

Documenting the process of developing the Victorian voluntary assisted dying legislation

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Abstract. Many countries across the world have legislated for their constituents to have control over their death. Commonalities and differences can be found in the regulations surrounding the shape and practices of voluntary assisted dying (VAD) and euthanasia, including an individual's eligibility and access, role of health professions and the reporting. In Australia there have been perennial debates across the country to attempt legislative change in assisting a terminally ill person to control the ending of their life. In 2017, Victoria became the first state to successfully legislate for VAD. In describing the Victorian process that led to the passage of legislation for VAD, this paper examines the social change process. The particular focus of the paper is on the vital role played by a multidisciplinary ministerial advisory panel to develop recommendations for the successful legislation, and is written from their perspective.

What is known about the topic? VAD has not been legal in an Australian state until legislation passed in Victoria in 2017.

What does this paper add? This paper describes how the legislation was developed, as well as the significant consultative and democratic processes required to get the bill to parliament.

What are the implications for practitioners? In documenting this process, policy makers and others will have an understanding of the complexities in developing legislation. This information will be useful for other Australian jurisdictions considering similar legislative changes.

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Introduction

Over many years, several countries across the world have legislated for their constituents to have control over their death; there

are many commonalities and differences in the regulations surrounding the shape and practices including an individual's eligibility and access, role of health professions and the reporting.

The issue of assisting a terminally ill person to control the ending of their life has been perennially debated in state legislatures across Australia over many years. Despite strong public support of 75% in favour of legislative reform (<http://www.abc.net.au/news/2016-05-25/vote-compass-euthanasia/7441176>, accessed 17 April 2018), all efforts have ultimately been unsuccessful, with the exception of the Northern Territory, where legislation was passed in 1995 but repealed by the Federal Parliament in 1997. In 2017, Victoria became the first state to successfully legislate for voluntary assisted dying (VAD).

Social change is concerned with examining the structure of social relationships as they shift and move in response to a range of factors. The causes of particular social change are a study in themselves, but of relevance here is the rise of the value of individualism and personal autonomy, from the end of the 20th century or so. Drawing on the seminal work of J. S. Mill,¹ who elucidated an individual's right against utilitarian views of the greatest happiness for the greatest number, Tocqueville² describes the tension between the bureaucratic and centralised state and that of individual freedom. Tocqueville² further argues that the 'restlessness' of democratic societies can be attributed to individuals seeking to maximise their place in that society, by expressing their individuality and autonomy in a variety of ways. The rise of a consumer voice in health and the emergence of a focus on consumer or patient decision making reflects a cultural shift in understanding the relationship between the citizen and the professions in a movement away from paternalism.³

Adopting a public health approach towards the process of developing the VAD legislation meant there was an overt goal to translate new knowledge and skills and to be inclusive of everyone in a population. This approach used an evidence base, combining a scientific approach with social action and aiming for cost-effective interventions,⁴ and guided much of the emphases in the work of legislative change. Social action to effect change implies equity and collective action to benefit all people in a community, intimating a 'bottom-up' approach to change, thus contextualising the change sought.⁴ This contrasts with previous approaches to health, by which policy makers were the holders of information and used 'top-down' methods to initiate policy changes.

In the Victorian *Voluntary Assisted Dying Act 2017* (Vic), 'voluntary assisted dying' is defined as 'where the individual person has made a decision about the timing and manner of their death' and voluntariness is 'an emphatic statement that it is a decision initiated by a person who is suffering and who takes responsibility for that decision'.⁵ The voluntary nature of such a decision reflects the person-centred approach that underpins the framework of the legislation.⁶ In the legislation 'voluntary assisted dying' means the administration of a VAD substance and includes steps reasonably related to such administration, with a lengthy description of those steps provided.⁵

This paper describes the process undertaken in Victoria that led to the passage of ground-breaking legislation, with the aim of documenting the process to assist other jurisdictions in their deliberations. The paper is written from an 'insider' view, representing the perspectives of the Ministerial Advisory Panel

(MAP), with particular focus on its vital role in developing recommendations for the successful legislation.

The context

Barry and Yuill⁷ trace changes in societal understandings of death and dying over time. Based on the seminal work of Aires,^{8,9} Barry and Yuill⁷ argue that in contemporary modern societies death is mostly a taboo topic. Characteristics of the modern death include it being rationalised through documentation and categorisation, regarded as a medical event rather than a life event, secularised by becoming removed from the control and teachings of religion and focused on individualisation, moving away from communal experiences.

Legislation for euthanasia and physician-assisted suicide has been enacted in several parts of North America and in Western European countries⁶ over the past three decades, reflecting increasing community expectations for individual control over aspects of end-of-life care. The reasons for this shift are attributed to broader societal changes like those noted above, as well as increased levels of education, secularisation and a growing emphasis on individual rights.¹⁰

As in most Western countries, Australians are living longer (see <https://www.aihw.gov.au/reports-statistics>, accessed 14 May 2018). With older age becoming a more lengthy stage of life, an expectation has emerged that whatever illnesses are acquired, there will be a medical intervention to provide a cure. For many, however, the burden of living with degeneration, illness and a poor quality of life is perceived as unsatisfactory, and so the need has arisen to legislate for protection of an individual's priorities and wishes at the end of life, including through advance care planning. For some for whom the burden of the final days of their illness is unbearable, this has raised the right to have assistance to die in a controlled and peaceful way.

In addition, advances in healthcare technologies in recent decades have seen significant improvements in life expectancy. Although this is a lauded development, there are criticisms in terms of burdensome and/or futile treatment to keep a person alive, questions about the benefits versus the burdens of care and a lengthened dying process.¹¹ A paradigm shift has developed in considering the quality of life over quantity of life, mainly led by consumers. In addition, easier access to information through technology has seen a shift in the traditional model of paternalistic medicine towards a more equal relationship, using shared knowledge and equal consideration of an individual's autonomy in decision making.¹² This is very evident in descriptions of a 'good death': having choice and control in many aspects of the dying process, including the timing, manner and place of death.¹³ All these developments have shaped ongoing discussions regarding a terminally ill person's right to refuse or discontinue life-sustaining efforts, or to seek an active end to their life. Thus, the growing community support of for 'right to die' legislation has been an important influence on the euthanasia debate,¹² as part of shaping end-of-life discussions.

In Victoria, the Charter of Human Rights and Responsibilities Act (<https://www.humanrightscommission.vic.gov.au/human-rights/the-charter>, accessed 18 April 2018) was passed in 2006 providing 20 fundamental human rights

to uphold and safeguard individuals, as well as guide the development of legislation. This Charter serves to protect an individual's human rights, in supporting autonomy as well as appropriately protecting them. Of particular note is that human rights must be in accord with the culture and values of the people it serves. Much of this Charter guided the work in developing the VAD framework, as well as forming the basis of much of the decision making of the MAP, particularly in fostering awareness of protecting vulnerable people.

The process

The Victorian process commenced in 2015 with the Labour Government request to the Parliamentary Legal and Social Issues Committee (the Committee) to inquire into the need for Victorians to make informed decisions regarding the end of their life. Of significance is that this Committee always comprises membership from all major political parties and cross-benches to address particular issues. The Inquiry was asked to cover practices already in use to assist people to make choices about their end-of-life care, including palliative care and advance care planning, to review the current legislation covering end-of-life care and to consider legislative changes in the light of Inquiry outcomes. Over 12 months, the Committee sought input from the community and received 1037 submissions, 925 from individuals and 112 from organisations. In the submissions, 92% expressed a view on assisted dying, with 59% in support, 33% opposed and 8% unclear or inconclusive.¹³ The Committee also undertook site visits and hearings around the State of Victoria and travelled to several European and North American countries where assisted dying is practised.

The Committee reported their findings to the Parliament in June 2016 and, despite including two dissenting reports, recommended to legislate for VAD.¹³ This demonstrated a political consensus process that established the grounds on which legislation was likely to succeed in the parliament; that is, like cautious legislation elsewhere in the world, VAD would only apply to people in end stages of terminal illness, while suggesting numerous safeguards and respecting conscientious objections on the part of clinicians. The Committee made 49 recommendations, mainly about the need for improved support for community palliative care and advance care planning, as well as the need to legalise assisted dying, by recommending a conscience vote in Parliament.

In 2017, to progress this work, the Victorian Health Minister established an advisory panel (MAP), comprising seven experts from a range of disciplines. The MAP was distinctive in that it used a multidisciplinary approach to address the work required. The Chair, a neurosurgeon, was the immediate past President of the Federal Australian Medical Association. The other members of the MAP consisted of three palliative care professionals who had held leadership positions and pioneered the discipline in Australia, with one having been Senior Australian of the year, a reputable lawyer who had been a Public Advocate in Victoria, an advocate for people with disability who engaged extensively with the disability community about VAD issues and a health consumer advocate, with long experience in the sector, who represented the important consumer voice. The latter two members were vital in ensuring that whatever was developed was

useable and accessible to the community. Using this range of discipline expertise within the MAP was one way that comprehensive safeguard measures were developed to reassure the community that vulnerable people would be protected.

The MAP had a specific brief drawn from the recommendations of the Committee: to continue work started by them, namely to advise the Government about implementing a framework for VAD taking into consideration a range of policy, clinical and legal issues. The Committee not only gave a clear recommendation to change the law, but also elaborated the framework for such a law, as well as the circumstances under which VAD would apply. In turn, this was the brief given by the government to direct the MAP's work and was beneficial in focusing their discussions. Furthermore, because the Committee had already sought community views for or against assisted dying, this was not considered to be part of the MAP's work.

A specialist group of staff from the Victorian Department of Health and Human Services (DHHS), with legal and policy backgrounds, was allocated to assist the MAP's work throughout the process. Their close attention to detail helped keep the process on track; for example, every table at every workshop and meeting undertaken was supported by a DHHS staff member taking notes. In addition, a staff member from the office of the Health Minister provided further guidance on the parliamentary process. This group was able to provide expert advice, highlight linkages with related legislation, liaise with the Parliamentary Counsel (who write legislation) and advise on dealing with the media.

The MAP developed a discussion paper¹⁴ early in their work that sought to focus (but not limit) people's thinking on helping with the work, raising awareness of various aspects of the proposed framework. In response, 176 submissions were received. Extensive meeting consultations, guided by this discussion paper, occurred during the early months of the MAP's establishment with health professionals and administrators, legal groups, medical colleges, nursing and allied health groups, consumer and carer groups and mental health providers. Peak bodies representing groups like palliative care, older people and those in aged care, disability and consumers also spoke to the MAP.

In addition, 14 consultative workshops across city and rural settings were conducted with anyone who wanted to participate in the process, including those not supportive of VAD. In all, 300 people attended, most being health professionals. The agenda for these workshops was to seek input into the shape of the legislation in regard to three aspects: (1) eligibility requirements; (2) the request and assessment process; and (3) oversight and governance. Using questions targeted at these areas, the workshops were valued by the MAP as a way to gather the community's views and concerns, which, despite robust discussions, were always respectful. Following the workshops, an interim report was released by the MAP in May 2017¹⁵ to summarise the issues and concerns that had been gathered. This report created much media attention, and the Chair assumed responsibility for leading responses. This helped provide a consistent message about the progress of the MAP's work to the community. The availability of MAP members to consult with decision makers (politicians) ensured timely responsiveness to queries and concerns. Some lobby groups were keen to see the issue progress;

these groups engaged in public campaigns to inform the community of various aspects of the developing legislation. They also directly lobbied politicians, serving to balance the efforts of detractors.

A final MAP report was delivered to the Health Minister in July 2017,⁶ comprising the deliberations and recommendations. This went to Cabinet and was accepted without change by the Government. The MAP had an opportunity to contribute to drafting the actual proposed legislation, which meant that they developed in-depth knowledge of both the process and contents of the Bill. This took several months, going backwards and forwards, and, in November 2017, the government tabled the Bill in Parliament for debate. Once the final report and then the Bill became available to parliamentarians, members of the MAP made themselves available to respond to any queries and concerns.

Over a period of 11 weeks, the Parliament deliberated and debated all aspects of the Bill, in unprecedented marathon sessions. Many safeguarding amendments were proposed by individual parliamentarians, who drew on their very personal as well as constituents' experiences of loved one's suffering at the end of life; these poignant testimonies reflected the seriousness of the decision they were making. The Bill initially passed through the lower house without any amendments, suggesting that the significant background work of the MAP reasonably reflected community feeling; however, some amendments were subsequently passed in the upper house and then ratified when the Bill returned to the lower house. In December 2017, the Bill was passed by the parliament and the Act will be brought into effect after an 18-month period of implementation work to establish practical aspects, such as the model of care, the medications to be used and the clinical guidelines.

Discussion and conclusion

The significance of this social change of legislating for VAD meant that the Parliament of Victoria undertook an extensive process to garner the views and concerns of the Victorian public in relation to various aspects of end-of-life care. This change represents a major shift in exercise of individual autonomy over that of the state.² In tolerant communities, it is noted that acceptance of control over dying links to other personal freedom-in-life choices.^{15,16} Following a public health approach meant that the broad involvement of the Victorian community was essential in harnessing varied responses; but it also required the MAP to use existing experience and evidence from elsewhere.^{4,6} What was sought was detailed, robust and carefully considered legislation that used evidence and international experience to propose legislation that met community standards of the Victorian Human Rights Charter, protected the vulnerable and respected contentious objection. This was especially evident in the appointment of a diverse MAP, and the extensive consultations, either in writing or in person, through workshops or meetings. Leading the community through this important social change required the MAP to balance the protection of the rights of those who did not want to participate as much as those advocating for law change. It was also important to develop assurance that people who may be considered as vulnerable to some form of coercion would be adequately

protected in legislation. Despite many unsuccessful attempts across Australia to legislate for assisted dying, there were several factors that contributed to the success of the Victorian process. These are now discussed.

As noted, the groundwork was laid by the cross-party Parliamentary Legal and Social Issues Committee so, from the beginning, VAD was an issue requiring the attention of all political parties. Extensive consultation and research was undertaken by this Committee to develop recommendations about end-of-life care, including establishing a framework for VAD legislation in Victoria. The Government then agreed to support the development of a Bill and established the MAP to direct the process. In contemporary societies, it is increasingly recognised that end-of-life care requires flexibility with different pathways to accommodate an individual's autonomous wishes, in keeping with their cultural and other symbols.¹⁷

The credibility of the work and recommendations of MAP members was no doubt enhanced by the Health Minister's thoughtful selection of the seven MAP members; as noted, each was prominent in highly relevant sectors and brought the breadth of available skills and disciplines, adding richness to the discussions so that proposals were analysed from varied perspectives, ultimately contributing to balanced legislation. The careful selection of these members was in itself influential in key sectors, with many members having 'grassroots' awareness of dying in contemporary Australia. In addition, the focus of the work remained on the individual, seeking to balance personal rights and autonomy with the requirement for legislation to protect the 'vulnerable'.

Access of MAP members to the expertise of the DHHS staff was invaluable in keeping the work focused and on time, in arranging meetings, in gathering and comparing international evidence, in documenting discussions, in drafting the interim and final reports, in engaging with parliamentarians and informing the MAP about the political progress of the Bill. Such resourcing had not been available in the development of previous private members' bills.

In the US, states such as Oregon and Washington have proceeded via citizen referenda, whereas in Canada legislation came about because of a legal decision in their highest court.⁶ The Victorian government's leadership and cross-party support for the development of this legislation contrasts with the many unsuccessful attempts by individual politicians in Australia to put private member's bills into legislation. It is difficult to analyse, but it seemed that government support was essential, especially in a process led by the Health Minister, who was able to dedicate the significant departmental resources required, for the process of consultation to develop a high-quality bill. It is also difficult to know the effect of the bill being a government bill on an individual parliamentarian's vote, whether this influenced undecided parliamentarians to support the bill or whether it had the opposite effect. What is known is that it was the Health Minister who enabled the formation and work of the MAP, as well as shepherding the Bill through the Parliamentary process. Together with the Premier, the Minister provided clear direction and added gravitas to the arguments. The additional recruitment of personnel and resources from the DHHS assisted and enhanced the work of the MAP in many ways.

Campbell¹⁸ notes that an essential feature of social change is ‘community mobilisation’, especially in health, where in seeking to change the status quo people need to own their ability to control their health and well-being. Community mobilisation is essential to the success of campaigns seeking changes to dominant policy and community practices.¹⁸ In legislative change of this magnitude, the lack of consultation may be an expected criticism; however, none was heard in this process. Indeed, the overt commitment to extensive consultation through workshops and meetings with particular stakeholders was an expensive but necessary process in order to hear the issues and concerns, and to bring these stakeholders along in the process. Invitations went far and wide and all views were sought using focused questions on the reality of the legislation to direct discussions. The work of the MAP was intensive, given time in both consultations and deliberations, as well as in needing to meet timelines for such a legislative process. Discussions were lengthy and thorough.

This process demonstrated the seriousness of the intent to be inclusive and to facilitate change that while respectful of community wishes, took an overall cautious approach to such significant change. Campbell¹⁸ notes that people need to see themselves as ‘active agents’ when agitating for change in areas like their health. Overt inclusion of anyone who wanted to be involved in the process meant that the thoughts, opinions and concerns of the community were contextually incorporated into a ‘bottom-up’ change process.⁴ That several reports were made publicly available^{6,14,15} through the process was another way to be transparent in involving and informing the community about the work of the MAP.

In addition, the numerous safeguards included in all aspects of the legislation mostly arose from the consultative work of the MAP. These safeguards were critical to the successful passage of the Bill and evidenced the seriousness given by the MAP to the consultation process. Many of the safeguards incorporated into the final legislation were attributable to the active involvement of the Health Minister’s office in discussions with individual parliamentarians both before the Bill was introduced and as the debate and voting progressed through Parliament.

The MAP members recognised the importance of involving members of the media in their work, to closely brief them separately and in detail before different milestones, such as the release of reports, to ensure that the public messaging of a complex model containing strict criteria was clear and that the work was reported accurately. In addition, different lobby groups undertook public campaigns to engage the media and the general public, as well as to directly lobby politicians, which was helpful in balancing the differing arguments. Together with having one spokesperson (the Chair), media training for all MAP members meant that they became skilled at delivering a consistent and accurate message.

The ultimate passage of the Bill through Parliament relied not just upon a thorough and considered process that produced a quality Bill, but also on the confluence of other factors, including the grassroots public support for legislative reform, the role of the media, effective lobbying of parliamentarians and the personal experiences of parliamentarians that formed their support for the Bill.

This paper has elucidated a strategy to clarify and contribute to further implementation of a social change that had been grumbling along in the community for a significant period of time. The movement away from medicalisation of life events has seen the empowerment of individuals in autonomously planning their own end of life, and control of dying itself is one such example.¹⁹ What is being exhibited by this now Act, is reflective of greater flexibility that individuals are exerting in making their overall lives meaningful, including how they die.²⁰ This process has been a tangible example of democracy at work at a time when many may feel cynical about political processes. The guiding principles drawn from the Victorian Charter of Human Rights underpinned the legislation and assisted the MAP’s work in seeking clarity and compassion, respecting personal autonomy and balanced against the need to protect vulnerable members of the community. In documenting the process, and the important role of the MAP, the authors hope to assist others seeking to engage in similar social change.

Competing interests

The authors have no competing interests to declare.

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