

# Palliative Care WA Inc

## Forum Outcomes Report

### A Matter of Life and Death Forum

Tuesday 28 May 2008 at the Perth Zoo Function Centre, South Perth

#### Background

Objectives – Palliative Care WA’s objectives for the Forum included introducing new concepts about ‘end of life’<sup>1</sup> to new audiences, and examining ways in which the implementation of WA’s proposed consent to medical treatment legislation can be undertaken most effectively.

Attendees – 55 people attended, representing a range of key constituencies.

Program – The event followed an ‘action forum’ format – the audience heard contextual information about a particular issue from expert guest speakers, and then participated in proposing ideas and solutions related to the implementation of the consent to medical treatment legislation in WA.

#### Outcomes

Forum participants addressed, in breakout sessions, a range of questions directly related to the implementation and operationalisation of WA’s consent to medical treatment legislation<sup>2</sup>. The breakout session groups put forward a range of suggestions and insights about consumer and health care provider education programs, a registry of advance care directives and future evaluation, research and review of the legislation.

Forum participants also adopted a ‘communiqué’ which confirms their commitment to the idea that supporting people at the end of life is a broader community responsibility and in which they undertake to work collaboratively in the future to progress this agenda.

PCWA successfully trialled the concept of bringing together key constituents to tackle a ‘live’ policy issue using an ‘action forum’ program format, and undertakes to run similar events as they are needed in the future.

#### Breakout Session Findings

In the second half of the event attendees were invited to select a ‘breakout session’. Each breakout session group addressed particular elements of the implementation of the proposed WA consent to medical treatment legislation. A small number of focused questions were provided to help structure group discussion. A spokesperson from each group then reported back to the entire audience.

*Palliative Care WA will use the suggestions and questions put by the groups in discussions with policy makers in government and other organisations as the implementation of the legislation is planned and undertaken in the coming months and years.*

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<sup>1</sup> end of life: The period of time marked by disability or disease that is progressively worse until death.  
<sup>2</sup> At the time of the forum, the *Consent to Medical Treatment (Acts Amendment) Bill 2006* was about to be passed by the upper house of the WA Parliament.

### Consumer Education Group

questions	suggestions
what should be the aim for the planned consumer education program about the consent to medical treatment legislation?	<ul style="list-style-type: none"> <li>▪ the main aim is for all people in our community to start appropriate 'key conversations' about end of life issues and the medical care they would like at this stage in their lives</li> <li>▪ these key conversations should be facilitated by peers</li> </ul>
in broad terms, how should this aim be achieved, and how will we know if it has been achieved?	<ul style="list-style-type: none"> <li>▪ number of advance directives registered</li> <li>▪ changing patterns of care at the end of life</li> </ul>
what will be the single most significant problem the education program is likely to confront? – how can it be overcome?	<ul style="list-style-type: none"> <li>▪ the main barrier to an effective education program will be the resourcing – government needs to provide sufficient funding to do the job</li> </ul>
three dotpoints – three priority actions?	<ul style="list-style-type: none"> <li>▪ approach the education sector to help introduce the concepts to young people</li> <li>▪ approach the legal sector to encourage them to suggest that people complete or review their advance directives at the time they complete or review their will</li> <li>▪ work with community groups who can help get the message out to their members and clients</li> </ul>

### Healthcare Provider Education and Implementation Issues Group

questions	suggestions
what should be the aim for the planned healthcare provider education program about the consent to medical treatment legislation?	<ul style="list-style-type: none"> <li>▪ the main aim should be cultural change within and across the entire healthcare system, and at all levels within organisations</li> </ul>
in broad terms, how should this aim be achieved, and how will we know if it has been achieved?	<ul style="list-style-type: none"> <li>▪ mandatory provider education about advance care planning and the legislation – starting with undergraduates and trainees</li> <li>▪ a consumer education program to create consumer interest will push health care providers to take this seriously</li> </ul>
what will be the single most significant problem the education program is likely to confront? – how can it be overcome?	<ul style="list-style-type: none"> <li>▪ resourcing and funding</li> </ul>
what is the most significant barrier to effective implementation of the legislation within the organised healthcare system? – how can it be overcome?	<ul style="list-style-type: none"> <li>▪ provider indifference – they are already so burdened by legislative, regulatory, quality and management regimes</li> <li>▪ indifference can be overcome by identifying and resourcing champions in high risk areas</li> </ul>
three dotpoints – three priority actions?	<ul style="list-style-type: none"> <li>▪ consultation with health care professionals and health consumers about the content of education activities</li> <li>▪ working with professional education providers to incorporate this information into existing training programs</li> <li>▪ adjustment of health care database systems to include flags indicating consumers have advance directives in place</li> </ul>

### Registry Issues Group

questions	suggestions
what should be the aim for the planned advance directives registry?	<ul style="list-style-type: none"> <li>▪ the main aim should be to make advance care plans and directives easily available to health care providers</li> <li>▪ the registry should not cost consumers and changing or withdrawing registry entries must be easy and convenient</li> </ul>
in broad terms, how should this aim be achieved, and how will we know if it has been achieved?	<ul style="list-style-type: none"> <li>▪ when emergency services, casualty, public and private clinicians of all types automatically access the registry if they see a new patient/client</li> </ul>
what will be the single most significant problem the registry is likely to confront? – how can it be overcome?	<ul style="list-style-type: none"> <li>▪ providing health care providers with easy access to the registry in the event of an emergency – data access using handheld devices would help</li> <li>▪ data quality – a web-based image repository would allow for scanned originals would minimise this problem<sup>3</sup></li> </ul>
three dotpoints – three priority actions?	<ul style="list-style-type: none"> <li>▪ a detailed study of the lessons learned interstate and overseas before implementation of the registry</li> <li>▪ a comprehensive consumer education program encouraging people to register their advance directive</li> <li>▪ a comprehensive education program explaining how the registry can help providers offer better care to their patients/clients</li> </ul>

### Review, Evaluation and Research Issues Group

questions	suggestions
what is the key aim for any review, evaluation and research activity related to the legislation	<ul style="list-style-type: none"> <li>▪ improvement of the law, the policy, and implementation at all levels and in all care settings</li> </ul>
in broad terms, how should this aim be achieved, and how will we know when it is?	<ul style="list-style-type: none"> <li>▪ ongoing evaluation of the application of the new law in practice to identify needs and gaps in, for example, education, consumer awareness etc</li> </ul>
what will be the single most significant problem likely to be confronted by review, evaluation and research efforts? – how can it be overcome?	<ul style="list-style-type: none"> <li>▪ lack of funding</li> <li>▪ lack of policy-maker interest in the findings as government moves onto other priorities</li> <li>▪ arguing for the inclusion of an evaluation component in legislation implementation budgets</li> </ul>
three dotpoints – three priority actions?	<ul style="list-style-type: none"> <li>▪ evaluation at regular intervals of actual medical treatments compared to care plans stipulated in advance directives at all sites of care</li> <li>▪ identification and prioritisation of broader end of live care research agenda</li> </ul>

<sup>3</sup> The US Living Will Registry ([www.uslivingwillregistry.com](http://www.uslivingwillregistry.com)) may be a useful model for the WA registry and, indeed, for a national registry.

## Communiqué

Forum participants endorsed the following Communiqué:

The participants in the *Matter of Life and Death Forum*, held in Perth on 27 May 2008, have a shared vision of increased awareness and acceptance of death as a part of life, and better care at the end of life<sup>4</sup> for all Western Australians, their carers and communities, in Western Australia.

We recognise that:

- the entire community has a role to play in supporting people at the end of life and those dealing specifically with dying, death and bereavement – and that the organised health system is not solely responsible for this
- communities, families and individuals need practical support and resources in order to effectively support and care for people at the end of their life
- ongoing system reform is needed to improve coordination, continuity of care, flexibility and sensitivity within the organised health system for those at the end of life, their families, carers and communities
- reform should be guided by the principles of dignity, empowerment, compassion, respect, equity, excellence and accountability.

We agree to meet again in future to share knowledge, insight and information about end of life care issues that affect all Western Australians, and in particular to consider:

- ways in which we can enhance the community's capacity to deal with the end of life
- the issues as they affect our own organisations, groups and constituencies
- ways in which we can advocate collectively for change if it is needed.

PCWA will now invite all organisations represented at the Forum to formally adopt the Communiqué.

### Next Steps

PCWA recognises that the success of the Matter of Life and Death Forum was due in part to the fact that it brought a diverse range of people together to address a real and current issue of importance to Western Australians.

Our aim is to hold events like this in the future, in accord with the final section of the Communiqué (above), bringing together a variety of participants with a particular interest in a 'live' issue of importance. PCWA offers to help facilitate occasional forums in which constituents can have a voice, are exposed to new ideas and information, and can develop their own and the community's capacity to advance reform, but are not burdened by the ongoing bureaucratic work associated with forming and maintaining a new organisation. In this way we can collaboratively address real issues in a strategic and efficient way.

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