Submission

Victorian Voluntary Assisted Dying (VAD) Bill Discussion Paper

Assisteddying.frameworkresponses@dhhs.vic.gov.au

Date: 10 April 2017
Author: Mark Green
Title: National Director of Mission
Little Company of Mary Health Care Limited, trading as Calvary, appreciates the opportunity to give feedback on the Victorian Voluntary Assisted Dying (VAD) Bill Discussion Paper.

Calvary is a charitable Catholic not-for-profit organization with more than 12,000 staff and volunteers, 15 public and private hospitals, 15 retirement and aged care facilities, and a national network of Community Care centres. We operate across six states and territories within Australia.

Since the establishment of Calvary in Sydney in 1885, with the arrival of the Sisters of the Little Company of Mary in Australia, Calvary has become renowned for the provision of health care to the most vulnerable, including those reaching the end of their life. We provide aged and community care, acute and sub-acute care, specialist palliative care and comprehensive care for people in the final years of their life.

Calvary Health Care Bethlehem in Caulfield Victoria is recognised as a leader in a Specialist Palliative Care Service.

Our services are valued in the Victorian community. We support over 4000 patients and their families each year. Calvary is known for our innovative model of care, our interdisciplinary team work in collaboration with the patients, GPs, community health, aged, disability and other health services; and our efforts to ensure that care is easily accessible and coordinated across inpatient services, centre-based clinics, a day centre and at home.

Please find attached our submission for your consideration.

Yours faithfully,

Mark Green
National Director of Mission
Voluntary Assisted Dying (VAD) Bill Victoria
Calvary Submission to Ministerial Advisory Panel

Responsible for Submission: National Director of Mission
10 April 2017

Contents

Introduction and Preliminary Remarks ........................................................................................................... 3
Principles .................................................................................................................................................................. 5
Response to Key Issues being canvassed ............................................................................................................... 7
  1. The person ....................................................................................................................................................... 7
  2. Access and eligibility ........................................................................................................................................ 8
  3. Making a request ............................................................................................................................................... 8
  4. Properly informed ........................................................................................................................................... 8
  5. Confirming a request ....................................................................................................................................... 9
  6. Conscientious objections ............................................................................................................................... 10
  7. Administering a lethal dose of medication .................................................................................................... 10
  8. Monitoring the use of a lethal dose of medication .......................................................................................... 10
  9. Attendance .................................................................................................................................................... 11
  10. Lethal dose of medication not effective ....................................................................................................... 11
  11. After a person has died ................................................................................................................................. 11
  12. Oversight, additional safeguards, liability and insurance ........................................................................... 11
Concluding Remarks ........................................................................................................................................... 11

Introduction and Preliminary Remarks

Calvary notes the following statement from the Chair of the Ministerial Advisory Panel (the Panel) in the discussion paper:

Please note that the panel will not consider feedback that expresses an opinion for or against assisted dying. The panel is seeking feedback that is based on people’s expertise and experience to provide perspectives on the access, safeguards and practical considerations in creating a compassionate and safe assisted dying framework.

To be clear Calvary cannot and does not support the introduction of the proposed legislation. Calvary’s rationale for this stance is based on 131 years of expertise and experience in the provision of care at the end of life.

Nevertheless, Calvary trusts that the following stakeholder views will be respected by the Panel in the spirit of the Chair’s third principle on page v of the discussion paper (and cited below).

Acknowledgement that providers will hold differing views about voluntary assisted dying and recognise that while individuals may seek to contribute to developing the legislation, they may choose not to participate in its implementation.
For reasons which will be presented, Calvary does not believe that Parliamentary legislation can create an acceptable compassionate and safe assisted suicide framework for people with serious and incurable conditions.

No safeguards can be 100% effective.¹

Nor are the interests of the common good (the good of all people in the community) served by any framework which asserts that in some cases the community, as represented by its health care professionals, can assist a person to kill themselves. Each person’s life in the community is of value to that community to their last breath, no matter what the individual’s circumstances or perception of their life’s circumstances may be.

By making medical practitioners central to the legislation, as the discussion paper currently does, we are reshaping the role of health practitioners. Currently in Victoria and in Australia, doctors and other health professionals are seen as people involved in healing and caring. The discussion paper proposes that they actively participate in bringing about the death of people, their patients, who are not necessarily dying. There is a risk that we could undermine trust in the health care system as a vehicle of care and healing.

If legislation to legalise assisting people, who experience a serious and incurable condition, to commit suicide proceeds, Calvary submits this assistance should be rendered by an agency and individuals who are not regulated by the mainstream health care system but rather by a specific and separate state-sanctioned legislative framework.

In the words of Professor Douglas Bridge, an Emeritus consultant at Royal Perth Hospital, clinical professor in the University of Western Australia’s School of Medicine and Pharmacology, a consultant physician with WA Country Health Service, and past president of the Chapter of Palliative Medicine, Royal Australasian College of Physicians:

> Good palliative care helps patients and families avoid both overtreatment and neglect of treatment. It enhances patient autonomy and decision-making capacity by improving symptom control and empowering patients to participate in their care. We affirm the patient’s right to choose their therapy; decline futile therapy; choose the place of dying; choose who should be present; receive the best possible relief of symptoms, even, on rare occasions, deliberate palliative sedation (not terminal sedation); and refuse to prolong the dying process. Ideally, this should be readily available for all those with life-limiting illness.

> Autonomy does not include the right to demand that a clinician kills the person. Contrary to public opinion, the use of therapeutic doses of analgesia or sedation in order to relieve difficult and intractable discomfort does not hasten death and is not a form of euthanasia. Appropriate end of life prescribing of analgesia is simply good clinical practice when the patient is actively dying.²

¹ For example, how can any legislation ensure that a vulnerable person or a minor does not gain access to lethal medication stored in the dwelling of a person who intends to take their own life in the imminent future? Calvary acknowledges that the discussion paper addresses this very question on page 17. Calvary, however, questions the veracity of argument. The prescription of a lethal substance designed to kill is not in the same class as “many prescription medications and other household items that may cause death if they are ingested.” This substance has a single purpose, namely to bring about death. Prescription medications and other household items may become dangerous when used incorrectly but they are not of themselves lethal substances or designed to kill. The state needs to take particular care to ensure that a lethal substance designed to kill is appropriately regulated.

Parliamentary intervention to establish a framework to assist people to kill themselves because a serious and incurable condition is subjectively causing them enduring and unbearable suffering that cannot be relieved in a manner they deem tolerable is neither compassionate nor safe. Rather, to attempt to establish a framework which relies so heavily on the participation of members of the health care profession flies in the face of a fundamental good which the parliament is also obliged to support, namely that each person's life in the community is of value to that community to their last breath, no matter what the individual's circumstances may be. It is this later value which is the raison d'être for medical intervention, for health care and care of people in the last phase of their lives.

As a society we are making every effort to counteract suicide. This legislation, if enacted, would recognise that some suicides are acceptable and that health professionals will assist in that process. We already know the impact that suicides have on families and those close to the individual. The introduction of voluntary assisted dying legislation, together with the redefinition of societal values its enactment would represent, could have significant and unforeseen consequences in the community. What care and services are going to be put in place and funded to support families who are grieving not only because of the death of a loved one but also because of the means by which they chose to take their own life?

**Principles**

The submissions Calvary makes in this document are offered to assist the Panel to reflect on some of the questions raised in the discussion paper. These submissions must not be construed as implicit or tacit support for the proposed Bill.

Calvary notes that in the Discussion Paper assisted dying and end-of-life-care are inextricably linked. They should not be. Assisted dying or assisting a person who has a terminal illness to take their own life is not part of palliative care practice.

At Calvary, this is what we mean when we use the terms palliative and end of life care:

**End of life** refers to that period of time when a person is living with an advanced, progressive, life limiting illness and likely to be in the last 6 to 12 months of their life.

**End of life care** is care provided to people who are approaching and reaching the end of their life. This care can be provided by all health and community care professionals, regardless of where they work in health, community, specialist palliative care or aged and retirement care services.

**Palliative care** refers to designated specialist services provided by an interdisciplinary team of specialist palliative care professionals whose substantial work is with patients who are approaching the end of their life.

Professor Owler states

> The consultation process will be guided by a set of principles that will respect the variety of views and expertise of the stakeholders and commits the panel to focusing on problem solving and resolution of the key considerations in developing the legislation.

The principles are:
• The person, and the needs of the person, will be the central consideration in all discussions about voluntary assisted dying.

• Respect for the range of expertise and judgement of all people – providers, family and carers – supporting people at the end of their lives.

• Acknowledgement that providers will hold differing views about voluntary assisted dying and recognise that while individuals may seek to contribute to developing the legislation, they may choose not to participate in its implementation.

• A focus on problem solving and resolution of issues that will help create compassionate and safe voluntary assisted dying legislation.

• That the development of the legislation will be applied in a way that respects the diversity of culture and values of Victorians.

Care needs to be taken in restricting the range of principles considered in drafting legislation in which a wide stratum of the community has an interest because the outcomes and effects of the legislation will not be confined to a small circle of people, as is often imagined.

The first of the five principles focuses on the person. The experience of the dying person is an important experience. So also is the experience of their family members, friends, professional and social networkers, people who respect them and the community circles in which they presently live and in which they have lived in the past. The person is important. So are other people with their needs, hopes and dreams. People are the central consideration. It is important that the interests of many people are considered; that the common good is a central consideration in the consultation process.

The second principle perhaps reflects this wider consideration; but restricts the respect to be shown to all people to their expertise and judgment. There is no mention of their experience, hopes, dreams, desires, beliefs or values. This is to value one individual's experience above the experience of the many people among whom they live. The differing experiences of those who are dying and of those who live around them are surely equally to be valued.

The proposed legislation is very silent on families being involved in the decision making process. As a specialist palliative care provider, Calvary deals with conflict within families and the decision making process at the end of life on a frequent basis. Our experience of all these people is a central consideration in the shared goal of assisting the dying person to die well.

The logic of the fourth principle is deficient. A focus on problem solving and resolution of issues will not necessarily help or contribute to or result in compassionate and safe legislation. The method does not guarantee the outcome. Calvary submits that there hasn’t been broad discussion of possible models.

The fifth principle is difficult to achieve. This is ultimately a discussion about shaping the culture and values we will be required to hold in common. The discussion on page 15 of the paper on conscientious objections is a case in point.

Currently, a health practitioner can conscientiously object to providing medical treatment but must take any steps necessary to ensure their patient’s access to care is not impeded. In some circumstances, such as under the Abortion Law Reform Act 2008, there are more prescriptive requirements. The Abortion Law Reform Act 2008 requires a health practitioner who conscientiously objects to abortion to inform a woman who requests an abortion of their objection and to refer the woman to another registered health practitioner in the same regulated health profession who the practitioner knows does not have a conscientious objection to abortion. This more prescriptive requirement ensures that a woman will still be able to access the treatment without having to recommence the process of finding an appropriate health practitioner.

In this respect, the law cited above does not respect the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia (2.23). If the Panel adopts the model in the Abortion Law Reform Act 2008 for the Assisted Dying legislation, significant numbers of people in the community and a large number of health professionals who work in end of life care will not perceive that their cultures and values are respected by the Victorian Parliament. They will be placed in positions of significant personal and professional conflict. This is not
Response to Key Issues being canvassed

The Key Issues being canvassed are as follows:

1. The person
2. Access and eligibility
3. Making a request
4. Properly informed
5. Confirming a request
6. Conscientious objections
7. Administering a lethal dose of medication
8. Monitoring the use of a lethal dose of medication
9. Attendance
10. Lethal dose of medication not effective
11. After a person has died
12. Oversight

Additional safeguards
Liability and insurance

1. The person

Calvary draws attention of the Panel to limitations of the Parliamentary Committee’s (majority) Recommendations:

- An adult, 18 years and over, with decision-making capacity about their own medical treatment.
- People whose decision-making capacity is in question due to mental illness must be referred to a psychiatrist for assessment.
- Ordinary resident in Victoria and an Australian citizen or permanent resident.

It may be disputed that seeking assistance to take one’s own life can be defined as medical treatment. Given the enormous ramifications of such decisions for the individual and the society, the test set out in the Medical Treatment Planning and Decisions Act 2016 is not a suitable decision-making capacity test to utilise in legislation such as that being proposed.

Decision making capacity is something which grows with the person and is shaped by their experience. The legal definition and presumption of decision making capacity has limits. Mental illness is recognised as a potential impairment to this capacity by the Committee. There are other circumstances which may impinge upon this capacity when a person is considering suicide including:

- the degree to which they can gain access to support and suitable care, which may be impinged through loneliness and isolation, extreme age, grief and lack of a support network;
- the fact of elder abuse, family conflicts and other pressures, real or imagined;
- experiences of past abuse and trauma;
- poor self-esteem and experiences of rejection by significant others;
- their physical condition, the nature of the disease and cognitive impacts;
- other changes of which they are presently afraid (not being able to stay at home).

It is well known that people with cancer and other life threatening diseases have a higher incidence of depression. What safeguards will be in place to ensure adequate treatment not just of their depression but of the whole person?

Some existing patient groups have cognitive changes associated with the disease process, which also change over time. Health professional competency in terms of assessment of this cognitive change is variable, can be complex and may require neuropsychology testing.
A medical practitioner, making an assessment of capacity, may not have a full and comprehensive knowledge of the person seeking assistance to end his or her own life. How can the Parliamentary legislation ensure that these decisions are truly free actions? A large range of experiences and factors, such as those listed above, which may be influencing decision making need to be raised, considered, assessed and weighed if a person and those assisting them are to come to any convincing place of freedom.

2. Access and eligibility

Calvary supports the points made in Catholic Health Australia’s submission on this key issue.

In considering access and eligibility, the Parliament needs to consider

- Whether persons with a serious and incurable psychiatric condition will be eligible for VAD in Victoria?
- Will all Victorians have access to VAD, regardless of where they reside?
- Will Victorians who reside in regions where there are no adequately funded high-quality multi-disciplinary palliative care service gain access to VAD before they gain access to good palliative care services?
- Will there be adequate access in the cities and the regions to the professionals that have been proposed to make the assessments of eligibility, i.e. psychiatrists and psychologists with end-of-life experience, or physicians with formal training in palliative care?

As there will – in the majority of cases – be implications social and psychological for the family, the physicians and the community, it is critical that the government’s proposed support services incorporate the provision of accessible and evidence-based guidance for all members of the community.

Many disabled people insist that people should be given the right to live well before they are given the right to die with assistance.

As a first step, Calvary submits that the Parliament must first ensure that all Victorians have reasonable access to affordable, high-quality and multi-disciplinary palliative care.

VAD legislation should not be the first step for individuals with advanced disease who have no feasible alternative when in need of end-of-life care because they live in a region which is without adequate palliative, medical, mental health and other social services.

At the very least, if someone with a terminal illness has unbearable suffering then we should be ensuring that early referral to specialist palliative care or other appropriate services is possible and is made. This is of greater value for many, Calvary submits, than any limited right to access VAD legislation.

3. Making a request

The discussion paper itself highlights how difficult the task is to ensure, let alone document, a decision to commit suicide is voluntary, free of coercion, enduring and involves no criminality on the part of another or others.

It is very difficult to safeguard against elder abuse or to address the pain of those who feel they are a burden to their family.

The role of the health care team is critical to explore the concerns behind any request. Often it is fear of dying, being a burden, loss of control and existential distress rather than pain that lead to such queries.

This is precisely what Calvary’s specialist palliative care services are skilled in eliciting and treating.

The common good of all outweighs individual right when the benefit of meeting the needs of a particular individual is outweighed by the risk legalisation creates for many other more vulnerable individuals.

4. Properly informed

The Parliamentary Committee recommendation is striking.
A person must be properly informed. The primary and secondary doctor must each properly inform the person:

- of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results;
- of palliative care and its likely results;
- that they are under no obligation to continue with a request for assisted dying and may rescind their request at any time; and
- of the probable result and potential risks of taking the lethal drug.

In relation to the first two bullet points, Calvary submits that it would be a failure of public policy if people were hearing about treatment, therapeutic options and palliative care from two medical practitioners at the point when they were requesting help to take their own lives. Generally, this discussion should have taken place several times at much earlier phases in the progression of the illness.

We know that not all health professionals are comfortable in having these ongoing conversations with their patients and the Medicare system doesn’t support time spent in long consultations. This challenge needs to be addressed.

Secondly discussions about treatment, therapeutic options and palliative care should not be linked with requests for VAD.

Calvary disputes that VAD is a clinical intervention in the normal sense in which clinical intervention is understood because prescribing and/or administering a lethal substance with the intention of assisting someone to kill themselves is not by its nature therapeutic. And it should not be treated as such.

For all of these reasons, discussions about VAD should take place through a framework which is different and distinguishable from medical, therapeutic and health care practice. Those who may be licenced by the state to assist people to end their lives should have titles and designations which demonstrate that they are not providing therapeutic advice, palliative care or health care.

As previously noted, in the Discussion Paper assisted dying and end-of-life care are inextricably linked. They are very different philosophically, in intent and in practice.

### 5. Confirming a request

Calvary submits, if the Parliament is minded to proceed with this legislation,

- the legislation should not mandate that medical practitioners must participate in or are essential to an assisted suicide framework; the legislation should, however, protect those practitioners that wish to opt in and provide assistance;
- there should be a requirement that any person seeking assisted suicide, should have already been in the receipt of end of life care or palliative care services with an evident plan of care in place.

Providing information about palliative care is not sufficient.

This legislation has significant social and public policy ramifications. It is in the interests of the common good that people who wish to gain access to a state sanctioned service to end their own lives have first had the opportunity to experience high quality care at the end of life and/or palliative care and that they should have tested its benefits.

People are valuable, no matter what they are experiencing and no matter how they perceive themselves. People are worth investing in. People are worth quality care at the end of life. Quality health care manages the causes of patients’ distress rather than ending life. In our experience, requests to terminate life prematurely are uncommon and often a cry for help. Calvary’s experience is that a person’s desire for hastened death changes over time and reduces when care is good. It is not good policy to consider euthanasia legislation before ensuring there is universal access in the State to good end of life care. Every Victorian is going to die. We want each person to have an experience of dying well. Not every Victorian will want assistance taking their own life.
6. Conscientious objections

Calvary submits that no doctor, no health care practitioner, no clinician, no aged care worker, no home care worker nor any health, aged or community care service can be forced to participate in assisted dying or assisted suicide. Nor should anyone or any service be forced to refer a person to another person, service or organisation that may assist them. This is because in making such a referral, a person or service is being forced to cooperate in order to bring about the very thing which their conscience prohibits.

Calvary further submits that a right to conscientious objection should be entrenched in legislation such that a future parliament could not remove this right except by referendum; or by a vote in favour of abrogating the right which attains a majority of 75% or more of the members of each house present and voting.

Calvary submits

- The will or desires of what will be a minority of the population should not be forced on the medical profession, on nurses, on people who work in aged care facilities, in the provision of home care and allied health professionals (including pharmacists) who, in conscience, do not wish to participate.
- No individual or group provider of health care, aged or disability services must be compelled to participate in or facilitate assisted suicide. Nor should any institution (including Catholic colleges and Universities) or any individual working in or for them be required to teach medical and nursing students how to prescribe and/or administer lethal drugs and doses of medication intended to kill people.
- If such legislation is to be introduced then it should be administered and implemented by an agency responsible outside of the mainstream health system with health professionals given the option to opt in. This protects health professionals, hospitals and organisations like Calvary who have relationships with patients, residents, clients and their families based on a Code of Ethics which does not support such conduct.

7. Administering a lethal dose of medication

Calvary submits that this issue should simply be entitled “Administering a lethal dose”. The Merriam Webster defines medication as

- a substance used in treating disease or relieving pain
- the act or process of treating a person or disease with medicine

The points made in relation to conscientious objection above apply here. A person who wishes to self-administer a lethal substance, or have their medical practitioner assist them to do so, may choose where this is to be done within certain limits. Legislation must protect services, practitioners, nursing homes and aged care facilities, together with their patients, clients and residents, who conscientiously object to this pathway from ever being forced to cooperate in or witness its practice. The Parliamentary Committee did not recommend that a person should have unlimited and unrestricted choice as to where they take their own lives.

8. Monitoring the use of a lethal dose of medication

As noted earlier, prescription medications and other household items may become dangerous when used incorrectly but they are not of themselves lethal substances or designed to kill. The state needs to take particular care to ensure that a lethal substance designed to kill, which is made available to a member of the public, is appropriately regulated.

How will the state manage the criminal process of investigating the alleged premature death of a person who has been lawfully issued with a lethal substance and who is permitted to ingest the poison at a date and time of their choosing several months after the substance was issued?
What safeguards will the state put in place in the event of theft or to limit access to a black market?

An agency established to oversee this process will need to ensure that there are adequate safeguards in place, including training, prescribing, provision, possessing, monitoring the use of lethal substances in order to protect practitioners willing to opt in to the process as well as the wider public.

How will the disposal of unused lethal substances be managed?

The legislation needs to take account of recent experience with medicinal cannabis, in particular, the uncertainty generated by lack of policy, resources, education, no Medicare items and no standards in relation to the quality of the product.

Monitoring is not the role nor the responsibility of palliative care or community services.

9. Attendance

What supports will be put in place to counsel those who may be involved in voluntary assisted suicide?

Calvary submits that any legislation enacted should not require the involvement of or supervision by medical practitioners or health care professionals. The state should establish a body with its own agents to administer and implement this legislation.

10. Lethal dose of medication not effective

Calvary submits that as with any person who has attempted to take their own life, treatment needs to be offered in accordance with the appropriate goals of care. The treatment should be effective for the purpose of achieving the goals of care. The benefit of the treatment should outweigh any burden the person may experience because of its administration. If the appropriate goal is to assist the person to die well, then the treatment and care offered should align with this goal.

11. After a person has died

Calvary submits that the cause of death should be stated on the death certificate as the lethal substance ingested. It should be a reportable death.

12. Oversight, additional safeguards, liability and insurance

Safeguards could be legislated and could include the authorization of a superior court judge or magistrate or specifically constituted tribunal in each individual case affirming that all necessary conditions have been met and a list of specially licensed persons authorized to administer assisted suicide or euthanasia established.

The entire process could be overseen and monitored by a specifically constituted, state appointed Board.

As far as possible for social and public policy reasons assisted suicide and euthanasia should be kept out of medicine and used as rarely as can be achieved.

Special licensing would help address freedom of conscience issues for healthcare professionals.

Concluding Remarks

Calvary cannot and does not support the introduction of the proposed legislation. Calvary does not believe that Parliamentary legislation can create an acceptable compassionate and safe assisted suicide framework for people with serious and incurable conditions.

Calvary submits that the introduction of this legislation will distract from more important tasks in the interests of the common good, namely the provision of adequate palliative, medical, mental health and other social services in every region of Victoria.

Continuing the Mission of the Sisters of the Little Company of Mary