Calvary | Little Company of Mary Health Care Ltd

Hospitality
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Respect

28 January 2022

Hon. Wes Fang, MLC
Committee Chair, Legislative Council
Standing Committee on Law and Justice

Response to Supplementary Question One to Mark Green and Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW)

We refer to the above subject. Calvary submits the following response to the question from the Committee.

Supplementary Question

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

Calvary's earlier submission

We refer to our submission dated, 22 November 2021.

Calvary agrees with Dr Natasha Moore who writes,

> For an early death to be on the table – legally and medically sanctioned – it changes the "table" for everyone. The evidence from other jurisdictions suggests that adding it to the mix does not leave other elements unaffected: the resources available for palliative care; the patient-doctor relationship; family dynamics at the end; our understanding of dementia, disability, suffering in general. And as is so often the case, it's the already vulnerable who have most to fear.

Uncertainty and fear mandate comprehensive information provision and symptom management. The unmet need and distress is highly complex and VAD legislation simply does not and cannot address this.

There will be changes to the care ecology of NSW if VAD is introduced.

There are challenges arising from a culture which allows doctors and health care staff to present, suggest and offer VAD as a choice. Whilst doctors may consider that they are being objective and impartial by presenting patients with all the options, the suggestion of VAD may be taken by patients as a negative value judgement on the worth of their lives and it may contribute to making them feel like a burden.

Understanding care and 'patient-centred care'

Patient-centred care must be understood in the context of the *raison d'être* of healthcare: the healing of and caring for the sick.

The risk of the approach articulated in the question and in some of the quotes which are included as part of the question is a *commodified view of healthcare* in which satisfying the wants of the consumer are the sole objective. That is outside the bound of medicine as traditionally practised and is not patient-centred care as we have understood this concept until now. Moreover we tend to speak about person-centred care rather than patient-centred care. The former expression focuses on the subject who has an inherent dignity as a human person and who is viewed holistically.

In the fourth quote in Question 1, patient-centred care and "religious-centred" care are set up as opposing views. This is, of course not the case at Calvary.

We acknowledge and respect the dignity of every person who seeks our care. We listen to each person and to those who care for them. We seek to involve each person in care tailored to their needs and goals. Each person's wellbeing inspires us to learn and improve. We complement compassionate clinical care with dedicated spiritual and emotional support; particularly when people are searching for meaning and purpose at vulnerable moments in their lives. The recognition of the innate dignity of each person influences all of our decision-making and informs the manner in which we look after the people who seek our care.

The purpose of the Bill is "to provide for, and regulate access to, voluntary assisted dying for persons with a terminal illness; to establish the Voluntary Assisted Dying Board; and to make consequential amendments to other Acts." Schedule 1 defines voluntary assisted dying (VAD).

> ***voluntary assisted dying*** means the administration of a voluntary assisted dying substance and includes steps reasonably related to the administration.

This is a purely technical act. Calvary does provide person-centred care. We do not regard VAD as healthcare but as a form of euthanasia.

On 9 December, 2021 one of our patients wrote

> I am dying. I've never done it before, I have no idea of what I'm going to face and this unknown is very daunting
>
> Where do I turn to for help, who can help me with the unique experience of having to face my own death, fully knowing it is imminent?
>
> Mentally and emotionally I'm dealing with an enormous amount
>
> My wife and family are also going through this experience and they need help dealing with it as well
>
> Where do I go for information to help demystify the great unknown of facing my own death?
>
> This is where I hope Palliative Care can help me, help me with all of this; and the things I haven't even thought of yet
>
> I hope Palliative Care can ensure I'm comfortable as I can be, as informed as I can be, my loved ones are also considered in this situation and they make the whole process as easy as possible and help reduce the stress of the whole issue.

There is nothing in the VAD Bill which responds to the questions:

> Where do I turn to for help, who can help me with the unique experience of having to face my own death, fully knowing it is imminent?
>
> Where do I go for information to help demystify the great unknown of facing my own death?

This is what a patient-centred (or better person-centred) care seeks to do. We are first and foremost teachers and guides.

Conclusion

When our patients or residents are dying, we strive to ensure that they do so in comfort and with dignity.

Consistent with our ethic of care, Calvary will not provide or administer a lethal substance to someone in our care. This position is consistent with the Hippocratic Oath and is shared by the Australian Medical Association and the World Medical Association – that is to do no harm.

Relieving suffering is a primary concern of good medical and clinical practice – as is improving the wellbeing of every person with a life-threatening illness and supporting their families in the process.

To relieve suffering is not to expedite someone's death, but rather to provide high quality care that relieves pain, alleviates stress and cares for the individual so that they can live as fully as possible to the very end of their lives.

A person who is facing their death is entitled to the same care as every other human being who is experiencing mental ill health, social isolation, the sense of being a burden, loss of meaning and loneliness.

No one should need to take their own life because of these things.

As we stated in our submission:

> There is a risk that a VAD culture may undermine such a message by making the value of the lives of people living with a terminal illness conditional on their own appraisal. Doubt and/or existential suffering is often part of the journey. The fact that a person is experiencing this kind of suffering does not take away from the value of their lives.

The profound and complex communication skills of a clinician in the face of this suffering broaden medicine from the purely technical to the deeply personal. This is critical.

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Hon. Wes Fang, MLC
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Standing Committee on Law and Justice

Response to Supplementary Question Two to Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW) per Mark Green

We refer to the above subject. Calvary submits the following response to the question from the Committee.

Supplementary Question

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

Clause 6

6 Decision-making capacity

(1) For the purposes of this Act, a patient has ***decision-making capacity*** in relation to voluntary assisted dying if the patient has the capacity to—

(a) understand information or advice about a voluntary assisted dying decision required under this Act to be provided to the patient, and

(b) remember the information or advice referred to in paragraph (a) to the extent necessary to make a voluntary assisted dying decision, and

(c) understand the matters involved in a voluntary assisted dying decision, and

(d) understand the effect of a voluntary assisted dying decision, and

(e) weigh up the factors referred to in paragraphs (a), (c) and (d) for the purposes of making a voluntary assisted dying decision, and

(f) communicate a voluntary assisted dying decision in some way.

(2) For the purposes of this Act, a patient is—

(a) presumed to have the capacity to understand information or advice about voluntary assisted dying if it reasonably appears the patient is able to understand an explanation of the consequences of making the decision, and

(b) presumed to have decision-making capacity in relation to voluntary assisted dying unless the patient is shown not to have the capacity.

(3) In this section—

voluntary assisted dying decision means—

(a) a request for access to voluntary assisted dying, or

(b) a decision to access voluntary assisted dying.

Presumption

The statutory presumption exists because of the use of the words *"is presumed to have"* in the Bill. Because of the statutory presumption, the doctor is under no duty to undertake any cognitive testing; in fact, the practitioner could assess the person as having decision making capacity under sub-clause (1) because there is *"no evidence to the contrary".*

As to the practitioner being satisfied that the consent of the patient is an informed consent (understanding, etc.), the statutory presumption operates so that the medical practitioner may conclude that it *reasonably appeared* to him or to her that the patient understood the consequence of a decision to proceed with VAD.

The Bill might have applied a contrary presumption - or said nothing at all. If it had said that a person is presumed not to have decision-making capacity unless there is evidence to the contrary, then the responsibilities upon the medical practitioner would be significantly heightened. In that scenario, the practitioner would need to undertake specific examination of the patient to be satisfied that he or she has requisite decision-making capacity. The evidence to be relied upon would, primarily, be the conduct of that examination by the doctor.

Specific threats and dangers

In theory, at least, VAD would not be accessible by a patient who suffers from dementia or some other mental illness which impairs the patient's ability to understand, remember or evaluate. **But there is no positive duty in the Bill requiring a PMP or CMP to interrogate the clinical history of the patient.** The patient's own GP would, by contrast, be across that medical history as well as any existing prescribed drugs for the patient which might reveal the presence of a mental illness.

It is possible to conclude on this basis, therefore, that the requirement that a patient has demonstrable decision-making capacity is not sufficiently robust, and is entirely dependent upon the opinion of two medical practitioners neither of whom may have set eyes on the patient before. The drafters' calculated decision to exclude any compulsory role for the patient's own GP in this process is significant: it means that the opportunity for exploitation of the vulnerability of aged and infirm patients may be unnecessarily increased.

The Bill *enables* the CMP, **in** conducting the first assessment, to have regard to any relevant information about the person that has been prepared by, or at the instigation of, another registered health practitioner (i.e. the person’s own GP). However, this clause is permissory, not mandatory. The **Bill** would be more protective of vulnerable persons if each of the coordinating and consulting medical practitioners were required to consult with the person's usual GP or, at the very least, to obtain the person's medical history from the general practice usually attended by the person. Without such a requirement, how can it be said per Clause 4, that that "[the] therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and **maintained.**

The Bill recognises situations where the decision could not be said to be voluntary (duress, coercion etc brought to bear upon a person). The Bill therefore recognises, and identifies, in both express and implicit terms, the very situations where abuse of vulnerable elderly patients is most likely to occur the person's own family and aged-care providers.

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Hon. Wes Fang, MLC
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Response to Supplementary Question Two to Mark Green and Question Five to Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW)

We refer to the above subject. Calvary submits the following response to the question from the Committee.

Supplementary Question

2. Assuming the *Voluntary Assisted Dying Bill 2021* is passed by the New South Wales Parliament in its current form, including:

- Clause 9 (and related provisions) – Registered health practitioners may refuse to participate in voluntary assisted dying; and
- Part 5 – Participation

what do you say will be the specific impact on residential facilities and health care establishments operated by your organisation?

Response

Clause 9

9 Registered health practitioner may refuse to participate in voluntary assisted dying

(1) A registered health practitioner who has a conscientious objection to voluntary assisted dying has the right to refuse to do any of the following—

(a) participate in the request and assessment process,

(b) prescribe, supply or administer a voluntary assisted dying substance,

(c) be present at the time of the administration of a voluntary assisted dying substance.

(2) Subsection (1) does not limit the circumstances in which a registered health practitioner may refuse to do any of the things referred to in the subsection.

The schedule provides a definition of registered health practitioner.

> ***registered health practitioner*** means a person registered under the *Health Practitioner Regulation National Law* to practise a health profession, other than as a student.

Calvary submits that many people who are responsible for the care of people in our residential facilities and health care establishments are not registered health practitioners as defined by Clause 9. In particular those who provide substantive care to residents in our residential homes are not all registered health practitioners. This Bill does not afford them any protection if they have a conscientious objection. They cannot refuse to be involved in the VAD process. Whilst Clause 89 (2) purports to offer this group of staff some rights such as registered health practitioners have, Clause 89 (3) has the effect of neutering or gelding Clause 89 (2).

Clause 9 needs to be amended and broadened to cover all who provide care including staff and others in community and residential care settings. This will provide comfort to many of our carers who will have no legal recourse under the Bill if they are asked to be present at the time of the administration of a voluntary assisted dying substance in one of our homes. Clause 9 (1) (c) would give them that protection and enable them to continue to work in the residential facility in good faith.

Some on the Committee may argue that clauses in Part 5 of the Bill (as presently constructed) will not require any particular staff member of a residential facility to be present during the administration of a voluntary assisted dying substance.

The Committee needs to bear in mind, however, that Commonwealth Law, the *Aged Care Act*, the Charter of Rights, quality and safety standards and all the other supporting delegated legislation impacts of the way care is delivered in a residential facility. A provider may not be able to simply stand aside and allow the VAD substance to be in a permanent resident’s care without some supervision to protect and uphold the rights of other residents to be kept safe.

During the lead up to a *self-administration* process (under Clause 97), a Provider continues to have obligations if something goes wrong, if harm is being done or has become aware of circumstances which suggest that to continue the process would be wrong. Accordingly a provider may need to monitor the process and therefore to ask staff to be present throughout the administration process, or parts thereof, in ways some individuals may feel is a violation of their conscience.

If Clause 9 applies to them, these staff will have greater confidence in speaking up to say that they do not want to participate or be present in the process because they cannot. This is important. Many of the staff who work in residential facilities need their jobs and do not have the level of experience nor the level of training available to a registered health practitioner.

Part 5 – Participation

Division 3 of Part 5

Division 3 of Part 5 is unacceptable as presently written. *If the effect* of these Clauses is to allow persons who are not medically responsible for the care of the patient in the health care establishment (who is admitted under the care of a particular admitting doctor, surgeon or physician) to interfere in the management of that patient’s care, this is neither in the public interest nor does it advance the practice of safe and quality care. Our hospitals cannot allow persons who are not credentialed under our hospital bylaws to operate in our hospitals. We would simply lose our accreditation.

The situations Division 3 is trying to protect are already addressed in present practice. If a patient, presently admitted to a hospital, needs to access another service not provided in that the hospital, as soon as the patient is stable they are transferred, discharged or granted an appropriate period of leave to obtain the services sought. Given that the length of stay in a hospitals is generally short, we submit Division 3 is both unnecessary and, for the reason proffered in the above paragraph, misconceived.

We submit that the clauses could be redrafted to give effect to what is present practice and clarify that the effect of the Division is <u>not</u> and <u>cannot be</u> to override the leadership in care of a credentialed admitting doctor.

Division 2 of Part 5

Clause 88 defines deciding practitioner.

> In this Part—
>
> ***deciding practitioner***, for a decision about a person, means—
>
> (a) the person's coordinating practitioner, or
>
> (b) if the person's coordinating practitioner is not available—another medical practitioner nominated by the person.

Calvary submits that for the purposes of the Division, the deciding practitioner should be the person's <u>usual medical practitioner</u> or if that person is not available—another medical practitioner nominated by the person.

Decisions about a person's suitability for transfer to receive another service are best made by the practitioner who has a therapeutic relationship with the person, who knows the person, understands any comorbidities the person is experiencing, other treatments the person is receiving and make the requisite judgments about the appropriateness of transfer – or otherwise.

Sub-clause (4) of Clauses 93-97 directs the decision making process of a deciding practiioner. The weighting is focused on whether there would be adverse affect on the person's access to VAD. Given the definition of deciding practitioner, there would appear to be an inbuilt bias.

The application of **Subdivision 3** will be most problematic for faith based organisations – like Calvary – and services which do not facilitate VAD.

Non-participating residential aged care providers must not be forced to provide or to oversee the administration of the VAD substance in their homes. As noted above, Clause 89 (2) of the Bill ostensibly offers this protection. However Clause 89 (3) effectively takes away or eliminates the protections offered by Clause 89 (2) by making the protection subject to Divisions 2 and 3 of the Bill.

Under this Bill, organisations like Calvary, may clearly state, under Clause 98, that the entity does not provide, *at a residential facility services associated with voluntary assisted dying, including access to the request and assessment process or access to the administration of a voluntary assisted dying substance*. The effect of Subdivision 3, and Clause 97(2) in particular, is to force the entity's participation in the very thing they have said they will not do.

What is the overarching public interest at play here? Does VAD have a status greater than any other service – human or medical – which many residential facilities do not provide? After the legislation is enacted and comes into operation people, for whom VAD is an important requirement could surely select a residential care facility which is supportive of VAD.

Calvary submits that if Subdivision 3 is to remain in the Bill, sub-clause (2) could be amended so that it applies to permanent residents living in the entity's residential facility before the Act comes into operation. After the Act comes into operation sub-clause (3) could apply to permanent and non-permanent residents alike.

It is submitted that this is in the public interest because it better respects the values and ethos of faith-based organisations and a plurality of views and desires in the community.

As previously stated, In the same environment and indeed in the same room may reside a person or people who do not want to be associated with any form of euthanasia. As Calvary stands aside to allow their fellow resident to take the VAD substance, how are we to deal with those other people's rights, beliefs, fears, anxiety and even anger that we have allowed this to happen in their home without their consent? How do we explain to them that we are upholding principle 4(k):

> All persons have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics.

This person might say, this act has violated my sanctuary and left me with grief and suffering I did not expect to have to bare at this point in my life.

Finally, permanent and non-permanent residents should be required to inform their residential care provider that they are applying for VAD. Residential aged care providers can be informed, without compromising their conscientious objection, if they are not forced to participate in the process.

Concluding Remarks with respect to Division 2 of Part 5

The Bill as it presently stands exposes care providers, their staff and other patients/residents at aged care facilities to significant risk.

The Bill seeks to offer choice in end-of-life matters, but if it passes in its present form it appears neither to protect nor respect the choice of people in aged care facilities who don’t want anything to do with assisted dying.

The effect of Division 2 of Part 5 doctors to access any aged care service and use its facilities for the purpose of assisted dying. A doctor can do this without informing the institution involved.

This impacts upon the duty of care we owe our residents at aged care facilities. It creates an unacceptable level of risk to other residents, as well as the safety and wellbeing of our employees.

In aged care facilities who do not want to participate in VAD, the Bill could expose workers in these facilities to handling lethal drugs and the euthanising of vulnerable people with whom they have a caring relationship.

It could also cause severe distress by exposing other residents in shared accommodation to assisted dying taking place.

In a climate post Royal Commission into Aged Care, which exposed challenges facing the elderly, these are risks that could be better mitigated.

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Hon. Wes Fang, MLC
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Response to Supplementary Question Three to Mark Green and Question Six to Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW)

We refer to the above subject. Calvary submits the following response to the question from the Committee. We also direct the Committee to our responses to, and the material covered in, our responses to six other questions.

Supplementary Question

Assuming the *Voluntary Assisted Dying Bill 2021* is going to be passed by the New South Wales Parliament in its current form and having regard to:

- Clause 9 (and related provisions) - Registered health practitioners may refuse to participate in voluntary assisted dying; and
- Part 5 – Participation

what specific amendments do you propose to the Bill that would enable your organisation to continue to perform its work in the provision of Residential facilities (Part 5, Division 2) and Health care establishments (Part 5, Division 3) covered by the proposed legislation?

Response

This response is extracted from our response to Question 2 (Green) and 5 (Hughes).

Clause 9

Clause 9 needs to be amended and broadened to cover all who provide care including staff and others in community and residential care settings. This will provide comfort to many of our carers who will have no legal recourse under the Bill if they are asked to be present at the time of the administration of a voluntary assisted dying substance in one of our homes. Clause 9 (1) (c) would give them that protection and enable them to continue to work in the residential facility in good faith.

Part 5 – Participation

Division 3 of Part 5

We submit that the clauses could be redrafted to give effect to what is present practice and clarify that the effect of the Division is not and cannot be to override the leadership in care of a credentialed admitting doctor.

Division 2 of Part 5

Calvary submits that for the purposes of the Division, the deciding practitioner should be the person's usual medical practitioner or if that person is not available—another medical practitioner nominated by the person.

Non-participating residential aged care providers must not be forced to provide or to oversee the administration of the VAD substance in their homes. As noted above, Clause 89 (2) of the Bill ostensibly offers this protection. However Clause 89 (3) effectively takes away or eliminates the protections offered by Clause 89 (2) by making the protection subject to Divisions 2 and 3 of the Bill.

Under this Bill, organisations like Calvary, may clearly state, under Clause 98, that the entity does not provide, *at a residential facility services associated with voluntary assisted dying, including access to the request and assessment process or access to the administration of a voluntary assisted dying substance*. The effect of Subdivision 3, and Clause 97(2) in particular, is to force the entity's participation in the very thing they have said they will not do.

Calvary submits that if Subdivision 3 is to remain in the Bill, sub-clause (2) could be amended so that it applies to permanent residents living in the entity's residential facility before the Act comes into operation. After the Act comes into operation sub-clause (3) could apply to permanent and non-permanent residents alike.

It is submitted that this is in the public interest because it better respects the values and ethos of faith-based organisations and a plurality of views and desires in the community.

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Response to Supplementary Question Three to Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW) per Mark Green

We refer to the above subject. Calvary submits the following response to the question from the Committee.

Supplementary Question

3. 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)

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

Calvary makes the following observations about "choice" and "choices":

Choices to accept treatments

It has always been the case – in Calvary and many other services – that the dying person is free to decide whether or not to accept any further treatment. Treatment has *always* been voluntary. And, one of the noblest activities of hospitals and the medical profession has been to assist such patients as they are dying.

It is perfectly lawful for a medical practitioner, in appropriate cases, to administer drugs to a dying patient with the intention of relieving that patient's pain and suffering, even though the practitioner knows, or even expects, but does not intend, that the patient's life may be shortened. These are distinctions with very important differences.

Moreover, there is no duty upon medical practitioners to prolong the life of a dying patient. It is bad medical practice to provide treatments that offer no realistic possibility of helping a dying person or which are burdensome for such a patient.

There will be people who can be assessed as having freely given informed consent to a medical practitioner to provide them with and/or administer the VAD substance. For people in this category, the Bill offers sufficient protections. But they are not the ones who really need protection. *Legislation of this type is to be considered by reference to the public good and the public good should not be compromised to the advantage of a limited* *group of people.*

Capacity to make informed choices

Many people approaching death lose the capacity to make any such informed choice. Both depression and the onset of dementia cause confusion and a willingness to go along with the suggestions that those closest to the dying person may wish to make.

As many legal practitioners who works in the area of probate, administration and guardianship know, the involvement of the relatives of the dying person in testamentary matters can be malign. The law reports contain innumerable cases where courts have found that the dispositions of a dying person were not free and informed but resulted from pressure being placed on the dying person by those who stand to profit from his or her death. There will be more cases, not less, as life expectancy increases as it has profoundly over a generation. The temptations placed before potential beneficiaries who observe their expected patrimony being eaten up by long term care will be considerable. The pressure can be very subtle and, as the testator who is subject to this legislation approaches death, the ability to give free and informed consent diminishes rapidly.

The capacity of medical practitioners to know whether a person is making a free choice

The critical decisions to be made under the Bill - for example, as to whether the patient has a terminal illness, is suffering intolerably on account of that illness, has requisite decision-making capacity, whether their decision is voluntary, and their consent is informed as to the nature and finality of the consequences of their action – **all of these matters are evaluated by medical practitioners.**

However several of these matters, particularly whether the decision has been made free from pressure or duress, are not necessarily medical judgments at all. They are more usually regarded as forensic decisions to be made on the basis of evidence and inquiry, not impression or assumption.

The Bill requires doctors to have acquired a certain level of professional qualification, but it does not require them to *know*the patient or to have had any prior consultative *relationship* with the patient. The Bill does not require the doctors to be specialist or experienced in the illness or disease from which the person is suffering.

Positive duty

So how is it to be determined that a particular person's decision is truly voluntary and not caused, or contributed to, by pressure, duress or manipulation? In truth, the Bill requires no active inquiry into the existence of these matters. *Provided that no evidence or circumstances of pressure or duress is otherwise apparent to the doctors*, that is all that is required for the doctors to conclude that the person is acting without pressure or duress. In other words, the inquiry is not proactive, but reactive. The Bill would appear to impose no duty on the doctor(s) to prepare notes of what he or she observed at the time the decision of eligibility is made, in terms of the absence of pressure or duress.

There is no positive duty of inquiry on the part of the doctor. Nor is the doctor required to consult with the patient's own GP who might be expected to know the personality of the patient, past expressions of wishes when diagnosed with a terminal illness, or the dynamic within the patient's own family. The complexity of inquiries needed to be undertaken to decide whether a person is subject of undue influence, pressure or duress is the subject of much research. The Bill enables, but stops short of, requiring the coordinating practitioner and the consulting practitioner to have regard to the person's existing medical history. Thismeans an assessment of eligibility can be made without any attempt at obtaining that history.

It is not realistic for two doctors, who may know nothing about the patient, the patient's personality, family relationships or the possibility of past and present elder abuse by family members of the patient to arrive at a sufficiently informed decision on a sometimes vexing matter when, before a judge, such an inquiry will often take a significant period of time to determine safely.

Minimum Changes

At the very least, the Bill could be amended to ensure that a person's own GP is consulted by the two VAD doctors and that the latter must obtain the patient's medical history before any assessment of eligibility is undertaken by them. The Bill should also be amended to require the VAD doctors to record the reasons relied upon by them in concluding that the person is eligible to access VAD. This would not be an onerous obligation - doctors do very little without recording matters in clinical notes.

Concluding Remarks

To say that VAD laws are “voluntary and no-one is compelled to be involved” is simply not accurate.

Even though the Bill ascribes the right for residential aged care facilities to opt out of providing voluntary assisted dying at the facility they must still allow access to VAD practitioners from the first assessment right up to administration of a lethal substance. This imposition infringes the rights of the people working, living and being treated at our members’ facilities. People who have intentionally sought to join a community providing compassionate care, free from any intentional taking of life, would be exposed to VAD. This exposure could be as a bystander (for example, witnessing someone undertaking VAD) or by unintentional participation in the practice (for example, through being handed a lethal substance). The VAD laws are not voluntary for these people.

Choice cannot be defined simply as freedom to act without coercion. Such a definition fails to take into account whether (i) the patient has access to other options and (ii) their circumstances which may limit their access to these options.

The Bill also neglects adequately to address the issue of coercion, which is of particular concern in the case of elderly patients. Our society is aware of the prevalence of elder abuse; almost 40 per cent of people living in residential aged care experienced some form of abuse or neglect, according to the Royal Commission into Aged Care Quality and Safety. This law should not have the effect of heightening the risk of such elder abuse.

It is also worth noting that the VAD training for medical practitioners under the Victorian scheme, takes only six hours to complete online. This is hardly adequate training to enable any person or any practitioner to identify the subtle forms of coercion. https://www.health.vic.gov.au/patient-care/health-practitioner-information It should not be presumed that any doctor who applies to be a participant in the scheme is well-versed in identifying when a human being may be being influenced or coerced.

Finally, the Bill references the rights of people in rural and remote areas to have equal access to VAD; **but people living in rural and remote areas do not have equal access to palliative care currently**. To enshrine a right equitable access to VAD without an analogous guarantee of palliative care access is **no choice**. Regional and remote Australians experience higher morbidity and mortality rates and poorer access to healthcare services. Often they need to travel long distances to access healthcare. If VAD presents their only opportunity to die at home with their loved ones in their communities, that is not a state of affairs commensurate with a voluntary choice.

Mark Green

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(Calvary Health Care)

For more information

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28 January 2022

Hon. Wes Fang, MLC
Committee Chair, Legislative Council
Standing Committee on Law and Justice

Response to Supplementary Question Four to Dr Rachel Hughes from Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW) per Mark Green

We refer to the above subject. Calvary submits the following response to the question from the Committee.

Supplementary Question

4. In regard to the evidence referred to above in question 3 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

We refer to *Response to Supplementary Question Three to Dr Rachel Hughes from Legislative Council Law & Justice Committee Voluntary Assisted Dying Bill 2021 (NSW) per Mark Green* Calvary makes the following observations about the real and actual implications for citizens who may have access to VAD but who 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.

As noted in our original submission to this inquiry, First Nations Peoples experience a much higher burden of disease and live shorter lives than their non-Indigenous counterparts. Existing mistrust of the health care system will only be exacerbated by the introduction of a practice so radically at odds with cultural practice. Many of our First Nations people reside in rural, regional and remote NSW.

In the eyes of our First Nations Peoples, dying holds particular significance. Their ancient culture recognises the inherent interconnectedness between people. Their strong connection to Family and Country enables to see more clearly that even the expression of individual autonomy occurs in relation to other people and that at a societal level this means the right to do something must be weighed up against the impact on the others. Many Elders have expressed concern at the introduction of VAD in other states and much is lost by not listening to their insights and wisdom.

While our capacity as a State to provide palliative and end-of-life care, particularly in regional, rural and remote areas, is at best inconsistent, people cannot be said to have equitable access to quality needs-based care as they approach and reach the end of their lives. Despite experiencing higher levels of morbidity and mortality, people living in rural and remote areas have poorer access healthcare, including palliative care services. Pain management, medication management, staff knowledge and training are critical ingredients of an effective palliative care service. See Wenham S, Cumming M, Saurman E. Improving palliative and end-of-life care for rural and remote Australians. Public Health Res Pract. 2020;30(1):e3012001.

We quote from the research.

> Recent reports highlight an inconsistent provision of palliative and end-of-life (palliative) care across Australia, particularly in regional, rural and remote areas. They recommend that systematic solutions be developed to address the identified gaps and improve the access to and quality of palliative care and support for patients, their families and carers.[1,2]
>
> Palliative care improves quality of life and the experience of dying, and all people should have equitable access to quality needs-based care as they approach and reach the end of their lives.[3,4] Palliative care is provided by specialists (clinicians with advanced palliative training), generalists (other clinicians, including general practitioners), and even lay carers, making it "everyone's business".[3-6] Specialist palliative care, where available, is most effective when it is provided early in accordance with assessed need and for complex cases.[5] In Australia, 12% of those who died in 2014-15 from a known chronic or life-limiting disease received specialist palliative care in their last year of life.[7] There is a reliance on generalists to provide palliative care, particularly in rural and remote regions where there is a shortage of specialists and providing quality healthcare faces well-recognised challenges of a limited workforce, poor access, and vast geography.[8] These clinicians are expected to have appropriate skills, knowledge and access to training and support; however, generalist staff report that they feel ill-equipped to provide palliative care to their patients.[9,10]
>
> A 'palliative approach' to care aims to improve quality of life for a person with a life-limiting illness by identifying and treating their physical, emotional, spiritual, cultural and social symptoms, and providing support to their families and carers by any provider.[11] This approach is usually associated with aged care and generalist services, offering evidence-based processes from a specialist palliative care perspective for a generalist doctor audience. A palliative approach has been documented to improve patient care and outcomes in the last year of life, including resulting in fewer hospital admissions and an increased likelihood of dying at home.[6] This palliative approach is crucial in rural and remote Australia.

If we do not address this existing inequity, we are not offering any semblance of a real choice to people who are living with a serious and potentially very frightening disease to find a way to live as fully as they can until they die.

Legalising VAD does not address this inequity. Legalising VAD offers those persons with a terminal illness residing in rural, regional and remote NSW access to voluntary assisted dying – or more precisely "to the administration of a voluntary assisted dying substance". If we do not address this existing inequity, we do not offer any semblance of a real choice to people who are living with a serious and potentially very frightening disease to find a way to live as fully as they can until they die. We do not offer them improved patient care and outcomes in the last year of their lives.

And yet the Bill espouses, in Clause 4, the following principles (emphasis added):

> (a) **every** human life has equal value,
>
> (b) a person's autonomy, including autonomy in relation to end of life choices, should be respected,
>
> (c) a person has the right to be supported in making informed decisions about the person's medical treatment and **should be given, in a way the person understands, information about medical treatment options, including comfort and palliative care and treatment**,
>
> (d) **a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life**,
>
> (e) a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained,
>
> (f) a person should be encouraged to openly discuss death and dying, and the person's preferences and values regarding the person's care, treatment and end of life should be encouraged and promoted,
>
> (g) a person should be supported in conversations with the person's health practitioners, family, carers and

community about care and treatment preferences,

(h) **a person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in New South Wales** and having regard to the person's culture and language,

There is a real risk here of sending a message that the lives of people in remote, regional, and rural parts of NSW are welcome to VAD but not "high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life."

The operation and continuing operation of a Bill like this must be predicated on year-on-year investment in high quality care and treatment, including palliative care and treatment in remote, regional and rural NSW.

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For more information

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