

# Should voluntary assisted dying in Victoria be extended to encompass people with dementia?

The Victorian *Voluntary Assisted Dying Act 2017* came into effect in 2019 after a prolonged and fierce public debate.<sup>1</sup> Other Australian states soon followed, and legislation has now been passed allowing the territories also to legalise voluntary assisted dying (VAD). Although opposition persists in some quarters, VAD schemes now command broad acceptance — or at least, acquiescence — among both practitioners and the broader community.

It is possible that the uneasy equilibrium that has been struck among the multiple stakeholders will be disturbed in coming months by the review of the operation of the Victorian system mandated in the legislation. While the terms of reference of the latter do not explicitly mention it, one of the big issues that could require debate is the question of whether the law should be extended to include people with dementia.

VAD for people with dementia has long been controversial. It is available in some overseas jurisdictions, including in the Netherlands, Belgium,<sup>2</sup> Luxembourg,<sup>3</sup> Switzerland,<sup>4</sup> and Canada.<sup>5</sup> However, it is not practically available in Australia owing to legal limitations. In Victoria, activism to change the law has arisen in recent months,<sup>6-10</sup> supported by claims that people with dementia, like other people, should be entitled to choose when and how they die, and that in severe cases, prolongation of life may exacerbate suffering. Accordingly, it has been proposed that individuals should be able to secure access to VAD through a process involving advance care directives or substitute decision making based on prior stated wishes about fears of anticipated suffering.<sup>6,11</sup>

The extension of VAD to people with dementia raises serious philosophical, ethical and social questions that challenge the way VAD is currently understood, enacted and applied. Specifically, such an extension signals a challenge to the basic precepts of VAD as they have been agreed in Australia, poses questions about the nature and effects of dementia itself, and generates concerns about possible wider implications, including the destabilisation of the fragile nation-wide consensus that underlies legislation of VAD.

We consider each of these sets of issues in turn. First, all VAD legislation around Australia requires three key conditions to be satisfied for eligibility. Although the precise wording differs, access to VAD is limited to individuals in advanced stages of a terminal illness who are experiencing suffering that they themselves judge to be intolerable and who possess the capacity to make relevant decisions. While many agree that advanced dementia may well be considered a terminal illness, the prognosis is usually difficult to define. Further, because of the nature of the condition itself, by the time it is advanced, decision-making capacity will in almost all cases have been significantly impaired. In addition, for the same reasons, the ability to communicate the existence of suffering and to

express a view about its tolerability is also likely to be diminished. In other words, many — perhaps most — people with dementia will be unable to satisfy the three conditions for eligibility for VAD in existing legislation.<sup>12</sup>

The proposed use of the devices of advance care directives and substitute decision making are unlikely to overcome the difficulties in view of recognised problems and uncertainties associated with them.<sup>13</sup> First, although advance care directives provide for people to express preferences about care, which may include binding decisions to refuse particular kinds of treatment, they cannot compel practitioners to provide specific treatments. Further, claims that a future medical condition, such as dementia, would be experienced as intolerable could not constitute proof of actual suffering at the time of the illness and, in addition, would raise the troubling possibility of preventing patients from changing their minds about previously stated preferences for VAD should their new circumstances incline them to do so.<sup>14-16</sup>

Second, the clinical circumstances themselves are inherently very difficult to define. Any legislation providing access to VAD for people with dementia would need to specify precise criteria for the diagnosis of dementia itself, the assessment of its severity, and the determination of the presence of suffering and its effects. Commonly used definitions of advanced dementia tend to rely on descriptions of lost or maintained cognitive, communicative and social function which, while important categories, are invariably subjective, contextual and reliant on the reports of individuals other than those with dementia themselves. Not surprisingly, validated approaches with sufficient reliability for determining prognosis or elucidating the private experiences of people with dementia are presently unavailable.<sup>17</sup> Also, again because of the inherent nature of dementia, the impairment of competency raises inevitable questions about the validity and force of any statements about end-of-life decisions. At best, the latter may vary according to illness contexts, family and other personal relationships, cultural factors, and other variables that may be difficult or impossible to test. These considerations may appear to be mainly of a technical nature. Nonetheless, how they are resolved depends on deep ethical choices about the durability of the concept of personhood, the validity of decisions made under conditions of attenuated capacity, the nature of statements of intention about future states, the meaning of suffering in the setting of cognitive limitation or impairment, and where applicable, statements anticipating future psychological and emotional states that cannot be verified in practice.<sup>14,18,19</sup>

Third, a public policy that formally accepts a diagnosis of dementia as a condition for voluntary

Paul A Komesaroff<sup>1</sup>

Michael Chapman<sup>2</sup>

Geetanjali Lamba<sup>3</sup>

Ian H Kerridge<sup>4</sup>

Cameron L Stewart<sup>4</sup>

Alex Holmes<sup>5</sup>

Sophie Lewis<sup>4</sup>

Jennifer Philip<sup>5</sup>

<sup>1</sup> Monash University, Melbourne, VIC.

<sup>2</sup> Calvary Health, Canberra, ACT.

<sup>3</sup> Ballarat Health Services, Ballarat, VIC.

<sup>4</sup> University of Sydney, Sydney, NSW.

<sup>5</sup> University of Melbourne, Melbourne, VIC.

paul.komesaroff@monash.edu

assisted dying may carry profound and unpredictable effects for the many patients and families grappling with this condition. All forms of dementia already attract significant stigma, greatly exacerbating fear and pain. Cognitive impairment is often associated with a reduced ability to exercise choices, especially when substituted decision makers are appointed for a person.<sup>20</sup> Many people with a diagnosis of dementia continue to lead happy and satisfying lives; for these people and their families, the widespread acceptance of an assumption that death may be preferable to life with dementia — even if proposed for supposedly humanitarian reasons — may well generate devastating and irreversible consequences.<sup>21</sup>

Finally, a radical revision of the VAD framework that supplants the three principles established through sustained and meticulous social consultation and debate may put at risk the fragile social compact on which it has come to rest. The effective development and implementation of the VAD system depends largely on the perceived legitimacy of the process by which the legislation was developed, including the public debate and the principles that arose out of it. It also requires the cooperation and good faith of many stakeholders, including health professionals and faith communities, who may continue to harbour misgivings about it. The safeguards built into all legislative frameworks across Australia were devised to offer reassurance to those who remained uncertain, and to provide an assurance that no incremental extension, or “slippery slope”, would occur. The complex regulatory apparatus thereby crafted was claimed to prevent coercion by doctors, family members or others, and ensure that the agreed ethical criteria for VAD would be satisfied. The success of the VAD regimes already operating across the country depends critically on the respectful acknowledgement of contending points of view and assurances that agreed boundaries will not be crossed.

The deliberate decision to avoid triumphalist assertions of victory on behalf of one set of ethical, cultural and religious perspectives over another remains a core — if perhaps not directly visible — condition of the success of the important social reform that VAD represents. The erosion of the balance may well exacerbate social divisions and undermine confidence in reform processes more generally. It would undoubtedly also obstruct efforts to establish a harmonised national legislative framework that could facilitate consistent processes of surveillance, regulation, and reimbursement.

In summary, proposals to extend the existing VAD legislative framework to include people with dementia present fundamental social, ethical and clinical challenges. While some may prove less intractable than others, and it is not impossible that in time all will be able to be addressed effectively, a necessary condition for such a change is a renewed and sustained social debate that re-examines basic premises and assumptions. VAD in dementia would constitute a completely different entity from the current regime. Debate about it should be welcomed and fostered but

we must be prepared for the conversation to be lengthy and difficult.

**Acknowledgements:** Paul Komesaroff received salary support, together with infrastructural and other research support, from National Health and Medical Research Council (grant 1161502).

**Open access:** Open access publishing facilitated by Monash University, as part of the Wiley - Monash University agreement via the Council of Australian University Librarians.

**Competing interests:** No relevant disclosures.

**Provenance:** Not commissioned; externally peer reviewed. ■

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