

Palliative Care WA Inc

Position Statement: Advance Care Planning in Western Australia

Background – Advance Health Directive Legislation in WA

Amendments to the Western Australian *Guardianship and Administration Act 1990*, which are effective from 15 February 2010:

- permit an adult with full legal capacity to appoint one or more enduring guardians who may make decisions on the appointer's behalf at any time the appointer is unable to make reasonable judgments in respect of matters relating to his or her person
- identify (and prioritise) those people who may make treatment decisions on behalf of a person who is unable to make reasonable judgements in respect of matters relating to his or her person
- permit an adult with full legal capacity to make an advance health directive containing treatment decisions in respect of the person's future treatment
- permit the State Administrative Tribunal, amongst other things, to:
 - decide whether an enduring power of attorney, an advance directive, or the decision/s recorded in the advance health directive is valid or invalid, or revoke or impose conditions on the exercise of these instruments
 - declare that the maker of an enduring power of attorney or an advance health directive is unable to make reasonable judgments in respect of matters relating to his or her person
 - recognise enduring powers of guardianship and advance health directives created under the law of other jurisdictions.
- indemnify health professionals who provide urgent or emergency treatment to a person who cannot make reasonable judgments in respect of the treatment, and when it is not practicable for the health professional to determine if the person has an advance health directive which contains a contrary treatment decision
- indemnify health professionals who, in accord with a treatment decision made by a person, their enduring guardian or recorded in an advance health directive, institute palliative care or who discontinue or do not commence a course of treatment even if that treatment action hastens the death of the person.

Amendments to the Western Australian *Criminal Code* grant protections to health professionals who, in good faith and with reasonable care and skill, withdraw or do not commence futile health treatments.

Palliative Care WA Inc endorses this legislation for three main reasons. The legislation:

- provides a consistent framework within which Western Australians can appoint substitute healthcare decision-makers and complete advance health directives – this improves the likelihood that their end of life¹ care preferences will be upheld
- protects health professionals who make reasonable decisions, in good faith, to cease futile treatments which may cause unwarranted distress to dying people, or who provide, in good faith, emergency treatment to a person without capacity in the absence of a valid treatment decision (in the form of an advance health directive or direction from the person's enduring guardian)
- allows for the recognition of advance health directives and appointments of substitute decision-makers made under the laws of other jurisdictions.

It is important to note that the legislation does not guarantee quality care at the end of life, even for those Western Australians who take advantage of it to complete valid advance health directives or appoint substitute healthcare decision makers.

¹ end of life – “that part of life during which a person is living with, and impaired by, an eventually fatal condition – the prognosis may be ambiguous or unknown” - *Strategic Plan and Glossary 2008-11* - Palliative Care Australia, Canberra, 2008 – page 11

For example, the large-scale Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) – amongst other studies – found in the 1990s that:

- patient preferences change, and can be hard to record using advance health directives
- care often does not involve decisions but is dictated by systems or cultures in care organisations
- seriously ill patients and their substitute decision-makers often do not want to face hard decisions
- people are often unwilling to use information based on rational decision-analytical approaches.²

The Act is, however, valuable legislation which can underpin and enable a comprehensive advance care planning program in Western Australia.

Advance Care Planning – Basic Concepts

Palliative Care Australia defines advance care planning as:

the process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources... Advance care planning supports patients in communicating their wishes about their end of life.³

Street and Ottman summarise the potential advantages of advance care planning:

Advance care planning (ACP) is directed at improving quality of care, facilitating patient self-determination and reducing unwanted and unwarranted medical treatments and hospitalisations. By respecting every person's right to autonomy, dignity and fully informed consent, health professionals can assist individuals to reflect upon, choose and communicate their wishes regarding their current and future health care.

Palliative Care Australia has published a *Position Statement on Advance Care Planning*.⁴ As a member of Palliative Care Australia, Palliative Care WA Inc supports this Position Statement, which includes the following key points:

- quality care at the end of life is realised when a person's needs are met and their care preferences are upheld
- advance care planning offers everyone, and especially people living with a terminal condition, their families and significant others, the opportunity to take control of decisions which affect their care, placing patients at the centre of medical decision-making
- advance care planning should be ... considered as an ongoing conversation between an individual, their care team and as appropriate, their family, significant others and carers
- advance care planning ... is not the exclusive domain of any particular health care sector or setting
- health workers at all levels of the health system should be skilled and educated to engage in end of life care discussions and advance care planning
- advance care planning should not be reduced to a singular focus on advance health directives.

The Position Statement goes on to say that 'providing patients with the opportunity to consider and identify care preferences through advance care planning... should be regarded as part of the role of the end of life care team whether it is comprised of specialist or generalist palliative care providers.'

² "Rethinking fundamental assumptions: SUPPORT's implications for future reform" – Lynn J & Arkes H – *J Am Geriatric Society* 48 (10), 2000 – cited in *State of the Science Review of Advance Care Planning Models* – Street AF & Ottmann G – LaTrobe Uni, Bundorra, 2006 – page 10

³ *Strategic Plan and Glossary 2008-11* - Palliative Care Australia, Canberra, 2008 – page 10

⁴ *Advance Care Planning Interim Position Statement* – Palliative Care Australia, Canberra, December 2008 – accessed at www.palliativecare.org.au 09 Jan 09

Palliative Care WA Inc acknowledges that attaining the vision laid out in the Palliative Care Australia Position Statement is currently difficult in Western Australia due to:

- community reluctance to openly discuss dying, death and bereavement and to plan for the end of life
- the varying capacity of health professionals to discuss end of life care issues with patients, carers and families.

Advance Care Planning in Western Australia

Bearing in mind these limitations, Palliative Care WA Inc, echoing the recommendations laid out by Street and Ottmann in their *State of the Science Review*⁵ and the policy of Palliative Care Australia, calls for the implementation of a multi-pronged advance care planning program in Western Australia which includes:

- support in the community and health system for ongoing values-directed care planning discussions involving consumers, their families and health professionals
- a transformation of systems to support advance care planning across a range of institutional settings
- adequate funding to ensure the insertion of advance care planning into clinical practice and culture
- the involvement of communities and the wider public
- excellent education and applied research to support the process.

Such an advance care planning program should be:

- comprehensive (system-wide), integrated, and equitably available to all Western Australians, and especially those at the end of life or living with chronic or life limiting illnesses
- effective and efficient in a variety of settings and for a range of patient populations
- based on the best available evidence
- tending to promote healthy ways of living, dying and grieving and build community capacity to cope with death as a part of life
- consistent with any advance care planning program guidelines developed at the national level
- above and beyond any initiative to provide health professionals and the broader community with introductory information about the Western Australian *Consent to Medical Treatment Act 2008*⁶
- focussed on improving the quality of care at the end of life (not the rate of completion of advance health directives).

Palliative Care WA Inc, although it is aware that several existing advance care planning programs have proven to be more or less effective in pilot studies and other countries, does not endorse (or disendorse) any particular program or product.

Planning for a comprehensive advance care planning program in Western Australia should commence as soon as possible.

More Information

More information about Western Australia's advance care planning legislation is available from:

- Palliative Care WA Inc on 1300 551 704 during business hours, or www.palliativecarewa.asn.au or email pcwainc@palliativecarewa.asn.au
- The WA Department of Health at www.health.wa.gov.au/advancehealthdirective/home/
- The WA Office of the Public Advocate at www.publicadvocate.wa.gov.au/E/enduring_power_of_guardianship.aspx.

⁵ *State of the Science Review of Advance Care Planning Models* – Street AF & Ottmann G – LaTrobe Uni, Bundorra, 2006 – page 4 'Key Recommendations'

⁶ note Street and Ottmann's assertion, based on 1990s research, that 'quick fix educational interventions don't work' – *ibid* – page 8

Appendix A

World Health Organisation Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁷

Appendix B

About Palliative Care WA Inc

Palliative Care WA Inc is a not-for-profit association incorporated under the Western Australia *Associations Incorporation Act 1987*.

The objectives of Palliative Care WA Inc include to:

- be a representative community organisation which seeks to improve the quality of care and support available to all Western Australians at the end of life
- promote the principles and practices of palliative care with the intention of enhancing the broader community's capacity to provide care and support at the end of life
- advocate for appropriate services and benefits for Western Australians confronting issues and problems commonly associated with the end of life
- advocate for appropriate palliative care education and training for all who provide care and support to people at the end of life
- promote the aims of the Association through cooperation and collaboration with stakeholders in palliative and end of life care
- act as a coordinating body and information resource for organisations and service agencies which provide care at the end of life and which promote the principles and practices of palliative care
- establish and maintain committees which are active in areas including, but not limited to, clinical services, standards and quality, education and community capacity building.

Palliative Care WA Inc is a founding member of Palliative Care Australia.

Visit our website at www.palliativecarewa.asn.au to learn more about our organisation, access information and resources or download a membership form.

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⁷ accessed Aug 08 at <http://www.who.int/cancer/palliative/definition/en/>