neurologists—to help patients die painlessly and gracefully. And she would physically remove the dying from the oncology wards: in 1967, she created a hospice in London to care specifically for the terminally ill and dying... It would take a full decade for Saunders’s movement to travel to America and penetrate its optimism-fortified oncology wards. “The resistance to providing palliative care to patients,” a ward nurse recalls, “was so deep that doctors would not even look us in the eye when we recommended that they stop their efforts to save lives and start saving dignity instead . . . doctors were allergic to the smell of death. Death meant failure, defeat—their death, the death of medicine, the death of oncology.”

Hence, voluntary assisted dying (VAD) is a separate philosophy and approach to suffering, compared with palliative care. The Royal Australasian College of Physicians (RACP) supports this view: “**Voluntary assisted dying must not be seen as part of palliative care**”.³

Healthcare professionals encounter people at their most vulnerable, experiencing life at critical and emotional times. COVID has highlighted the long-standing issues in our healthcare systems, including the burnout and moral injury affecting staff. In Victoria, VAD has disrupted the necessary teamwork and inter-professional relationships to deliver and sustain optimal end-of-life care. Clinicians have been caught between legal, professional, and personal positions that have divided opinions about optimal end-of-life care.

Examples of the effect of VAD on the healthcare system can be seen in the following cases:

² Mukherjee, Siddhartha. *The Emperor of All Maladies* (p. 225). HarperCollins Publishers. Kindle Edition.

³ https://www.racp.edu.au//docs/default-source/advocacy-library/racp-voluntary-assisted-dying-statement-november-2018.pdf?sfvrsn=761d121a_4

- A hospital patient requested VAD on a palliative care unit. The treating teams respected the need to keep VAD and palliative care separate. A transfer to another ward was organised. The hospital over-ruled the clinicians and the patient had VAD on the palliative care unit. Staff were distressed and the clinicians felt disempowered in their roles.
 - A patient could not be transferred to a ward for VAD. Staff on the ward felt uncomfortable about VAD occurring on their ward and the possible stigmatization of their ward in the future.
 - Palliative care staff have felt pressured to deliver VAD on their units, despite the RACP position. They have felt uncomfortable about their potential facilitation in the VAD process.
 - Palliative care staff have continued to provide care for patients requesting VAD, but there is no provision of similar care by the clinicians involved in the VAD process. Patients have commented on the significant difference between clinicians providing ongoing holistic care and the doctors assessing them for VAD.
 - Many patients have enquired or requested VAD to avoid transfer into a residential aged care facility. Given the Royal Commission into Aged Care and the reported experiences of residents before and during COVID, this highlights a problem to be resolved in the healthcare system for the elderly population.
2. Clause 6 of the Voluntary Assisted Dying Bill 2021 deals with the matter of decision-making capacity. Sub-clause 6(2) deals with the specific matter of patients, for particular purposes of the legislation, having “presumed capacity”. Can you please comment on the presumed capacity provisions (sub-clause 6(2)) of the Bill and in doing so, express your view about the appropriateness, or otherwise, of such provisions in a bill that provides for the establishment and operation of a Voluntary Assisted Dying procedure? Do the provisions pose any particular and specific threats and dangers to certain patient cohorts?

Response to Question 2

The presumption of capacity, specific to VAD, requires careful assessment. Many people have been choosing to pursue VAD in Victoria as their cognitive function is deteriorating. The diagram below provides some idea of the complexity of decision-making at the end-of-life.⁴ The health literacy of the individual is important to consider, alongside the other relationships that can bias the decision-making process, e.g., family, friends, and society.

⁴ Romo RD, Wallhagen MI, Smith AK. Viewing Hospice Decision Making as a Process. Am J Hosp Palliat Care. 2016;33: 503–510

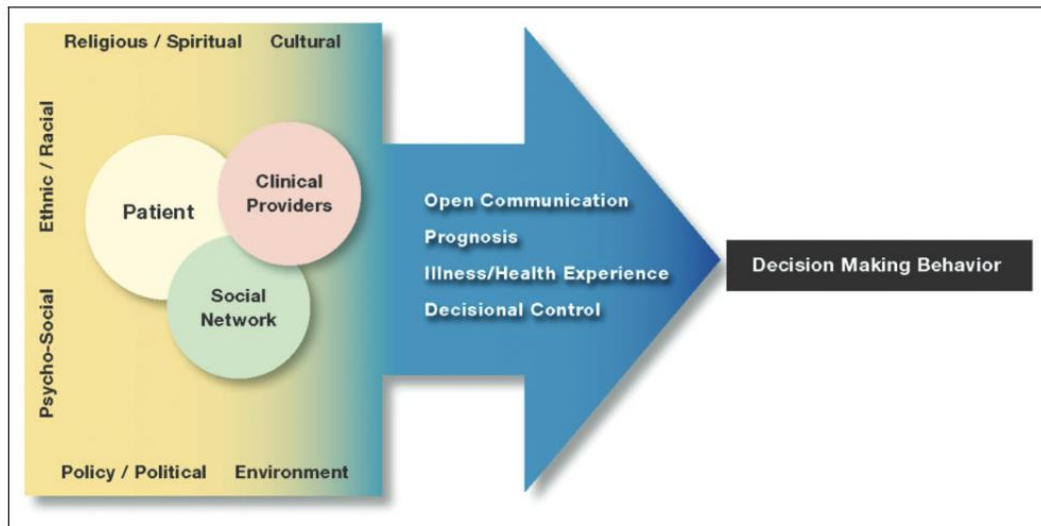


Figure 1. Decision-making process at the end-of-life.

Our decisions are influenced by so many factors and rarely occur in a vacuum. It is important that we ensure people understand the relevant information and the subsequent decisions that emanate from their choice of action – whether that is consent to treatment, or the refusal of treatment. It should be noted that informed consent should include, but often does not, the option of not having the intervention in question.

In Victoria, a person is required to have capacity throughout the VAD process. However, once the substance is dispensed, is capacity checked before the ingestion of the substance? Anecdotal reports from cases in Victoria do not confirm that this is happening.

Capacity assessments for people with cognitive deficits can be difficult to make without the necessary experience in these assessments. Hence, older people may be deemed to have capacity when they do not. There should also be interpreters for people from a non-English speaking background. In these cases, interpreters may not be available or willing to be involved in VAD assessments. The translation of VAD may also create false perceptions, e.g., the Cantonese translation for VAD does not convey the taking of a substance to end one's life.

Coercion is a major component in decision-making process. There have been cases in Victoria of family members requesting VAD for their relative, even though the person does not want VAD. Family conflict has been observed in many cases, as end-of-life decisions are complicated by seeking VAD.

It is also possible for the information being conveyed to be incorrect. Poor prognostication and misdiagnosis can occur. Patients are often given a poor prognosis but continue to live longer than expected. Decisions are often made based on such prognostication. For example, a patient given a poor prognosis of pancreatic cancer (adenocarcinoma) was found to have a type of pancreatic cancer that had a better outlook (neuroendocrine). The histology report was incorrect. The patient was well-

supported and was looking forward to the birth of their child. Had a request for VAD occurred, the pathology would not have been reviewed and an avoidable hastened death would have occurred.

3. Various elements of the New South Wales *Voluntary Assisted Dying Bill 2021* are very similar to, if not identical to provisions contained in the Victorian *Voluntary Assisted Dying Act 2017*. A number of witnesses to this inquiry, in their submissions and/or oral evidence have asserted that the Victorian *Voluntary Assisted Dying Act 2017* is operating as was intended by the legislature without any unintended consequences for patients, medical professionals, nurses, allied health workers, and operators of private and faith based medical, health and aged/residential care facilities. Can you please provide any information or case study examples (de-identified) that you have knowledge of and believe should be brought to the attention of this inquiry regarding both intended and unintended consequence arising from the legalisation of Voluntary Assisted Dying in Victoria?

Response to Question 3

I have summarised the VAD issues in Victoria in the slide below, with the most important listed in yellow.



We have discussed the need to consider coercion and how people make their decisions, based upon many factors. There have been many cases where a request for information has been interpreted as a request for VAD. For example, a 58-year-old patient with metastatic cancer requested information about VAD. The information was provided, and care delivered as usual on the palliative care ward. Feeling better, the patient returned home. On subsequent admissions, the family wanted the patient to have VAD despite the patient's decision not to pursue a request.

A 63-year-old patient recognised the deterioration in their life-limiting illness. Their spouse was struggling to cope at home and was advising them to have VAD. The patient did not want VAD. The patient became unwell and requested a hospital admission. However, the spouse was heard pressurising the patient to request VAD instead of an admission. The patient was eventually admitted and stabilised, but subsequently died with specialist palliative care support.

The importance of optimal professional practice is critical to medicine. The introduction of VAD legislation creates an over-riding legal imperative on doctors to follow a process rather than best practice care. Two cases can highlight this point.

Case 1

Patients who attempt suicide, usually require a psychiatric assessment upon recovery. However, a hospital case following the introduction of VAD led to palliative care referral because the patient requested VAD. Firstly, this demonstrates evidence of the conflation of VAD and palliative care that exists in the healthcare system and in our society. Secondly, the decision to refer for VAD ignored the clinical assessments required as part of best practice.

The patient was diagnosed with depression, confirmed by the psychiatry consultant, and antidepressants were prescribed. A request to die was made to another treating doctor and so a VAD assessment was arranged. The antidepressants would not have taken effect yet. No psychiatric follow up had been provided, highlighting another problem in systemic care. The patient was deemed ineligible for VAD due to their prognosis. The next of kin did not want anything to do with VAD. There were multiple reasons for the patient's depression, including caring for a spouse and grieving the deaths of many people in their social network.

Case 2

A 78-year-old patient was diagnosed with advanced lung cancer. A month into treatment they are referred to community palliative care. A month later, the treating doctor advises that the treatment is not working. The patient's only symptom is fatigue. They are distressed however, by "jobs to do at home" and so want to "go into care". They are also afraid of pain and suffering in the future and so request VAD.

Without any further discussion, the treating doctor arranges for the first VAD assessment. Prior to the legislation, and more importantly now, the reasons behind this

request need to be explored. The patient did not have pain and no effort was made to find out more about the issues at home. No discussion of the role or further involvement of palliative care was raised.

Many proponents of VAD talk about access to VAD, however, the access to optimal palliative care is not considered in the same light. The fear of pain and suffering should require more attention before the VAD process is commenced. This case may seem patient-centred, but it does not provide the informed consent to ongoing care required in clinical practice. Furthermore, why was the referral to palliative care services not made at diagnosis, for someone with a known poor prognosis? An earlier conversation about the prognosis and referral to palliative care could have alleviated fears and provided support for the patient and their families.

4. At the inquiry hearing on 13th December, three medical professionals from Victoria provided oral evidence. They were Dr. Cameron McLaren, appearing as a private individual, Dr. Greg Mewett, Palliative Care Physician, Grampians Regional Palliative Care Team, Ballarat Health Services and Associate Professor Charlie Corke, Acting Chair, Voluntary Assisted Dying Board. Their evidence is found at Hansard pages 67-74. Given that you are a medical professional from Victoria working in areas that completely or substantially overlap with the three abovementioned witnesses, are there any aspects of their evidence provided on 13th December that you would like to specifically comment on?

Response to Question 4

Dr McLaren's statement

I did not want a patient for whom I had cared throughout their journey with cancer to have to seek external providers that they chose to pursue this option

We have established that optimal holistic end-of-life care requires a collaborative approach. This continuity of care is admirable, but does the same occur for patients who do not request VAD?

having been educated in medicine with a strong focus on patient-centred care, I felt that my opinion on VAD was irrelevant to whether my patients should be able to access it.

We have cited a definition of "Patient-centred care" (PCC) from the academic literature. PCC is often misinterpreted to convey "allowing the patient to choose what they want". Patients do not have the choice to have any chemotherapy they desire, or any surgery they think will cure them. Hence, the healthcare professional has a responsibility to use resources wisely and not promote futile treatment. It is also the professional role of the clinician to consider their personal biases, in order to ensure they are adjusting that bias to facilitate unbiased consultations.

I have to date been involved in 176 cases

This equates to one person doing 20% of the cases. We are yet to see if Dr McLaren's expectations will eventuate regarding other doctors participating in VAD. However, the shortage of doctors wanting to be directly involved with VAD raises questions for patients wanting to access this option. We are aware that doctors may be supportive of VAD, but their eagerness wanes as they are required to be more involved.^{5, 6}

I have founded an organisation to educate and support other practitioners as we work together to improve the quality of assessment provision and patient care in this field.

There has been no similar organisation set up to support clinicians opposed to VAD or affected by VAD's impact on their practice/ wellbeing. It might be presumed that these assessments were already high-quality, given the consequences. Dr McLaren's statements suggest that the education and assessments require more work. This is not surprising, as we know that healthcare professionals get minimal palliative care education in their training. Even fewer have the communication skills to have these conversations. Perhaps we should enable all clinicians to have the ability to manage basic end-of-life care, communicate compassionately and deliver holistic care before any VAD laws are passed?

I hope that I can provide some insight into how I assess capacity, coercion and the conversations I have with patients and their families when they choose to explore VAD as an end-of-life care option.

As I have stated, capacity assessments can be basic, but are often complex in a deteriorating patient. There is no education around assessing coercion.

When I meet someone for a VAD assessment, I start by talking about everything but VAD: "Where were you born? Tell me about your parents. Tell me about your family. What did you do for work? What are you proud of? What do you still enjoy?" These responses start to give structure to the psychosocial framework in which this person sits. Then I ask them around their illness: "When were you diagnosed? What treatments have you had? Are you having any more treatments? What has been explained to you about further treatments? What are your expectations on your prognosis?"

Doctors invariably do not have the "whole picture" from just their assessments. People often do not tell the doctor their innermost issues. They may talk to someone else in the team more, e.g., the social worker, nurse, or physiotherapist. Dr McLaren's assessment alone cannot provide a complete picture - it is one perspective only. Furthermore, it is the perspective the patient wants the doctor to see, depending on the relationship.

⁵ Fuscaldo G, Gwini SM, Larsen R, Venkataramani A. Do health service staff support the implementation of voluntary assisted dying at their workplace? Intern Med J. 2021;51: 1636–1644.

⁶ Yoong J, Franco M, William L, Poon P. Perspectives of cancer treatment providers regarding voluntary assisted dying in Victoria. Intern Med J. 2018;48: 770–773.

I have stopped asking patients about their pain and their nausea

Why has Dr McLaren stopped asking patients about their symptoms? Cancer pain is poorly managed internationally. Pain may affect their decisions, and it needs to be treated effectively to ensure the request is not biased by pain and the suffering that emanates from it.

I tell them that I will make up a reason that they are ineligible, this is not something that they truly want to do

If he will make up a reason here, will he make up a reason in other circumstances?

It took four separate home visits in one week to explore this adequately and it turned out the patient was educated about the existence of VAD by their family member, but as soon as they heard about it knew that they wanted it.

Are the same efforts undertaken to ensure people understand palliative care?

People talk about forcing institutions and forcing staff to be complicit in this act, but when you have an institution that conscientiously objects you are also precluding those patients from conscientious involvement. That in my mind is a greater risk factor for issues such as moral injury of death since the staff are exposed to situations that they find ethically conflicting and are having to act in one way that is not in accordance with their personal ethical framework. So, to me, that is a much greater risk for those individual nurses and carers and that is why I prioritise the individualisation of involvement of staff and also an individual right of access of the patients or people who are residents in those nursing homes.

There is a problem here in both situations. The dilemma of this approach for health care services is the contentious nature of voluntary assisted dying. Organisations consist of people some of whose individual values and beliefs are unlikely to align neatly under the organisational approach when it comes to voluntary assisted dying. Therefore, health services face the challenge of navigating between the principle of justice and equity in access to health care and the responsibilities to their employees. Health practitioners cannot conscientiously object to the routine care of a patient who has elected to undertake voluntary assisted dying.

What struck me about that argument is that I do not understand why the resident next door is privy to the information of that resident and what business it is of theirs. I have issues with confidentiality in that case. There is no reason why someone next door needs to be aware of what is going on. So I feel the risk of harm is much less when individualisation is allowed.

People living in an aged care facility demonstrate grief about their former life and home. Transitioning into aged care is often a traumatic experience, requiring support in the adjustment to the new environment. Given the nature of the population living in aged care,

people are more likely to witness death and dying that they would have at home. Friends are made in aged care that help support people in their psychosocial and existential wellbeing. It is therefore not a question of confidentiality, but rather a lack of appreciation by Dr McLaren that human beings support each other in difficult times. This involves discussing their emotions, grieving the loss of newly-formed relationships, and helping each other cope in their uncertain futures.

Dr Mewett's statement

I combine this with my usual palliative care day to day in my palliative care practice.

This is Dr Mewett's view and not representative of the practice of the majority of palliative medicine specialists. In reference to the earlier quotation about Cicely Saunders, oncologists were prepared to leave dying patients and their families at that time in a single room on a ward because they couldn't cure them. Medicine cannot cure as many people as it would like to. How is the healthcare system and society dealing with this inability to cure, amidst increasing chronic disease, ageing, and frailty?

Fifteen of these patients have died before the completion of the VAD process, which therein lies another story. Nineteen of the deaths have been by self-administration; most of those, 13, have been in private homes, four of them have been at our local palliative care unit, one in a regional hospital and one in a nursing home. I have not been involved in any practice which has administered voluntary assisted dying, but I am certainly prepared to do so should the necessity arise. I have eight pending cases that are still yet to be determined or come to conclusion.

Late diagnosis and conversations about dying affect all end-of-life options - VAD and palliative care. Hence, there are many deaths that occur quickly. If prognostication of less than six months is so reliable, why aren't more people being referred for palliative care in their last year of life? Why is an end-stage lung cancer patient with brain metastases at diagnosis not getting palliative care support at this point?

Coercion is not an issue that I have come up against and, as Dr McLaren has alluded to, I have seen many people being coerced into doing things by their family when they perhaps should not be in health care generally.

If coercion exists from one perspective, then it must exist in the other. The push for people to accept treatment is also present to stop treatment.

Sure, the stakes are higher in VAD requests, and it behoves us all to be more attentive to capacity assessment and to assessing whether a patient's mental health condition might be impacting on the decision-making

This needs to be optimised across the whole of healthcare before VAD is introduced.

This is really focusing on patient-centredness, really listening, leaning into these people and having a really good conversation.

All people need to have these conversations. If clinicians had them earlier, then issues can be addressed earlier. Do we need VAD to enable these important conversations to happen?

Palliative care is a style of care which, near the end of life, VAD is one type of choice in that care – they are not mutually exclusive

Not according to the Royal Australasian College of Physicians and many other international palliative medicine organizations.^{7, 8}

Associate Professor Corke's statement

The board is of the opinion that the Victorian Act is working, with overwhelming positive feedback from patients and families who have used the service. Our experience is documented in our reports of operation. The priority of the board is to ensure compliance with legislation.

These are a self-selected group. The VADRb does not hear from people who don't access the scheme, nor the people who are ineligible. They do not routinely follow up carers in bereavement. They do not assess the issues raised in organizations.⁹

The second role of the board is to ensure that patients have reasonable access to voluntary assisted dying and the board has identified significant issues in this regard.

What is being done to ensure reasonable access to palliative care? What is being done to ensure aged care residents get the care they deserve?

5. In evidence provided to the inquiry hearing on 8th December, Ms Penny Hackett, President, Dying With Dignity NSW said:

“The key feature of this law is choice. It is voluntary and no-one is compelled to be involved. Those who oppose VAD laws are not required to use them or to participate in the process.” (Hansard, page 3)

⁷ <https://www.racp.edu.au/advocacy/policy-and-advocacy-priorities/voluntary-assisted-dying>

⁸ <https://hospicecare.com/policy-and-ethics/ethical-issues/statements-on-euthanasia-and-physician-assisted-suicide/>

⁹ Fuscaldo G, Gwini SM, Larsen R, Venkataramani A. Do health service staff support the implementation of voluntary assisted dying at their workplace? Intern Med J. 2021;51: 1636–1644.

Can you please comment on what the actual meaning of the word “choice” is, as generally understood by the population at large and in the specific context of medico-health decision making?

Response to Question 5

There has been a recognised move towards a consumerist approach to healthcare. The public have been given “choices” in their care, but there has not been an honest conversation about what choices are not available to patients. The choices for end-of-life care between palliative care and VAD cannot be a reasonable one if one person has access to best practice palliative care, yet another has no access to such a service.

Furthermore, the lack of end-of-life care education for healthcare professionals leads to substandard “generalist” palliative care – once again affecting the choice provided to people. This can be viewed in terms of cardiology education. Undergraduate education provides cardiology training to deal with non-complex cardiology problems. Cardiologists do not see everyone with a heart, only those who require their expertise. Similarly, palliative care specialists do not see everyone who is dying. However, the level of basic education for non-complex dying does not prepare healthcare professionals adequately. This is an international issue, as has been seen during the COVID pandemic.

Some may people feel that they have the choice of determining their end-of-life, but this may not be the case. I have mentioned chemotherapy and surgery as examples – i.e., people cannot choose to have any chemotherapy or surgical procedure they desire. People who want to choose VAD, feel cheated when they are deemed illegible for VAD. We have yet to see the repercussions from these decisions – which teams are supporting these patients and is there an increased risk of suicide? The latest evidence on suicide research highlights the risks that can move people towards suicide attempts – see diagram below.¹⁰ It is common for people with life-limiting illnesses to feel defeated, humiliated, and trapped by their circumstances. Are we doing enough in healthcare and society to address these issues?

¹⁰ O'Connor, Rory. *When It Is Darkest* (p. 103). Ebury Publishing. Kindle Edition.

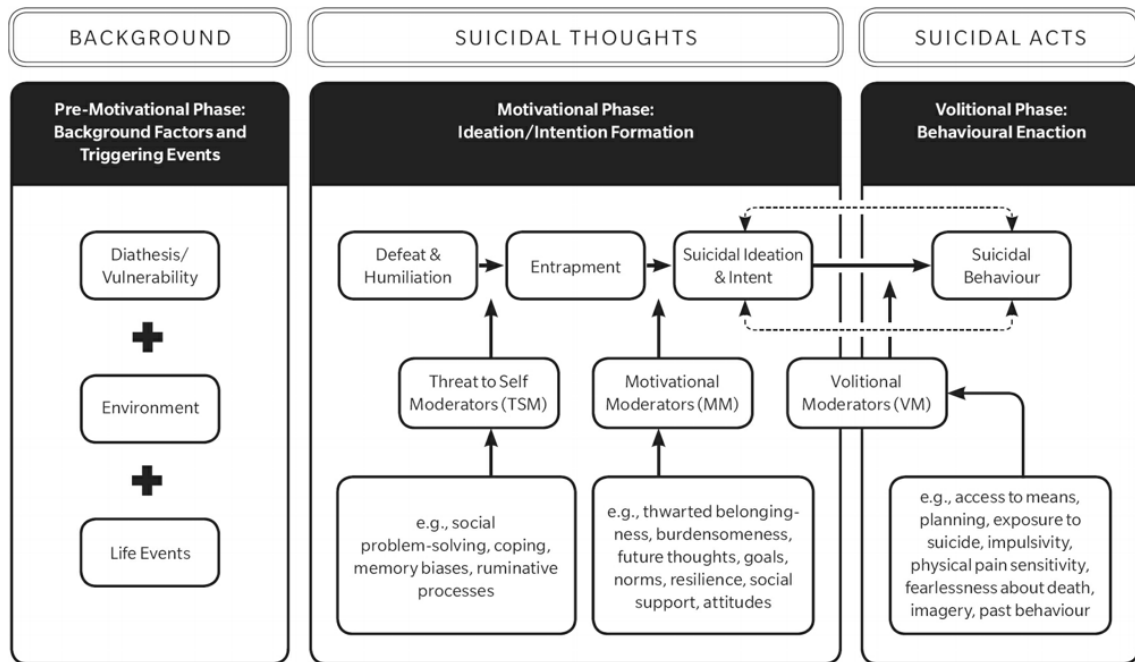


Figure 1. The integrated motivational-volitional model of suicidal behaviour².

1. Phase one covers the background context in which suicide risk may emerge (pre-motivational phase).
2. Phase two focuses on the emergence of suicidal thoughts (motivational phase).
3. Phase three maps out the factors that make suicidal acts more likely if someone is thinking about suicide (volitional phase).

6. In regard to the evidence referred to above in question 5 and the issue of “choice”, what would be the real and actual implications for citizens who, while potentially meeting eligibility and other requirements of the *Voluntary Assisted Dying Bill 2021*, are not able to have provided to them high quality, readily available palliative care, particularly with respect to those residing in rural, regional and remote NSW?

Response to Question 6

I have described this in question 5. It is apparent in all areas of healthcare, that rural, regional and remote areas of any State and Territory suffer from the tyranny of distance. Palliative care is a smaller specialty compared with other medical specialities and hence funding, workforce planning, and service delivery models need to be optimised in order to better support palliative care patients. The obvious risk is that without the access to generalist or specialist palliative care, VAD becomes the only option and therefore choice is absent.

7. In the Victorian *Voluntary Assisted Dying Act 2017* there is a strict prohibition on the subject of Voluntary Assisted Dying being initiated with a patient (clause 8). An equivalent strict prohibition provision is not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include a strict prohibition provision similar to clause 8 of the Victorian *Voluntary Assisted Dying Act 2017*?

Response to Question 7

Clause 2 has certainly caused much confusion about the difference between a request for information, a “wish to hasten death statement” (WTHDS), and an actual request for VAD. In all cases, whatever the request, there needs to be a competent and experienced clinician, with compassionate communication skills, to listen and understand the experience of the patient. Furthermore, the clinician needs to be able to address the concerns or refer for more support. It is recognised that these skills are not present enough in the health professional population and that communication is the biggest source of complaints in healthcare.

The dilemma for any legislation is the need to balance informed consent about a legal procedure, with the ability to mitigate perceived coercion of the patient and the potential for suicidal contagion in society.

8. The Victorian *Voluntary Assisted Dying Act 2017* has, with respect to minimum requirements for co-ordinating medical practitioners and consulting medical practitioners, a requirement for the involvement of a medical specialist and an individual with relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed (clause 10). Equivalent provisions are not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include provisions similar to clause 10 of the Victorian *Voluntary Assisted Dying Act 2017*?

Response to Question 8

Given the problems with prognostication generally in Medicine, it would seem prudent for specialists in the field of concern to be able to give their expert opinions. There are many other reasons for experienced clinicians to provide their opinions, e.g., the ability to query a diagnosis, or offer an option of treatment that may not have been offered to the patient. Hence, I would recommend that this is included in the NSW legislation.