



**Palliative Care WA (Inc)**

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24 July 2009

Dr Simon Towler  
Chief Medical Officer Western Australia  
Department of Health  
Level 1, 1 Centro Ave  
SUBIACO WA 6008

**AND**

Ms Pauline Bagdonavicius  
Public Advocate of Western Australia  
PO Box 6293  
EAST PERTH WA 6892

Dear Colleagues

**Draft Advance Health Directive and Enduring Power of Guardianship Paperwork**

Palliative Care WA Inc is the peak body representing all Western Australians who seek to secure better care and support for those dealing with the problems of dying, death, and bereavement.

Respecting the healthcare wishes of people at the end of life brings numerous and far-reaching benefits for patients, their carers, families and communities, for clinicians and the healthcare system. We welcome the *Acts Amendment (Consent to Medical Treatment) Act 2008* as a core component of what might eventually become a comprehensive advance care planning regime in Western Australia.<sup>1</sup>

Several members of Palliative Care WA Inc attended the consultation workshops about the new Enduring Power of Guardianship (EPG) and Advance Health Directive (AHD) paperwork during early July 2009. The Executive Committee has also examined the draft documents.

In general, Palliative Care WA Inc is of the view that the draft AHD and EPG forms need substantial changes in order to be useable in the broader community, and we were glad to hear reassurances at the workshops that this would be a priority for you both. The information guides are comprehensive and well structured and are a good start in the education process. Implementation of the legislation will be a huge challenge – we recommend thorough consultation within the community and amongst healthcare providers in order to help ensure quality outcomes.

The attached Submission addresses the five questions distributed to the workgroups during the consultation workshops.

Palliative Care WA Inc's representatives would be very pleased to meet with you or your teams at any time to further discuss this issue. Please contact me at this office to arrange a meeting.

Yours sincerely

Will Hallahan  
Executive Officer

<sup>1</sup> *Advance Care Planning in WA: A Position Statement* – Palliative Care WA Inc – March 2009 – available at [www.palliativecarewa.asn.au/policy.php](http://www.palliativecarewa.asn.au/policy.php)

### **How might the draft EPG/AHD forms be strengthened, modified or otherwise improved?**

Acknowledging the detailed feedback about stilted legalese in both draft forms that was provided at the workshops, Palliative Care WA Inc has ongoing concerns about the 'Statement about legal or medical advice' on the AHD. We appreciate this is required by the legislation, but it needs very careful drafting and clear supporting information for the benefit of both consumers and clinicians.

We note concerns about the practicality of attaining valid treatment decisions from 'joint guardians' and suggest that:

- section 1B be removed from the EPG (and this version then be promoted as the main form)
- a separate Joint Enduring Power of Guardianship form be available for those people who wish to take up this option.

It might be helpful to have a standard form which individuals could use to easily revoke AHDs and EPGs.

All forms need thoughtful graphic design with careful attention accorded to delineating the discrete parts and their logical sequencing. Any digital versions of the forms should retain the look and feel of the hardcopy version to avoid confusing users.

### **How might the draft guides to the AHD/EPG process be strengthened, modified or otherwise improved?**

We like the question and answer information format in both guides. The case studies in the AHD are helpful and we hope that similar examples could be included in the EPG guide. The 'Guide for the Appointer' on page 9 of the EPG guide is helpful and we hope that a similar table could be included in the AHD guide. We recommend the World Health Organisation's definition of palliative care be used in the glossary of the AHD guide.<sup>2</sup>

### **What are the key issues to be addressed in the implementation process?**

Western Australia has an excellent opportunity to use the consent legislation implementation process to begin to introduce advance care planning across the entire health system. A comprehensive regime has the potential to elevate end of life care issues in the minds of all healthcare providers, including those who have not traditionally engaged with palliative care. Palliative Care WA Inc's *Position Statement: Advance Care Planning in WA*, enclosed, lays out some underlying goals and principles (see page 3).

We know that substantial changes at a systems level – which in turn can affect organisational culture – will be needed if advance care planning is to be widely taken up in Western Australia. In this context, Dr Towler's idea of creating a simple software module which health professionals, working with relevant patient populations in a range of settings and using a variety of information systems, could readily access and use to structure an advance care planning conversation and populate the fields in the forms, is worth further consideration. Evidence suggests that conversations sensitively facilitated by clinicians are more likely to result in plans which are targeted, tailored and flexible. Such plans are more likely to be respected and seen as helpful not burdensome by healthcare providers and families.

In terms of the immediate implementation strategy, we support Prof Anne Wilkinson's argument that populations receiving advance care planning interventions should be prioritised by age, medical status and personal circumstances.

The need for education of both healthcare providers and consumers is widely recognised as critical. The following points occur to Palliative Care WA Inc:

- education and public awareness campaigns need to be ongoing and government will need to budget for this as a recurrent expense
- education and public awareness initiatives need to be tailored to different audiences and learning styles – content should be standardised but delivery should meet local needs
- changes to culture and practice cannot be achieved by education alone – healthcare providers and consumers need supportive systems and infrastructure.

<sup>2</sup> available at <http://www.who.int/cancer/palliative/definition/en/> - accessed July 2009

**What role can community and professional organisations play in the implementation of this new legislative provision and what capabilities or assistance might they require?**

Community and professional organisations bring together, or provide information to, groups of people who have an interest in advance care planning as either healthcare providers or consumers, or both. In many cases, information provision and targeted education or training can be undertaken by those groups more effectively and efficiently than by the Office of the Public Advocate or Department of Health (which would have to go to the effort of constituting their own groups).

The legislation and its implications are complex, and the quality of information, training and education provided by community and professional organisations should be supported by a wide range of standardised materials and resources, and, where possible, with instructor training.

**What role can Palliative Care WA Inc play?**

Palliative Care WA Inc is the organisation, at the state level, which concerns itself with the quality of care and support available to all Western Australians at the end of life. We play an important role in providing information about palliative care and end of life care issues to the general community and within the healthcare system. It is evident to us that there is a congruence between the objectives, concerns and activities of Palliative Care WA Inc and the fact that the majority of people will use the AHD and EPG instruments to plan for their end of life care.

Specifically, Palliative Care WA Inc can:

- distribute information about the consent legislation – including forms and information guides
- provide training and education to healthcare consumers and providers
- help the Department of Health and Office of the Public Advocate to develop systems which support advance care planning in Western Australia
- participate in evaluation and review of this initiative.