

PARLIAMENT OF SOUTH AUSTRALIA

JOINT COMMITTEE ON END OF LIFE CHOICES

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Introduction

Thank you for the opportunity to contribute to the discussion on the Terms of Reference (TOR) for the South Australian Parliamentary Joint Committee on End of Life Choices. I strongly support expansion of end of life choices to include voluntary assisted dying under a carefully constructed legal framework. How we die is an important ethical, social justice, and social policy issue. The vast majority of Australians endorse legislative change to the current law which can entrench futile and un-relievable suffering (1,2). Peer reviewed international literature reveals successful implementation in those jurisdictions that have legislated for voluntary assisted dying (3). It is also now accepted that palliative care and voluntary assisted dying are complementary concepts of care (4). It is within this broader context that I make this submission specifically addressing aspects of TOR (C):

What legislative changes may be required, including consideration of: The appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria's Voluntary Assisted Dying Act (2017); and An examination of any federal laws that may impact such legislation.

The need for legislative change

Death by starvation and dehydration

I address TOR (C) by describing my own, and my extended family's experience of supporting my mother through an elected death by starvation and dehydration. This was the only legal means available to her to circumvent the inevitable, and possibly long-term, trajectory of unbearable and hopeless suffering. Her situation was caused by a constellation of medical conditions that could never be alleviated, even with the best nursing and medical care.

My mother died in 2016 in a South Australian residential care facility aged 92 years. She had resided there for approximately six years under high-level care. While only requiring low-level care she had lived for approximately one year in another care facility when activities of daily living became too difficult at home. My mother had been a particularly active woman in her earlier years, but had become paraplegic six years before her death as the result of complications associated with approximately 20 orthopaedic procedures over several years that had impacted her spine. She was a stoic and positive woman who always made the most of her personal situation. She was neither inwardly-focused nor clinically depressed. She was considered to be a very positive influence on other residents in the care facility; actively

befriending people and making an acknowledged contribution to the facility's activity programs to the best of her ability.

As well as living with paraplegia my mother had glaucoma, macular degeneration, was high-level hearing impaired, and had developed leg wounds from poor circulation that could not heal despite the best nursing care. She remained cognitively alert and tried to continue reading and watching television but this became more and more difficult. Her suffering therefore became even greater as she could no longer enjoy the few activities that gave her any pleasure.

Due to her paraplegia she needed to be hoist-lifted and wheeled to the bathroom to be toileted and showered by staff. This action caused her pain, even though she had pain management delivered through a Fentanyl (opioid) patch, a range of oral pain and other medications, heat-packs, and a hospital bed with an undulating air mattress; all facilitated by high-quality nursing care. However, my mother needed to carefully calibrate the level of medication in her Fentanyl patch to accord with her wish to remain alert enough to converse with her family, and to avoid associated chronic constipation that was exacerbated by her paraplegia. This was a particularly difficult constraint to bear given that she had to be toileted by others. My mother began to dread what she called the 'hoisting routine' that needed to occur three times daily, and she had an understandable concern over her perceived loss of dignity. While this is a reality experienced by many people due to a range of life circumstances, it was something she was never able to reconcile with her own sense of self. The prospect of continuing to live in this situation, possibly for several years, constantly played on her mind. She wished to be able to die at the 'right moment' surrounded by her loved ones in a spirit of life-celebration.

Limitations of the current end of life legal framework

Sadly, my mother clearly understood that the choice of a peaceful death through voluntary assisted dying would be denied to her at that time due to South Australia's current end of life legal framework. She accepted the possibility that she may adopt the only legal avenue available to her: death by starvation and dehydration. My mother identified as a Christian and had reconciled such a difficult decision with her faith. She had discussed it with a very caring Minister who supported her in a non-judgmental and affirming manner. She also informed the pastoral care worker and key staff at her residential care home of her future intentions should a timely death not occur through natural causes. She recognised and acknowledged that this decision might possibly be difficult for certain staff members with whom she had formed very good relationships and friendships over the years.

After more than a year had elapsed after considering this course of action, my mother, together with her immediate family, had a formal consultation with palliative care staff concerning the options available to her to mitigate the worst of the suffering that she imagined would eventuate. Having been nurse during World War Two, she was no stranger to suffering. My mother was very well informed about the range of options, but also the prevailing legal limitations of pain relief administration. This had to be done in a way that ensured that her death could not be construed as 'hastened'. She was also fully informed by professional staff about the symptoms she would likely experience throughout the process of death by starvation and dehydration. She was assured that the best available palliative care and pain medication would be provided to her to alleviate the inevitable suffering that accompanies this slow and otherwise painful death.

Following this professional consultation my mother ceased eating, but soon realised that unless she also stopped drinking the dying process would be even more drawn-out and harrowing. Five days later she stopped drinking. Part of the palliative process was to refresh her mouth with mouth swabs and initiate low-level sedation and a level of pain relief which was open to review. It took my mother nearly three weeks to die, being bed-toileted and bathed, and turned by staff every two hours; day and night. This appeared to sometimes cause her pain and associated anxiety preceding the next turning event. It necessitated further ‘top-up’ medication. She received the best available professional care and pain relief at all times; albeit carefully monitored to ensure that there could be no question of ‘hastening’ her [chosen] death. This occasionally meant that the ‘top up’ pain relief was reactive rather than proactive. Her family agreed that staff always acted in her best interests; within the current end of life framework which is governed by the doctrine of double effect. The issue of adopting a necessarily defensive approach to opioid provision by some medical practitioners and the underlying reasons have been the subject of recent commentary in the legal and palliative care literature (5).

Her loving family were naturally saddened by her need to take this action, but were determined to support, advocate, and stay by her side throughout her ordeal. Advocacy was assisted by her clearly stated Advance Care Directive that had been updated from an original version completed decades ago. My mother was both a Christian and a strong supporter of the right to voluntary assisted dying; as is the majority of the laity (6,7). She had taken an interest in the debates concerning this issue over many years. She sometimes reflected on and spoke about being perplexed to know that a powerful but small minority of people holding certain religious views, both inside and outside parliament, were those who were mainly thwarting any law that would have granted her and others the choice to die on their own terms, if and when suffering became too great. She said that she could not reconcile such ‘cruelty’ with her understanding of Christian charity or love. My mother also spoke of her hope that one day others would not have to face the prospect that she was facing.

Devising appropriate end of life legislation

The role of the parliamentary inquiry by members of the Joint Committee into End of Life Choices is to consider any changes to existing legislation. In addressing TOR (C) on *the appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria’s Voluntary Assisted Dying Act (2017)* I submit that if one recommendation is to introduce voluntary assisted dying legislation, it is important to consider the situation of those many people, like my own mother, who have incurable conditions but are not necessarily terminally ill. Their situation can best be described as hopeless, as the associated physical, emotional, psychological and existential issues become even more harrowing the longer life continues. A terminal illness by its very definition is likely to be one of shorter duration and therefore involving a much shorter term of intolerable suffering. I therefore submit that the criteria of any Bill to legislate for voluntary assisted dying should not be confined to terminal illness alone.

My mother considered herself fortunate. Compared to many others she was well cared for at the end of life; considering current legal constraints. Therefore, even though she did not die according to her wishes, she did avoid the very worst of what Allan Kelleher, Professor of Sociology, refers to as truly ‘shameful deaths, racked with pain and indignity’ that others are forced to endure (8). I argue that any legal constraint that forces a person to die slowly, albeit legally over weeks, rather than having the choice of a peaceful death through voluntary assisted dying, is of no benefit to the patient, her or his loved ones, or the wider community.

As renowned philosopher the late Ronald Dworkin argued, “Making someone die in a way that others approve, but he [sic] believes a horrifying contradiction of his life, is a devastating, odious form of tyranny (9).”

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