

**July 2005**

**Submission from Palliative Care WA (Inc)**

**on**

**MEDICAL TREATMENT FOR THE DYING**

Palliative Care WA (Inc) (PCWA) welcomes (1) the opportunity to make this Submission on the May 2005 Discussion Paper prepared at the request of the Attorney General and Minister for Health, Mr Jim McGinty MLA, by the State Solicitor's Office, and (2) the following statements in the Discussion Paper:

*This Discussion paper has been prepared to assist appropriately focused community debate and input into the development of legislation which will facilitate ... advance health planning, and in particular end of life decision-making, and which will provide an acceptable level of certainty and protection for health professionals and others involved in this critical area of decision-making.*

*... it is to be emphasised that legislation to allow euthanasia is not being considered and will not be introduced.*

*Legislation is to be introduced to enable a person, who has attained 18 years of age and has capacity, to make an advance health directive about all future health care matters including the withholding or withdrawal of life-sustaining measures. An advance health directive will be operative only on a person's incapacity.*

PCWA represents individuals and organisations who provide palliative care services throughout Western Australia. As the coordinating body for palliative care in this State, it plays a major role in providing palliative care information to the public, government and health professionals.

PCWA provides a united voice for palliative care providers, promoting and supporting palliative care research, and facilitating the ongoing development of palliative care policies, standards and services. It has input at a national level to palliative care issues and policies through its affiliation with the national peak body, Palliative Care Australia.

As the collective voice for palliative care, PCWA is able to promote the needs and views of people who are dying, and those who care for them, to governments and to the wider community. The knowledge and expertise which exists amongst its members enables it to advise on the development of policies and priorities in palliative care. It also runs community forums to canvass the views of the general public on palliative care and social issues.

PCWA began the process of gathering information for its submission in response to the Discussion Paper by commissioning research into issues facing the implementation of advance health care directives and legislation in force in Australia and internationally. This research was initially circulated to members of the PCWA Executive Committee for comment and discussion.

PCWA encouraged community debate on the Discussion Paper by distributing copies of the Discussion Paper, its research paper and a Questionnaire for PCWA Members June 2005 seeking input from PCWA members on the questions starting at page 31 of the Discussion Paper. A copy of the Questionnaire is attached as appendix 1 to this Submission, and a table of responses to the Questionnaire is attached as appendix 2 to this Submission.

PCWA also facilitated a workshop on 7th July 2005, where responses to the Questionnaire and the Discussion Paper were debated to refine this submission and to encourage further input from interested community members. A list of organisations involved in the community consultation is attached as Appendix 3.

Accordingly, PCWA offers the following submissions on the questions in the Discussion Paper and the development of the proposed legislation, and would appreciate the opportunity to comment further when draft legislation is ready.

### **Formalities**

***Should common law advance health directives continue to be legally binding or should the statutory scheme apply to all advance health directives?***

1. PCWA submits that the statutory scheme should apply to all AHDs.

***What practical system could and should be introduced to increase the likelihood of health providers becoming aware that a patient has made an advance health directive?***

2. PCWA submits that a voluntary registry of AHDs should be established.

### **Scope of Authority to Give a Direction in an Advance Health Directive**

*Should a person be able to give a direction in an advance health directive to withdraw or withhold life-sustaining measures? If so, should the definition of life-sustaining measures include artificial nutrition and artificial hydration?*

3. PCWA submits that a person should be able to give a direction in an AHD to withdraw or withhold life-sustaining measures.

4. PCWA submits that the definition of life-sustaining measures should include artificial nutrition and artificial hydration, as follows:

*life sustaining measures* means: medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation.

*Should a person be able to give a direction in an advance health directive to refuse the provision of palliative care?*

Whilst acknowledging that many people in the community consider that the principle of patient autonomy would be compromised by legislation prohibiting a person from giving a direction in an advance health directive to refuse palliative care, PCWA considers that an acceptable level of certainty and protection for health professionals and others involved in the critical area of end of life decision-making is unlikely to be attained without such legislative prohibition.

5. PCWA submits that a person should NOT be able to give a direction in an AHD to refuse the provision of palliative care defined as follows:

*palliative care* means : measures directed at maintaining or improving the comfort and dignity of a patient who is, or would otherwise be, in distress.

### **Operation of Advance Health Directive**

*Should an advance health directive cover any situation in the future where a person may be incapable of making his or her decisions regarding health care or, alternatively, should the legislation restrict the operation of an advance health directive?*

6. PCWA submits that the legislation should restrict the operation of a person's AHD to where the person:

1. is at some future time in the terminal phase of a terminal illness, or
2. is in a persistent vegetative state, or
3. is permanently unconscious, or
4. has an illness of such severity that there is no reasonable prospect that he or she will recover to the extent that his or her life can be sustained without the continued application of life-sustaining measures.

6A. PCWA submits that the legislation should include the following definitions:

*terminal illness* means: an illness or condition that is likely to result in death.

*terminal phase* of a terminal illness means: the phase of the illness reached when there is no real prospect of recovery or remission of symptoms (on either a permanent or temporary basis).

### **Requirements for a Legally Valid Advance Health Directive**

*What criteria must be met for a legislated advance health directive to be valid?*

7. PCWA submits that the following criteria must be met for an AHD to be valid:

1. the person making the directive was competent at the time that it was made.
2. the directive was made voluntarily and without inducement or compulsion.
3. the directive was based on appropriate information and understanding of the choices and consequences.
4. the directive was intended to apply to the circumstances that have arisen.
5. there have been no changes in the wishes expressed and the directive has not been revoked.
6. the person who made the directive is incapacitated.
7. there are no reasonable grounds for believing that new circumstances exist which did not exist at the time the person made the directive.

*If one of the criteria is to be that an advance health directive must be based on appropriate information and understanding of the choices and consequences, is it necessary for that information to be given by a health professional?*

8. PCWA submits that it is necessary for that information to be given by a registered medical practitioner or registered nurse practitioner.

### **Good Medical Practice**

*Should a health professional be required to have regard to good medical practice before giving effect to a direction in an advance health directive?*

9. PCWA submits that medical practitioners and persons administering treatment under medical supervision should not incur civil or criminal liability for an act or omission made in accordance with proper professional standards of medical practice.

9A. PCWA submits that the proposed legislation should include the provisions set out in this Submission under **The Application of the Criminal Code.**

### **Scope of Enduring Power of Guardianship**

*Should a substitute decision-maker appointed under an enduring power of guardianship be given the authority to make decisions to withhold or withdraw lifesustaining measures?*

10. PCWA submits that a substitute decision-maker should be given authority to make decisions to withhold or withdraw life-sustaining measures.

*Should the definition of life-sustaining measures include artificial nutrition and artificial hydration?*

11. PCWA submits that the definition of life-sustaining measures should include artificial nutrition and artificial hydration, as follows:

*life sustaining measures* means: medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation.

*Should a substitute decision-maker appointed under an enduring power of guardianship be given authority to refuse the provision of palliative care?*

12. PCWA submits that a substitute decision-maker should NOT be given authority to refuse the provision of palliative care defined as follows:

*palliative care* means : measures directed at maintaining or improving the comfort and dignity of a patient who is, or would otherwise be, in distress.

### **Restrictions on Exercise of Power by Substitute Decision-maker under Enduring Power of Guardianship**

*Should the substitute decision-maker be required to have regard to the best interests of the appointor when making a decision about future health care?*

13. PCWA submits that the substitute decision-maker should be required to have

regard to the best interests of the appointor when making a decision about future health care.

***Should a substitute decision-maker under an enduring power of guardianship be required to seek advice from or consult with a health professional before making a decision about the future health care of the appointor?***

14. PCWA submits that a substitute decision-maker under an enduring power of guardianship should be required to seek advice from a medical practitioner before making a decision about the future health care of the appointor.

### **Good Medical Practice**

***Should a health professional be required to have regard to good medical practice before giving effect to a decision of a substitute decision-maker under an enduring power of guardianship?***

15. PCWA submits that a medical practitioner should not incur civil or criminal liability for an act or omission made in accordance with proper professional standards of medical practice.

15A. PCWA submits that the proposed legislation should include the provisions set out in this Submission under **The Application of the Criminal Code**.

### **GUARDIANSHIP ORDERS**

#### **Scope of Authority of Guardian**

***Should a guardian appointed under the Guardianship and Administration Act 1990 be given the authority to make decisions to withhold or withdraw life-sustaining measures?***

16. PCWA submits that a guardian under the Guardianship and Administration Act 1990 should be given the authority to make decisions to withdraw or withhold life-sustaining measures.

***Should the definition of life-sustaining measures include artificial nutrition and artificial hydration?***

17. PCWA submits that the definition of life-sustaining measures should include artificial nutrition and artificial hydration, as follows:

*life sustaining measures* means: medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable

of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation.

***Should a guardian appointed under the Guardianship and Administration Act 1990 be given authority to refuse the provision of palliative care?***

18. PCWA submits that a guardian appointed under the Guardianship and Administration Act 1990 should NOT be given authority to refuse the provision of palliative care defined as follows:

*palliative care* means : measures directed at maintaining or improving the comfort and dignity of a patient who is, or would otherwise be, in distress.

### **Restrictions on Exercise of Power by Guardian**

***Should a guardian be required to have regard to the best interests of the represented person when making a decision about future health care?***

19. PCWA submits that a guardian should be required to have regard to the best interests of the represented person when making a decision about future health care.

***Should a guardian be required to seek advice from or consult with a health professional before making a decision to withhold or withdraw life-sustaining measures?***

20. PCWA submits that a guardian should be required to seek advice from a medical practitioner before making a decision to withhold or withdraw life-sustaining measures, defined as follows:

*life sustaining measures* means: medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation.

### **Good Medical Practice**

***Should a health professional be required to have regard to good medical practice before giving effect to a decision of a guardian?***

21. PCWA submits that a health professional should be required to have regard to good medical practice before giving effect to a decision of a guardian.

21A. PCWA submits that the proposed legislation should include the provisions set out in this Submission under **The Application of the Criminal Code.**

## **Scope of Authority of a Person under Section 119**

***Should a person referred to in section 119 Guardianship and Administration Act 1990 be given the authority to make decisions to withhold or withdraw life-sustaining measures?***

22. PCWA submits that a person referred to in section 119 Guardianship and Administration Act 1990 should be given the authority to make decisions to withhold or withdraw life-sustaining measures.

***Should the definition of life-sustaining measures include artificial nutrition and artificial hydration?***

23. PCWA submits that the definition of life-sustaining measures should include artificial nutrition and artificial hydration, as follows:

*life sustaining measures* means: medical treatment that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation, and includes assisted ventilation, artificial nutrition and hydration and cardiopulmonary resuscitation.

***Should a person referred to in section 119 Guardianship and Administration Act 1990 have the right to refuse the provision of palliative care?***

24. PCWA submits that a person referred to in section 119 Guardianship and Administration Act 1990 should NOT have the right to refuse the provision of palliative care defined as follows:

*palliative care* means : measures directed at maintaining or improving the comfort and dignity of a patient who is, or would otherwise be, in distress.

## **Restrictions on Exercise of Power by a Person under Section 119**

***Should a person referred to in section 119 Guardianship and Administration Act 1990 be required to seek advice from or consult with a health professional before making a decision to withhold or withdraw life-sustaining measures?***

25. PCWA submits that a person referred to in section 119 Guardianship and Administration Act 1990 should be required to seek advice from or consult with a medical practitioner before making a decision to withhold or withdraw life-sustaining measures.

## **Good Medical Practice**

*Should a health professional be required to have regard to good medical practice before giving effect to a decision of a person referred to in section 119 Guardianship and Administration Act 1990?*

26. PCWA submits that a health professional should be required to have regard to good medical practice before giving effect to a decision of a person referred to in section 119 Guardianship and Administration Act 1990.

26A. PCWA submits that the proposed legislation should include the provisions set out in this Submission under **The Application of the Criminal Code**.

## **Reasonable Conduct in Good Faith in the Consent Context**

*Should protection from civil and criminal liability in the consent context require that specified enquiries be carried out by a decision-maker or health professional before it can be said that the person has acted reasonably and in good faith?*

27. PCWA submits that relevant protective provisions should simply require that the person seeking the protection has acted in good faith and reasonably.

27A. PCWA submits that the proposed legislation should include the provisions set out in this Submission under **The Application of the Criminal Code**.

## **The Application of the Criminal Code**

*In view of the current uncertainty as to the precise application of the provisions of the Criminal Code in the circumstance of a contemplated withholding or withdrawal of life-sustaining measures for an incompetent patient, should there be specific legislative amendment to achieve an increased measure of certainty?*

28. PCWA submits that there should be specific legislative amendment to achieve an increased measure of certainty.

*If legislative amendment is appropriate, what circumstances should that amendment address and what criteria should have to be met to gain protection?*

29. PCWA submits that legislative amendment similar to the scheme in sections 16 and 17 South Australia's *Consent to Medical Treatment and Palliative Care Act 1995* would best serve the Western Australian community, and submits that the legislation should include provisions similar to the following:

A medical practitioner responsible for the treatment or care of a patient, or a person participating in the treatment or care of the patient under the medical

practitioner's supervision, incurs no civil or criminal liability for an act or omission done or made—

- (a) with the consent of the patient or the patient's representative or without consent but in accordance with an authority conferred by this Act or any other Act; and
- (b) in good faith and without negligence; and
- (c) in accordance with proper professional standards of medical practice; and
- (d) in order to preserve or improve the quality of life.

(1) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, incurs no civil or criminal liability by administering medical treatment with the intention of relieving pain or distress—

- (a) with the consent of the patient or the patient's representative; and
- (b) in good faith and without negligence; and
- (c) in accordance with proper professional standards of palliative care,

even though an incidental effect of the treatment is to hasten the death of the patient.

(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, in the absence of an express direction by the patient or the patient's representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.

(3) For the purposes of the law of the State—

- (a) the administration of medical treatment for the relief of pain or distress in accordance with subsection (1) does not constitute an intervening cause of death; and
- (b) the non-application or discontinuance of life sustaining measures in accordance with subsection (2) does not constitute an intervening cause of death.

This Submission is signed on behalf of Palliative Care WA (Inc) by:

Clive Deverall AM Hon D Litt (Curtin)

President

July 2005

## APPENDIX 2

### Response to PCWA survey for submission to the Medical Treatment for the Dying Discussion Paper.

Question	Yes	No	Blank	Abs	N/A	Total	Agree	Disagree
1	66	2	2			70	94.2%	2.8%
2	67	3				70	95.7%	4.3%
3	69	1				70	98.5%	1.5%
4	67	3				70	95.7%	4.3%
5	55	13	2			70	78.5%	18.5%
6.1	65	5				70	92.8%	7.2%
6.2	66	4				70	94.2%	5.8%
6.3	65	5				70	92.8%	7.2%
6.4	66	4				70	94.2%	5.8%
7.1	69		1			70	98.5%	0%
7.2	69		1			70	98.5%	0%
7.3	69		1			70	98.5%	0%
7.4	68	1	1			70	97.0%	1.5%
7.5	69		1			70	98.5%	0%
7.6	61	7	2			70	87.1%	10%
7.7	66	3	1			70	94.2%	4.3%
8	64	5	1			70	91.4%	7.1%
9	67	2	1			70	95.7%	2.8%
10	65	3	2			70	92.8%	4.2%
11	68	1	1			70	97.0%	1.5%
12	61	7	2			70	87.1%	10%
13	67		1	1	1	70	95.7%	0%
14	66	2	1	1	1	70	94.2%	2.8%
15	67	2	1			70	95.7%	2.8%
16	66	1	2		1	70	94.2%	1.5%
17	68	1	1			70	97.0%	1.5%
18	62	6	2			70	88.5%	8.5%
19	67		1	1	1	70	95.7%	0%
20	66	2	1		1	70	94.2%	2.8%
21	64	3	1	1	1	70	91.4%	4.3%
22	65	4	1			70	92.8%	5.7%
23	67	2			1	70	95.7%	2.8%
24	60	9			1	70	85.7%	12.8%
25	63	4		1	2	70	90.0%	5.7%
26	62	4	1	1	2	70	88.5%	5.7%
27	66	3			1	70	94.2%	4.3%
28	69	1				70	98.5%	1.5%
29	68	2				70	97.0%	2.8%

250 surveys were sent out, and a total of 70 responses received. Some respondents have written N/A or Abstain on their surveys. These have been included in the table.

### Appendix 3

In preparation for its submission in response to the discussion paper entitled Medical Treatment For The Dying, Palliative Care WA undertook extensive consultations with a number of medical and community organisations as well as within its own membership. Consultation with these organisations took the form of interviews, a workshop, and talks to community groups.

Organisations that contributed information to the submission through interviews or submissions include:

- ? Western Australian Clinical Oncology Group;
- ? The Health Consumers Council of WA;
- ? Council of the Ageing (National Seniors);
- ? Alzheimers Association;
- ? Aged and Community Services;
- ? Nurses Board of WA;
- ? Australian College of Emergency Medicine.

A workshop was held on the 7<sup>th</sup> of July and was well attended by members of Palliative Care WA. In addition members from the following organisations were represented in the workshop:

- ? Cancer Council Consumer Group
- ? Silver Chain Hospice Care Service
- ? Cancer Council WA
- ? Hollywood Hospital
- ? Nurses Board WA
- ? Murdoch Community Hospice
- ? Department of Health - WA
- ? Royal Perth Hospital
- ? Cottage Hospice
- ? National Seniors
- ? Carers WA
- ? Australian Lawyers Alliance