Submission to the Legal and Social Issues Committee

Inquiry into End of Life Choices

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Inquiry into End of Life Choices Terms of Reference

On 7 May 2015 the Legislative Council agreed to the following motion:

That pursuant to Sessional Order 6 this House requires the Legal and Social Issues Committee to inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

(1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;

(2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and

(3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.
30 July 2015

Lilian Topic
Secretary
Legal and Social Issues Committee
Parliament House
Spring Street
Melbourne VIC 3002

Dear Secretary

Inquiry into End of Life Choices

Thank you for the invitation to contribute to this inquiry. This submission is made by the Caroline Chisholm Centre for Health Ethics. It has been prepared by the Director and Senior Researcher of the Centre.

We understand that our submission is a public document, and that it will be made available to the public on the Committee’s website.

We would welcome the opportunity to speak with the Committee at a public hearing.

We call for a well-planned and well-funded strategy to continue to develop the provision of palliative care and end of life care throughout Victoria. This should include ongoing education for all health professionals to ensure that they are qualified to provide palliative care and end of life care. We also call for a sustained public education initiative to encourage both community understanding of palliative care and end of life care, and community engagement with end of life decision making and advance care planning. We strongly recommend that euthanasia and assisted suicide should not be legalised in Victoria.

Yours sincerely

Rev Kevin McGovern
Director

Sr Dr Caroline Ong RSM
Senior Research Assistant
Executive Summary

The Caroline Chisholm Centre for Health Ethics welcomes the opportunity to contribute to this Inquiry.

Our submission sets out the vision and practice which currently informs palliative care and end of life care throughout Australia. In articulating this vision, we have drawn particularly on the National Consensus Statement: Essential elements for safe and high-quality end-of-life care, issued by the Australian Commission on Safety and Quality in Health Care on 27 May 2015. We have particularly highlighted that providing for the cultural, spiritual and psychosocial needs of patients and their families and carers is as important as meeting their physical needs.

We have drawn on the Victorian Auditor-General’s Report on Palliative Care, 2015 to highlight significant deficiencies in current palliative care services in Victoria. These include a complicated and unwieldy funding, policy framework and performance monitoring that hampers more than assist; inadequate all-round support for carers who bear the brunt of caring for patients at the end of life; ongoing limited community awareness and accessibility of palliative care services and advanced care planning; lack of resources to implement, access, sustain and evaluate an integrated patient management system making coordination of referrals and services easier; and an inability of resource-limited services to meet the significant rising demand of an aging population. There is also limited funding for further research in this relatively new field of palliative medicine as well as research into the needs of the community and how best to address them. There is also a great need to educate health professionals on end of life care.

We are aware that the Committee will consider euthanasia and assisted suicide (EAS), and we place on record our strong recommendation that euthanasia and assisted suicide should not be legalised in Victoria. We offer the following observations:

- Legalising EAS would involve a radical and massive shift both to current end of life practice and to the foundational values of our society.

- There is so much more that can be done to improve end of life care than is being done. Education of health professionals on what constitutes good end of life care is an imperative. Easily accessible and timely good palliative care needs to be in place before a true debate on EAS can be had.

- Public opinion polls are only somewhat valid if they are preceded by education on the definitions of EAS, clarifications as to what constitutes good end of life care and what constitutes EAS, and contain unbiased and clear questions.

- Contrary to the rhetoric of the advocates of EAS, there should not be unbearable suffering at the end of life if good palliative care is provided with a focus on relieving physical, psychological, social and spiritual pain and distress.
• There cannot be effective safeguards in any law which legalises EAS. Over time, so-called safeguards will neither limit EAS to a particular group of people nor protect vulnerable people from EAS.

• Our society limits individual choice when these choices could harm others, damage important institutions in society, or harm society as a whole. For this reason, we should continue to restrict individual choices about EAS.

• Medicine seeks to heal the whole person, addressing physical and psycho-socio-spiritual suffering, not to kill or end life prematurely. Legalising EAS would compromise the trust imperative in the doctor-patient relationship. Vulnerable patients may fear doctors deeming their life not worth living.

• Traditional morality does not support EAS or any other form of suicide. It counsels instead that we should provide compassionate care to all people, including those who are approaching the end of life, and their families and carers.

• Cultural change happens slowly and subtly. An inadequate health service may lead to legalisation of EAS. Killing is then condoned. What begins as an exception can lead to acceptability, and eventually to normality. After which all safeguards and barriers would no longer apply, as evidenced in Belgium. This radical shift in the moral tenet of protection from the deprivation of life to that of total vulnerability to being killed, shatters the very foundation of society.

Our submission concludes with six recommendations, which are presented on the next page.
Recommendations

The Caroline Chisholm Centre for Health Ethics recommends that the Victorian Government:

1. Continue to fund, provide and develop palliative care and end of life care throughout Victoria,

2. Provide significant new funding for palliative care and end of life care,

3. Engage with the community, health institutions and health professionals particularly those working in palliative care and end of life care to develop priorities, strategies and implementation schedules for the planned, ongoing development and provision of palliative care and end of life care throughout Victoria,

4. Continue to develop mechanisms for the reporting and assessment of the quality of palliative care and end of life care throughout Victoria,

5. Continue to develop and provide education to all health professionals so that they are properly qualified to provide palliative care and end of life care,

6. Fund, develop and deliver a sustained public education initiative to encourage community understanding of and engagement with palliative care, end of life care, the limits of medicine, end of life issues, end of life decision making, and advance care planning, and

7. Decide not to legalise euthanasia and assisted suicide (EAS).
At the Caroline Chisholm Centre for Health Ethics, we welcome the opportunity to make a submission to the Inquiry into End of Life Choices being conducted by the Parliament of Victoria’s Standing Committee on Legal and Social Issues. The Chisholm Centre is sponsored by all the public and private Catholic hospitals of Victoria: Cabrini Health, Calvary Health Care Bethlehem, Caritas Christi Hospice, Mercy Hospital for Women, Mercy Werribee Hospital, Mercy Palliative Care, St John of God Health Care (Victoria), St Vincent’s Hospital Melbourne, and St Vincent’s Private Hospital Melbourne. We are in effect their joint ethics department. We are involved with our sponsoring hospitals in a variety of ways: contributing to the development and review of policies and procedures, providing education and formation in ethics, offering ethics consultation and advisement, participating in the ethical review of research, and so on. We are also involved in the wider community – for example, our Director Rev Kevin McGovern has been a member of one of the principal committees of the National Health and Medical Research Council, the Australian Health Ethics Committee. He is currently on the working group which is revising Australia’s ethical guidelines for IVF and the Assisted Reproductive Technologies. He has also taught at the University of Divinity and Australian Catholic University. More can be learnt about the Centre by visiting our website at [http://chisholmhealthethics.org.au/](http://chisholmhealthethics.org.au/).

Our submission to the Inquiry into End of Life Choices has four sections. Firstly, we seek to articulate the vision which currently informs end of life care both here in Victoria and around Australia. When this vision is well implemented, it offers people many choices at the end of life, and provides very good end of life care. However, in the second section of our submission, we draw on the several resources including the recent report by the Victorian Auditor General on palliative care in Victoria to identify a number of significant shortfalls in services. In our opinion, the best strategy for continuing to improve end of life care in Victoria is to continue to draw on this well-articulated vision of excellence in end of life care, and to continue to remedy existing shortfalls in services throughout Victoria. We recognise that this is not a simple or easy path. It requires the establishment and/or ongoing development of suitable health care institutions, the recruitment and development of appropriately qualified and skilled health and allied health professionals, and a considerable investment of both money and passionate commitment. Even so, we believe that this path will provide Victorians with many choices and very good end of life care which they will truly value. After all, it cannot really be called a choice if someone settles on euthanasia because of the inadequacy of end of life care.

Euthanasia and assisted suicide (EAS) are currently not permitted by Victorian law. We recommend strongly that euthanasia and assisted suicide should not be legalised. EAS is one of the matters which this Inquiry must consider, and the third section of our submission expresses our views on this controversial question. We counter some of the arguments which have been advanced in support of EAS. We also set out some of the reasons that we oppose EAS.

The final section of our submission sets out briefly our recommendations to the Inquiry.
1. A Vision of End of Life Care

As the Standing Committee familiarises itself with the current vision and practice of end of life care, an excellent resource which you should study carefully is the National Consensus Statement: Essential elements for safe and high-quality end-of-life care issued by the Australian Commission on Safety and Quality in Health Care (ACSQHC) on 27 May 2015.¹ This document was prepared through a process which drew upon many already existing resources which detail excellence in various aspects of end of life care, and which also involved extensive consultation both with health professionals and consumers in the Australian community. (Documents and websites that were drawn upon are listed in Appendix B of the Statement; the process of consultation and community engagement is detailed in Appendix C.)

The Statement is informed by 15 guiding principles. In our submission to the Standing Committee, we highlight four of these principles – Principles 1, 4, 3 and 15 – and offer our own observations about them:

The first principle reminds us that “dying is a normal part of life and a human experience.” (p. 4) When we compare ourselves to previous generations, we see that we modern-day human beings have become quite separated and alienated from death and from the process of dying. In the not too distant past, many people were cared for by their families, and died in the family home. Young people learnt about death, and came to know that death and dying were indeed a human experience which is a natural and normal part of life. That ready familiarity with death is rarer now. People live longer, which means that there are many people in Australia today who have reached middle age or even older without experiencing the death of a close loved one. Nowadays, too, many people die not at home but in hospital, with their families more distant from their dying. In this context, dying and death can become unknown. Indeed, they can become much more fearful than they really are. It is therefore most important that all of us who participate in this Inquiry continue to remind ourselves that dying is indeed both a normal and natural part of life, and a human experience which might challenge us but which might also have much to teach us as our life draws to its end.

The fourth principle is that it is “essential” to recognise “when a patient is approaching the end of their life.” (p. 4) It needs to be said that health professionals are not always good at this, for recognising this requires having sometimes difficult conversations with patients and their families.

There are two important times when this recognition should be made. The first is “when the patient is likely to die in the medium term (i.e. within the next 12 months).” (p. 17) This recognition allows discussion of what is important to the patient, and what their goals are in the time which remains to them. This in turn informs discussion and shared decision-making about what treatment options are either appropriate or inappropriate for this patient at this time.

Different people from different cultures have different views about what decisions are acceptable here. Some religious communities value human life so greatly that they want everything done to preserve life. Indeed, they want this even if treatment will only extend life by a relatively short period. In the Catholic community, we believe that we have “a moral responsibility to use those means of sustaining our lives that are effective, not overly burdensome and reasonably available,” but that we have “a moral right to refuse any treatment that is futile, overly burdensome or morally unacceptable.”

(We call the former ‘ordinary’ or ‘proportionate’ means, and the latter ‘extraordinary’ or ‘disproportionate’ means.) The law itself gives a competent patient the right to refuse all treatments. With very few exceptions, it also permits health professionals not to provide treatments which are overly burdensome or which do not offer a reasonable hope of benefit. Drawing on these different frameworks, different people may make quite different decisions. But while different decisions may be made, it is vitally important that patients are given the opportunity to decide what is appropriate for them particularly as they move towards the end of life. Wise decision-making at this time can prevent treatment which might offer little benefit but which might inflict considerable burdens.

The patient should also be invited to consider who they would want to speak for them at any future time when they are not able to speak for themselves. While the law tries to identify an appropriate substitute decision-maker, for all sorts of reasons the individual might wish to make a different decision. Hopefully, they will also want to speak with their substitute decision-maker to give him or her some idea of their values, goals of care and wishes.

All these decisions must be documented and acted upon. Sometimes it is sufficient to record them in the doctor’s notes or the care plan in a residential aged care facility. However, it usually makes sense to use official forms, advance care plans, or advance directives to record our values, goals of care and wishes.

We have noted that there are two important times when we should recognise that a patient is approaching the end of life. We have discussed the first of these, which is when we would not be surprised if the patient died in the next year. The second important time is “when the patient is likely to die in the short term (i.e. within days to weeks.” (p. 17) This is important because priorities and goals of care should be reconsidered and might have to be revised once death is close.

The third principle tells us that “providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs.” (p. 4) Let us expand this point by discussing spiritual care for the person and his or her family as death approaches. For some people, this will involve the ministry and perhaps the rituals of the faith tradition to which they belong. However, we stress that we are speaking here about spirituality in the broadest sense of the term. We human beings have a deep intuition that there should be purpose and meaning in our lives. What is more, “illness is a time when, regardless of one’s religious
belief or lack of it, questions of a spiritual nature rise to the surface. This is especially the case when someone is approaching the end of their life.”³ At this time, we want to make sense of the journey which has been our life. There may be unfinished business which we sense we would like to complete, such as completing certain tasks, making a will, having significant talks with loved ones, or perhaps trying to set things right where there has been a longstanding quarrel or where we have done the wrong thing. Struggling with these existential questions, particularly as death approaches, may cause us profound spiritual distress.⁴ Spiritual care is spiritual accompaniment: attentive listening as the person articulates their existential struggles, honouring the importance of their struggles and questions, and travelling with them as they search for meaning and purpose in the final chapter of their life. It is also spiritual accompaniment of the person’s family in their own journey and their own search for meaning and purpose at this time.

In a perceptive article, Dr Bruce Rumbold from La Trobe University noted three different narratives which we might experience when we face serious illness or impending death. The first of these is the restitution narrative. This is the story we all want: ‘I got sick; I got treated; and now I’m completely recovered.’ Sometimes, however, it is clear that we are not going to recover. Many people then experience a chaos narrative. At this time, nothing makes sense any more. They cannot insert their present reality into a story which connects their past and present to a meaningful future, and which therefore gives them hope. This is a hard time, and a time when people may be tempted to escape this time of struggle, meaninglessness and despair through euthanasia or assisted suicide. However, if we persist – if we hang in there – often we will come to what is called the quest narrative. This is the story of the man or woman who journeys to a strange land in search of a treasure. This time, however, the strange land is the world of suffering and sickness. But there is treasure there too. Dr Rumbold describes this quest narrative well:

A quest narrative constructs illness as a journey – neither an aberration nor a dead end. It is a journey that begins with a call to leave the safety of the known and journey into the unknown experiences of serious illness. Responding to the call involves initiation into suffering and trial, then (hopefully) transformation...⁵

When people discover that illness and dying can be a quest – and especially if they are receiving excellent palliative care and the support of spiritual care – this time at the end of life can be a remarkably fruitful and fulfilling time. A British man named Philip Gould felt this so strongly that he wrote a memoir about his cancer journey from his diagnosis early in 2008 until his death towards the end of 2011. He wrote:


⁴ A Practical Guide to the Spiritual Care of the Dying Person, 10-12.

[It] is the personal journey of cancer that really matters. I have learnt that fear can be defeated and, if it is, then human possibility is unlocked; that we are stronger than we think and as we overcome what seems to be an impossible challenge then we get stronger still; that the power of community is limitless and gives us courage we did not know we had; that optimism and hope can help to defeat fear and darkness; that the human spirit within us all is more powerful and more resolute that we can ever imagine, and that although cancer is a terrible disease, it has the capacity to transform us.6

He also wrote about the meaning which he found during this time of his life and its profound significance:

Intensity comes from knowing you will die and knowing you are dying…. Suddenly you can go for a walk in the park and have a moment of ecstasy…. I am having the closest relationships with all of my family…. I have had more moments of happiness in the last five months than in the last five years…. I have no doubt that this pre-death period is the most important and potentially the most fulfilling and most inspirational time of my life.7

Dr Michael Barbato has been a palliative care physician for more than two decades. In that time, he has seen so many lives transformed at the end of life that he hopes he will not die suddenly but only after a period of illness and decline. He has said, “I would feel cheated if I died suddenly. So yes a slow journey towards death is my preference.”8

Dr Bill Bartholome was an American doctor who died of oesophageal cancer. Before he died, he wrote what has become a famous reflection on the positives of living in the light of death. He said that during this time “life doesn’t seem like a box of chocolates; it seems like endless servings of incredibly rich chocolate mousse.” Then he said:

I wish that the ‘final’ chapter in all your stories will be one in which you are given the gift of some time to live with whatever illness proves to be your fatal illness.9

Unlike Dr Bartholome, we do not hope that everyone experiences serious chronic illness at the end of life. Even so, we recognise that if this did happen to any one of us, this would offer us significant possibilities for personal change and growth – and indeed, possibilities which might not exist at any other time in our lives. With excellent palliative care, with the support of spiritual care, and with the discovery that sickness and dying can be a spiritual quest, dying and death can become a remarkably

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7 Ibid., 127-129, 143. For an article about Philip Gould’s book, see Kevin McGovern, “Lessons from the Death Zone.”
fruitful and meaningful time. Providing the sort of care which makes this possible must be our greatest priority. This is the challenge which this vision of end of life care places before us.

In our commentary on the National Consensus Statement on high-quality end of life care, there is one more principle to note. It is Principle 15: “Care of the deceased person, and care for families and carers extends to the period after the patient has died.” Ongoing care for family and carers after the death of their loved one is also vitally important. This includes helping them to understand grief and its various manifestations, and assuring them that they are not alone and that we continue to journey with them and support them in their grief.

This, then, is a thumbnail sketch of the vision of end of life care which informs palliative and end of life care both here in Victorian and around Australia. It is a remarkably clear and complete vision. It is the vision which is lived out in the care delivered by countless health and allied health professionals. It is also a demanding vision. Whether we are health and allied health professionals, patients and their families and carers, or the community which must fund end of life care and support it in many other ways, this vision asks a lot of us. But if we are to provide Victorians with real choices at the end of life – if we are truly to provide excellent end of life care – this is the vision which must inform us.
2. The Limits of Current Practice

It is difficult to get an accurate summary of the limits of current practice nation-wide. It seems the imperative for better palliative care services is only now beginning to be addressed seriously. NSW Health has reported that the inadequate availability and access of palliative care services to all communities led to their 2012-2016 plan to increase access.\(^\text{10}\) In May 2015, Queensland Health recognising the deficit in services put into place a similar strategy.\(^\text{11}\) Also in May 2015, the Federal government announced a $52m funding for palliative care projects. These health strategies highlight the fact that education, research, availability and access to high quality palliative care is very much wanting in Australian society. Victoria is said to be the leader in palliative care provision in Australia, yet significantly more needs to be done to even begin to meet the demands of end of life care in the communities. Personal stories flood the media of such inadequacies resulting in the cry to legislate euthanasia and assisted suicide.

The Victorain Auditor-General’s Report on Palliative Care, 2015\(^\text{12}\) has highlighted the very **significant deficiencies in current palliative care services** in Victoria—the findings are summarised here for convenience:

**Funding, Policy framework and performance monitoring**

The Department of Health and Human Services’ (DHHS) “monitoring framework is overly complex and not fit for its purpose:”\(^\text{13}\)

- inability to track progress: services unaware of how they perform at system level;
- 314 key performance indicators: unclear relevance of these
- difficulty identifying gaps in system, hence inability to fill these and meet the needs of patients at the end of life.
- Funding for palliative care services—public, private (predominantly non-governmental, not-for-profit organisations)—is from DHHS.
  - Slow progress was found in DHHS implementation of systems to facilitate funding.
  - There were significant problems with its performance monitoring framework, resulting in
    - delayed funding
    - lack of accountability
    - poor evaluation systems—inability to adequately determine the gaps

**Support for Carers**

- inadequate access to respite for carers
- inadequate assessment and screening for needs of carers after death of loved ones

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\(^{10}\) NSW Ministry of Health, *The NSW Government plan to increase access to palliative care 2012-2016* (Sydney: NSW Ministry of Health, 2012).


\(^{13}\) Ibid., 11.
• poor support options for carers bearing enormous responsibilities and associated stresses caring for loved ones at home
• inadequate financial support for carers who leave the workforce indeterminately to look after their loved ones

Awareness of palliative care and advanced care planning
• Progress is slow in DHHS initiatives to increase awareness of palliative care in culturally diverse communities—accessibility and inclusivity.
• Reporting complexities make it difficult to determine if diverse communities have accessibility to services or are even aware of the existence of services.
• Reporting on Advance Care Planning (ACP) implementation is poor even though evidence indicates ACP helps decrease anxiety and grief in families and carers.
• Only half of patients supported by palliative care community services have ACPs.
• Uncertainty of inpatient services using this tool.

Coordination and referrals
• Coordination of patient care across services is hindered by lack of access to integrated patient management systems,
• Some services lack systems to manage internal electronic files,
• The few audited inpatient services indicate timely admissions for patients but routine audits of all services would give a better picture.

Demand for services
• The resource-constrained community palliative care sector in metropolitan Melbourne is struggling to keep up with demand.
• These demands grow significantly as the ageing population grows.
• Significant concerns are reported by these services for their patients to be able to access palliative care services at home in a timely manner.
• It is even more daunting for those without or with limited access to carers.
• Carers are given huge responsibilities regardless of time availability, expertise, and capability (some don’t like the sight of blood).
• The long-waiting lists add significant stress to both patients and carers.
• Risk of patients being discharged home having to wait to access care in the home.
• Regionally-based services need a clearer understanding of how to access the range of psychosocial and allied health services so that their communities are not disadvantaged.

These findings have led the Auditor-General to put forward 12 significant recommendations, which will take time to be implemented adequately, let alone robustly, and to be evaluated for further improvements.

These significant frustrations result in poor experiences of palliative care today. This may lead many to call for all to have the option of euthanasia and assisted suicide available. Band-Aiding does not fix what’s broken, especially if the Band-Aid is such that there is no turning back.
Palliative Care Workforce

In February 2015, the Centre for Palliative Care, St Vincent’s Hospital, Melbourne issued a report on the Victorian Regional/Rural Project in Palliative Care stating that “there are insufficient Palliative Medicine specialists currently practising in regional/rural Victoria to meet current service needs for an ageing population and for the future expansion of services in these areas.”

The 2013 DHHS Palliative Care Workforce Study revealed a heavy reliance on volunteers in the provision of services—the number of hours worked being equivalent to 30 per cent of paid full-time employees. The percentage of workers who undertake unpaid work increased from 36 per cent in 2007 to 49 per cent in 2013. The average number of unpaid hours has also increased from 3.5 in 2007 to 4.3 in 2013. Eighty-six per cent of employees deem themselves to be either in the middle or at the end of their career.

These and other studies indicate that in general, there is great need to educate health professionals on:

- spotting triggers of decline in health resulting in the need for end of life care,
- initiating and continuing the discussions about dying and end of life care,
- how to introduce and discuss Advance Care Planning with patients and relatives,
- the timing of referrals to palliative care services; acknowledging at the same time the current limited capabilities of palliative care services to respond to need,
- what palliative care encompasses,
- the definitions and limits of current statutes e.g. the principle of double effect and that there is no evidence that morphine in appropriate and gradual incremental doses causes death directly,
- how to truly listen to patients’ innermost desires based on their worldviews and respond appropriately (there are many reports of patients not wanting further treatment but health professionals pursuing other options on the slim chance of gaining a few more days of life),
- how to listen to family members and loved ones when they say “enough is enough,”
- the false perception that the death of a patient equals failure on the part of the health professional,
- the meaning of holistic care, and the possibility healing the whole patient even in the midst of their dying, and
- the difference between keeping a patient alive and burdensome care.

14 Riki Long, Victorian Regional/Rural Project in Palliative Care.
15 Victorian Department of Health and Human Services, Palliative Care Workforce Study: Volunteers and Employees (Melbourne: DoHHS, 2013).
3. Euthanasia and Assisted Suicide (EAS)

We are aware that the Standing Committee will consider euthanasia and assisted suicide (EAS), and it is to this topic that we now turn. As we begin, however, we must record our strong intuition that EAS is something radically different from the palliative and end of life care which we have so far discussed. Palliative and end of life care are about valuing human life. They draw on the skills of health and allied health professionals to manage distressing symptoms. They involve caring for the social, psychological and spiritual needs of patients and their families and carers. They dare to hope that this time in someone’s life can be relatively free of distressing symptoms, and indeed that this can be a meaningful time both for the person and for their family and carers. By contrast, the proposal to provide EAS negates all this. It implies that despite the best efforts of health and allied health professionals, distressing symptoms cannot be managed. It also implies that there can be nothing meaningful or worthwhile in the experience of dying and death. The advocates of EAS often propose what they euphemistically call ‘aid in dying’ as if it was simply one more modality of care within palliative and end of life care. As we reflect on both the care which we have so far described and EAS, we cannot accept this. For us, EAS is something radically different from palliative and end of life care.

As we have read and listened to the advocates of EAS, we have noted that they use quite different arguments to try to justify EAS. For example, one rationale restricts EAS to those who are terminally ill, while another rationale bases EAS on free choice. These differing rationales lead to different views about who might access EAS, and who determines whether an individual satisfies the criteria. Clearly, the former rationale is quite restrictive as regards access to EAS, whereas the latter would provide very broad access. It also seems to us that those who put forward a restrictive rationale at the same time either support actual cases of EAS which fall outside their rationale, or at least remain curiously silent about these cases. For example, there have been at least two recent cases in Victoria of women who took their lives through EAS who really could not be described as terminally ill. The first of these was Beverley Broadbent, who took her life on 11 February 2013. Ms Broadbent was 83. She did not have a terminal illness. While she feared developing dementia, there was no suggestion that she had developed this condition. She was ageing, and had some age-related ailments. However, she felt that she had completed her life, and that elderly people of sound mind should be able to choose how and when they die.17 The second of these women was Dorothy Hookey, who

took her own life on 26 November 2014. Mrs Hookey was 86. She had arthritis which was painful. Again, she could not be described as terminally ill.18 We did not see any comment by any advocate of EAS that these women were outside the restrictive rationale for EAS which many of them propose. To the contrary, EAS advocates used these stories to advocate for EAS.

We are left with a concerning suspicion that advocates of EAS will argue for a restrictive rationale for EAS whenever legalisation of EAS is being considered, that they will claim that this is all they want, but that they really think of this as getting a foot in the door so that they can move over time from a restrictive permission for EAS to an increasingly broader and broader one.

As the Standing Committee considers EAS, we hope that you will seek clarity from EAS advocates. What is their rationale for EAS? If this is a restrictive rationale, why do they think EAS can and should be restricted to a certain group? Or if they offer a broad rationale, what does logic suggest is the group who would be suitable candidates for EAS?

In this section, we make a number of points. We counter some of the arguments which have been advanced in support of EAS. We also set out some of the reasons that we oppose EAS.

A radical and massive shift

On 24 June 2015, internationally-renowned Australian-born ethicist Professor Margaret Somerville AM spoke about EAS in Melbourne at an event organised by Palliative Care Victoria. She subsequently also spoke on the same issue at the University of Notre Dame in Sydney. She stated that “euthanasia is not an incremental change to current end of life practices, but a radical and massive shift in our society and civilisation’s foundational values.” She continued, “Euthanasia is not just an incremental expansion of current ethically and legally accepted end of life decisions, such as refusals of life-support treatment, as pro-euthanasia advocates argue.”19

The Australian Catholic bishops made a similar point many years ago:

There are big steps and there are little steps. The biggest step is a leap from saying ‘no one may kill’ to saying ‘some may kill’. The little step is from saying ‘someone may kill this person’ to saying ‘someone may also kill that person.’

18 Julia Medew, “A woman ends her pain, but the law just won’t let go,” The Age, 24 March 2015. See also Paul Russell, “Woman’s suicide wrongly used to justify euthanasia,” News Weekly, 11 April 2015, http://www.newsweekly.com.au/article.php?id=56900. Russell commented, “Mrs Hookey was not dying. Certainly, she was in pain and discomfort. Why this was not being effectively managed is not mentioned. But she would not have been a candidate for euthanasia under any of the bills presented in Australia in recent years.”

The Dutch took the big step some years ago, and ever since then they have not been able to stop taking many little steps....

Australia must not take the big step. 20

Some may of course disagree with the bishops’ conclusion. Despite differing views about EAS, however, this is no place for obfuscation. As we consider the potential legalisation of EAS, we should all be clear that this would be a very big step.

Dysthanasia

Dr Charlie Corke, an intensive care physician, in his book Saving Life... or Prolonging Death: Finding the way in a world of medical technology proposes the use of the word ‘dysthanasia’—an “unpleasant, prolonged and medicalised death.” 21 Such has been the memory of those who have watched their loved ones die within a system currently inadequate to deal with “difficult deaths.” These memories are often what flashes back for those proposing the legalisation of euthanasia and assisted suicide (EAS): the only options they see are either dysthanasia or ending life prematurely. The reality however, is that palliative care has advanced significantly since their experiences, and is continuing to do so, such that physical suffering can be said to be managed reasonably well by true experts in the field. 22 At this point in time, palliative care physicians may not be able to claim that they can relief all people’s suffering, however they do make this claim:

We have witnessed thousands of deaths where, in the lead-up, the patient has been comfortable, able to communicate their wishes, and say farewells, and families have commented on how peaceful the death was. In addition, many family carers seem to derive personal growth and identify positive aspects associated with their caregiving role. 23

It is prudent to recall that there are many more people who did not access specialist palliative care, who have also found this final phase of living to be an enriching and peace-filled experience.

More research needs to be done for the minority of patients whose physical symptoms are not as easy to control, but even for these patients much more can be done for them than is being done. What is evident, as described above, is that access to services is limited. And for those who do access it, some do miss out on timely care. In an age when technology can prolong life, palliative care is often accessed too late to be of significant assistance in good end of life care—the line between

21 Charlie Corke, Saving Life... or Prolonging Death: Finding the way in a world of medical technology (York: Erudite Medical Books, 2010).
saving a life and enabling a person to die with enough time for reconciliations and goodbyes, is often blurred. Corke highlights this based on his many years of experience as an intensive care physician when he wrote:

Very often people don’t recognise that they are actually making end-of-life decisions for the simple reason that they don’t consider that the illness represents (or could represent) an end-of-life event. They see it simply as disease that ‘needs treatment’. The fact that the decisions were end-of-life decisions only becomes clear in retrospect—after the person has died. Simply considering it is possible that this could be the final illness might help us think differently…. Progressive improvements in medical technology have provided many more ways of avoiding or delaying death and it is now unusual for anyone (particularly families and doctors) to accept the inevitability of death until a significant amount of medical treatment (including life support) has been tried and failed.

This unfortunately is still true. Neil Orford, the Director of Intensive Care at University Hospital Geelong and Director of Critical Care Services at St John of God Hospital, Geelong highlighted this stance of health professionals and the lack of communication in end of life care, in an article he wrote in The Age newspaper entitled “Give death its due in a system focussed on life,” based on his recent experience of his father dying. As a specialist physician familiar with dying and death, Dr. Orford still had to fight for his father’s peaceful death. Fight, as he says, “the passive resistance to providing care focused on a comfortable death, rather than care focused on cure.” There seemed to be the lack of understanding amongst the healthcare team that “we could simultaneously love this man, while advocating for care that allowed him to die without agitation and suffering.” Communication was poor between the family expressing his father’s likely wishes and the healthcare team making decisions, such that timely treatment was not available resulting in unnecessary suffering. Eventually when the family was heard but it came at a cost: “to my father, who suffered when he could have been peaceful; to my family, left to feel guilty for demanding comfort over cure; to me, because the days spent advocating as a doctor could have been spent grieving and saying goodbye as a son.” More needs to be done to educate health professionals.

For the very few patients whose symptoms cannot be controlled, there is the option of proportionate palliative sedation. This involves the informed consent of the patient or their substitute decision maker. The intent is to sedate the patient enough to relief them of their distress temporarily. It involves ongoing decision-making between the healthcare team and the patient or their proxy. The intention is never to kill, only to relieve distress. Some would argue that there is a fine-line and intentions are difficult to prove. William Sullivan rightly argues in turn that

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24 Ibid.; Corke,12-14.
25 Ibid.; Corke, 12.
by maintaining the focus in decision-making on appropriate goals of care that are informed by well-established principles of good palliative care and ethics, the distinction between palliative sedation and euthanasia can be clarified in practice and the overall good of the patient promoted.28

Much can be done even in end-stage chronic obstructive pulmonary disease—the use of oxygen and opioid within a mixed-management model.29 Here the goals of care include symptom management and its associated psycho-spiritual impact, rather than cure. The patient is assisted in the letting go of this time, of reconciliation in relationships with self, others and God for believers, and if important, the ability to leave behind a lasting legacy for their loved ones and generations to come.30

The suffering of the whole person needs to be taken into consideration. There is abundant literature that highlights the predominance of psycho-spiritual suffering over physical suffering and the obvious interconnection between the two.31 There can be a loss of identity related to their roles as spouse, parent, bread-winner, significant member of local community. There may be a loss of physical function (for example, incontinence, inability to transfer from bed to chair) leading to embarrassment, loss of modesty or a sense of being a burden on others—even though it may not be perceived as such by others. This is even more significant when the trajectory is that of chronic diseases—long-term limitation with intermittent acute episodes—that may carry with it a sense of being a “burden,” of unresolved grief, social isolation and existential questionings. This is why end of life care must involve a multidisciplinary team that hopefully can address not just the physical but the significant psycho-socio-spiritual distress of both the dying patient and their loved ones.

The complexities of end of life care afford it no easy answer. Our health system struggles to meet the demands of an ageing population living longer. Justice in accessibility remains contentious, and overall real funding reduced because of other priorities. There has also been a significant drop in medical research funding. Based on the Victorian Auditor-General’s report, it seems we need a more efficient system for the limited funding. What is clear though is that end of life care is more complex than the simple option of either dysthanasia or EAS. There is the third option of excellent, well-timed, easily accessible multidisciplinary care that is supported by ongoing research in the management of suffering, currently probably limited by funding and bureaucracy.

28 Ibid., 15.
30 Dignity therapy is one such approach.
Public opinion

On this backdrop of:

- lack of accessibility to multidisciplinary palliative care services that are currently unable to meet demands;
- the general attitude of health professionals intending to ‘save lives’ whilst technology is available—diseases and death are ‘enemies’ to be ‘battled’ with;
- the inability to recognise triggers for palliative care;
- the lack of communication between health professionals and the patients and public; and
- the misunderstandings of what constitutes palliative care—including the myth of proportionate opioid use causing death,

the public is asked to given their opinion as to whether euthanasia and/or assisted suicide should be legalised.

Such opinions may be based on memories of unpleasant, even distressing, experiences of watching loved ones suffer, rather than informed reasoning. There may be lack of knowledge of the availability of multidisciplinary palliative care services or the untimeliness of such services. There may be the struggle of unresolved grief, and the sense of powerlessness, perhaps even guilt, often associated with being with a loved one who is dying.

One of the many hurdles of having a truly informed, reasoned debate on EAS lies in the confusion and multiple definitions of EAS, even within the medical profession. For instance to claim that the withholding or withdrawal of futile treatment is euthanasia is false and only misleads. This lack of definition makes public opinion polls unreliable and inaccurate. Experts in the field know that questions in opinion polls can be manipulated to get the result that is sought. Opinion polls unless preceded by accurate definitions and comprehensive information rather than emotive language are often inaccurate and cannot be relied upon.

For a poll to reflect informed opinion, those who are polled will need to be educated about definitions and given further information. The Australian Medical Association’s *Position Statement on the Role of the Medical Practitioner in End of Life Care 2007 (amended 2014)* for instance offer these definitions:

**Euthanasia** is the act of deliberately ending the life of a patient for the purpose of ending intolerable pain and/or suffering.

**Physician assisted suicide** is where the assistance of the medical practitioner is intentionally directed at enabling an individual to end his or her own life.\(^{32}\)

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Euthanasia is voluntary if it is done at the specific request of the competent patient. It is non-voluntary when the patient has not requested it, has not consented to it or is unable to competently make the decision e.g. in a coma, has dementia or is a child. It is involuntary if the patient has not requested it, and in fact has a desire to live, hence considered by some as murder.

The proportionate administration of opioids has not been shown to cause death. Yet this is still one of the commonly held beliefs amongst health professionals fearful of giving patients adequate analgesia, resulting in unnecessary physical suffering. Opioids do cause respiratory depression if given in excessive doses. “Tolerance to the respiratory side-effects develops rapidly, ‘allowing aggressive upward dose titration’.... Patients in pain also respond differently to opioids....” 33 Susan Fohr in her 1998 article gave evidence that if titrated appropriately, large doses of opioids may be safely administered. 34 This unfortunately is not known as widely as it should be, even amongst health professionals. Education is of prime importance.

If the commission would truly like to know society’s views about EAS, then more education and research needs to be done. We suggest that if an opinion poll or survey is carried out, it needs to be preceded by definitions of the varying terms, and, clarifications as to what constitutes good end of life care and what constitutes EAS.

“Intolerable suffering”?

Advocates of EAS frequently speak of “intolerable suffering” when they try to convince other people of the need for EAS. Often without exactly saying so, they imply that “intolerable suffering” is not uncommon at the end of life, and that the only remedy for this is EAS. This is of course meant to frighten people. If what they imply is the real situation, who would oppose EAS? Let us look more closely:

We might think that “intolerable suffering” could only be unbearable physical pain. But with good palliative care nowadays, unbearable physical pain is extremely rare. Even with good care, there may be times when the treating team struggle to manage some distressing symptoms. And no one can guarantee that every single case can be managed effectively. But in a recent letter to The Age, palliative care specialists Professors Peter Hudson and Brian Kelly, and Associate Professors Jennifer Philip, Rosalie Hudson and Mark Boughey described the real situation well:

The overwhelming majority of media reports about end-of-life care focuses on conceptions of dying as always being painful, undignified and traumatic. This is untrue. As palliative care specialists we cannot claim that everyone can be guaranteed a peaceful death. We have, however, witnessed thousands of deaths where, in the lead-up, the dying person has been

33 Ibid.; Fohr, 316.
34 Ibid.
comfortable, able to communicate their wishes and families have valued sharing this final phase.35

A recent case report from the Massachusetts General Hospital illustrates how even intractable pain can be managed without resorting to EAS. This case involved a 44-year-old woman with metastatic (stage IV) non-small-cell lung carcinoma. The report describes the care of the patient over nearly 2 years, and the various treatments used to manage her pain. These included intrathecal drug delivery – that is, “infusion of opioids and other analgesics into the subarachnoid (intrathecal) space in direct proximity to opioid receptors in the dorsal horn of the spinal cord, where small doses can have profound analgesic effects.” In this case, however, the treating team were concerned that a time might come when they were no longer able to control her pain, and so they had ongoing discussions with her and her family about palliative sedation – that is, “an intervention to relieve intractable pain in terminally ill patients by means of continuous infusion of a sedation medication.” The paper reports how this was done, how her pain was monitored, and how medication was adjusted accordingly. The patient “died with no evidence of discomfort, with her family at her side, 4 days after the initiation of palliative sedation.”36

The US state of Oregon is one of the few jurisdictions in the world which has legalised EAS. It reports annually on EAS, and these reports indicate that EAS is not primarily about unbearable physical pain. The most recent report is for 2014. In that year, 105 Oregonians ended their lives with EAS. Their three chief concerns were loss of autonomy (reported by 96 of the 105 or 91.4%), decreasing ability to participate in activities that make life enjoyable (reported by 91 of the 105 or 86.7%), and loss of dignity (reported by 75 of the 105 or 71.4%). By contrast, “inadequate pain control or concern about it” was reported only by 33 of the 105 or 31.4%. EAS in Oregon is tightly controlled by supporters of EAS, who do not allow a breakdown into those who had inadequate pain control, and those who had concerns – albeit perhaps unrealistic concerns – about pain control. However, it is most probable that the vast majority of this group had concerns about pain control, rather than pain control which was already inadequate.37

We have spoken about pain management when good palliative care is provided. Some patients of course may experience unbearable physical pain because they received inadequate palliative care. However, it seems perverse to argue that EAS should be legalised because some patients receive inadequate palliative care, for that would imply that patients who have received inadequate care should then die early as a result of that inadequate care. Surely a better response would be to improve the provision of palliative care!

Advocates of EAS claim that existential suffering can be “intolerable suffering.” Existential suffering is psychological, social and spiritual distress. It would, for example, include the three concerns which led Oregonians to end their lives with EAS: loss of autonomy, decreasing ability to participate in activities which make life enjoyable, and loss of dignity. We should all recognise that the changes and limitations brought about by serious illness do indeed present us with difficult challenges. But are these challenges such that they provide justification for assisting someone to end their life? We conclude that they do not. We have four reasons for this conclusion:

Our first reason is that these existential challenges have always been part of the human experience of sickness, dying and death. In the first section of our submission, we set out the principles which should inform end of life care. The first of these is that “dying is a normal part of life and a human experience.” From this perspective, existential challenges which have always been part of the human experience of sickness, dying and death simply cannot provide justification for assisting someone to end their life.

A second reason why these challenges do not provide justification for EAS is that it is through facing these and similar challenges that we undergo personal growth and development. Many of us, for example, value our independence. For this reason, most of us will struggle with the increasing dependence which comes with sickness and dying. But if we stay with this experience, we can come to recognise that we have never been as independent as we might wish to think – and that being dependent on other people is ok.

A third reason why these existential challenges do not justify EAS is called response shift.38 Response shift is “an adaptive response to a changed health status.” It is a “positive phenomenon.” For example, a person’s first response might be, “I don’t want to go to a nursing home!” But after some time to adapt, they might decide, “Actually, being in a nursing home is not too bad.”

*Tw...s with Morrie*, Mitch Albom’s memoir of his college sociology professor Morrie Schwartz, provides an example of response shift. Seventy-eight-year-old Morrie had motor neuron disease. He was confined to a wheelchair; he was becoming more and more dependent; and he knew that his condition was terminal. In March 1995, he was interviewed by Ted Koppel from the US ABC-TV’s ‘Nightline’ program. Koppel asked Morrie what did he “dread the most about his slow, insidious decay”? “Morrie looked straight into the eyes of the most famous interviewer in America. ‘Well, Ted, one day soon, someone’s gonna have to wipe my ass.’”

Several months later, Morrie had a different perspective:

‘Mitch, it’s funny,’ he said. ‘I’m an independent person, so my inclination was to fight all of this – being helped from the car, having someone else dress me. I felt a little ashamed, because our culture tells us we should be ashamed if we can’t wipe our own behind. But then

I figured, *Forget what the culture says. I have ignored the culture most of my life. I am not going to be ashamed. What’s the big deal?*  
‘And you know what? The strangest thing.’  
What’s that?  
‘I began to enjoy my dependency. Now I enjoy when they turn me over on my side and rub cream on my behind so I don’t get sores. Or when they wipe my brow, or they massage my legs. I revel in it. I close my eyes and soak it up.’³⁹

Our final reason that existential challenges should not be justification for EAS is that this would lead to too many cases of euthanasia which many people would find problematic. Belgium is another of the few jurisdictions around the world which have legalised EAS, and its law does allow euthanasia for “constant and unbearable… mental suffering which cannot be alleviated.”⁴⁰ On 19 April 2012, EAS was carried out on 64-year-old Godelieva De Troyer. Her married son Tom and his family were not informed until after her death. In a formal complaint, Tom has argued that his mother suffered from clinical depression, that her depression was treatable, and that the doctor involved was not qualified either to detect or treat depression.⁴¹ In December 2012, this law permitted the euthanasia of 45-year-old deaf twins Marc and Eddy Verbessem, who were going blind. In October 2013, it permitted the euthanasia of 44-year-old transgender man Nathan Verhelst, who was distressed after gender reassignment surgery. (He had commented, “When I looked in the mirror, I was disgusted with myself. My new breasts did not match my expectations and my penis had symptoms of rejection.”) In September 2014, it was announced that the law would permit the euthanasia of an elderly couple Francis, 89, and Anne, 86, who planned euthanasia together on 3 February 2015, their 64th wedding anniversary. In February 2014, this law was extended to permit the euthanasia of children, provided they had discerning capabilities and their parents approved.⁴² We recognise that each of these persons face difficult challenges. But we are not convinced that the best response to these situations is to assist these persons to end their lives. And we are very concerned that if EAS was permitted for existential suffering, it would permit far too many cases of EAS which many people would find problematic.

Let us conclude this section with a comment about how palliative care professionals respond when a patient expresses a wish to hasten death (WTHD). There is considerable peer-reviewed literature on this topic.⁴³ After their analysis of this literature, Monforte-Roya and her colleagues noted a

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⁴³ There is much, peer-reviewed literature on this. See, for example, Brian Kelly et al., “Factors associated with the wish to hasten death: a study of patients with terminal illness,” *Psychological Medicine* 33 no. 1 (2003): 75-81; Cristina Monforte-Roya et al., “What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspectives of patients,” *PloS ONE* 7, no. 5 (May 2012): e37117; Maggie Hendry et al., “Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying,” *Palliative Medicine* 27 no. 1 (2013): 13-26; and Kathrin Oehsorge, Heike Gudat, and Christoph Rehmann-Sutter, “What a wish to die can mean:
common insight: “The expression of the WTHD in these patients is a response to overwhelming emotional distress and has different meanings, which do not necessarily imply a genuine wish to hasten one’s death.” A wise clinician will recognise the patient’s distress, and inquire into its cause. It might be many things – for example, clinically significant depression and/or anxiety, concerns about increasing dependence, hopelessness and loss of meaning, fear of pain, fear of being a burden, unmet social needs, or spiritual distress. Significantly, however, when these concerns are addressed, most patients do not want their life ended. In the vast majority of cases, therefore, a WTHD is not a request for EAS, but a cry for help. To assume that a WTHD expresses a genuine desire to end one’s life – and indeed to provide the means to do this – would be to seriously misunderstand what is actually going on.

“Safeguards”?

Since 1995, there have been at least forty-two bills around Australia which have sought to legalise EAS. There have been sixteen in South Australia, eight in New South Wales, six in Western Australia, two in Tasmania, one in Victoria in 2008, none in Queensland, two in the Australian Capital Territory, one in the Northern Territory, and six in the Commonwealth Parliament. Apart from the 1995 bill in the Northern Territory, none have ever become law. Each of these bills has included safeguards which are claimed to restrict EAS and to protect the vulnerable. We consider these so-called safeguards here, and reveal the flaws in each of them:

Some legislation tries to restrict EAS to those with an illness which will lead to death within either six or twelve months. This is, for example, a requirement of the legislation in Oregon, one of the few jurisdictions in the world which has legalised EAS. The flaw in this, of course, is that we cannot know the future with absolute certainty. Estimates of how long a person has are simply informed guesses, which are often very wrong. The report of EAS in Oregon which we have already cited provides an example of this problem. Eleven of the patients who ended their lives through EAS in 2014 were given the prescription for the lethal drug in either 2012 or 2013. Those who were given the lethal drug in 2012 – and perhaps others as well – lived far longer than six months.

Here is another example. In March 1999, the NSW Voluntary Euthanasia Society ran an ad featuring a 59-year-old woman named June Burns who had bladder cancer. Mrs Burns said that she was planning to kill herself, and called for the legalisation of EAS. Had EAS been legal, she probably would have been a candidate. Instead, six months later, her cancer went into remission. Though she did eventually kill herself with Nembutal, June Burns lived another 8½ years.

Another commonly proposed safeguard is that the person must be informed of their diagnosis, the likely prognosis, and alternatives to EAS such as palliative care. Once again, the obvious problem is that there is always so much that is not known. There can be errors even in diagnosis. The prognosis is always to some extent uncertain. And before going down that path, we cannot know with certainty how effective alternatives to EAS may be. Given the measure of uncertainty about each of

reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care,” *BMC Palliative Care* 13, no. 1(2014): 38-51.
these factors, are they together sufficient to allow someone to make a decision to end their life? We are not convinced that this is the case.

Here is an example of what could happen. On 22 May 2002, Gold Coast grandmother, 69-year-old Nancy Crick took her life through EAS. She had had several operations for bowel cancer, was again experiencing abdominal pain, and believed that the cancer had come back. However, an autopsy after her death revealed that she was cancer-free, and that the pain she had been experiencing was caused by adhesions of her large and small bowel. In all probability her condition could have been remedied through surgery. Who knows how many more years she could have had enjoying her extended family? That future was lost when she took Nembutal.

Yet another commonly proposed safeguard is that two doctors must be involved in the process of decision-making about EAS. (Commonly, this means that one doctor is involved in the process, and another doctor is consulted.) Once again, this is much less of a safeguard than we might at first imagine. Almost certainly, both doctors will be supporters of EAS. It is also most likely that neither of these doctors will have had a long-term relationship with the person. The person’s long-term doctor will probably not be part of this process of decision-making about EAS, and may even be unaware that EAS is being considered.

Again, experience in the few jurisdictions around the world which have legalised EAS confirms that the limitations of this proposed safeguard. In Oregon, there are a small number of doctors who are particularly available for consultations about EAS. For example, its 2014 report notes that, while 155 prescriptions for lethal EAS drugs were written in that year, 12 of these were written by one doctor. Similarly, in the Netherlands, there are now mobile euthanasia units that will travel around the country.

Another proposed safeguard is that the person considering EAS should not be coerced. The difficulty here is that some influences on a person are very difficult to detect and/or question. A family might fail to care for a sick, elderly parent. They may fail to visit, and neglect him or her. And during their infrequent visits, they may be unavailable emotionally, distant and cold. All these things will certainly influence a person’s decision about EAS. Would they be identified as coercion? We doubt it. Sadly, we must also recognise that some families might encourage an elderly parent to undergo EAS simply because they will inherit much wealth when the old person dies.

Yet another proposed safeguard is that the person considering EAS must not be depressed. The problem here is that it is often not easy even for mental health professionals to detect depression. We know that a significant percentage of people with serious illness are depressed, and that their depression is both under-diagnosed and under-treated. Mental health professionals report that it is very difficult to detect depression in one or two consultations. Of course, it becomes even more

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difficult if a patient is trying to hide his or her depression because he or she is seeking to end their life through EAS.

One of the reports which has considered the detection of depression in patients considering EAS is the record of euthanasia in the Northern Territory which has Dr Philip Nitschke as one of its authors. This is because the Northern Territory legislation required a psychiatrist to confirm that patients were not suffering from a treatable clinical depression. The report notes:

Confirmation was not easy since patients perceived such a mandatory assessment as a hurdle to be overcome. PN [Philip Nitschke] understood that every patient held that view. To what extent was the psychiatrist trusted with important data and able to build an appropriate alliance that permitted a genuine understanding of a patient’s plight? In case 1, there was important background detail about the death of one child and alienation from another, which was withheld during the psychiatric assessment. These experiences may have placed the patient in a lonely, grieving, demoralised position: an unrecognised depression may have led to suicide. Four of the seven cases had symptoms of depression, including reduced reactivity, lowered mood, hopelessness, and suicidal thoughts. Case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management. PN judged this patient as unlikely to respond to further treatment. Nonetheless, continued psychiatric care appeared warranted—a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia. Ganzini and colleagues showed that only 6% of psychiatrists in Oregon, USA, thought that they could be a competent gatekeeper after a single assessment of a patient. This finding illustrates the difficulty of legislation of this sort—there is an important role for psychiatry in oncology and palliative care to ensure that depression is actively treated, but a gatekeeping role may be flawed if seen as adversarial by patients and viewed as blocking successful treatment, rather than being one part of proper multidisciplinary care.46

One of the authors of this study, Professor David Kissane, subsequently spoke further about one of these cases, 66-year-old Bob Dent who was the first man to die via legal euthanasia in the Northern Territory:

So it is quite challenging for us I believe to accurately recognise depression and let me be provocative and take Bob Dent as an example because there’s an instance where one psychiatrist has put a view that this person doesn’t have severe depression at the time of their death, and yet in a very public statement Bob Dent said how suicidal he felt over the final months of his life. And as I recall it, he said that if he’d had a gun he would have used it. When I’ve had the opportunity to talk with some palliative care nurses who worked in the

46 David W. Kissane, Annette Street, and Philip Nitschke, “Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,” The Lancet 352 (3 October 1998): 1097-1102 at 1101. We recommend that the Standing Committee read the seven cases reported in this study. We were particularly saddened by Case 5, an isolated 69-year-old man with no family who had cancer of the stomach. It concludes, “PN [Philip Nitschke] recalls his sadness over the man’s loneliness and isolation as he administered euthanasia.” Surely we can do offer someone something better than EAS, particularly at the end of life!
Northern Territory and who had an opportunity to meet him, their comment, volunteered and not sought at that stage, was that he was a person who was depressed and yet his depression was never treated.\footnote{Norman Ford, ed., \textit{Ethical Aspects of Treatment Decisions at the End of Life: Proceedings of a Conference held at St Vincent’s Hospital, Fitzroy – 15 November 1996} (East Melbourne: Caroline Chisholm Centre for Health Ethics, 1997), 114.}

For all the talk by advocates of EAS about “safeguards,” therefore, we conclude that there really can be no effective safeguards in legalised euthanasia. We are not convinced that these so-called safeguards would be at all effective either in limiting EAS to a particular group of people or in protecting vulnerable people from EAS.

Choice

Another argument which is used to try to justify EAS is expressed in the statement, “It’s my choice.” This can seem like an unanswerable argument to some people, for how can there be any restriction on me if it’s my choice? In fact, society does limit individual choice. It does so if the choice of one individual will harm, or is very likely to harm, another individual. Society also limits individual choice if those choices are likely to harm important institutions within society. And it also imposes limits if choices are likely to harm society as a whole.

Professor Margaret Somerville AM spoke about this in her talk in Melbourne on 24 June 2015 at the event organised by Palliative Care Victoria. She has also written about this matter:

> The strongest case for legalizing euthanasia and physician-assisted suicide is at the level of the individual person... But we must also consider where such legalization would lead and what its impact would be on other people, the institutions of law and medicine, and the foundational values of society. And we must take into account, not just its impact in the present, but also in the future.\footnote{Margaret Somerville and Arthur Schafer, “Read and vote: Should patients be allowed to request suicide?” \textit{The Globe and Mail}, 15 October 2014, \url{http://www.theglobeandmail.com/globe-debate/read-and-vote-should-patients-be-allowed-to-request-suicide/article21106527/}.}

Recognising the need to protect our physical ecosystem, Professor Somerville argues that we must also protect our metaphorical ecosystem:

> Just as we now realize our actions could destroy our physical ecosystem and we must hold it in trust for future generations, we must also hold our metaphysical ecosystem — the collection of values, principles, beliefs, attitudes, shared stories, and so on that bind us together as a society — likewise, in trust for them.

We agree with Professor Somerville that legalising euthanasia would damage our metaphysical ecosystem. It would harm the institutions of medicine and health care. These institutions are there to help and heal, to cure and care. They would be damaged — and our relationships with our doctors and other health professionals would also be damaged — if they became involved in judgments about...
the appropriateness of EAS for an individual, and the delivery of lethal means with which to end life. Relations within our families would similarly be damaged. Try to imagine what it would be like for an elderly woman facing a terminal illness if her adult children and their families responded to her plight not with the promise to stand with her in this time of declining health, but with the suggestion that it might be easier for her and for all of them if she opted for EAS. Finally, the relationship between individuals and society would also be damaged. As things stand, society is there to care for us, to help us and heal us when we face serious problems. While we may sometimes wish that more help was available, society should be there to help us when we are threatened by natural disasters such as fire, drought and flood, or when we face serious and perhaps life-threatening sickness. The relationship between individuals and society would be irrevocably changed if one option for society was to provide lethal means to end someone’s life. With Professor Somerville, we conclude that a concern for the metaphysical ecosystem “requires that we reject euthanasia.” As Professor Somerville both wrote in her article and said during her talk in Melbourne, “Ask yourself: ‘How do you not want your great-great grandchildren to die?’”

We should also note that choice is the most worrying rationale for EAS. If the ultimate rationale for EAS is choice, how can EAS be restricted, for example, to those with a terminal illness who have only six or twelve months to live? If it is all about choice, how could we judge that one reason for wanting EAS is acceptable, while another is not? Or how could we limit EAS to those at the end of life? The logic of choice would require that EAS should be an option for any competent person, and for any reason which they consider sufficient to justify EAS. The changes might be slow and incremental, but if EAS is legalised on the basis of choice, the logical progression is that it would gradually be extended. For example, it could extend from those who have a terminal illness to those who are elderly and who feel that their life is over. And if we permit it for those who are elderly and who feel that their life is over, how could we deny it to those who are middle-aged, or those who feel that their life has no meaning, or indeed to any competent person who decides for any reason to end their life? Logically, this extends as far as sixteen-year-olds who are judged to be mature minors. Choice is therefore a very, very worrying rationale for EAS.

Medical care

The medical profession’s primary role is a healing one. The maxims “first do no harm” and “to cure sometimes, to relief often and to comfort always” captures the moral stance. The Hippocratic Oath adopted for centuries as the medical code of ethics specifically states: “Nor shall any man’s entreaty prevail upon me to administer poison to anyone; neither will I counsel any man to do so.”

The following are excerpts from the Australian Medical Association Position Statement on the Role of the Medical Practitioner in End of Life Care 2007 (amended 2014),

10.1 The AMA believes that while medical practitioners have an ethical obligation to preserve life, death should be allowed to occur with dignity and comfort when death is inevitable and when treatment that might prolong life will not offer a reasonable hope of benefit or will impose an unacceptable burden on the patient.
10.2 Medical practitioners are not obliged to give, nor patients to accept, futile or burdensome treatments or those treatments that will not offer a reasonable hope of benefit or enhance quality of life.

10.5 ...The AMA believes that medical practitioners should not be involved in interventions that have as their primary intention the ending of a person’s life. This does not include the discontinuation of futile treatment. [Emphasis added].

10.6 Patient requests for euthanasia or physician-assisted suicide should be fully explored by the medical practitioner in order to determine the basis for such a request. Such requests may be associated with conditions such as a depressive or other mental disorder, dementia, reduced decision-making capacity, and/or poorly controlled clinical symptoms such as pain. Understanding and addressing the reasons for such a request will allow the medical practitioner to adjust the patient’s clinical management accordingly or seek specialist assistance.49

Hence not initiating or withdrawing of futile and burdensome treatment and “the administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death,” do not constitute EAS. Again it is emphasised that there is no evidence of direct causation of death from proportional administration of opioids.50

Medical care involves the healing of the whole person—physically, spiritually, socially, psychologically. Primary in this healing process is the re-establishment and the deepening of the sense of self, their relationship to themselves, their family and loved ones, God and all of creation. The end of life phase of living is a significant time for doing this. Whilst the re-establishment and deepening of these relationships may be orchestrated to some degree, the significance of unexpected and treasured healing moments cannot be ignored. These may happen even in the silence of presence, of sitting with our dying loved ones. There is no residual guilt of causing their death, partaking of the fulfilment of their desire to end their life pre-maturely or witnessing their suicide. Medical services may assist this in recognising the triggers that call for allowing a person to die rather than prolonging their life and imposing unnecessary burdens. More education is needed.51

Hudson et al also highlighted that, “the physician who is inexperienced with pain and symptom management or uncomfortable with discussing existential concerns may more readily agree that the suffering is ‘unbearable’ or arrive at the conclusion that the patient’s symptoms are refractory.”52 And again, “Decision making may also be compounded by the doctor’s own response to suffering, their capacity to tolerate patients’ suffering, and their ability to identify when psychological intervention is needed.”53 As this is just as evident throughout the patient’s life, education and self-awareness on the part of the health professional would be best done during undergraduate training, with encouragement for on-going evaluation.

49 Ibid.; AMA, Role of Medical Practitioner in End of Life Care.
51 Once again, this is highlighted in Dr Orford’s article: Give death its due on a system focussed on life.
52 Ibid.; Hudson et al., 3.
53 Ibid., 4.
Another consequence of legalising EAS is the negative effect on the trust relationship between the doctor and health professional and the patient. This is evident on two fronts: the patient not willing to seek medical attention for fear of the doctor willing to euthanise them; and the disability movement fearing that doctors will now view their lives with disability as not worth living hence euthanizing them when most vulnerable.\(^{54}\) There are suggestions that the former concern about the deterioration of the level of trust in the doctor-patient relationship lack evidence. Studies biased either way have been largely inconclusive. However it is argued that regardless of statistics, even if there is one case of deterioration of trust, it is perhaps one case too many.

It is the plea of palliative care physicians and organisations all over the world, that what is needed is not the legalisation of EAS but the education of physicians, health professionals and the public about end of life care, hospice and palliative medicine.\(^ {55} \) What is needed is the recognition that end of life care begins with the acceptance that morbidity and mortality is part of life and not an enemy to be battled with; that when end of life does come it can be an opportunity to “wind-up” and make right our loving relationships with self, others, God and all creation; that medicine practised well with the whole patient healing as its focus can aid significantly in this process; and that end of life care begins not in the few weeks or months before death but long before. Only then will optimal end of life care become a reality.

Above all, medical care is not about killing or aiding in suicide but about relieving as much as possible all suffering and in that, facilitating the healing of the whole person. It is about respecting all of life: its beginning, its duration and its ending.

**Traditional Morality**

Morality is essentially about human flourishing. When we identify something as morally right, we are saying that it truly contributes to human flourishing. On the other hand, when we identify something as morally wrong, we are saying that it truly hinders or harms human flourishing. At the Chisholm Centre, we often quote Albus Dumbledore on morality and ethics. Dumbledore was of course the headmaster of Hogwarts, the school for young wizards in the *Harry Potter* series. In the 2005 movie *Harry Potter and the Goblet of Fire*, Dumbledore remarked, “We must all face the choice between what is right and what is easy.” There is considerable moral wisdom here. What is right is often hard. What is easy is often wrong. And ethics is one of the resources we draw on to help us do the right, hard thing, rather than the wrong, easy thing.


\(^{55}\) End of life care is broader than palliative care. It encompasses all care in the dying phase of life, often provided by family members, general practitioners and other health professionals e.g. in aged care facilities. Palliative care is whole-person care that relieves symptoms of a disease or disorder, whether or not it can be cured. Hospice is a specific type of palliative care for people who likely have 6 months or less to live. In other words, hospice care is always palliative, but not all palliative care is hospice care. American Academy of Hospice and Palliative Medicine, *Palliative Doctors FAQs*, AAHPM, Chicago, [http://palliativedoctors.org/faq](http://palliativedoctors.org/faq).
Human beings have a natural instinct and inhibition against killing each other. We also have an innate appreciation of the great value of human life. For all these reasons, we know that, except in very unusual circumstances, it is wrong to kill either oneself or another human being. Indeed, there are very few exceptions to this general rule. In all these exceptions, two conditions are simultaneously present:

i. Someone poses a serious and imminent threat to human life or to values virtually as important as life (e.g. liberty), and

ii. The only way to eliminate the threat is to kill this person.

There are three or perhaps four situations in which it might be morally permissible to kill another human being:

The first is resisting lethal attack. Someone attacks us. They are not just after our wallet or handbag: they intend to kill us. What is more, we do not have a non-lethal way of defending ourselves: our only means of resisting their attack will most likely cause their death. But because of the great value of human life, even in these cases, there is considerable legal jurisprudence about what might or might not be acceptable. Consider, for example, this guidance from the Australian case of *Palmer v The Queen*, on appeal to the Privy Council in 1971:

> It is both good law and good sense that a man who is attacked may defend himself. It is both good law and good sense that he may do, but may only do, what is reasonably necessary. But everything will depend upon the particular facts and circumstances.... It may in some cases be only sensible and clearly possible to take some simple avoiding action. Some attacks may be serious and dangerous. Others may not be. If there is some relatively minor attack it would not be common sense to permit some action of retaliation which was wholly out of proportion to the necessities of the situation. If an attack is serious so that it puts someone in immediate peril then immediate defensive action may be necessary. If the moment is one of crisis for someone in imminent danger he may have [to] avert the danger by some instant reaction. If the attack is all over and no sort of peril remains then the employment of force may be by way of revenge or punishment or by way of paying off an old score or may be pure aggression. There may no longer be any link with a necessity of defence...  

Within all these criteria, there is a carefully circumscribed area in which it is permissible both morally and legally to use lethal force resisting attack.

The second situation in which it might be permissible to kill another human being is in war. Once again, because of the great value of human life, there are many rules about what might or might not be acceptable. For example, we may target enemy combatants. We cannot directly target non-combatants, though some, proportionate collateral damage may be accepted. Even in our targeting of enemy combatants, there is another test of proportionality: the end which is sought perhaps through a battle must be of sufficient importance to justify the taking of human life. Once again,
within all these criteria, there is a carefully circumscribed area in which it is permissible both morally and legally to use lethal force in war.

A third area involves several quite tragic obstetric cases. A woman is pregnant. A pathological condition imminently threatens both her life and the life of the unborn fetus. Action must be taken fairly quickly. And the only option is an intervention which will save the life of the mother, but will result in the death of the unborn fetus. In other words, the only two choices are to save the only life we can, or to allow two to die. Of course we save the one life, even though our action leads to another death. Some ectopic pregnancies and some pathologies of the womb are examples of these quite tragic obstetric cases.

A fourth situation in which it might be permissible to kill another human being is capital punishment in very exceptional circumstances. One of the purposes of jails is to protect society from dangerous criminal action. If we are able to lock a dangerous criminal in a secure jail, there is no ethical justification for capital punishment. But if we were not able to lock a dangerous criminal in a secure jail, and the only way we could defend society from his dangerous and potentially lethal criminal action was to kill him, this use of capital punishment might be morally justified. Nowadays, of course, this set of circumstances is virtually non-existent, particularly in countries like Australia.

It should be clear that EAS does not fit into this traditional set of exceptions to the general rule that it is wrong to kill either oneself or another human being. This is one reason why the great religions of the world oppose EAS and all other forms of suicide. Indeed, most streams of the Abrahamic faiths of Judaism, Christianity and Islam, the Dharmic faiths of Asia including Hinduism, Buddhism and Sikhism, and most other world religions oppose EAS and other forms of suicide. It is also why EAS is forbidden with very few exceptions in just about every one of the 195 or so countries of the world.

Traditional morality also counsels that we should provide ongoing and compassionate care to all people, including those who are approaching the end of life, and their families and carers. This reminds us again of the importance of high quality palliative care and end of life care.

Because of the great value of human life, traditional morality permits the taking of human life only in certain, very carefully circumscribed circumstances. From this perspective, traditional morality opposes EAS. This moral position is cross-cultural and universal. Even if there are those who would dismiss this, we should be aware that legalising EAS would go against the collective traditional moral wisdom of humanity.

**Cultural change**

The debate on EAS has been long standing. What is concerning however is the subtle, unconscious but real change in societal values that seems to lead to acceptance, then normalization of the killing of another, beginning with the vulnerable (as seems to have happened in Belgium). Uninformed debate, confusion with definitions and what procedures actually constitute euthanasia, could potentially result in significant shifts in moral norms and the foundations upon which we live as a society. The active engagement of the media in promoting EAS without comprehensive background
facts, can significantly contribute to this, especially if all that is available to base decisions on is personal unresolved negative experiences.

Palliative care services are currently stretched, underfunded and unable to meet demands. This may result in negative experiences for those who are dying and for their loved ones. The perception that suffering is unbearable and cannot be managed is perpetuated, and it is wrongly perceived that the only alternative is EAS. This perception could change if people’s experiences of dying are different, with easy and timely access to services. The moral norms of “first, do no harm” and the protection of the individual’s right not to be deprived of life, would remain.

The suffering experienced by the dying is often predominantly the fear of severe intractable pain; loss of control; disabilities and its associated dependence on others; social isolation; and the loss of sense of self, identity and role in the family and community and the associated dignity these bring. Feelings of being a burden to others may predominate in a culture focussed on independence rather than interdependence. These sufferings however, may be recognised, addressed, treated and healed. Intractable pain can be managed but if compounded by depression and other psycho-socio-spiritual sufferings may be harder to manage. If these underlying psycho-socio-spiritual issues can be addressed, a peaceful, good death is more likely. Dying can be the rich experience that is already the experience of the majority. Again, the moral norm of not killing another, whether it is in the context of “hastening death” or aiding suicide, remains.

However, this basic tenet of our societal agreement with ourselves shifts radically when we decide as a society that it is acceptable to take the life of another or aid a person in killing themselves. There is no longer the inviolable right to protection from the deprivation of life for the individual. As posited above, the argument of “exceptional case at the end of life” is but a small step that opens the door for a radical shift in our foundational values as human beings. It raises many questions for us.

By legalising EAS, are we saying that it is acceptable not to address these metaphysical issues in those who are dying? Are we saying that these lie in the “too hard basket,” that we as a society do not have the time and resources to address these in our fellow human beings? Are we saying that it is okay to kill another now? Are we saying that aiding a loved one to suicide is okay? Are we saying that a life of disability is a life not worth living—a grave concern that disability advocates have voiced for a long time now and still have not felt heard? Are the poor, marginalised and vulnerable of our society no longer our concern or have they fallen far too low on the list of our priorities? Are we prepared to be the generation, the society, which changed the fundamental value of inviolable respect for life and so radically change the way we relate to one another? Or could we be instead the generation, the society, which more and more recognises that we are all interdependent and reliant on one another, and so instead commit ourselves toward the healing of the fracturing of society and civilisation?

Cultural and moral shifts brought about by legislative changes are real, alarming and often subtle. Legislating EAS condones the practice of killing another and aiding in another’s suicide, and its subtle effects on societal moral norms may not be known for years after. It is likely that with increasing numbers of EAS cases, it will become acceptable, and then eventually the norm. It has taken Professor Theo Boer—a highly respected Dutch ethicist and once an advocate of assisted suicide with the certainty that safeguards work—twelve years to recognise its negative impact and now advocate against it internationally, at least until more is known. There was the initial stabilisation of numbers in Dutch EAS practice, then after seven years there began an annual jump of 15% of cases which is continuing to rise. It would be prudent to listen to his caution:

Euthanasia is on the way to become a ‘default’ mode of dying for cancer patients....

Other developments include a shift in the type of patients who receive these ‘treatments’. Whereas in the first years after 2002 hardly any patients with psychiatric illnesses or dementia appear in reports, these numbers are now sharply on the rise. Cases have been reported in which a large part of the suffering of those given euthanasia or assisted suicide consisted in being aged, lonely or bereaved. Some of these patients could have lived for years or decades....

Whereas the law sees assisted suicide and euthanasia as an exception, public opinion is shifting towards considering them rights, with corresponding duties on doctors to act. A law that is now in the making obliges doctors who refuse to administer euthanasia to refer their patients to a ‘willing’ colleague. Pressure on doctors to conform to patients’ (or in some cases relatives’) wishes can be intense. Pressure from relatives, in combination with a patient’s concern for their wellbeing, is in some cases an important factor behind a euthanasia request. Not even the Review Committees, despite hard and conscientious work, have been able to halt these developments.

I used to be a supporter of the Dutch law. But now, with twelve years of experience, I take a very different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have had better safeguards? Or is it because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort? Before those questions are answered, don’t go there. Once the genie is out of the bottle, it is not likely to ever go back in again.58

There are significant implications in legalising EAS. It seems more needs to be done—in providing alternatives to EAS, education on end of life care including earlier multidisciplinary palliative care and so on—before a true debate on legalising EAS can be had. The debate then needs to include the consideration of the radical moral shift in the fabric of our lives.

4. Recommendations

The Caroline Chisholm Centre for Health Ethics recommends that the Victorian Government:

1. Continue to fund, provide and develop palliative care and end of life care throughout Victoria,
2. Provide significant new funding for palliative care and end of life care,
3. Engage with the community, health institutions and health professionals particularly those working in palliative care and end of life care to develop priorities, strategies and implementation schedules for the planned, ongoing development and provision of palliative care and end of life care throughout Victoria,
4. Continue to develop mechanisms for the reporting and assessment of the quality of palliative care and end of life care throughout Victoria,
5. Continue to develop and provide education to all health professionals so that they are properly qualified to provide palliative care and end of life care,
6. Fund, develop and deliver a sustained public education initiative to encourage community understanding of and engagement with palliative care, end of life care, the limits of medicine, end of life issues, end of life decision making, and advance care planning, and
7. Decide not to legalise euthanasia and assisted suicide (EAS).