

## Edith Cowan University

### ***Guidelines for a Palliative Approach for Aged Care in the Community Setting***

#### **Stakeholder Comments on the Drafted Document**

Please use this form for submitting your comments to the University.

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2. Please insert the **chapter and page number** in the 1<sup>st</sup> column. If your comment relates to the document as a whole, please put '**general**' in this column

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<b>Chapter and Page Number</b> Indicate <b>chapter and page number</b> or ' <b>general</b> ' if your comment relates to the whole documents	<b>Comments</b>  Please insert each new comment in a new row.
General	<p>Palliative Care Australia (PCA) supports the ComPAC project in its intent to promote good practice in end of life care for elderly people living in the community.</p> <p>The APRAC <i>Guidelines for a Palliative Approach in Residential Aged Care</i> have contributed to the development of units of competency for education and training of health professionals.</p> <p>PCA believes it is important that the ComPAC <i>Guidelines for a Palliative Approach for Aged Care in the Community Setting</i> are similarly able to achieve this.</p> <p>PCA offers the comments below in the interest of ensuring the best possible outcomes are realised from the project. This will be to the advantage of all those requiring, and delivering, end of life care in the home.</p> <p>PCA strongly supports moves towards regarding the home as the primary place of end-of-life care. PCA believes that the provision of high quality care at the end of life requires greater capacity to support care in the home and make dying in-place a meaningful choice for more Australians.</p> <p>A health service delivery model that increases in-home support, integrating community care with specialist palliative care services, promises to better meet patients' care needs and preferences, and to drive appropriate demand for care in accordance with the</p>

	<p>PCA Service Provision Model for Quality Cares.</p> <p>We recognise the development of these guidelines and good practice points as one element in furthering this agenda.</p> <p>It is clear that the Government’s health reform agenda will have a major impact on the structural framework for service delivery models which these guidelines will be seeking to influence.</p> <p>PCA recognises the difficulties faced by the ComPAC project in preparing these draft guidelines parallel to (and in many cases in advance of) this reform process.</p> <p>PCA believes it is possible for the guidelines to consider how the principles of a palliative approach to community care can be relevant and sustainable in the context of the Government’s health reform agenda.</p> <p><b>PCA recommends that the ComPAC guidelines frame the principles of a palliative approach to community care in the context of the overall health reforms so that they can provide relevant and sustainable guidelines for end of life care in the community into the future.</b></p>
<p>General – Concept of good practice points</p>	<p>In the light of the limited evidence to support comprehensive evidence-based guidelines we welcome the concept of incorporating good practice points that are derived from evidence, or based on wide expert consultation.</p> <p>To ensure optimal adoption and utilisation of these important guidelines and good practice points we recommend that they are tailored to specifically relate to the provision of care at the end of life where this differs from care ordinarily provided by community services. This would enable the good practice points to be published separately as a short, user-friendly guide.</p> <p>PCA believes that the ‘good practice points’ can be effectively used by service providers, health professionals, and carers within the context of a broader guidelines document.</p>
<p>General – Use of terminology</p>	<p>On a number of occasions the document refers to ‘end of life care’ with an implied meaning of ‘last days’ or ‘last stage of lives’.</p> <p>PCA has recently published a Glossary of terminology (2008). This recommends the use of the term ‘end of life care’, defined as follows:</p> <p><i>“End of life care is care provided to people who are living with, and impaired by an eventually fatal condition. It is not limited by prognosis. End of life care can be provided by all health care professionals and is not limited to care provided by palliative care services or specialists. Quality end of life care is realised when strong networks exist between specialist palliative care providers, generalist health care professionals, other clinical specialists and support care providers and the community – working together to meet the needs of the population of people requiring care.”</i></p> <p>PCA acknowledges palliative care as “specialist care provided for</p>

	<p><i>all people living with, and dying from, an eventually fatal condition and for whom the primary goal is quality of life.” (PCA, 2008; 16.)</i></p> <p><b>PCA recommends the adoption of consistent use of language around end of life across the health sector in accordance with the definitions outlined above.</b></p> <p><b>PCA recommends consideration of how the term ‘a palliative approach’, as fostered under the APRAC guidelines, may be generating perceptions of a quality differential with care available under the term ‘palliative care’. While this is problematic and there is no easy remedy, we urge consideration of the terms and definitions used in the PCA Glossary.</b></p>
<p>General – linkage to existing policy</p>	<p>PCA was disappointed by the lack of linkage in this document to existing policy relevant to end of life care.</p> <p>In particular, we note potential benefit in ensuring linkages between the guidelines and good practice points with the <i>Standards for providing quality palliative care for all Australians</i> (PCA, 2005) which outlines many similar and, in some cases more specific, points than provided by the good practice points.</p> <p>These standards are currently informing practice across Australia, at both a primary care (including community care) and specialist level, and thus provide an important point of linkage.</p> <p>PCA also notes the benefits to be gained from greater linkage to <i>Palliative Care Service provision in Australia: A planning guide</i> (PCA, 2003). This includes information on role delineation among service providers that is a notable absence in the good practice points.</p> <p><b>PCA recommends that the widely supported and used policy documents <i>Standards for providing quality palliative care for all Australians</i> (PCA, 2005) and <i>Palliative Care Service provision in Australia: A planning guide</i> (PCA, 2003) are identified in the ComPAC guidelines in a way that supports their significance to those practicing palliative and end of life care.</b></p>
<p>General – generalist nature of good practice points and length of document</p>	<p>We note that many sections and specific points in the ‘Summary of good practice points’ can be considered to be of a generalist nature pertaining to community care in general.</p> <p>The APRAC <i>Guidelines for a Palliative Approach in Residential Aged Care</i> included a summary document which has proven to be most successful in communicating and engaging with staff and health professionals in residential aged care facilities.</p> <p>Similarly, a short plain English summary document is imperative to the success of the ComPAC <i>Guidelines for a Palliative Approach for Aged Care in the Community Setting</i>.</p> <p><b>PCA strongly urges the preparation of a more compact version of the guidelines for general distribution, with</b></p>

	<b>references to a more detailed document, or other documents, for further information.</b>
Chapter 1 Introduction 3. When to Provide a Palliative Approach to Care Page 3	<p>This section discusses when to provide a palliative approach to care and notes 3 points when “a palliative approach to care is appropriate.”</p> <p>These recommendations are very general and may indicate need for end of life care or for specialist palliative care. For example the reference in the first of these 3 points to “particularly complex symptoms” is often recognised as requiring referral to and assessment by a palliative care specialist rather than simply being an indication of the need for a “palliative approach.” A recommendation in relation to this point is included in the comment below.</p>
Chapter 1 Introduction 5. Good Practice Points Page 6	<p>Recommendation iii suggests the introduction of end of life care on an “individual needs basis.”</p> <p>PCA fully supports this concept, and notes that guidelines for assessing individual need in relation to care provision and services involved are needed. This would support those using this document to identify people requiring end of life care, and to assure that quality needs-based care is delivered.</p> <p>This information is critical to providing practice points that are useful to everyday practice and which promote quality care.</p> <p><b>PCA recommends that guidelines for assessing individual need should include:</b></p> <ul style="list-style-type: none"> <li>• <b>when end of life care (as per the broader PCA definition) is required;</b></li> <li>• <b>role delineation for services outlining who is best placed to meet varying levels of end of life care needs;</b></li> <li>• <b>referral protocols clearly outlining when referral to specialist palliative care is warranted.</b></li> </ul>
Chapter 3 Delivering a Palliative Approach in the Community Setting 1.2 Short term care provision Transitional care Page 21	<p>PCA agrees that “a range of services and environments designed to promote the safe and timely transfer of patients from levels of care or across settings” is extremely important to the success of community-based care.</p> <p>PCA notes that under current arrangements (at least in most States and Territories), it is only possible for patients to be admitted to transit care beds in hospital through the hospital setting itself, either from in-patient status, or from the emergency department.</p> <p>PCA notes that this is a specific example of the problem referred to under General comments on page 1, of the need for us to consider how the principles of a palliative approach to community care can be relevant and sustainable in the context of the Government’s health reform agenda.</p> <p><b>PCA recommends that consideration be given to broad principles under which the CompAC guidelines on delivering service options can be made relevant and sustainable</b></p>

	<b>guidelines for end of life care in the community into the future.</b>
Chapter 3 Delivering a Palliative Approach in the Community Setting 1.4 Volunteer Support Page 26	<p>PCA acknowledges the benefits of involving volunteers in supporting those with end of life care needs in the home.</p> <p>The guidelines could usefully consider in more depth some specific issues related to the use of volunteers to support dying people in the home, e.g. issues relating to insurance for volunteers, and privacy issues (especially when volunteers may be drawn from small, inter related communities), OH&amp;S issues, and supervision, education and training for volunteers.</p>
Chapter 3 Delivering a Palliative Approach in the Community Setting <i>Summary of good practice points</i> , Point viii Page 73	<p>This point provides information regarding necessary actions to implement when a death is imminent, or has occurred.</p> <p>The good practice points assume the availability of GPs to certify death on a 24/7 basis, and do not provide guidance on how to support families and best practice where availability of GPs or geographical location means that the body of the deceased may be in the home overnight or for many hours.</p> <p><b>PCA recommends that further detail be given to enhance the good practice point on provision of information when a death is imminent, or has occurred.</b></p>
Chapter 5 Advance Care Planning and Advance Health Care Directives Page 163	<p>PCA supports the promotion of advance care planning as a mechanism for empowering individuals in the course of their end of life care.</p> <p>PCA strongly agrees with Good Practice Point vi (pages 168-9) about the necessity of supporting health care professionals to develop their skills to consult their patients regarding advance care planning.</p> <p>PCA suggests that health professionals could be better supported along this journey if the guidelines included information on how to obtain support for advance care planning, including appropriate access to multi-disciplinary teams involved in specialist palliative care.</p> <p>We similarly support the notion advocated in point viii that older adults should have the opportunity to have a family member or friend with them when discussing advance care plans and/or directives.</p> <p>While acknowledging that the involvement of family should be in accordance with the individual's preferences, we suggest that this point could be enhanced by highlighting how involving family in the planning can be a critical element toward promoting their support in realising the plan. Too often plans and directives are not actuated because family members offer objection at critical moments.</p> <p>We support the advice provided in point x that advance care plans and directives need to be communicated to involved health care providers. Achieving this critical communication can be difficult as a consequence of a number of organisational barriers including</p>

	<p>the absence of a shared medical record.</p> <p><b>PCA recommends that the guidelines include specific suggestions of how plans should be communicated along the continuum of care to ensure all health professionals and carers are informed of patients' preferences.</b></p>
<p>Chapter 6 Symptom Assessment Management Summary of Good Practice Point ii Page 215</p>	<p>This point highlights the necessity of educating individuals and their carers about the effective use of medication charts in dealing with the issue of polypharmacy in older adults with comorbid illness. PCA strongly supports this point.</p> <p><b>PCA recommends that the good practice points be expanded to include education about broader aspects of the safe use of medicines in the home, especially opioids, e.g. administration, storage and disposal.</b></p> <p><b>PCA recommends that discussions with the Australian Pharmaceutical Advisory Council would be an appropriate course of action to further the effectiveness of the guidelines.</b></p>
<p>General – Sustainability</p>	<p>PCA strongly supports the thrust of the draft ComPAC guidelines to develop guidelines for end of life care at home.</p> <p>It is our hope that these guidelines can contribute towards generating genuine and sustainable change to both service models, and to attitudes, in the same way that the APRAC guidelines have succeeded in making end of life care an integral part of aged care in the residential setting.</p> <p>Much has been learnt about introducing effective, sustainable guidelines through the APRAC implementation. It is critical that this experience is not lost. This point is critical when considering who is the consumer, that is, the patient and their families, who are likely to experience community based, and residential aged care facility based, end of life care. Much discipline,e is required so that there is no difference in the language or the approach by the guidelines.</p> <p><b>PCA recommends that additional consultation with people involved at the community level is required in order for this document to effectively promote uptake and achieves its goal of seamless continuity of care at the community level.</b></p>
<p>General – concluding remarks</p>	<p>PCA welcomes the development of the ComPAC guidelines as a vital step in the process of reform which will see end of life care becoming fully integrated within the health and aged care systems.</p> <p>PCA has appreciated the opportunity to be represented on the reference group for these guidelines, and looks forward to engagement in the guidelines' further development and implementation.</p>

**How to make your submission**

You may make this submission in writing (by post, fax or email).

Please fax your submission to (08) 6304 2255, email [compac@ecu.edu.au](mailto:compac@ecu.edu.au) or post to:

COMPAC public feedback, Western Australian Centre for Cancer and Palliative Care, School of Nursing, Midwifery and Postgraduate Medicine, Edith Cowan University, 100 Joondalup Drive, Joondalup, WA 6027

Submissions must be received by **5pm WST on June 16, 2008.**