

## **1986.6. Options for Dying with Dignity**

*Submitted 30 May 1986 to the Victorian Parliamentary Inquiry into Options for Dying with Dignity*

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This submission addresses each of the terms or reference set out by the Social Development Committee in its *First Report on Inquiry into Options for Dying with Dignity*.

### **1. Whether it is desirable and practicable for the Government of Victoria to take legislative or other action establishing a right to die**

The Humanist Society of Victoria (HSV) proposes that it is not only desirable and practicable for legislative and other action to be taken to establish a right to die, but that it is essential that such steps be taken. The grounds for this position are:

1.1 There is a need to determine the proper responsibilities of the groups which presently have some involvement in the area. The courts, the medical profession and the church are the main organised interests which lay claim to responsibility for decision making in the area, but their respective roles are ill-defined and vary from case to case.

1.2 Growing community concern is seen to derive from two interrelated issues. In Victoria at present there is no legal protection of the expressed wishes of people who have made a statement regarding their exercising a right to die, in the form of a “living will”, nor is there protection of those who may assist them in this exercise. The situation noted in 1.1 above compounds this unease, with the possibility of challenges to “living wills” coming from different quarters and being based on different claims.

1.3 While it is recognised that assisting people to die is an accepted practice in certain circumstances in medical care, the guidelines that apply, most obviously in Not For Resuscitation cases, have not been subject to community view, and it appears that there may be considerable variations from one institution to another, or even from one practitioner to another. As part of public debate, the HSV seeks the release of all such guidelines and sees the review and recognition of current practice as an important contribution to the development of legislation. Current practice should provide a useful basis for reaching a commonly accepted set of standards and practices that could be incorporated in legislation.

1.4 There is ample evidence that society neither does provide nor believes that it should provide all possible treatment to prolong life in all circumstances, that is, there is not an accepted unalienable right to life-sustaining treatment. To the contrary, there is widespread community acceptance of the view that people should be allowed to die with dignity, in a variety of circumstances; the main cause for concern appears to be the legal uncertainty of current practices to this end, not the practices themselves.

1.5 The particularly Humanistic perspective is that the right to die is a secular concern. Accordingly, the community is seen to have the capacity to determine its moral principles

regarding a right to die, and to give them legal sanction, without the involvement of religion and theology. The HSV is concerned to ensure that the church is not seen to have a prerogative in this area and that a secular view is widely advanced.

1.6 The whole community should not be subject to the views of minorities who are opposed to a right to die, nor should such views prevent the formulation of legislation that would allow all to behave according to their belief, within legally defined limits. The voluntary nature of a legally sanctioned right to die would give equal protection to those who wished to exercise that right as to those who do not.

**2a. The fundamental question as to whether, and what circumstances, if any, a person should have a right to die**

The HSV supports the view that people should have the right to die, and that the circumstances in which this right can be exercised should be defined with regard to:

2.1 evidence of mature and informed judgement on the part of the dying person, who has given conscious and usually written direction of his or her intentions;

2.2 given the above conditions are met, the burden of proof that the person does *not* want to die should rest with the authorities, rather than the person or their associates having to establish the wish to die;

2.3 different approaches and guidelines will be needed for different cases, such as:

- those dying from terminal illness, where death is inevitable;
- those whose lives are sustained only by life support systems, which would have to be suspended to enable them to die;
- those who have expressed a wish to die in a form that is legally recognised, who reach advanced old age and suffer multiple mental and physical infirmities but without suffering any terminal illness, requiring a decision on the point at which action will be taken to assist them to die;

2.4 Special recognition will need to be given to cases where the person is unable to express or exercise their own choice due to impaired autonomy. Such impairment should not be taken to override intentions that have been previously expressed and that would meet the conditions set out in 2.1 above; thus if legal protection is given to autonomously expressed wishes, this protection should not be removed in the event of reduced autonomy;

2.5 recognising that many persons may have previously given informed consent to treatment, it will be necessary to establish means by which such consent can be countermanded. Particular attention should be given to circumstances in which the commencement of treatment may not meet with commonly accepted views of informed consent, for example, in the case of low birth weight infants and cases of trauma; a review of guidelines applying to the implementation of treatment in such circumstances may be informative in regard to the conditions under which such treatment is to be continued or terminated;

2.6 that due regard be given to the self respect, integrity and suffering of the individual, in accord with community standards of dignity of the dying.

## **2b. What is an acceptable definition of “death”**

Definitions of death for purposes of legislation of the type envisaged in Victoria vary from country to country. The HSV supports the adoption of a definition based on brain death, involving such substantial damage to the autonomic nervous system that the person cannot survive without intervention.

## **3. The right of an individual to direct that in certain circumstances he or she be allowed to die, or assisted in dying, and the form which such direction should take**

The HSV supports the legislative provision of directions associated with a right to die, whereby a person can direct that they be allowed to die or to be assisted to die.

3.1 The direction to be recognised should be in the form of a “living will”.

3.2 Where direction is given regarding assistance to die, that assistance should be in the least painful way.

3.3 The decision to enter a hospice care program and consent to the treatment offered, namely palliative care without “heroic” treatment, should of itself be taken as an expression of the persons direction that they be allowed to die, or be assisted to die.

## **4. The right of the individual who has not [given], and is incapable of giving, such a direction to be allowed to die, or assisted in dying**

Where a person has not given or is incapable of giving direction as to a right to die, three considerations arise:

4.1 A distinction might be drawn between circumstances requiring passive and active responses, the latter involving the suspension of life support systems.

4.2 A search should be made not only for evidence of a wish to die, but also of an absence of evidence of a wish to live in all circumstances.

4.3 provisions for a right to die should not override provisions for making minors Wards of the State in order to give emergency treatment, such as blood transfusions, where permission for such treatment may be withheld by parents or legal guardians.

## **5. Protection for medical, nursing and other professionals who allow an individual to die, or assist an individual in dying, including the need for guidelines for carers in the case of life-sustaining equipment and procedures and the need for continuing counselling and after care**

Three factors need to be considered in giving protection to those involved in care of the dying and who may be in a position to assist persons to die. The protections should apply not only to professionals but also to lay persons who may be intimately involved in the care of the dying person.

5.1 The wishes of the dying person, expressed in appropriate and recognised form, are to be respected over and above the beliefs of carers.

5.2 Recognition is given to the proviso that those who have a conscientious objection to assisting a person to die not be subject to orders to do so. This proviso does not mean that assistance should not be given, but that only those agreeable to giving assistance should be asked to do so,

5.3 A significant effect of having legislation covering a right to die would be to remove anxiety and uncertainty of those who now work with the dying but who have no protection and who work under guidelines that at present could be challenged legally. Legislation would endorse and strengthen the trust underlying the doctor-patient relationship in a way similar to other legal sanctions, such as informed consent, that already govern this relationship.

**6. Relevant literature, legislation, judicial decisions and other relevant developments in Australia and overseas including, but not limited to:**

- i) the Quinlan case in the USA,
- ii) the Barendregt case in the Netherlands,
- iii) the Californian and South Australian Natural Death Acts and the Yale Legislative Services Model Bill: Medical Treatment Decision Act, 1973, iv. the ongoing work of the Victorian Law Reform Commission, but not to consider any issue associated with the termination of pregnancy.

A list of material consulted by HSV in preparing this submission is attached. Reports of public opinion in Australia are listed as the basis of statements of community views made in this submission. Several members of the HSV also have relevant professional experience.

**7. Three other issues which the HSV considers as particularly pertinent to debate about a right to die are:**

7.1 The provision of public funding for secular bereavement counselling and support services, including hospice care, with public hospitals and community health centres being appropriate channels for the development of such services, and that sufficient resources be allocated to hospice care to offer a real choice to all those who may wish to be cared for in such programs.

7.2 The need for greater public education, with an education program being seen as an essential adjunct to any legislation on a right to die, to ensure that people have a full understanding of the meaning of a "living will" or any similar provision that may be introduced.

7.3 While the Victorian Government should examine the experience of other states, both those having legislation in the area and developments in those which have proposals for such legislation, with a view to reaching a common national position, it should not delay taking independent action until a national position emerges; rather,

action by the Victorian Government will make a significant contribute to the development of a national position.

***IN CONCLUSION:***

The Humanist Society of Victoria urges the Parliament to legislate on a right to die, to the best of its ability and taking into account legal, medical and philosophical issues drawn to its attention in the course of this Inquiry. The HSV is concerned that the Parliament should not protract this endeavour unnecessarily by attempting to anticipate every such issue nor be inhibited in formulating legislation because it cannot encompass every eventuality. Carefully and reasonably framed legislation will meet the wishes of the ordinary citizen, with opportunities for amendment in line with social change and in the light of experience with the legislation. *The prospect of continuing without legislation in this important area constitutes a far greater problem for dying individuals, those who care for them, and society as a whole.*

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