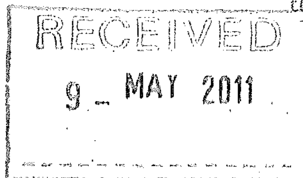
dying with dignity victoria

respect for the right to choose



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

Submission No. 13

SUBMISSION TO THE VICTORIAN LAW REFORM COMMISSION BY DYING WITH DIGNITY VICTORIA

IN RELATION TO THE REVIEW OF THE GUARDIANSHIP AND ADMINISTRATION ACT (1986) With particular reference to ADVANCE HEALTHCARE DIRECTIVES

Dying With Dignity Victoria (previously the Voluntary Euthanasia Society of Victoria) is a law reform organization, whose aim is to promote legal change in relation to end of life, based on the principles of autonomy and the necessity to relieve suffering. We have, over 15 years, advocated to Victorian Government, the need to extend the right of Victorians to refuse treatment for a "current condition" to a right to refuse treatment for a future condition via an advance healthcare directive.
While such a right may exist under common law, and that right has been strengthened by the precedent of the decision of the Supreme Court of NSW (McDougal J in *Hunter and New England Area Health Service v A [2009]),* and the Supreme Court of South Australia (Kourakis J in *H Ltd v J [2010]),* there is no statute law in Victoria that formally recognizes advance healthcare directives.

Your draft document (p9) states that

The greatest challenge in designing new guardianship laws is to develop a coherent body of legal rules that responds to the needs of all people with impaired decision-making capacity because of disability, and does so in a way that respects their dignity and encourages them to be as autonomous as possible.

One way of doing this is to encourage substitute decision makers to make the decision that the person themselves would have made if they were able to do so.
DWDV agrees with these concepts, and notes that the MTA 1988 makes the latter a requirement for medical agents in order to refuse treatment. How is this best accomplished? An advance directive makes it clear what decision that person would have made. Moreover, the stress on a medical agent, faced with a difficult decision and having to remember a conversation about treatment which may have occurred years before, can be very significant.

Your draft document (p11) suggests the need for

Clearer provisions for a person to indicate by way of an advance directive, when they are capable of doing so, what provisions they would want to make in particular circumstances in the future.

DWDV agrees with this proposition and argues that there is no better way to ensure this than by an advance directive to guide the agent, and make it clear to all that the agent is acting on the decision that the person would have made themselves.
DWDV agrees with Q2 (*Do you agree with the Commission's draft statement of purpose for new guardianship laws?).*

Your draft document (p15) proposes that

All adults are presumed to have the ability to make decisions that affect their lives unless this is shown not to be the case.

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This proposal is in line with current law on capacity and competence. It is important to state this explicitly as, in our experience, many doctors have thwarted advance directives by the assumption that "they might have changed their mind", without any evidence for this opinion. Therefore it is equally necessary to stipulate that, if there is a longitudinal record of a stable point of view on aa particular healthcare matter, it is also presumed that this point of view has not at law changed now that the substitute decision maker is deciding.

Your draft document (p24), Question 28 asks

Should an online registration system be created for enduring powers?

DWDV strongly supports this proposal. The commission may be unaware that some 23 years after the MTA was passed, many hospitals do not record in their admission data the details of a medical agent. In an emergency, information regarding the person with legal decision making power may be required urgently – an online registration system meets this need (cf. organ donor register). DWDV would go further and suggest that an online registration system to record the existence of an advance directive would be equally valuable. It may be too difficult to actually record the details of all advance directives. DWDV suggests that registration should be voluntary – debarring an applicable advance directive simply because of a failure to register it would be a denial of justice.

Your draft document (p26) states

Hybrid directives allow individuals to appoint a personal decision maker and provide an instructional directive at the same time.

DWDV supports this initiative as efficient and likely to increase the use of instructional (advance) directives. Individuals should have an option as to whether an instructional directive should be binding on personally appointed decision makers (agents).

Your draft document (p42) states that

The focus of substituted judgment is always on the actual or assumed wishes of the represented person, rather than the protective best interests approach.

DWDV asserts that the actual wishes are far superior to the assumed wishes (which may be incorrect). In the absence of an instructional (advance) directive, previous oral wishes cannot be shown to be actual, and must always have an element of assumption if they have not been affirmed recently. The decision of McDougal J indicated that an advance directive could only be applicable if

- The individual was capable when completing the directive
- The directive was completed without duress
- The directive applied to the particular situation, and
- There was no ambiguity or uncertainty.

It needs to be recognized that the creation of an instructional (advance) directive that applies to a particular situation, and is certain and unambiguous, is a task that requires medical knowledge, and drafting skill. It is beyond the ability of most non-medical persons. One of the reasons for the so-called failure of such directives is the abject failure of medical, health and legal bodies to undertake this task and promote effective documents. The important circumstances when such documents are invaluable are for persons entering nursing homes, for persons at risk of, or in the earlier stage of dementia, and for persons at risk of stroke. In fact they may be of great value for anyone with a significant illness, or over 50 (they may even rarely be invaluable for a 29 year old who develops PVS due to trauma.). DWDV has developed a number of particular circumstance directive forms for situations such as dementia, HIV/AIDS, and entering/residency in a nursing home.

Your draft document (p43) Question 96 concerns distinct principles for medical decision making. DWDV recommends the following:

- Respect for the autonomy of the individual, expressed directly or indirectly via an agent and/or an instructional (advance) directive.
- Recognition of the necessity for maximal relief of pain and suffering
- The assumption of the persistence of a clearly expressed request regarding treatment or its extent or its refusal, unless there is strong evidence to the contrary
- Medical practitioners and nurses should be proactive in establishing the future healthcare wishes of individuals by using carefully prepared instructional directives.

Dying With Dignity Victoria is grateful for the opportunity to make a submission to this VLRC Inquiry.
Yours faithfully.

Dr Rodney Syme (Vice President) 2nd May, 2011