



the overwhelming majority of australians believe in the right of the terminally ill to seek and obtain medical assistance to end their life with dignity

respect for the right to choose

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Level 3, 333 Collins Street  
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## Submission to the VLRC 'Guardianship' Reference

Dear Professor Rees,

Thank you for the opportunity to make a submission to the Commission's Guardianship Reference. We believe there are a number of significant modernisations that can be made to the *Guardianship and Administration Act (1986)* and related legislation. The Act came into effect nearly a quarter of a century ago. Community attitudes towards "disabilities," Department of Human Services realignment and changes to service delivery practices from institutional to community-based, as well as advancements in assistive technologies, have changed the landscape considerably since then.

We respond in regard to selected terms of reference:

*1.d) the increase in Victoria's ageing population;*

We all recognise the inevitable statistics regarding the ageing population. Advances in medical technology and practice mean that many more people will live through very old age, with a raft of physical and mental challenges. Many of these challenges may cause serious diminution of capacity to participate in effective decision-making. Of great concern is the expected significant growth in Alzheimer's and other dementias. DWDV recommends that dementia receives special consideration in a revised Guardianship Act according to more modern principles and practices.

*3.a) the role of guardians and administrators in advancing the represented person's rights and interests and in assisting them to make decisions; and 3.i) the appropriateness of the current requirements for and criteria pertaining to the treatment (medical and otherwise) of a represented person;*

DWDV recommends that a revised Act or Acts more clearly articulate the principles of what "best interests" comprise. In regard to consent to or refusal of medical treatment, while some guidelines currently do exist, a clearer statement of the degree of being informed, of weighing and balancing of potential benefits and harms, consideration of the values and beliefs of the client (if known, and to what degree it is reasonable to try and find out), and that of immediate family (if any, and again reasonableness of effort to find out), and where significant ambiguity or serious conflicts of opinion still exist, consultation of an ethics committee or board, should be paramount. In our view, the current Act provides insufficient guidance as to the expected standard of conduct, nor clarity to the terms of dismissing a guardian or administrator for inappropriate conduct.

We also strongly recommend the requirement of inclusion of an easily understandable brochure of those responsibilities with relevant documents of determination and appointment — such as

comprising part of the *Appointment of Enduring Power of Attorney (Medical Treatment)* document so that Agents and administrators are better informed from the start when they receive a copy. We recognise that this recommendation may form part of Regulations or simply practice, rather than being stipulated in an Act.

*3.b) striking the right balance between the "best interests" of a represented person, and their human rights as expressed in the United Nations Convention; and 3.e) ensuring that the powers and duties of guardians and administrators are appropriate and consistent with human rights obligations;* DWDV refers the Commission to the Charter right of a person (including those with some kind of capacity impairment) to "protection from cruel, inhuman, degrading treatment or punishment including medical and scientific experimentation performed without consent." DWDV recommends legislative clarification as to whether forcing a person to endure, through continued living and against their express wishes, what for them is a torture of diminished and unimprovable capacities, constitutes "cruel, inhuman or degrading punishment". We believe firmly that it is.

*3.d) the validity and efficacy of informal decision making; and 3.h) additional mechanisms for review of decisions made by guardians and administrators;*

DWDV recommends that a faster and more equitable process for the review of both formal and informal decisions made by guardians and administrators be put in place using a complaints-based approach. Where a serious complaint is made, or multiple complaints are made about ongoing decision-making, provision for a *formal* review of the guardian or administrator's decision making should be enshrined in legislation. This in part would help protect the principles and standards we discussed in section 3.a.

We commend to the Commission the value of clients who have at a point in time sufficient mental capacity, in preparing Advance Healthcare Directives which stipulate their beliefs, values and preferences regarding health care and medical treatment, to help inform the decisions of agents, guardians and administrators. This would go some way to reducing ad hoc informal decision-making—particularly in times of crisis—and establishing a more reasoned and evidentiary-based approach.

We also believe that effective legislation would more clearly articulate the Parliament's intentions regarding what is in the patient's "best interests" in regard to an *Enduring Power of Attorney (Medical Treatment)* that is being challenged at VCAT. We believe that except in exceptional circumstances, the fact that the patient has appointed the Agent is paramount evidence that the patient trusts the Agent and the Agent's understanding of the patient's values, beliefs and wishes. That someone of simply a different opinion might hold sway over that perhaps because the Agent's decision foreseeably may result in the shortening of the patient's life, would be a travesty of process and the patient's wishes. This type of standard is not articulated in the current regime, giving rise to potentially vexatious changes of executive power. Similarly, clear and equitable guidelines about the process of appeal against a doctor who or institution which is refusing to enact a reasonable health care request, or enacting one already refused, would be a valuable addition to the suite of appropriate measures. This is currently only very partly covered in the *Medical Treatment Act 1988*, strictly in regard to the refusal of "medical treatment."

We also strongly urge the Commission to recommend further proper, empirical *research* about decision making processes and *outcomes* of guardians and administrators decisions. This will help to properly inform principles and policy over time as to whether a review system ought to move more in the direction of *monitoring* rather than remaining merely complaints-based.

*3.j) whether the language of 'disability' is the appropriate conceptual language;*

DWDV believes that "disability" is prejudicial language and focuses only on the person's physical or mental "faults". It omits to recognise the dignity of the whole person. The prefix "dis" further

suggests a complete absence of ability, which is rarely the case. In the majority of cases ability is only partially or intermittently impaired, and only in certain ways: it is neither total nor across all potential competencies.

We urge the adoption of more neutral language and suggest "capacity-impaired" or similar notation. We do not recommend "vulnerability" terminology because it conveys a negative sense of victimhood—despite the reality of potential abuse. "Impaired capacity" is clear and conveys a positive sense that such a person ought to receive the consideration and support required for a humane life.

We also note that despite a comprehensive glossary in the VLRC's *Guardianship Information Paper*, "disability" is not a term that is defined in it. We find this curious in an information paper about the representation of those with a "disability". We note the summary definition of "disability" given under "When is a guardian appointed?" However, the summary confusingly mixes mental and non-mental impairments ('intellectual impairment, mental disorder, brain injury, physical disability or dementia') in its definition.

We further urge that a more clear legislative distinction be made between those who have impaired *cognitive* capacity — who require assistance in decision making — and those with adequate cognitive capacity yet impaired other capacities which make it difficult for them to communicate their wishes or exercise their rights without assistance. These are two *quite different* scenarios. Effective legislation would more clearly recognise and *test* the cognitive capacity of the former to make their own decisions and have them respected and honoured.

We further believe that effective legislation would more clearly articulate the need for proper assessment of mental capacity for decision-making. In addition, we believe it would be valuable to further encourage the health services sector to proactively agree and establish suitable, formalised standards of assessment, and of resulting "classes of capacity" that differentiate important boundaries in decision-making capabilities and the kinds of support and services required. This would help ensure that those of lesser capacity received heightened decision-making assistance, while those with adequate decision-making capacity were listened to rather than patronised or ignored.

*\* Limitations to the terms of reference.*

DWDV would further urge the Commission to communicate in its report, to the fullest extent available to it, the community's dissatisfaction with the negative constraint of one of the terms of reference: "Issues associated with end-of-life decisions, beyond those currently dealt with by the *Medical Treatment Act 1988*, are not within the scope of the review."

We find this constraint repugnant, as though persons with impaired capacity ought never to either think about, or have thought about on their behalf (if their wishes were made known earlier in a state of cognitive capacity), an assisted death. Many persons with impaired capacity experience joy in their lives with the help of family and community services, and it is wonderful that this is so. However, a small proportion experiences their life as the torture of a living hell. In such circumstances, consideration of a competent, enduring and tested request for assistance to die peacefully in a manner that is consistent with the supported person's beliefs and values, is a humane response...but one that is denied by the Attorney General's terms of reference.

Eighty five percent of the community believe that such an option should exist. That includes three out of four Catholics, four out of five Anglicans, and nine out of ten of those practicing no religion. To deliberately exclude the issue from consideration and debate is to treat the community with contempt. DWDV believes that Victorians deserve a much higher standard of Parliamentary and legislative representation than that currently being demonstrated by the Attorney General on this



matter. Again, we urge the Commission to communicate this community view on the terms of reference themselves, in its report to the fullest extent possible.

We commend these considerations to the Commission for inclusion in its report, and thank you once again for the opportunity to formally participate in community discussion about these important matters.

Yours sincerely

Neil Francis  
President and CEO

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Non-exclusive permission is hereby granted to the Victorian Law Reform Commission to publish this complete submission in the context of its Guardianship Referral consultation 2009-2010, including if permissible our Society's general contact details: phone number, office address and web URL. We would prefer our email address is *not* published in readable form in order to help minimise spam.