To:

The Ministerial Expert Panel on Voluntary Assisted Dying
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My background: I am Dr Andrew McGee, a Senior Lecturer in Law in the QUT Law School and a member of the Australian Centre for Health Law Research and QUT Law Lab. I am an expert on voluntary assisted dying and euthanasia, having published papers in leading national and international peer reviewed journals on these and related issues over the last 10 years, some co-authored with international experts from the United States of America. More broadly, I am admitted to practice as a lawyer of the Supreme Court of Queensland and the High Court of Australia, and hold a PhD in philosophy from the University of Essex, UK.

In what follows I have endeavoured to use my academic expertise as a researcher in the field of voluntary assisted dying to answer some of the questions raised in the Ministerial Expert Panel’s Discussion Paper. I have only answered those questions that relate to my direct area of expertise and accordingly have not responded to questions that either fall outside my expertise or might best be answered by others who have greater expertise than I do. I first reproduce each question I have selected to answer from the Discussion Paper, and include my response below it. Please note that while I am a member of the QUT Law School, the views expressed in this submission are my own and do not necessarily reflect the views of other members of the QUT Law School.

Questions to Consider

Are there other guiding principles that should be considered for the Bill?

I wish to comment on the principle “Every human life has intrinsic value”. An equivalent panel to WA’s Ministerial Expert Panel on Voluntary Assisted Dying, the Ministerial Advisory Panel on Voluntary Assisted Dying in Victoria, embraced the same principle in a report, and the principle is in the Victorian Voluntary Assisted Dying Act 2017 (Vic), s 5(1)(a). In a critique of that Victorian report, it was countered that the principle is incompatible with permitting VAD. See John Keown ‘Voluntary Assisted Dying in Australia: The Victorian Parliamentary Committee’s Tenuous Case for Legalisation.’ Issues in Law and Medicine 33(1); 2018: 55-81, p 64. Derivatively, it can be claimed that the principle is inconsistent with the principle of autonomy if, according to the principle of autonomy, competent patients decide that their lives are no longer of value, and are allowed to end their lives in accordance with that decision. By allowing them to end their lives—so the argument runs—we condone the decision and thereby acquiesce in their judgement that their lives are not worth living, and so cannot in all consistency embrace the principle that every human life has intrinsic value. On
this basis, it might be thought that the principle ‘every human life has intrinsic value’ is mere empty window-dressing in legislation designed to permit VAD, and so should not be included.

The principle that every human life has intrinsic value is a fundamental principle, and should definitely be included. But we must answer Professor Keown’s criticisms of the Victorian Ministerial Panel’s equivalent endorsement of the same principle, to justify including it in legislation introduced in WA.

Professor Keown has claimed that allowing VAD necessarily implies that some lives are not worth living, and so do not have intrinsic value (see reference above). This claim would be correct only if the legislation were permitting non-voluntary or involuntary assisted dying, not voluntary assisted dying. Where voluntary assisted dying is concerned, we defer to competent persons’ own views of whether they can bear their pain and suffering, motivated by the universal human attitudes and emotions of respect and empathy. It is possible to believe their lives have intrinsic value, yet simultaneously believe that their own decisions to end their lives should be respected. There is no logical incompatibility between these two beliefs. If a group of people face only two choices: 1) immediate death at their own competent, voluntary request or 2) a longer process of being burned alive first, followed by death as a natural consequence of being burned alive, it is not an offence to the principle of the intrinsic value of life to take pity on these people by allowing them to end their lives immediately rather than face being burnt alive and dying naturally as a consequence of being burned alive. Keown’s argument implies that pity and empathy in this situation – if they take the form of allowing these people to end their lives immediately – are inappropriate emotions, because we don’t sufficiently value the lives that would be lived while they are burning to death. Clearly an argument that leads to this conclusion is unacceptable and must be rejected. Far from being inappropriate, pity and empathy are emotions that actually disclose the value of these people’s lives (we cannot, for example, feel pity and emotion for the coal we burn at the fireplace). What we disvalue is the experience of being burned alive, not the people who are being burned alive. Similarly, we disvalue the experience of unbearable pain and suffering, but not the people who are experiencing the pain and suffering. In some cases, the only way to show true pity and empathy is to allow people to end their lives so as to avoid those experiences. Accordingly, the principle that every human life has intrinsic value can be defended and should be included as the Panel suggests.

What safeguards should there be to ensure that a request is voluntary?

Opponents of VAD say that if people consider themselves to be a burden, and state that the desire not to be a burden is the reason for their request for VAD, the decision is not voluntary but is coerced. This conclusion does not automatically follow. It depends on whether the desire not to be a burden stems from the patient’s own values, or whether it’s a position that has been imposed on the patient by family members or treating staff. This is why assessing the voluntariness requirement can be complex and requires careful investigation. If, however, it is clear, following investigation, that the desire not to be a burden stems from the patient’s own values, the decision is not coerced
and it should be respected as a voluntary decision. We should not, therefore, rule out the desire not to be a burden as incompatible with the voluntariness requirement. A safeguard that does so is one safeguard too many.

**Should the assessing medical practitioner be able to refer to other health practitioners with relevant competency to assess that the decision is voluntary?**

Not only should this be optional, as the language in this question implies; it should be compulsory if the assessing practitioner does not have the competence to make the assessment, or is otherwise unable to make it. It is vital that those who assess whether the decision is voluntary have the competence, expertise and opportunity to do so.

**Should health practitioners be able to discuss voluntary assisted dying with their patients in the same way they raise and discuss other health or medical decisions and care options?**

Yes. WA should avoid imposing a requirement that a person raise VAD of their own volition when discussing end of life options with a medical practitioner. This requirement was imposed in the Victorian legislation as an extra safeguard, but it is not needed because it is possible to ensure that a decision is voluntary and not coerced even if the option is mentioned by the practitioner. By way of example, no one argues that, if a patient is on life-sustaining ventilation, the medical practitioner should not be the first to raise the possibility that, if the patient finds the ventilation to be too burdensome and is competent, and their choice is voluntary, they are lawfully entitled to ask for it to be withdrawn, even though its withdrawal would be fatal. People need to be advised of all available options, so that they can genuinely make a voluntary and informed choice. If a person is not made aware of the option of VAD, this failure to advise them limits their choices and arguably makes other end of life choices less autonomous and, possibly, coerced. We should avoid imposing any requirement that leads to this unintended consequence.

**Should there be particular consideration given to people who lose capacity after they have started the process?**

In the discussion paper at page 25, the following statement is made:

> “Requiring the person to have decision-making capacity at all stages in the process is consistent with most other jurisdictions with a form of legalised voluntary assisted dying. It is a safeguard to ensure that the process remains self-determined throughout.”

It is unnecessary to require a person to have decision-making capacity at all stages in the process, *provided the person has written a valid and legally enforceable advance directive (AD) with the material directions*. This is relevant because capacity is assessed at the time the AD is made, but the AD is meant to cover the circumstances that arise when the patient wants to end their life but no longer has capacity. The whole objective and rationale of the AD is to overcome the problem by
anticipating those circumstances in advance, and directing what medical practitioners should do when the circumstances actually arise. The directing is done while the patient is competent (otherwise the AD is not valid), but what the patient directs to be done is done at the time the patient has lost capacity. At some stage, Western Australia must confront the problem of ADs, and whether we should allow people who anticipating losing capacity later to have their lives ended at that later time, on the basis of their advance directive. Up until now, the fear has been that allowing people to have access to assisted dying via ADs is unacceptable because, at the time the circumstances arise in which, according to their earlier decision as recorded in the AD, they would want their lives ended, they will not have capacity. So – the logic goes – since their decision is not capacious, the patient is vulnerable and we risk helping a vulnerable patient end his or her life. Similarly, since capacity is a precondition of the voluntary taking and exercise of a decision, we cannot be sure that their decision is voluntary.

The problem with this argument is that it simply rejects the whole rationale of an advance directive as incoherent. The solution to the worry about the decision having made in advance, and about whether, if the decision were to be made on the day the circumstances have arisen, the decision would still be the same is, in my opinion, straightforward. We should allow the advance directive to be effective and fulfil the patient’s wish where the patient continues to request VAD up to and including the point at which VAD would be performed. However, we should not allow the advance directive to be effective and fulfil the patient’s wish where either:

(a) The patient expressly disavows the advance directive or otherwise expresses any desire not to have VAD or any desire, or any behaviour, inconsistent with realising the decision in the AD; or
(b) The patient is indifferent about whether VAD proceeds, and so does not exhibit the required ongoing and enduring request.

In short, it is not necessary to require “the person to have decision-making capacity at all stages in the process” in order to have adequate safeguards. I admit that it might be more difficult to have a Bill pass that allows people anticipating, say, later stages of dementia to end their lives at that later time. But it must be remembered that, if we do not allow people to request VAD by an AD, these people may in some cases feel compelled to end their lives earlier, while they have capacity. This is a realistic problem where, as is also proposed in the discussion paper, death need only be a “reasonably foreseeable outcome of the condition”. If ADs are not allowed to be used for VAD, these people become vulnerable patients – they are vulnerable to having to end their lives earlier than they otherwise would if they could rely on their ADs. WA should consider facing and dealing with this problem; I have offered one suggestion for dealing with it above.

If voluntary assisted dying only applies to an illness or disease that is terminal, is specification of a timeframe either desirable or necessary?
* Would a timeframe help or hinder access to voluntary assisted dying? From the perspective of the person? Or medical practitioner?

* If a timeframe is to be specified should it be defined as: - reasonably foreseeable outcome of the eligible condition? - reasonably foreseeable outcome for this person? - 6 months? (with 12 months for neurodegenerative disorders) - 12 months? - other?

My answers below pertain to each one of these questions, and so I take the questions all together.

I note the problem of arbitrarily restricting access to people who are terminally ill only, if “terminally ill” is defined under legislation by an arbitrary time period of 6 months or 12 months. VAD should also be available to people who suffer from neurodegenerative illnesses or diseases or chronic illnesses or disease for whom death is reasonably foreseeable. Perhaps in a broader – and arguably the ordinary – sense of the term, we could regard such people as ‘terminally ill’, but it might be better simply to include people with neurodegenerative and chronic illnesses or diseases in a separate category from the ‘terminally ill’ as is currently proposed under the Discussion Paper.

There has been some debate about the workability of the term ‘reasonably foreseeable’ in this context, with some commentators suspecting that the term is too vague, and might give rise to burdensome litigation (with people claiming they fall under the term when a decision might have been made to say that they don’t). Since WA is proposing to use the phrase “death is a reasonably foreseeable outcome as a result of the eligible condition”, this problem needs to be confronted. One objection to the reasonable foreseeability criterion can be stated as follows. Consider a 22 year old who has just undergone genomic testing, and discovered that they have Huntington’s disease and are therefore likely to develop cognitive and physical dysfunctions before reaching middle age. On a reasonable foreseeability criterion, would this patient qualify now, at the age of 22, on the basis that death is a “reasonably foreseeable outcome of the condition?” Some critics claim that they would, and that this consequence is unacceptable.

I believe we can reject this conclusion, and answer “no”. Reasonable foreseeability would only be enlivened once the symptoms of this disease started to appear and/or caused physical suffering. Indeed, if necessary a provision could be added to this effect.

The other option is to stipulate a time in the legislation, as has occurred in Victoria, which allows qualifying people who are terminally ill to avail themselves of VAD up to 6 months prior to death, and those suffering from neurodegenerative diseases to do so up to 12 months prior to death. There are two problems with this option. First, prognosis is notoriously difficult, with many people living much longer than prognosed. Second, it arbitrarily excludes people who ought to have the option of VAD. For these two reasons, the certainty such a stipulation appears to provide is an illusion, and creates more problems than it solves. There is a third problem. This is that some people may starve themselves in order to try to bring themselves within the arbitrary timeframe stipulated in the
legislation. Professor Jocelyn Downie from Canada has discussed this issue. But she has also claimed that it can arise even with the criterion of ‘reasonable foreseeability’; people might starve themselves in order to get within its ambit. See J Downie, ‘Medical Assistance in Dying: Lessons for Australia from Canada’. *QUT Law Review* 2017; 17(1): 127-146.

My colleagues [redacted] have suggested that we might only include the requirement that the condition “will cause the person’s death” rather than requiring death to be a “reasonably foreseeable outcome” of an eligible condition (personal communication). However, this solution might mean that our 22 year-old above who discovers he has Huntington’s disease would be eligible now to end his life even though he won’t develop the symptoms until middle age. We might need to accept that no solution is ideal; each one might have unforeseen problems.

**Must a person’s suffering be ‘grievous and irremediable’ to be eligible?**

Requiring that, in addition to death being a reasonably foreseeable outcome of the condition, the patient must have grievous and irremediable suffering to be eligible arguably provides an extra safeguard. The state has an interest in protecting people who are vulnerable and upholding the value of life (this is one of the principles which WA Expert Panel has mentioned should be included in the legislation). Most of us recognise that if suffering is unbearable, death can be a release from such suffering. Contrary to the views of some critics such as professor Keown, this attitude need not express the view that such lives are not worth living. However, most of us feel that, unless the patient is suffering unbearably, the state has an interest in not allowing lethal medication to be used to enable a person who is not suffering unbearably to end his or her life. Life is something to be valued and cherished, so people who are not suffering unbearably should be helped and supported in another way.

There is one exception to this point. This is that, where someone is close to the end of their lives, and so in the terminal phase of their illness, we should not wait until they are suffering unbearably, before granting them access to VAD. It is defensible to allow the principle of autonomy to be absolute when people are genuinely approaching the end of their lives, on the basis that they are dying already in the true sense of ‘dying’ – they are in the terminal phase of the illness – and so we are merely making dying more comfortable.

* **Must the person’s suffering be related to the eligible condition?**

I leave it open whether the person’s suffering should be related to the person’s condition. We should avoid the possibility of irresolvable argument or dispute about whether it is related or not, however.

* **Should a medical practitioner or health service that conscientiously objects have an obligation to refer the patient to a practitioner or service that has no objection?** If so, how should the medical practitioner find out which doctors are willing to provide voluntary assisted dying?
Yes, a medical practitioner or health service that conscientiously objects should definitely have an obligation to refer the patient to a practitioner or service that has no objection.

It has been claimed that such an obligation undermines the point of having conscientious objection, since it forces a medical practitioner or health service to act against conscience by making a referral to another practitioner or health service that will carry out that to which the conscientious objector objects.

WA should definitely reject this claim. VAD is a matter of individual conscience, and nobody is entitled to impose their own view on another person in matters of conscience or personal belief. For this reason, a legal requirement should be imposed on a conscientious objector to refer the patient to another practitioner or service provider who does not hold (or whom the practitioner can reasonably ascertain does not hold) the same conscientious objection. This legal requirement does not infringe on the conscientious objector’s own personal values and beliefs, because the patient is not requesting that the conscientious objector himself or herself actually carry out VAD, nor to believe in VAD, nor is he or she requesting the conscientious objector to avail himself or herself of VAD in the conscientious objector’s own case, but only to respect the different beliefs of the patient. The only way to meaningfully respect the different beliefs of the patient himself or herself, and to respect the right of this patient to act in accordance with his or her own conscience, is to impose an obligation to at least refer the patient to a practitioner or service that has no objection. This requirement is a reasonable compromise between the respect for the conscience of the conscientious objector, and respect for the conscience of the person requesting VAD.

Those who disagree with this conclusion might argue that referring itself constitutes participating in VAD. However, although about a word in a statute about abortion, the UK House of Lords has held that the word ‘participate’ refers to actually taking part in administering treatment and did not refer to any arrangements preliminary to, and intended to bring about medical or surgical procedures aimed at, performing the act to which the conscientious objector truly objects (Janaway v Salford Area Authority [1989] AC 537). We can apply the same logic to VAD, and to the words “providing assistance”. An obligation to refer is not an obligation to participate in VAD, nor is it an obligation to take part in administering, or providing, lethal medication to a patient. Any other view is likely to strike the wrong balance between the right of the conscientious objector to abide by his or her own values and beliefs, and the right of requestors to abide by theirs. We should also remember that the practitioners and service provides owe obligations to all their patients to provide the services requested, so the right to conscientious objection must be limited in a reasonable way so as not to undermine this obligation. (Professor Julian Savulescu, on whom I rely in making this last point, has published a highly cited peer-reviewed paper ‘Conscientious objection in Medicine’ BMJ 2006; 332 in the prestigious British Medical Journal. This paper may help the panel if further argument is needed on this point.)
What should be included in the training for health practitioners involved in voluntary assisted dying?

Please refer to the work of my colleagues Professor Lindy Willmott and Professor Ben White on VAD training for health practitioners. Professors Willmott and White have used their extensive expertise to provide VAD training, with the Victorian Government, to practitioners in Victoria. Information on the Victorian training is found at this link: https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-practitioners/vad-training-for-medical-practitioners

My colleagues have also provided a more general discussion on clinical implementation of VAD in a recent publication in the Medical Journal of Australia. Please see Ben P White, Lindy Willmott, and Eliana Close, ‘Victoria’s voluntary assisted dying law: clinical implementation as the next challenge’ MJA 2019; 210(5): 207-209.

Should a medical practitioner only be permitted to administer the medication if the person is physically incapable of self-administration?

If VAD is to be a voluntary assisted dying regime (rather than a voluntary euthanasia regime), then it might be argued that it should primarily involve a competent person acting voluntarily to end his or her own life. Having the person himself or herself be the one who administers the fatal dose provides an additional safeguard over euthanasia (where a third party, usually a medical practitioner, administers the lethal dose to the patient, and so one person kills another person). However, it is compatible with this point to allow a third party to administer the fatal dose in very limited circumstances, where a patient is not physically able to end his or her own life, as is the case in Victoria. The peer-reviewed empirical evidence published in the highest quality journals in the world such as the Journal of the American Medical Association (JAMA) does not support the view that euthanasia is intrinsically more open to abuse than VAD. See, for example, Ezekiel J Emanuel et al, ‘Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe’ JAMA 2016; 316(1): 79-90. In a study for the period 1947 to 2016, this paper concluded:

In no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than those in the general population.

This evidence, along with other evidence cited in WA’s My Life, My Choice Report suggests that it would be safe to allow a third party to administer the fatal dose where a person is incapable of self-administering it. However, it might be thought that this evidence means that euthanasia should be made available for all rather than merely for those who cannot end their own lives. This would reflect the practices that have been made lawful in the Canadian Medical-Assistance-in-Dying regime and in European jurisdictions such as Belgium and the Netherlands.
There might be a public policy argument against this extended option, however. This is that, in VAD, there is no homicide; no third party kills another person. Instead there is only one person voluntarily ending their own life. By contrast, euthanasia involves one person killing another person. It might for this reason be claimed that VAD is preferable – an argument that does not depend for its validity on the statistics concerning vulnerable patients, but rather on the plausible claim that one person killing another is unethical, save in very exceptional circumstances. These exceptional circumstances are where patients are incapable of self-administration. This argument is more likely to appeal to those who believe that the role morality of medicine precludes a medical practitioner from actually taking the life of another person. A Bill that restricts availability to VAD only, and allows only euthanasia in exceptional circumstances to avoid discrimination, might also have a greater chance of passing.

WA should also note that, if VAD is to include third party administration without it being limited to exceptional circumstances where a person is unable to self-administer, then it would be more transparent to call the regime VADE, to include ‘euthanasia’, as in the ‘Voluntary Assisted Dying and Euthanasia Act’. If the word ‘euthanasia’ is unattractive, then it could instead be called the ‘Voluntary Assisted Dying and Ending Life Act’. The term ‘assisted dying’ should be restricted to its natural and ordinary meaning, in which it refers to a case of self-administration. When a third party ends another person’s life, it is too weak, and hence misleading, to claim that the third party assists people to end their lives by themselves. Instead, the third party *ends* the patient’s life. There is a risk that a lack of transparency will be seized upon by opponents of VAD in parliamentary debates. But as noted above, it is defensible to carry on using ‘Voluntary Assisted Dying’ if the cases of third party administration are limited only to those cases where a patient is incapable of self-administering. In that case, ‘VAD’ should continue to be used.

**Should it be required that voluntary assisted dying is listed as a contributing cause of death on: the Medical Certificate Cause of Death? - the publicly available Death Certificate?**

Some critics have claimed that it is patent nonsense not to list VAD but only the terminal, neurodegenerative, or chronic condition as the cause of death on the Medical Certificate Cause of Death or the publicly available Death Certificate. However, it is defensible not to list VAD as a contributing cause given the well-known reasons for not doing so. We should accept that the practice of not doing so is a legal fiction in these circumstances, but legal fictions are commonplace and used in many other areas of the law, including deeming provisions in criminal law, and in corporations law, where the rule that a corporation is a person is a legal fiction. On this basis, provided that it is clear that this is a legal fiction, there is no reasonable objection to the practice of not listing VAD as a contributing cause on the Medical Certificate Cause of Death or the publicly available Death Certificate.

**How should health practitioner training and education be provided?**
Once again, please refer to the work of my colleagues Professor Lindy Willmott and Professor Ben White on VAD training for health practitioners. Professors Willmott and White have used their extensive expertise to provide VAD training, with the Victorian Government, to practitioners in Victoria. Information on the Victorian training is found at this link: https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-practitioners/vad-training-for-medical-practitioners

My colleagues have also provided a more general discussion on clinical implementation of VAD in a recent publication in the Medical Journal of Australia. Please see Ben P White, Lindy Willmott, and Eliana Close, ‘Victoria’s voluntary assisted dying law: clinical implementation as the next challenge’ MJA 2019; 210(5): 207-209.

This concludes my answers to the questions I have selected to answer from the Expert Panel’s Discussion Paper. I would welcome the opportunity to give further evidence to the Expert Panel if required.