

Risks to the welfare of vulnerable persons

Submission by
Caroline Chisholm Centre for Health Ethics
to the
Discussion paper on the proposed Voluntary
Assisted Dying Bill.

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Professor Brian Owler
Chair
Ministerial Advisory Panel

Dear Professor Owler

Submission to the discussion paper on the Voluntary Assisted Dying Bill

The Caroline Chisholm Centre for Health Ethics (CCCHE) tenders the attached submission to the discussion paper on the proposal to draft legislation to permit Voluntary Assisted Dying in Victoria.

For the avoidance of any doubt, no comments in relation to access, safeguards or practical considerations that are made in this document should be interpreted as indicating that CCCHE supports any legislative changes to permit Voluntary Assisted Dying in Victoria. CCCHE strongly advocates for the current legislative provisions against assisted suicide and euthanasia and believes that the measures outlined in the consultation document involve very considerable risks to some of the most vulnerable people in Victoria.

CCCHE focuses its comments on the consultation document on ethical concerns in relation to the consultation document, rather than specific clinical issues, which are being considered by our partner organisation, Catholic Health Australia.

Yours sincerely



Dr Brendan Long
Director
Caroline Chisholm Centre for Health Ethics

The Caroline Chisholm Centre for Health Ethics

The Caroline Chisholm Centre for Health Ethics (CCCHE) is a Catholic bioethics research centre sponsored by public and private Catholic hospitals of Victoria: Cabrini Health, Calvary Health Care Bethlehem, Mercy Health, Southern Cross Care Victoria, St John of God Health Care (Victoria), St Vincent's Hospital Melbourne, St Vincent's Private Hospital Melbourne, and Villa Maria Catholic Homes. We are involved with our sponsoring organisations in a variety of ways including contributing to the development and review of policies and procedures, providing education and formation in ethics, offering ethics consultation and advisement, and participating in the ethical review of research.

We are also involved in the wider community providing services to other organisations and members of the public, researching and publishing about health care issues, providing education and training about health ethics to health professionals and the general community. We assist any person who seeks help in making decisions about health care, over the phone or face to face. We contribute to community discussion and debate by making public comments about important matters related to health care.

CCCHE strongly advocates for the current legislative provisions against assisted suicide and euthanasia in Victoria

More can be learnt about the Centre by visiting our website at <http://chisholmhealthethics.org.au/>.

Executive Summary

CCCHE believes that there are a range of important ethics issues raised in the consultation document that need to be addressed by the Victorian Government. These issues converge around a latent philosophical option displayed in the consultation document towards an individualistic reading of health ethics and a preference for a utilitarian paradigm of assessing the needs of dying patients and what constitutes the public interest. In contrast, CCCHE favours a more holistic approach to the needs of the dying person based on a more rigorous notion of their welfare that more fully appreciates their medical, personal, familial, and spiritual needs. CCCHE's approach is to seek to express the ethical tradition that inspires the work of Catholic health care professionals. This perspective attends to the welfare of both the individual and the community, in a way that it is attentive to all the elements in "common sense" ethics: intention, motivation, the moral status of acts themselves, their likely consequences, the wider context, it is therefore a wholly different approach to ethics compared to political or ethical individualism.

CCCHE is concerned that the welfare of vulnerable people is potentially increased by proposed assisted suicide and euthanasia measures. The concerns are as follows:

1. People with mental illness: there is a strong risk that dying people with mental illness will activate the assisted suicide/euthanasia process as a result of their mental infirmity rather than a decision relating solely to their primary medical condition. There are significant ethical dangers in allowing persons with mental illness to be able to access this regime.
2. People with dementia: many persons in the final period of their life may suffer dementia. Such clients have constraints on their capacity to make clear informed choices to activate the assisted suicide process. People with dementia should not be able to access this regime.
3. Persons of linguistically diverse background: people in this cohort can find it very difficult to understand the intricacies of a complex legal framework that would apply in the proposed assisted suicide/euthanasia regime. There is a real concern that cultural and language barriers could lead to a frustration of informed consent under the proposed regime.
4. People with disability: persons in this cohort facing a terminal illness of significant duration face extraordinary struggles which few of us can even imagine. There is a real risk that the assisted suicide/euthanasia process could exacerbate a comorbid condition of latent depression or mental illness, with risks that persons with disability with ultimately terminal conditions might activate the assisted suicide process in an episodic moment of depression or anxiety.
5. In relation to elder abuse: there is a real risk that persons who are elderly and dying might activate the assisted suicide/euthanasia process out of a sense of being a burden to their family. There is also the risk that some family members might encourage such a perception for financial motives.
6. The state itself has to account for the position that it has an incentive to reduce costs of caring for vulnerable persons, costs which would be reduced if assisted suicide/euthanasia procedures are in place.
7. International experience indicates that the quantum of applicants for assisted suicide/euthanasia processes regimes expands over time, leading to the unintended consequences of a sense of normality associated with activating these processes, rather than the regime operating as an exceptional regime.

All of these concerns are of ethical concern and involve insurmountable implementation challenges. CCCHE adjudges that these ethical concerns are not dealt with in the consultation document in any serious way. Consequently, proceeding with legislation based on the consultation document would constitute an unwarranted risk to the welfare of vulnerable Victorians.

Specific Issues for considerations

The person

Parliamentary Committee recommendation:

- 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.

Issues

- Is the existing decision-making capacity test in legislation such as the *Medical Treatment Planning and Decisions Act 2016* sufficient.
- In what circumstances should a psychiatric assessment be required? Are there any other specialist referrals that would be appropriate for assessing decision-making capacity?

CCCHE's response is that the approach taken to the "person" in the consultation document is a very narrow one. The "person" is seen solely as an individual with a capacity to make a decision. The ethical and political philosophy that is at stake here is individualism which sees ethics and the role of government as the sustainment of the free choices of individuals without a value judgement being placed on the choice itself. So, what is ethical is what the "person" wants and the government needs only to be sure that this intention is freely made to mandate in law the choice of the person. The consultation document's specification of the person is a textbook expression of political individualism.

However, such a philosophical option is by no means universally agreed upon in Australia and is the subject to some standard criticisms. The broad criticism placed on a philosophy of political individualism is that seems to place insufficient regard on the duty we all have to each other. The state needs to form legislation that balances private interests with the notion of the common good. In the case of medically assisted suicide and euthanasia governments have generally taken the position that the common good is best achieved when medical professionals focus on the delivery of therapeutic care services and follow a regime consistent with their Hippocratic Oath. This is supported by the medical profession. Departure from this practice to assist suicide and euthanasia erodes confidence in the system of palliative care. The social costs to the community from this change in medical practice are sufficiently great that they outweigh the benefits associated with an individual's stated intentions no matter how sincerely felt. This logic pertains even with the framework of strong proponents of political individualism like John Stuart Mill. His system ultimately allows individual's right to be subordinated to government policy where such policy creates the greatest good to the greatest number. It is argued here that medically assisted suicide interferes with palliative care models which are effective forms of alleviation of suffering for dying persons, with negative costs to the community overall.

Another example in which the consultation document takes a strong position for political and ethical individualism is that it seeks to replace a negative right (to suicide) with a positive right (of assisted suicide and euthanasia). There is a difference between a positive right and a negative one. A positive right of an individual imposes a direct obligation on the community. A negative right is equated to a right to do what they want with their lives without interference from others e.g. a right not to be harmed by others. Granting the right to medically assisted death or euthanasia imposes on the community a positive right, extending beyond the negative right to suicide. The positive right to assisted suicide or euthanasia does not exist at the moment in most legal jurisdictions and is not recognised as a human right by the World Health Organisation or the United Nations.

CCCHE's approach is to seek to express the ethical tradition that inspires the work of Catholic health care professionals. In ethical terms, this is a deontological tradition that attends to the welfare of both the individual and the community, and that it is attentive to all the elements in 'common sense' ethics: intention, motivation, the moral status of acts themselves, their likely consequences, and the wider context. It is therefore a wholly different approach to ethics compared to political or ethical individualism. For example, CCCHE's perspective would seek to recognise the informal collectivistic approaches of families and care groups of diverse cultures and the more formalised structures of elders and community seen in traditional indigenous populations.

In seeking to make legislative change in any controversial area, it is open to the government to seek to capture, as best it can, a range of ethical traditions rather than relying on only one approach to philosophical ethics. In the context of the proposed legislation it would be preferable not to seek to describe the 'person' in a narrow legal manner but as an individual with emotional, social, physical, and spiritual needs, that are interwoven with the same needs of his/her family and community. Such a perspective is poorly reflected in the consultation doctrine that focuses on an individualistic ethical paradigm.

One of the key concerns in this area of the consultation document relates to uncertainty about whether a person with mental illness will be allowed to make use of assisted suicide. The recommendation of the Parliamentary Committee was only that where a person's decision-making capacity is in question due to mental illness, the request must be referred to a psychiatrist for assessment. This poses a number of dangers.

Mental illness is notoriously difficult to diagnose. This is the experience of professionals in Catholic hospitals in Victoria who have been consulted as part of this submission. There are two problems. The first is that it is a hidden disease. Without specialist clinical training, or a developed personal case history for the client, it is not easy for a GP to be able to distinguish mental illness from normal mood cycles or occasional aberrant behaviour. A GP faces significant challenges in distinguishing mental illness from a certain level of anxiety or depression that could be expected to be experienced by any patient facing a terminal illness. There is therefore a significant risk that a GP, when facing a referral for assisted suicide or euthanasia, may simply fail to identify latent mental illness and therefore fail to call for a psychological assessment of a dying patient who in fact seeks suicide as result of their mental illness.

Perversely, the increased prevalence of mental illness in the community may also exacerbate the difficulties with diagnosis. Data from the Australian Institute of Health and Welfare (AIHW) reveals a rapid rise in the mental illness cohort in the overall population in recent years. In *Mental Health Services in Brief* (2016, p.6) AIHW estimates that

“the incidence of mental health related encounters has increased by a rate of 4.4% per year between 2010-11 and 2014-15. “

This is a dramatic annual growth rate. When it becomes a daily reality in a GP clinic that clients may present with some signs of risks of mental illness, the diagnosis of psychological pathology, as distinct from an episodic mild depression, which is a natural response to diagnosis of a terminal disease, becomes a fine judgement. Many GPs will not be clinically trained to evaluate this situation. One way of determining if the mood change is a normal reaction or a pathological one is observing the patient over time but time is not a resource available to dying person and their GP. Diagnosis of mental illness is also a function of the depth of trust in the doctor-patient relationship. It is often easy to hide depression or anxiety when it is mild or moderate. This exacerbates the risk that a GP might fail to trigger a psychiatric assessment for a terminal patient with mental illness.

When we consider the international evidence, there are increased grounds for caution. The evidence available from Belgium and Holland, which has allowed assisted suicide and euthanasia for many years, shows a concerning rapid rise in people with mental illness seeking access to euthanasia. In

Belgium the proportion of deaths from euthanasia that involved psychiatric disorders has risen from 1.2% of cases in 2004/5 to 3.7% of cases in 2013/14: triple the reported incidence rate over the decade (with many cases of course not being diagnosed or reported). In the Netherlands data is available for both dementia and mental illness.¹ From 2012-2015 euthanasia cases with mental illness have risen from 14 to 56 with an average annual growth rate of 59%. Reported cases with dementia have risen from 42 in 2012 to 109 in 2015: an average annual growth rates of 37%. The consultation document should have given greater recognition to this data, and focused on wider causes of mental illness beyond depression. In addition, the Belgium and Netherlands experience is that safeguards to exclude candidates for euthanasia with mental illness and depression, through psychiatric evaluation, have proved to be weak and ineffective. Few candidates were referred and of those referred it was difficult to be objectively clear whether someone had mental illness or clinical depression.

There are ethical concerns that people facing death with mental illness will not be protected by medical professionals from the dangers that their disease presents to them. If we take an ethical model that all that matters is their choice, we have to be very sure that the choice is genuinely free. In the case of people with mental illness there are real doubts here. Those who emphasise a Kantian duty based ethical system would highlight a moral obligation of the individual to their own welfare, to act to safeguard their own lives as a statement of their autonomy and dignity as a person. In the Christian tradition, the obligation is simply to take reasonable care of our own lives. It is the responsibility of each individual to decide whether the benefits of a particular form of treatment (including life-sustaining treatments) are such as to compensate him or her for its burdens. Whichever ethical perspective is favoured, it has to be acknowledged that people with mental illness often fail to have sufficient self-regard, and fail to actualise their moral autonomy. This is even more likely to be a problem for people with both mental illness and terminal illness, who face the increased natural anxiety of impending death, which is likely to magnify the effects of any underlying psychological pathology. In justifying access to this regime its proponents argue that a level of depression is consistent with facing a terminal illness and seeking assisted suicide or euthanasia. However, it is important to examine the real source of the depression. If it is based on a sense of fearing suffering or seeing that their life bears no value, such depression can be addressed through effective palliative care and pastoral support.

Access and eligibility

Parliamentary Committee recommendation:

The person must be:

- at the end of life (final weeks or months of life); and
- suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.
- Suffering as a result of a mental illness only does not satisfy the eligibility criteria.

Questions to consider:

- Is greater specificity required to identify what constitutes a person being at the end of life and, if so, how should that specificity be worded?
- How should a 'serious and incurable condition' be defined?

¹ Dutch Regional Euthanasia Review Committee: Annual Reports various years.

The Parliamentary Committee seriously sought to address the difficult question as to what grounds should be taken to assess when 'end of life' (assisted suicide) can be presumed to apply to guide legislative drafting. This is a question of some ethical concern. Were a rather loose definition of assisted suicide to be legislated there would be a heightened risk that people facing the stress and suffering of terminal illness might seek to activate the assisted suicide/euthanasia legal process before having experienced the benefits that a professional palliative care service can bring to give them quality of life in its last phases. This is a real ethical issue because it is a duty of the state to provide effective palliative care options for the dying patient. In fact, it is reasonable within the framework of rights and obligations of the state and the citizen, for the dying patient to have a real right to palliative care. It is proposed here that enshrining this right in law, rather than legalising the 'quick fix' of assisted suicide or euthanasia, would be an effective legislative means of dealing with the recommendations of the Parliamentary Committee in its concerns with deficiencies in current palliative care funding and service delivery. Rather than talking of a right to death we should be talking of a right to the relief of pain.²

What the consultation document seeks to inform is a test as to when the suffering of the terminal patient becomes sufficient to warrant application of the assisted suicide procedure. The test proposed is a subjective one when the dying person self-assesses if they are in a position of unbearable suffering. However, it is the wrong question. The better question to ask is what deficiencies in palliative care are present for the person to come to an assessment that they can no longer cope. Again, we see the bias in the consultation document to a philosophy of individualism: the assessment is for the individual in their subjective view. However, as noted above, for vulnerable people, especially with mental illness, there are significant difficulties for the individual in forming this view decisively. The more proper question to ask is what level of palliative care service delivery failure can be taken to justify an objective assessment that pain and suffering becomes intolerable. A more communitarian perspective, which seeks solidarity of the plight of the suffering, terminally-ill patient would ask – what greater level of services can we offer the dying patient which gives them relief from perceived intolerable suffering?

Palliative care service delivery models are imperfect but largely effective. There are gaps. The first obligation of the state according to any common sense ethical perspective is to provide care and support to those most in need. The ethical question for the state is how to fund palliative care so as to minimise the situation where a person comes to the view that their suffering is unacceptable. It is the experience of palliative care professionals in the Catholic health system in Victoria that with adequate funding and effective service delivery clients in receipt of good palliative care tend not to feel that their suffering is intolerable. There is a negative correlation between palliative care service delivery and experience of extreme suffering. The more and earlier people access palliative care the less they see their suffering as unacceptable.³

So, the real ethical question is not to ask when to deem when a person can make a subjective assessment of intolerable suffering but how to augment palliative care funding and service delivery so as to reduce, as far as possible, that cohort who come to the view they can no longer cope. This is the most ethical and compassionate response, this would be a true expression of the rights of the individual, assessed under a rights-based democratic political philosophy or indeed a deontological or even consequentialist ethical paradigm. The state should fund that level of palliative care service

² Pain Relief as a Human Right, September 2004 (Volume 12, Issue 5) Frank Brennan and Michael J. Cousins.

³ See The Massachusetts General Hospital Handbook of Behavioral Medicine, Part of the series Current Clinical Psychiatry pp 277-296, November 2016, and Early Palliative Care for Patients with Advanced Cancer Joseph A. Greer, Vicki A. Jackson, Juliet C. Jacobsen, William F. Pirl, Jennifer S. Temel.

delivery which would reduce as far as possible the experience of subjective suffering. Any view about when suffering becomes so intense that assisted suicide/euthanasia procedures are contemplated can only be reasonably made when the maximum possible service delivery for palliative care is fully funded and effectively in place. This perspective, which aligns with the weight of the full consideration of the Parliamentary Committee of Inquiry report, suggests that the questions posed in the consultation document are moot until the maximal service delivery offering of palliative care is funded and in place. The cart should not be put before the horse.

Making a request

Parliamentary Committee recommendation:

- The request must come from the person themselves. The request must be voluntary and free of coercion. The request cannot be made in an advance care directive.
- The request must be enduring.
- The person must be able to withdraw the request at any time.

Questions to consider:

- What safeguards are necessary to ensure that a request is voluntary? How should this be assessed?
- Should there be a prescribed time period that must pass between the first and final request and, if so, what period?
- Should there be specific offences for those who fail to comply with the requirements in the Act or are the offences of homicide or aiding or abetting suicide appropriate and sufficient?
- Should there be a requirement that only the terminally ill person may raise the issue of assisted suicide or euthanasia?

The issue of coercion is certainly one of great ethical concern. In this regard, it is important to take note of the recent report by the Australian Law Reform Commission (ALRC) in relation to elder abuse. Using data from the World Health Organisation the ALRC suggests that elder abuse can occur in 2 to 14 percent of relevant cases.⁴ Elder abuse can take many forms through subtle emotional pressure, to direct coercion. In the analysis of public policy decisions that have financial implications for individuals, the ethicist will seek to examine the incentive structures that are in place. The question becomes whether these incentives are in fact aligned between parties concerned and aligned with the public interest.⁵ In the case of the situation of a vulnerable person experiencing a terminal illness, the incentives of the suffering person and the beneficiaries of their estate are in direct conflict. The beneficiaries, usually family members, have a strong financial incentive to expedite release of assets that might flow from a will. The interests of the suffering persons are protected when they are relieved of any emotional pressure, or sense of guilt for still being alive, or of holding up the financial benefit they will provide when they die to the people they love. It is a complex emotional situation, and one that is very difficult to manage through a regulatory regime as proposed in the consultation document. Moreover, the public interest is also not assisted by the misalignment of the interest of the suffering persons and the beneficiaries of their estate. The state's interest, is to serve its duty to provide full and effective palliative care to the terminally ill patient, free from external influences that might interrupt or truncate effective treatment. However, even the state itself is in a situation of conflict on

⁴ Australian Law Reform Commission, Elder Abuse – Discussion Paper 83, p.15 referring to WHO 2002 publication The Toronto Declaration on the Global Prevention of Elder Abuse.

⁵ There are many levels of coercion. The question arises as to whether a request such as this can ever be free of these emotions entanglements, and therefore if it is even possible to legislate access to euthanasia and assisted suicide that is genuinely a free act without coercion of any sense.

this issue. The Government has an incentive to minimise the costs of expensive palliative care in order to improve the state of the budget and release funding for other forms of health care. So, the state enjoys a financial benefit from the choice of the dying person to end their life earlier than would naturally occur. Any utilitarian motivation associated with redirecting scarce health funding resources from terminally ill patients to those with other health conditions must be rejected outright.

CCCHE does not propose solutions to government in dealing with these conflicts but simply seeks to highlight the ethical dilemmas involved and the difficulties of any regulatory model in this area adequately managing these ethical conflicts. Setting of a narrow time period of making the request and obtaining witnesses could itself make the 'deadline' a point of severe emotional impact which reduces the wellbeing of the dying person. Moreover, the experience of the failed Northern Territory legislation shows that prognoses is never particularly accurate. The Canadian model of allowing a medical practitioner to recognise a request made outside normal timeframes is highly undesirable as it undermines the autonomous free decision of the dying person and gives the medical practitioner a direct decision making authority in the life and death decision of their client. There is no basis for this extreme power to be given to anybody whatsoever.

Properly informed

Parliamentary Committee recommendation:

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.

Questions to consider:

- Should the legislation prescribe specialist expertise required for medical practitioners to participate in voluntary assisted dying?
- Should there be a requirement for a palliative care specialist referral or consultation?

In seeking to approach the issue of providing complete information to a dying person it is reasonable that the law places a high burden on the medical professional. In any social ethics which favours a rights based perspective, the more strongly held the right that a person is asked to waive, the higher should be the burden placed on the state and medical professionals to ensure that the person is fully informed of the implications of waiving that right.

In this case, we are considering the most fundamental of all rights that is proposed to be waived - the right to life itself. This perspective was recognised by the Parliamentary Committee who advocated that a strong test of informed consent applies for assisted suicide or euthanasia. It is most concerning that the consultation document seems to countenance the possibility a lesser threshold for judging 'informed consent' than model suggested in the Parliamentary Committee Report.

CCCHE emphasises the importance of a full disclosure of the medical and welfare benefits for the dying patient that palliative care service delivery can offer. From an ethical viewpoint, the greater the weight of any decision, the greater the burden on the state to ensure the client is fully informed of the implications of the decision. Effective palliative care service delivery offers considerable welfare benefits to the dying patient in terms of pain relief and pastoral care. The emphasis on full disclosure

of these benefits is a paramount consideration. In addition, the risks of adverse outcomes from use of end of life procedure also need full disclosure. The burden placed on the state to require such disclosure requirements must be seen to be very high indeed.

Conscientious objections

Parliamentary Committee recommendation:

- No doctor, other health practitioner or health service can be forced to participate in assisted dying.

Questions to consider:

- How should conscientious objection to voluntary assisted dying operate?
- Should health practitioners who conscientiously object be required to refer patients to other health practitioners?
- Should health practitioners who conscientiously object be required to declare their objection? If yes, when should this occur?

It is of paramount importance that the medical professionals should not be required by law to act against their conscience. If a medical professional, or their employer, does not support the proposed assisted suicide regime, it would be a grave moral evil to require them, or their employing institution, to have any active participation in the assisted suicide procedures. This would amount to a legal demand on medical professionals to act against their conscience or for institutions to adopt policies in direct violation of their key missionary and pastoral objectives associated with loving care for suffering people. It would be a very dangerous precedent, leading to a substantive debate about the rights and obligations of individuals and their employing institutions to participate in medical practices that they do not deem ethical. Any proposal that failed to allow for a strong position of legally recognised conscientious objection to any assisted suicide legislation would create fundamental ethical concerns for members of CCCHE.

Administering a lethal dose of medication

Parliamentary Committee recommendation:

A person should self-administer the lethal drug; the singular exception is where people are physically unable to take a lethal drug themselves. In this case, a doctor should be able to assist the person to die by administering the drug.

Questions to consider:

- Are additional safeguards required when a medical practitioner administers the lethal dose of medication and, if so, what safeguards would be appropriate?
- Where should a medical practitioner administer the lethal dose of medication, and what practical and other challenges would this create?

CCCHE strongly opposes any proposed measures that provide a medical practitioner a legal right to actively participate, through direct and clearly intended action, in the administration of a lethal drug to their clients.

Monitoring the use of a lethal dose of medication

Question to consider:

How can a prescribed lethal dose of medication be effectively monitored without placing undue burdens or pressure on people accessing or using the medication?

Attendance

Questions to consider:

Should a health practitioner be allowed to be present at the time the person self-administers the lethal dose of medication? If so, what should their role and obligations be?

There are real ethical concerns in this issue. If a dying patient is to be supervised in the taking of lethal drugs there will inevitably be subtle pressures on the patient to actually take the prescribed drug. The very presence of a medical professional in these circumstances would create implicit emotional pressure on the individual to proceed with the assisted suicide/euthanasia activity. This supervision might mitigate against any decision of the individual to change their minds at the last moment. People who are considering activating the proposed assisted suicide/euthanasia process are extremely vulnerable people. In spite of the most sincere position of any attending medical professional to in no way seek to influence the dying patient, there is a real risk that this very presence of the medical professional has the unintended consequence of placing a degree of emotional pressure on the dying person.

Lethal dose of medication not effective

Questions to consider:

- What should the obligations of a health practitioner be to treat a person who has chosen to ingest a lethal dose of medication?
- What is the best way to indicate that a person has chosen to take a lethal dose of medication?

If a person has ineffectively taken a medication, with obvious health consequences, it seems that they should be treated as any other person who faces a medical crisis. There is a patient in need of medical assistance and there are requirements in law for a medical professional to act according to their capacity to assist the suffering person. The patient's rights in this position are the same as the rights of any other person facing a medical emergency, and the obligations of medical professionals in this situation should be the same as they would be if the person had not sought to engage in the proposed assisted suicide/euthanasia process. While the patient is alive, they must be afforded their full autonomy as a person, which involves a potential subsequent decision not to repeat the process but rather to seek to activate palliative care services. Any decision not to provide medical assistance in this situation to sustain their life would amount to an abrogation of their freedom to choose their future medical treatment. Any decision to engage in assisted suicide/euthanasia processes cannot amount to a permanent decision – this would amount to a reduction in their rights as a person.

After a person has died

Questions to consider:

- What safeguards are necessary to determine whether or not the person has ingested the lethal dose of medication and to destroy the medication if it has not been ingested?

- What should be recorded as the cause of death for a person who has ingested the lethal dose of medication?
- Should death as a result of voluntary assisted dying be a reportable death?

There are already far too many dangerous drugs in the community. This is a matter of ethical concern. The greater the number of dangerous drugs in the community, prescribed for a medical purpose but not used, the greater the risk that these drugs will be used illegally. Australia has a major problem in the black-market trading of drugs, legal and illegal, which has major adverse social effects. Drugs prescribed to an individual for a specific purpose cannot be allowed to be used by other persons for whom they are not prescribed. This amounts to drug abuse. Here the government has little option but to take a zero-tolerance policy. Lethal drugs that are not used legally must be removed from the community. We cannot have a situation where lethal drugs remain lying around in homes, or in aged care facilities, where there is a risk that persons who are not legally allowed to use them can have access to them. Current strong Commonwealth law that regulates drug use should most definitely apply to any unused lethal prescriptions. Any other policy effectively undermines Commonwealth legal regimes on drug use and abuse.

The question of the incidence of assisted suicide or euthanasia is a matter of public concern. The state which funds medical procedures should be accountable to the people for how taxpayer funds on these services are provided. Full transparency of medical expenditure on all medical procedures should occur in a manner which protects patient privacy. The public have a right to know how many assisted suicides or acts of euthanasia occur in the State every year. This is the only way that the public can assess and review the incidence of the procedure.

Oversight

Parliamentary Committee recommendation:

That an Assisted Dying Review Board be established to review each approved request for assisted dying. Membership of the Assisted Dying Review Board should include:

- a representative of End of Life Care Victoria
- a doctor
- a nurse
- a legal professional
- a community member.

The function of the Board will not be to approve or reject requests from patients to access assisted dying. That is the role of the primary doctor and independent secondary doctor in each case. Neither will the Board hear appeals from people whose requests to access assisted dying have been rejected.

The purpose of the Board is to ensure that doctors are complying with requirements of the assisted dying framework.

If the Board finds a breach of the assisted dying framework, it should forward its report to the appropriate authority. Depending on the nature of the breach, this may be Victoria Police, the Coroner or the Australian Health Practitioner Regulation Agency. Those bodies will then determine whether to investigate the case further.

The Board should report to Parliament on the operation of the assisted dying framework, including any trends it identifies and recommendations for improvement. For the purposes of increased transparency and accountability, during the first two years of operation these reports should be every six months. Following that the Board should report annually.

Questions to consider:

What information should a medical practitioner be required to report to an oversight body such as the Assisted Dying Review Board?

At what stage should medical practitioners or pharmacists be required to report

- to the Assisted Dying Review Board?
- When should an oversight body be required to refer a matter to another agency?
- Should an oversight body have any investigatory powers, or should this be conducted by other agencies?
- Should a stand-alone review board be established? What are the alternatives? For example, would it fit within the investigative role of the Coroner's Court or the quality and safety mandate of a consultative council?

In any regulatory regime in an area which has strong ethical concerns with divergent views in the community it is incumbent on the Government to ensure that there is a strong public accountability regime. It is important that data is well collected and is reported through normal process of government. The reporting burden on government is even higher in the context of the proposed assisted suicide/euthanasia regime as the measures proposed involve an abrogation of the most fundamental right of the citizens, the right to maintenance of their own life.

Additional safeguards

Questions to consider:

- Does the Parliamentary Committee's framework provide sufficient protection to vulnerable people?
- What other additional safeguards could be considered?

CCCHE is concerned that the welfare of vulnerable people is potentially increased by proposed assisted suicide measures. The concerns are as follows:

1. People with mental illness: there is a strong risk that dying people with mental illness will activate the assisted suicide/euthanasia process as a result of their mental infirmity rather than a decision relating solely to their primary medical condition. There are significant ethical dangers in allowing persons with mental illness to be able to access this regime.
2. People with dementia: many persons in the final period of their life may suffer dementia. Such clients have constraints on their capacity to make clear informed choices to activate the assisted suicide process. People with dementia should not be able to access this regime.
3. Persons of linguistically diverse background: people in this cohort can find it very difficult to understand the intricacies of a complex legal framework that would apply in the proposed assisted suicide/euthanasia regime. There is a real concern that language barriers could lead to a frustration of informed consent under the proposed regime.
4. People with disability: persons in this cohort facing a terminal illness of significant duration face extraordinary struggles which few of us can even imagine. There is a real risk that the assisted suicide process could exacerbate a comorbid condition of latent depression or mental illness, with risks that persons with disability with ultimately terminal conditions might activate the assisted suicide/euthanasia process in an episodic moment of depression or anxiety. People with disability also fear that doctors may consider their life not worth living because of their disability and offer them euthanasia rather than sound medical treatment.
5. In relation to elder abuse: there is a real risk that persons who are elderly and dying might activate the assisted suicide process out of a sense of being a burden to their family. There is also the risk that some family members might encourage such a perception for financial motives.
6. The state itself has to account for the position that it has an incentive to reduce costs of caring for vulnerable persons, costs which would be reduced if assisted suicide/euthanasia procedures are in place.
7. International experience indicates that the quantum of applicants for assisted suicide/euthanasia processes expand over time, leading to the unintended consequences of a sense of normality associated with activating the assisted suicide/euthanasia process, rather than the regime operating as an exceptional regime.

All of these concerns are of ethical moment and represent insurmountable implementation challenges.

Liability and insurance

Questions to consider:

- What protections would be necessary for health practitioners who act in accordance with the new legislation in good faith and without negligence?
- How should insurance and other annuities of people who access voluntary assisted dying be protected?

The consultation document fails to consider manifest problems associated with common law contracts for life insurance which contain exclusion clauses for suicide. This issue also involves the operation of Commonwealth law. The consultation document is noticeably silent on measures to address relationships between state and Federal law.