Ms Janine Truter
[redacted]

Standing Committee on Legal and Social Issues

Inquiry into end of life choices

Thank you for the opportunity to address this inquiry on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices. I have addressed issues under the relevant terms of reference below.

(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.

Anecdotally, Victorians currently receive a very good standard of palliative care. When my father-in-law in March, the counselling and end of life care he received was excellent. My husband discussed his father's end-of-life wishes with him and was able to advise care staff what he wanted before and after he became unconscious. After two years of illness, he fell into a coma and was kept free from pain with a very high level of morphine. He died after four days. My husband was happy with this outcome, because it reflected his father's wishes and because his father was relieved of all pain, even if it may have shortened his life.

However, this 'good death' cannot be guaranteed. Not all patients discuss end of life issues, not all families are comfortable carrying out these wishes and not all pain is relieved at end of life.

Above all, I would hope that the Committee will recommend changes to enhance the autonomy of a person at end of life. People should be allowed to control what is done, or not done, to their bodies. They can – and in most cases must – consent to medical treatments. They can legally delegate this authority to others via a medical power of attorney. Although the state funds medical care and requires administrative evidence to prove delivery, it does not intrude into diagnoses or treatments and respects the rights of Australians to confidentiality about medical matters, and the moral right to make private decisions about their bodies. The government's respect for autonomy includes the right of an individual to refuse any medical treatment and to refuse food and drink, even where it hastens their death. A person at end of life is not automatically mentally deficient or an object, and can say when they have had enough and are ready to die.

The introduction of advance care directives has been an excellent step forward in recognising the autonomy of a person at end of life. It guides family and medical practitioners. Decisions should be made by an individual wherever possible, not for them. However, implementation of such directives in Victoria is patchy, and where advance care directives are in place, it would be reassuring for a person to know that their wishes will be respected even if they become unconscious. At the moment, there is no legal recognition of these directives and no central registration of directive to protect an incapacitated person from unwanted or inappropriate treatment. A medical power of attorney can help in this way, but an attorney may not be present and there are reports of difficulties in getting hospital staff to listen to attorneys. Advance care directives also only allow for current health issues, and this makes them of very limited value. Competent people are easily able to envision future circumstances, and their wishes should be respected, just as we respect their last will and testament. It would be good to all of these issues with advance care directives to be addressed by legislation to protect the rights of people at end of life.

The larger issue of concern is unrelievalbe suffering at end of life and protection of the rights of the person in these cases. Unrelievable suffering may be caused by untreatable pain (estimated by palliative care practitioners to be 5-10% of cases) or other factors such as loss of control of wits, bowels or bladder, or a certainty for those with motor neurone disease or oesophageal cancer that they will choke to death. Such suffering could include weakness such that a person is completely dependent on others for every intimate part of their daily care. It might include loss of autonomy, decreasing ability to participate in activities that made life enjoyable, and loss of dignity. These conditions can be degrading for the suffering person. Some people in these circumstances see no point to enduring suffering when death is inevitable and proximate. Currently, they may legally decline medical treatment, refuse food and drink and die of dehydration or be sedated until they die. (Terminal sedation is a medical intervention which meets the principle of 'double effect' where treatment is aimed to relieve suffering and incidentally hastens death.) None of these options end in a dignified death, and none are guaranteed to reduce suffering. A person also has the lawful option, where suffering becomes unbearable, and if they are able, to take their own life.

The option to take one's own life in these circumstances is not the same as suicide. A death in the near future is the inevitable outcome in these circumstances, and as with the principle of double effect, the aim is not necessarily a result of mental illness but a rational decision to minimise suffering, with death as the outcome in both cases. In terms of the brief of the Committee to 'to allow citizens to make informed decisions regarding their own end of life choices', then this is a significant gap in current information. People with unrelievable suffering are not being fully informed of options to take their own lives in these circumstances. Reasons for this may be the social stigma still attached to suicide, the poor information available or the inability of a suffering person to achieve this end as the means are beyond their physical or mental means. However, if the suffering person is to have their autonomy respected, and to have control over their own bodies during the whole of their lives, it is not the role of the state to prevent information being disseminated about this, and indeed, the state should ensure that the best information and resources are available for people at end of life. Alternatively, a medically-overseen option could be provided, which would limit the requirement to provide such information to the suffering person, as well as provide a more certain and peaceful option for the person with unrelievable suffering.

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

As noted above, a person may take their own life. However, the suffering person must ensure that it is done covertly. It is lawful in Victoria for any person to take their own life. What they cannot do is ask someone to help them (even if they are disabled) to do what is lawful. If a relative or doctor aids them in their request, the relative or doctor faces criminal charges under the Victorian *Crimes Act 1958*, S. 6B(2)(a). A person with unrelievable suffering may lawfully hang themselves, alone, to end their suffering, but they may not be supplied with the means of such death, even when it would be a more peaceful death, nor (for fear of prosecution) be in the company of their loved ones as they die.

Where a person decides to take their own life alone to escape end-of-life suffering, this has a significant impact on them, their families and their communities. A person with unrelievable suffering must decide while still physically and mentally capable whether to take their own lives, prepare in secret, deceive loved ones and die alone. Their death can be highly distressing to discover, for families who discover the body, or if the person sees no option but to die by violence, for the emergency crews, train drivers and community members who witness or discover the act. In other circumstances, families or hospital staff are legally prohibited from acting while the dying person writhes in futile pain and begs for assistance to hasten death. In these circumstances, some families and medical staff hasten death covertly by terminal sedation or active involvement such as prescribing lethal barbiturate. Statistics on such deaths are not kept, even though they occur in a medical context, and are not reviewed in any way as the aim of treatment is stated to be ‘to relieve suffering’.

The other concern with this part of the *Crimes Act* is that the Victorian Police do not enforce its provisions where assisted suicide meets the criteria of a voluntary request for relief of untreatable suffering. No charges are laid in these cases, even where medical practitioners have publicly admitted providing illegal assistance to the dying at their request (eg: the well-publicised admissions by Dr Rodney Syme). Nor do police prosecute those who travel with dying family members to Dignitas in Switzerland to access assisted suicide services there. If the law is not enforced, it makes it redundant or a source of mockery.

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

For legislators to take on this task is a serious matter. It brings the intervention of the state into a medical matter, not because of any wrongdoing, but because of the gravity of death. This should not prevent legislators for taking on this task – they receive a high salary because they are expected to do a hard job, and because they are to represent, after due consultation, the wishes of as many Victorians as possible. The issue of dying with dignity is supported by a large majority of Victorians, who want this option to be available for their loved ones, and also for themselves.

The Charter of Human Rights in Victoria asserts in section 10 that ‘A person must not be— ... (b) treated or punished in a cruel, inhuman or degrading way’. It also requires (s9) that ‘Every person has the right to life and has the right not to be arbitrarily deprived of life’ and (s21(1)) that ‘Every person has the right to liberty and security.’ Any proposed law should meet these requirements.

A recent case in the Supreme Court in Canada (Carter v. Canada (Attorney General)) judged that the criminal prohibition in aiding suicide, almost identical to the section of the Crimes Act discussed above, conflicted with their Charter of Human Rights, s7, ‘Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.' The Court stated that:

> The right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly. Here, the prohibition deprives some individuals of life, as it has the effect of forcing some individuals to take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable. The rights to liberty and security of the person, which deal with concerns about autonomy and quality of life, are also engaged. An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The prohibition denies people in this situation the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty. And by leaving them to endure intolerable suffering, it impinges on their security of the person.
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> The prohibition on physician-assisted dying infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice. The object of the prohibition is not, broadly, to preserve life whatever the circumstances, but more specifically to protect vulnerable persons from being induced to commit suicide at a time of weakness. Since a total ban on assisted suicide clearly helps achieve this object, individuals' rights are not deprived arbitrarily. However, the prohibition catches people outside the class of protected persons. It follows that the limitation on their rights is in at least some cases not connected to the objective and that the prohibition is thus overbroad.

I would hope that a law which meets the requirements of our Charter of Human Rights, and incorporates the principles explored in the Canadian courts, would address the concerns outlined above and provide choice and the possibility of relief for those at end of life. I would like to see the Committee recommend legal changes to provide a narrow legal channel for some people – the mentally competent person who is suffering unrelievably with no hope of recovery – to choose a peaceful death and, if they want, to be with their families at the end. It would provide them with the opportunity to seek meaningful help if they are afraid of dying, and it would provide a requirement to talk to a medical practitioner about dying that may result in longer life. It would reduce violent public deaths and the scars that this brings. It would provide scrutiny and accountability around medical services provided to the dying. And it would above all provide – for those who qualify – the option to choose a peaceful death and a relief from 'suffering-to-death'.

One option to address this has been suggested by Paul Komesaroff and Stephen Charles (see Appendix 1) that the *Crimes Act* be amended 'to provide a defence to a charge of homicide or manslaughter if a doctor has prescribed or administered a drug that hastened or caused the death of a patient with a terminal disease if the doctor: (a) reasonably believed that it was necessary to prescribe or administer the drug to relieve the pain or suffering undergone by the patient; or (b) prescribed or administered the drug with the intention of relieving such pain or suffering.

Another option which I prefer is to look at where laws allowing such dying with dignity have operated effectively oversea. Such laws have been operating in places like Oregon in the United States, for over 15 years. There is ample opportunity to interrogate this system to see if it worked as intended and if safeguards have been effective. The Oregon experience (see http://public.health.oregon.gov/ProviderPartnerResources/Evaluationresearch/deathwithdignityact/Pages/index.aspx) has been that during 17 years, an average of 50 terminally-ill people per year have lawfully used medication to help them to die peacefully at a time, place and in company of their choosing. 36% of people who requested medication to assist their dying did not use the medication but died naturally. The majority of those who hastened death were over 65, white, tertiary-educated and with cancer. 97% died and home and 85% were receiving hospice (palliative) care. Despite a persistent minority opposition to this law by those who would not use it, there is no evidence whatsoever that the system has been abused.

Any law on assisted dying must have safeguards, to confirm that the person is of sound mind and that their decision is made freely, and to apply significant penalties for abuse of the process. Any law would need oversight. This might be by a medical practitioner, although this could equally be by a public servant who assesses the relevant documentation. (This latter option may address some doctors' concerns that they are hastening death.) Above all, any law should not place any burdens on either the dying person or a medical practitioner. In particular, it would be absurd to require multiple medical practitioners to affirm someone is suffering unrelievably. A suffering person whose autonomy is respected can reach this conclusion and say this for themselves.

Additional comment

It has been argued by a few that by shortening life by a few weeks, days or hours, that a dying person loses the chance to reconnect with lost family, to repent of wrongs done, to enjoy periods of lucidity and even to live much longer than anticipated. Some even suggest that suffering has integral value, although it is not clear when looking at your untreatably suffering child, mother or father exactly how to define this value. These arguments, supported inflexibly by about 15% of Australians, do not engage with the suffering of the individual dying person, or their personal wishes. This minority does not make clear why a slow, unhastened death by dehydration or drug-induced coma against the express wishes of the dying person is morally superior to, or in the best interests of, a person actively choosing dying with dignity. Nor do they address why the dying should suffer for the beliefs of others, and why the dying cannot make their own decisions about their lives as they do with all other aspects of their existence. The decision to bring forward an inevitable death by a short period, to choose to avoid suffering, should not be subject to the interference of third parties.

Please do not hesitate to contact me if you wish to discuss any of these matters further.

Regards

Janine Truter
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Appendix 1

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Let's not over-complicate euthanasia debate

By Paul Komesaroff and Stephen Charles
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The long-running debate about whether voluntary euthanasia or assisted suicide should be permitted by law continues to create division in the Australian community and arouse passionate views on both sides.

In the latest rounds of the debate, a Senate Committee has called for a conscience vote when the matter next gets to Parliament, the Australian Medical Board has suspended the medical registration of euthanasia activist Dr Philip Nitzsche, and *The Age* has initiated a campaign of its own to influence public opinion. Sadly, despite the sound and fury, little progress is made: on the one side, the proponents of active voluntary euthanasia pursue the demand for enactment of "right to die" legislation, while on the other, their opponents continue to call for preservation of traditional values and practices.

The often strident and acrimonious tone of the debate obscures the facts that there is much agreement between the two sides and that there is a genuine problem in the current law that needs to be addressed. Recognition of this common ground might allow the social deadlock to be broken and for genuine progress to be made in the continuing controversy.

The agreement – which is demonstrated by all polls conducted on this subject – is that people suffering from terminal illnesses are entitled to adequate treatment of their symptoms and should be able to make key decisions about when and how they die. The problem with the law is that doctors who follow current best practice, by providing whatever care is needed to alleviate pain and suffering, cannot be confident that they will be protected from criminal prosecution for murder, manslaughter or aiding and abetting suicide arising from their active involvement in the death of their patient.

Of course, important areas of disagreement remain. Many members of the community find it hard to abide the prospect of institutionalised processes to promote killing in any setting, based either on their memories of the tragic history of the 20th century or on religious or philosophical convictions about the nature of death and ethical responsibility.

While the experiences from overseas jurisdictions – the US and Europe – are undoubtedly reassuring, it has to be accepted that these concerns are by no means frivolous. The possibility that the option of euthanasia might be seen by some as a device for addressing critical shortages in health budgets cannot be dismissed. Many doctors remain understandably nervous about the implications for their profession of what they see as a radical reversal of some of its most enduring precepts. The cases of people with chronic but not terminal illnesses remain difficult, and those of people without physical illness at all more difficult still.

We believe that a shift in the debate from the high-level – and inherently insoluble – abstractions about a "right to die" and the "sanctity of life" to a focus on practical issues that need urgent attention might allow the social deadlock to be broken and progress to be made at last in bringing about meaningful reform. To achieve this only modest changes in the existing law are needed.

We propose that legislation be enacted to amend the relevant Commonwealth and State Crimes Acts to provide a defence to a charge of homicide or manslaughter if a doctor has prescribed or administered a drug that hastened or caused the death of a patient with a terminal disease if the doctor: (a) reasonably believed that it was necessary to prescribe or administer the drug to relieve the pain or suffering undergone by the patient; or (b) prescribed or administered the drug with the intention of relieving such pain or suffering.

A simple legislative change to this effect would ensure that people facing serious illness could be confident that their needs will always be able to be met, and that doctors following accepted best practice in providing for the needs of their patients will be able to do so free from the threat of a criminal conviction. The responsibility of doctors to be able to account for their actions will not be diminished and protection for elderly and vulnerable members of the community will remain intact. The locus of end-of-life decision-making will be returned to where it should be: in the dialogues between patients, families and their medical carers.

This minimalist solution should be widely acceptable to the community, including to those who remain disquieted by attempts to purify death of its untidiness, uncertainty and risk. The difficult cases in which patients with severe chronic illnesses but without terminal illnesses request assistance with dying will remain unsolved, but the public debate will be able to move ahead to address the complex issues associated with them.

It is time to move on from never-ending, unproductive, circular discussions about end-of-life decision-making to a more practical approach that will solve pressing social problems and refresh the public debates.

Professor Paul Komesaroff is Director of the Centre for Ethics in Medicine and Society and author of *Riding a Crocodile: A Physician's Tale*, and Stephen Charles QC is a barrister and former judge of the Victorian Court of Appeal.

This story was found at: ***http://www.smh.com.au/comment/lets-not-overcomplicate-euthanasia-debate-20141120-11qbbe.html***