HUMANIST SOCIETY OF VICTORIA Inc.
(Reg. No. A0020272M)
Affiliated with the Council of Australian Humanist Societies (CAHS)
and the International Humanist and Ethical Union (IHEU), London, UK

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

Re: END OF LIFE CHOICES

SUBMISSION FROM THE HUMANIST SOCIETY OF VICTORIA INC. (HSV)

The HSV is a secular organisation whose members foster an ethical, reasoned and responsible approach to life. It supports human rights, democratic processes, and a just and inclusive governance.

It seeks to alleviate suffering, to promote well-being and the circumstances where all individuals can attain their full potential. It engages in educational, counselling and charitable activities.

The views that follow have been formulated at specially convened group discussions to which all HSV members are invited. Further supportive information is obtained from print publications, the Internet, public lectures and from individuals with relevant expertise.

The Convenor of the HSV Submissions Committee is authorised to present these views.
GENERAL REMARKS

1. Humanists throughout the world have long supported the right of the terminally ill and of those whose quality of life becomes unacceptably low, to choose the time, place and manner of their death.

   The core of this issue is respect for the autonomy of the individual. This and the freedom of choice are regarded as hallmarks of a mature and civilised society.

2. Australian Humanists were enthusiastic supporters of the Northern Territory's Rights of the Terminally Ill Act with its compassionate approach and safeguards against misuse. We were greatly disappointed when this Act was overturned by the Federal Parliament. We now have a law that denies the relief of prolonged and severe suffering for terminally ill humans but mandates it in the case of animals. It is an incongruous and a bad law.

3. Physician assisted dying occurs here in a clandestine manner and it is essential that it is open to scrutiny.

4. Victorian Humanists welcome this inquiry into End of Life Choices and congratulate the Victorian Government on initiating public debate on this vital issue.

SPECIFIC POINTS.

1. Modern medical science produces new, more efficient means of prolonging our lives.

   In cases of terminal illness, the rights of many who choose to prolong their lives are respected. We submit that the rights of the few who are unable to obtain relief and seek assistance in ending their lives, should be equally respected. Such need is sadly documented by the many botched attempts at suicide among the terminally ill. Palliative care experts state that their best measures fail to alleviate suffering in a significant number of cases. We enclose a copy of a relevant article from the Medical Journal of Australia. (4 March 2013)

2. As mentioned above, Australia's brief period of recognising The Rights of the Terminally Ill in the Northern Territory was, in our view, a compassionate and civilised act.

   Overseas, experience in the Netherlands, Belgium, Luxemburg, Switzerland, and in USA, Oregon, Washington, Montana, Hawaii, shows that under strict medical and legal supervision there are no cases of the predicted 'slippery slope' into involuntary euthanasia. Last year in Canada, the Supreme Court ruled "that the law has come to recognise that in certain circumstances an individual's choice about the end of her life is entitled to respect." Physician-assisted-dying will now be recognised as a medical service.

   In the USA, this year 20 states and the District of Columbia filed Bills to legalise doctor assisted suicide as reported in the New Scientist, 28 Feb 2015.
3. We believe that the current legislation is harmful for two reasons: it puts the compassionate, caring physician in breach of the law, and it maintains the potential for abuse. We submit that Voluntary Assisted Dying (VAD) should be available to a mentally competent, terminally ill adult with intolerable suffering who asks for help in ending his/her life. Two relevant medical specialists should supply written statements confirming that the patient suffers terminal or incurable illness. VAD should not be available to those suffering depression. The legislation should include a formal process that will provide effective safeguard protecting the vulnerable. Request for VAD must be unwavering and be subject to a cooling-off period. Two doctors or psychiatrists should confirm in official statements that the patient is mentally competent and, as far as it is possible to assess, has not been coerced or pressured by others in their decision. Previously supplied Advance Health Directives should be respected when the patient loses competence. Relatives or guardians should not have the right to contradict the wishes of the patient. Doctors assisting in VAD should not be prosecuted. Assistance can be refused by anyone opposed to VAD.

Yours sincerely

Stephen Stuart
Meeting end-of-life care needs for people with chronic disease: palliative care is not enough

...but what should a system that successfully combines interventional and palliative approaches look like?

Considerable efforts have been made, both nationally and internationally, to address the growing “epidemic” of chronic disease. Chronic disease accounts for more than half of all Australian deaths, and hospitalisations associated with chronic disease are a major component of this expenditure (see the Box for a definition of chronic disease as used in the context of this article). Systematic processes to prevent and manage chronic disease have been developed, and all incorporate the concept of a continuum of care from prevention and early intervention, through disease management to the end of life. While there is a strong focus on systematic care, health education, chronic disease self-management and regular review, comparatively scant attention is paid to the actual care required as people approach the end of their life.

In Australia, to date, the need for end-of-life care for people with advanced chronic disease has been addressed by recommending referral to a specialist palliative care service or by developing closer links between these services and specific disease services and primary care. It is assumed that a referral to palliative care can, and will, provide the most appropriate care for people dying with a chronic disease. However, often this process is poorly handled, and general practitioners and primary care clinicians are left to manage an uncoordinated and challenging situation. Inadequate and inappropriate end-of-life care has significant and costly implications: unnecessary hospitalisations; prolonged intensive interventions in acute care settings; patients dying in intensive care units rather than in their preferred place of death; poor symptom management; little opportunity for patients and their families to discuss issues around death and dying; and increasing stress on staff who are not trained in the provision of palliative care.

Originally, palliative care developed to provide support for people dying with cancer, with a trajectory of relatively predictable deterioration requiring intensive support over a fairly short period of time. Chronic disease tends to follow a much slower and more unpredictable trajectory that includes progressive functional decline, poor quality of life and increasing dependency on both formal and informal caregivers as well as the health system. Many people with chronic disease have multiple comorbidities, so it is vital they have access to active and systematic disease management.

However, there is a concurrent need for supportive and palliative care to effectively control distressing symptoms and to provide emotional, spiritual and psychological support for the patient and his or her family as the patient’s condition slowly deteriorates. Referral to specialist palliative care can mean that patients may not continue to have access to active disease management. A system that not only allows but actively supports the provision of active and palliative care is required.

Disease-focused health professionals and palliative care professionals may sometimes differ in their philosophical understanding of the basis of care provision. Many health professionals still view death as a defeat rather than accepting that death is an inevitable part of living, and palliative care may erroneously be seen as relevant only for the last days of life and as being “exclusive of life prolonging treatments.”

The term “palliative approach” is increasingly being used to describe care that allows continuation of active interventions while introducing elements of palliative care (Box 3), but there are few models of care that successfully combine chronic disease management (CDM) and palliative approaches. For CDM and palliative models of care to blend successfully, both need to be expanded to accommodate understandings that recognize their differing perspectives.

The practice of referring patients to palliative care suggests that there is a clear transition from active disease management to an approaching end-of-life period that triggers the referral. However, there is growing evidence that there is no clear transition for patients with chronic disease, but rather, a slow period of decline, where both interventional care and a palliative approach are required. Indeed, there is currently no common understanding in the Australian context of the term “end of life.” Palliative Care Australia’s definition of end of life (Box 3) is not specific enough to indicate when a referral should be triggered. The End of Life Care Strategy in the United Kingdom defines the end-of-life period as the last 12 months of a person’s life, however, this raises the issue of how to prospectively identify the last 12 months, which is not easily operationalized.
Doctors in support of law reform for voluntary euthanasia

Legalised voluntary euthanasia would provide options for a comfortable and dignified end to life

It is these situations that motivated the formation of a national lobby group of medical practitioners, Doctors for Voluntary Euthanasia Choice. Members lobby for the legalisation of voluntary euthanasia, so that people who are suffering and who will continue to suffer have the right to request assistance to die gently and, if possible, at a time of their choosing. It is often argued that legalisation of voluntary euthanasia is unnecessary. It is stated that, in the presence of pain, additional pain-alleviating morphine may lead to death at such an outcome is acceptable. Here, morphine used to alleviate pain secondarily causes cessation of breathing. A death occurs as an unintended side effect of the treatment - the so-called "double effect". One issue, however, is that legality of such treatment relies entirely on what is in the practitioner's mind. Provided the intention was to relieve pain and not to cause death, such management is not illegal, by the intention can never be ascertained without doubt. An unhappy person involved in the process somewhere in an instance of death by morphine could take a hostile view about the practitioner's intentions and seek to involve the law. A second, not infrequent issue is that pain may not be a prominent symptom, making death by morphine legally unjustifiable.

We believe that the current situation, in which voluntary euthanasia is illegal, inevitably leads to optimal management being denied to some patients. Some have unreliable forms of pain, others are forced to endure a wretched but ongoing existence. Legalised voluntary euthanasia now exists in seven European countries (eg, the Netherlands, Belgium, Luxembourg and Switzerland) and some states of the Unite States (Oregon, Montana and Washington), and has given medical practitioners in those jurisdictions the option of complete, compassionate medical care for their patients. Copies of voluntary euthanasia legislation can be obtained from various websites, for example, for Oregon and for Belgium.

Active or retired Australian medical practitioners in agreement with the position of Doctors for Voluntary Euthanasia Choice may register on the website (http://www.dfechoice.org) to receive information and to add their weight to lobbying for the legalisation of voluntary euthanasia in Australia.

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Provenance: Not commissioned; externally peer reviewed.

3 Muller-Buch C, Andres L. Aetiology of voluntary death - a critical analysis of 7 years experience. BMJ Palliat Care 2003; 2: 2
US states grapple with the right to die

The fight to legalise doctor-assisted suicide for people who are terminally ill will take centre stage in the US this year, with bills filed in 20 states plus the District of Columbia.

"I think it's a watershed year," says Peg Sandeen, head of the non-profit Death with Dignity, based in Portland, Oregon, which campaigns for doctors to be able to prescribe lethal doses of barbiturates to terminally ill people.

The practice is already legal or has been decriminalised in five states.

Sandeen says public opinion may have shifted significantly after Brittany Maynard, a 29-year-old with terminal brain cancer, moved to Oregon last year, where doctor-assisted suicide is legal. A video by Maynard in which she explained her reasons for choosing assisted suicide has been watched over 11 million times.

Maynard ended her life in November, but her story has given the existing death-with-dignity movement new momentum. Bills were recently filed in New York and California, two of the country's most politically influential states. Assisted suicide has just been legalised in Canada, after similar lawsuits there, although it will be a year before the law takes effect.

The outcome of the legal battles that are likely to ensue in the US are hard to predict. Assisted suicide faces opposition from religious groups as well as disability activists, who say it implies that those who are disabled, old or ill have lives that aren't worth living - and that people could be pressured into it.

Diane Coleman, head of advocacy group Not Dead Yet, which opposes assisted suicide, says the Oregon Health Authority's annual reports on the practice show the law isn't working as intended. She points to the motives people gave for choosing this option. According to the latest figures, released on 12 February, only a third of people who took a prescribed lethal dose of medication in 2014 cited pain or fear of pain as one of the reasons for doing so.

Supporters of assisted suicide often cite pain as a primary reason why people should have the legal right to die. But the state's report showed that people's concerns tended toward loss of autonomy (51 per cent), loss of dignity (71 per cent) or being a burden on their family (40 per cent). Coleman is particularly concerned that people are choosing assisted suicide because they feel it is a burden. "To me that feels more like a duty to die than a choice to die," she says.

What's more, according to the data available for Oregon, some people waited longer than six months between asking for the overdose and taking it. It isn't clear how many times this happened, but at least some people lived a few years after obtaining the drugs. Coleman is concerned that this means people are being accepted for assisted suicide who don't meet the criteria of having less than six months to live. "Those people were not actually terminally ill," she says.

Sandeen, however, says that while doctors sometimes underestimate how long people have to live, this is rare. She adds that the small number of people choosing assisted suicide - 105 in Oregon last year out of a population of around 4 million - is reassuring. "That should give other states solace that they will have the same experience - that it will be a rarely used option."

In the UK, the Supreme Court ruled last year that parliament should re-examine the issue as there is a "real prospect" of a future legal challenge succeeding. "There's an appetite for this now," says Jacky Davis chair of Healthcare Professionals for Assisted Dying. Clare Wilson

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