Submission by

the Roman Catholic Bishops of Queensland

to

the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying

[Paper No 3, 56th Parliament, 2019]

15 APRIL 2019

Introduction and Summary of Key Points

1. The Roman Catholic Bishops of Queensland welcome the opportunity to address the issues raised concerning aged care, end-of-life and palliative care, and voluntary assisted dying by the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee in its issues paper (Paper No 3, 56th Parliament, 2019).
2. Catholic agencies have a long history of providing health and aged care to Queenslanders and are substantial providers of palliative care services. The spirit of care for others that motivated the early Catholic pioneers of this care in Queensland continues to motivate those institutions today and motivates us too in making this submission.
3. The inquiry is an important opportunity for all Queenslanders. Through considering questions about what happens to us towards the end of our lives and the choices we have, we are indirectly considering far deeper questions about the kind of society we are living in, and the kind of society we want to live in.
4. Such questions are central to the notion of the common good, one of the founding values of the Commonwealth of Australia. Government and the laws it makes exist to protect the common good, the common wellbeing of all people.[1]
5. We are all members of this society: young and old, rich and poor, believers in God and non-believers alike. And together, through our elected politicians and the structures of government, we have a say in the kind of society we live in, in how best to protect the common good. This is especially important when the matters being considered will affect all of us—most of us will age, and all of us will die. All of us will have family and friends in that position.

   For many of us, this process of aging and dying may be a time of increasing vulnerability—physical, psychological, or spiritual. The deeper question that this inquiry is addressing, then, is how should we as individuals and as a society respond to the vulnerabilities inherent in aging and dying, inherent, in other words, in being human?
6. In what follows, we submit:

   - that our society is rightly founded on the protection of human dignity, human freedom and the common good, which is the good of all human beings, both as individuals and collectively. The common good includes human flourishing and the sum of material goods necessary for that flourishing. Consequently, the exercise of freedom is always qualified and understood in relation to the common good.
   - that in light of this commitment to freedom and the common good:
     - the current shortfalls in aged care should be addressed as a matter of urgency in ways that respect the human dignity of older Australians, and especially their flourishing through the use of their freedom in meaningful ways. Access to timely and adequate health services is very important for those in residential aged care.
     - Palliative care services should be improved both in quality and in accessibility.
     - Education about what high quality palliative care is, namely a commitment to improved quality of life for those with life-limiting conditions, should be supported to challenge the myths surrounding palliative care that create false and unwarranted fears and uncertainties about the dying process.

- Research into how palliative care can be improved, as well as into how palliative care can improve outcomes related to individual and community meaning-making in life and death, should be supported and encouraged.
- 'Voluntary assisted dying,' should not be legalised in the state of Queensland:
  - because it undermines human freedom by presenting a false choice between horrible dying and intentional killing;
  - because it undermines the meaningfulness of all life and with it the very idea of a society founded on respect for human dignity and protection of the common good;
  - because the law, which should affirm the equality and worth of all, would ultimately be sending the message that some lives are less worthy. Such a message puts vulnerable people at risk; and
  - because such legislation would send the wrong message at a time when Queensland has the second highest rate of suicide in Australia.

The Commitment to Freedom and the Common Good: freedom needs the right conditions

7. It is true, and indeed right, that we live in a society that recognises the need to protect human dignity and freedom. Our freedom should be protected from unjustifiable interference.

8. At the same time, our society is rightly concerned with ensuring that the necessary conditions are in place to allow people to use their freedom in appropriate ways: in ways that contribute to their own flourishing, the flourishing of others, and the flourishing of society as a whole. When these necessary conditions are not in place, our opportunities to make choices about the things that matter most are more limited.

9. It is also true, however, that the protection of human freedom it not without restriction. The law places numerous restrictions on human freedom. For example, the law does not allow us to do things that disproportionately endanger our lives, the lives of others, or the overall good of society. A very simple example are the rules of the road. Knowing which choices warrant such limitations is part of the challenge for law makers.

10. When it comes to matters of aging and dying, having our valid choices expressed, heard, and acted upon is very important for individuals and for society. This requires both that our freedom is protected from unjustifiable interference and limitation, and that society provides the necessary conditions for us to exercise our freedom in an appropriate manner.

11. We maintain that both the protection of freedom and the necessary conditions for the appropriate expression of freedom are not yet adequately met in our society in relation to questions of aging and end of life care.

    As a consequence, it might appear to people that their options when it comes to aging and end of life care are more limited than those options really ought to be. Indeed, it may lead them to believe incorrectly that what in other circumstances would clearly be the wrong thing to do, may be the right thing to do.

    The onus is on us as a society to make sure that the necessary conditions are in place to make the best choice. Otherwise, we are in danger of thinking that we are protecting people's freedom when we simply do as they ask, when in fact the choices they are making are not real choices because they are choices made in circumstances in which we as a society have failed to provide the necessary conditions for them to make better choices.

12. In listening to what people are saying about aging and dying, we need to make sure that we are hearing the question correctly. If not, we are in danger of giving the wrong answer—an answer that is ultimately unhelpful for the individual and ultimately frustrates the good of society as a whole.

    The fact that some people express a wish to actively end their lives does not mean that the answer must be to allow them to do so. The fact that many people experience suffering and loneliness in sickness and old age does not mean that the solution is to end the suffering by ending the life of the person suffering. The fact that many people fear becoming a burden does not mean that we should confirm to them that they are a burden and that it would be better for them and us if they were no longer here. The fact that many people fear what they think will be a loss of dignity or autonomy does not mean that the answer is to allow them to think that ending their own lives is the ultimate expression of their dignity or autonomy.

Rather, the question is how to deal with the experience of suffering, of feeling that one is a burden, of the fear of loss of dignity or autonomy, and of death in ways that ultimately affirm the meaningfulness of all human lives and our life together as a community? In other words, how do we best protect and foster human dignity, human freedom and the common good?

What kind of society are we living in?

13. The very fact that this inquiry is being held is evidence enough to know that that aged care is not always perfect, and palliative care is advancing but still not adequately resourced, accessible, understood, or integrated into clinical practice.
14. It is also clear that given these circumstances of the society we are living in, there are fears and uncertainties that lead many to ask whether death would not be better. These include fears of loss of dignity, independence, autonomy, control, pain and suffering, and being a burden. Indeed, in some cases, people resort to desperate measures and take their own lives.[2]

What kind of society do we want to live in?

15. The kind of society we want to live in is premised on two key and interrelated ideas: human dignity and the common good.
16. As affirmed in the Queensland Human Rights Act 2019, all human beings have inherent dignity and worth, equality and freedom.
17. The common good is the good of all these human beings, both as individuals and collectively. It includes human flourishing and the sum of material goods necessary for that flourishing.
18. Sometimes there can be conflicts in the interests or rights of individuals or groups, or between and individual and the society.
19. Nonetheless, such conflicts, which may result in the limitation of certain rights by authorities, should always be resolved in ways that do not separate the good of the individual from the good of society, nor the good of society from the good of an individual. Only in so doing can a society strike the fine balance in which all human beings can find fulfilment.
20. At the same time, the awareness of the common good implies that no individual within that society should insist on exercising, or should be allowed to exercise their rights in a way that damages the common good, either through damaging themselves, others, or indeed the fundamental fabric that holds a peaceful, considerate, and flourishing community together.
21. Given this understanding of the society we want to live in, i.e., a community of interconnected individuals whose individual wellbeing is always tied to the wellbeing of others, we frame our responses to the way things are, as highlighted by the issues paper and the questions it raises.

Aged Care

22. Populations in developed countries like ours are aging. But it is also true that people are living better more active lives for longer, and the time at which they need substantial care has been both delayed to much later in life and condensed in duration. Given this reality, dignity and the common good are best served when people are aided in living independently for as long as they are able and desire to. At the same time, encouraging independence should never end up as forced isolation or loneliness.
23. When older Queenslanders are infantilised or treated as less than a human of equal dignity, we have failed as a society. When living under such conditions leads to existential crises of such magnitude that some people will ask to die, we have failed as a society. Every effort should be made to improve aged care in ways that respect the dignity, equality and freedom of individuals.
24. Quality aged care must go beyond simply avoidance of harm and provision of basic survival needs like food and shelter. It must include attention to ways in which aging Queenslanders can continue to exercise as much control as possible over their lives, and continue to feel that they are related to others in meaningful ways, for their own good and the good of those who care for them. People realise their inherent dignity as a sense of pride and self-worth in and through meaningful interactions with others.
25. Provision of adequate health care to people in aged care facilities is of vital importance. Nobody should have their access to high quality health care (to which they are entitled as a member of the community) limited because of where they live. There is evidence that this is sometimes not the case in the care of aged care residents. Many of these issues are being addressed as part of the Royal Commission into Aged Care Quality and Safety. We would like to reiterate the concerns raised in the Catholic Health Australia (CHA) submission to the Royal Commission by CHA's Director of Aged Care, Nicolas Mersiades, in particular:
    - Access to high-quality GPs should be improved, especially for people who cannot travel easily to surgeries.
    - Aged care residents are more likely to die in distress in a hospital due to a lack of skills and resources regarding palliative care, especially in-reach services, in aged care. Such services should be improved.
    - Access to timely and effective dental care should be improved.
    - Access and provision of mental health services in aged care facilities should be improved, especially in light of the high rates of self-harm in aged care.
    - The interface between hospitals and aged care should be improved.[3]

Palliative Care and End of Life Care

26. In Queensland, high quality palliative care is offered in Brisbane by Catholic hospitals, the Mater (20 public/private inpatient beds shared with oncology), St Vincent's Private Hospital Brisbane (40 inpatient beds), and Canossa Private Hospital (6 public and 6 private inpatient beds). These services also are involved in outpatient and community palliative care. Other initiatives include the St Vincent's Health Australia, Northern Peninsula Area (NPA) Family and Community Services and Apunipima Health Council 3-year Palliative Care project in Cape York. Catholic services in Queensland have demonstrated ongoing improvement in these services, in line with other developments elsewhere in the Catholic sector in Australia and demonstrated in Catholic Health Australia's recent report on Palliative Care in the Catholic Sector.[4]

27. Nonetheless, palliative care funding in Queensland appears to be inadequate, which compromises the capacity of health care providers to adequately care for those dying. For example, Palliative Care Queensland, in its 2018/2019 Pre-Budget Submission, has stated there needs to be an additional $100 million in funding over three years to increase the specialist palliative care workforce to nationally recommended levels.[5]

28. When people suffer needlessly or undergo burdensome and futile treatment under the belief that they must stay alive at all costs, or because some in the medical fraternity are afraid to concede defeat, we have failed as a society. Whilst suffering is part of the human condition, needless suffering is deplorable. Consequently, we strongly support improvement in palliative care, access to it, resources for it, and integration of palliative care with other treatments, including those where there is still a prospect of beneficial treatment.

29. Palliative care should not be understood only as end of life care, or as something that happens when all hope is lost. It should especially not be understood as 'passive euthanasia' and should not be spoken about in a way that equates or includes as part of its understanding any kind of intentional direct ending of a patient's life, whether voluntarily by the patient, non-voluntarily, or involuntarily. There is high quality evidence to the contrary and every effort should be made to educate the health community and the wider community about what high quality palliative care is. Above all it is about improving the quality of life of patients with life-limiting conditions, their families, and their caregivers.[6]

30. We also support efforts to encourage people to have meaningful discussions with their loved ones about death and when it might be appropriate to withhold and withdraw treatment and to engage in advanced care planning.

31. There is a long tradition of moral reflection on the legitimacy of withholding and withdrawing treatment. We support respect for patient autonomy in questions of starting or ending treatment, which means respecting their wishes where these are known, and their best interests where these are not. Where treatment becomes disproportionate, that is, either overly burdensome, or very low likelihood of benefit, that treatment can be legitimately stopped or not started.[7] The intention is not to end the life of the patient, but rather to avoid overly burdensome or clinically futile treatment. Such an action does not constitute an intentional direct ending of the life of a person and so is not to be understood as 'voluntary assisted dying', euthanasia or physician-assisted suicide.

32. We the Roman Catholic Bishops of Queensland commit to doing our part to facilitate meaning-making in ways that affirm life and its meaningfulness.

Voluntary Assisted Dying

33. Should Voluntary Assisted Dying be legalised in Queensland?

No

34. If we as a society begin to embrace a rhetoric that some 'life is not worth living', then we have failed as a society. If we as a society begin to embrace a rhetoric that a person can do whatever they like, whenever they like and however they like simply because they are essentially free, then we have failed as a society. If we as a society allow people to believe that their only choice is between a slow and painful death, and so-called 'voluntary' assisted dying, then we have failed as a society. High-quality palliative care clearly shows that none of these outcomes are necessary.

35. What is presented in the issues paper as "Voluntary Assisted Dying" undermines human dignity, human freedom, and the common good.

36. What is 'Voluntary Assisted Dying'?
As the issues paper notes, there is not a common understanding of what 'Voluntary assisted dying' is. However, it is possible to clearly label the actions involved. A person who is judged competent (itself a disputed concept)[8] to make such a decision is legally aided, either through provision of the means or by active injection of the means by another, to intentionally kill themselves. Some might say that we should avoid the use of kill in this context because it is morally charged. We disagree: 'murder' is morally charged; 'kill' is not. Killing is a clear descriptive verb. The reason that killing is appropriate here is because, though a person who would access such a service may indeed be dying of some terminal disease, it is not the disease that ultimately kills the person in this case. It would be the intentional actions of the person and their assistants, actions which are intended to end the life of the patient before the disease or anything else does.

As explained in point 31 above, legitimate withholding or withdrawing of disproportionate treatments does not constitute 'voluntary assisted dying'. Proper understanding of these processes, of their place in dealing with the realities of human mortality, and how through early and supportive discussions about death and dying, including the use of advanced care planning, they can contribute to a 'good' death, is to be supported and encouraged.

37. Human freedom is undermined by false choices
Legalising intentional direct killing of oneself or another in a peaceful society ('voluntary assisted dying') especially undermines human freedom when a person is presented with a false choice between dying horribly and killing themselves. It undermines freedom because the choice offered is a false one. There is ample evidence that high quality palliative care means that death need not be a horrible experience.[9] If we are not providing high quality aged care and palliative care, then we should make every effort do so. No one should have to die horribly, and no one should have to feel that their only way to avoid it is to kill themselves. The offer of such a choice is a violation of human freedom and frustrates flourishing.

38. The common good is undermined because the meaningfulness of life is challenged

39. The common good is undermined because the role of the law as being good for all is challenged
Normalising intentional self-killing or aid in killing by legalising it through the law normalises the idea not only that some lives are meaningless, but that life can be meaningless. The law would no longer protect the common good or the dignity of individuals by affirming that life in common is always meaningful. Without this fundamental commitment, the law is in danger of

undermining the very reason for its existence, namely, to protect human dignity and the common good. If human life is not affirmed by the law as meaningful in a fundamental way, then the grounds to assert the recognition and protection of human dignity or indeed even respect for autonomy are undermined. Why should autonomy of the individual be respected if the law holds that the exercise of that autonomy is ultimately meaningless? Indeed, the purpose of the law and government itself is called into question. This is something we should resist. The law and the government are meaningful precisely because we affirm the meaningfulness not only of individual lives but also of our life in common.

40. Freedom and the common good are undermined by the message that some life is not worth living

A law that would allow direct intentional killing ('voluntary assisted dying'), even if only under strict circumstances, opens the way to a culture in which life is disposable. In such a society, even the provision of medical care can become subjected to a rationalisation of the worthiness of a particular person to receive it. Even with all the legal protections in place that say that aid in dying should only be voluntary, a subtle shift takes place in society such that when a person who some think 'ought' to elect to be killed asks instead to live out their days, they are met with derision and scorn. If it is true that some people feel that they want to die because they do not want to be a burden, how much more at risk would such people be in such a culture. In Oregon, the percentage of people who have listed feeling like they are a burden as among the reasons for accessing physician assisted suicide has steadily increased since the law's introduction in 1998 from 36.7 to 61.1 per cent. In 2018, feeling like a burden was the fourth most given reason for physician-assisted suicide in Oregon.[10]

41. Freedom and the Common Good are undermined if it increases the risk of suicide

A law that allows direct intentional killing ('voluntary assisted dying') may increase suicide at a time when Queensland has the second highest rate of suicide in Australia. The Werther Effect, whereby highly publicised suicides can lead to a series of copycat suicides, is well established. There is also evidence that this effect occurs in relation to assisted suicide.[11] Of particular concern here is that the law may be failing in its pedagogical duty to society by subtly sending the wrong message to people already vulnerable to suicide, namely that it is okay for them to kill themselves.

Surely, in the kind of society that we want to have, a society that affirms individual dignity, the common good, and the meaningfulness of life, it would be more reasonable to expect a request to be allowed to kill oneself to be met with help and support that affirms one's deep worth and meaningfulness rather than to be affirmed in one's feeling that one is worthless, that one's life is meaningless, and that one would indeed be better off dead? We maintain that affirming worth and meaningfulness is by far the more appropriate response. Legalising voluntary assisted dying risks sending the wrong message at a time when there is great concern about the levels of suicide in Queensland.

Conclusion

42. We, the Roman Catholic Bishops of Queensland, support the protection of human dignity, human freedom and the common good. It is clear that in the areas of aged care, palliative care and end of life care, there are many ways in which our society is not yet adequately achieving the protection of these values, and sometimes indeed violating these values. We applaud all efforts to improve aged care and palliative care that help us as individuals and communities deal in more meaningful and life-affirming ways with the vulnerabilities of our own mortality, especially in the current social conditions of Queensland. In light of this commitment, we also reiterate our conviction that no form of 'voluntary assisted dying' should ever be viewed as an entirely adequate solution to the problem of dying. There are better ways to die, and every effort should be made to support these, especially at a time where our society is not yet doing these in the best possible way.

[1] Official Report of the National Australasian Convention Debates: Sydney 1891 (Sydney: University of Sydney Library, 1999); available at http://adc.library.usyd.edu.au/view?docId=ozlit/xml-main-texts/fed0054.xml;collection=;database=;query=;brand=acdp

[2] R. Fedele, "Spotlight on the harsh reality of suicide in Australian nursing homes", online news article, Australian Journal of Nursing and Midwifery, 20 May 2018: available at https://anmj.org.au/spotlight-on-the-harsh-reality-of-suicide-in-australian-nursing-homes/

[3] Nicolas Mersaides, "Statement of Nicolas George Mersiades," Royal Commission into Aged Care Quality and Safety, 31 January 2019, pp. 3-5; available at https://www.cha.org.au/images/agedcare/2019/Statement-NGM-050219.pdf

[4] Ibid., p.13.

[5] Palliative Care Queensland, Time for Excellent Palliative Care in Queensland: 2018/2019 Palliative Care Queensland Pre-budget Submission, available at https://palliativecareqld.org.au/publications-positions-submissions/

[6] Catholic Health Australia, Palliative Care in the Catholic Sector (Catholic Health Australia, 2019), p. 5.

[7] Catholic Health Australia, Code of Ethical Standards (Catholic Health Australia, 2001), Chapter 5.

[8] Annabel Price, Ruaidhri McCormack, Theresa Wiseman and Matthew Hotopf, "Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying," BMC Medical Ethics, 15: 22 (2014): http://www.biomedcentral.com/1472-6939/15/32

[9] Michael Ashby, "How We Die: A View From Palliative Care," QUT Law Review, 16, 1 (2018): 5-21.

[10] Public Health Division, Center for Health Statistics, Oregon Death with Dignity Act: Data Summary 2018 (15 February 2019); available at https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYAC T/Documents/year21.pdf

[11] Tanja Neuner, Bettina Hübner-Liebermann, Göran Hajak, Helmut Hausner, "Assisted suicide on TV—the public 'License to Kill'?", European Journal of Public Health, 19, 4 (2009): p 359– 360, https://doi.org/10.1093/eurpub/ckp053.

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