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**Palliative
Care
Australia**

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Project Officer, Transitions
Health and Research Ethics Section
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cc Professor Warwick Anderson
Chief Executive Officer
National Health and Medical Research Council
by email: warwick.anderson@nhmrc.gov.au

Dear NHMRC Health and Research Ethics Section

Thank you for the opportunity to provide consultation comments on the National Health and Medical Research Council (NHMRC) Discussion Paper *Ethical Issues involved in transitions to palliation and end of life care for people with chronic conditions: A Discussion Paper for patients, carers, and health professionals*.

I attach the completed and signed NHMRC Consultation Submission Form.

As the peak national body representing the palliative care sector, and the interests and aspirations of all who share the ideal of quality care at the end of life, Palliative Care Australia (PCA) is very supportive of the need for this paper.

PCA agrees that the paper's 3 identified ethical priorities – respect for the value of autonomy and dignity, the standards and goals of health care, and acting in the best interests of the individual – are important, and are happy with this focus.

In particular, PCA supports the broad direction the NHMRC's Australian Health Ethics Committee has taken to articulate the ethical issues involved for people with chronic conditions who face transitions in care as the final phase of life is approaching, but death is not yet imminent – typically the last twelve months of life - and, the paper's description of this as "the transition phase – a 'no surprised period.'"

While there is nothing in the paper with which we disagree, there are some areas where we would suggest some additional thought, which could involve the inclusion of additional information, or in some cases some re-writing.

As a starting, overall point, we believe it is fundamental that good quality palliative and end-of-life care is a vital component of an effective health care system, and must be seen as being integrated into that health care system. The fact that this is often not the case at the moment poses overarching ethical issues in terms of the ability of people at the crucial end stages of their lives to access appropriate, quality care in the setting of their choice.

It is important that the fundamental rights of individuals to obtain access to quality care at the end of their lives is recognised and supported as an ethical right. All Australians ought to be able to expect to die with their preventable pain and other symptoms well managed, with the people they wish to be present, and whenever possible, in the place of their choice.

In terms of the structure of the Discussion Paper, its allocation of issues within each of the priority areas into

Sample questions for people facing transition, Sample questions for loved ones or carers, and Sample questions for health care professionals, while sensible at first glance, do pose some structural problems.

I will give you a couple of examples from section 2.5 on page 16 of the Discussion Paper. While this section notionally deals with Ethical Issues for Health Care Professionals, it really deals with fundamental questions about overall health care choices and options. In our view, these issues are also fundamental to health consumers – both the other 2 groups, namely the people facing transition, and their loved ones or carers.

- While the role of specialist palliative care providers is vital, PCA does not support the notion that to achieve the goal of quality care at the end of life for all, direct access to specialist palliative care is required in all cases. Rather, the implementation of needs-based end of life care should be informed by standardised referral criteria that outline the requirements for upward and downward referral relevant to aged care, primary health care and specialist palliative care.

PCA believes that quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community – working together to meet the needs of all people. The provision of quality end of life care for all is most efficiently and effectively – and probably ethically - achieved in accordance with a *needs-based* service delivery model that acknowledges that patients have different needs that may change over time.

In order to achieve this, more needs to be done to make primary health care skilled and sensitive to the care needs of people with terminal conditions. In addition, there are barriers, including inadequate pain relief and symptom management, preventing people being able to receive quality end of life care. These are ethical issues.

I attach the PCA position statement on *Primary Health Care and End of Life*, which has more information about these issues.

Accordingly, PCA would request further consideration of the sentiment in the last paragraph on page 16 about the nature of clinical care options for people entering this transition phase.

- On the issue of euthanasia, dealt with briefly on page 17 (also under section 2.5, Ethical Issues for Health Care Professionals – despite the fact that it clearly is an issue for everyone), I attach the PCA position statement on *Voluntary Euthanasia and Physician-Assisted Suicide*. This notes that “There are a wide range of views and perspectives in our society about the ethical issue of the deliberate ending of life for a person living with a terminal condition. These should be recognised and respected.” It goes on to note that “The practice of palliative and end of life care does not include deliberate ending of life through voluntary euthanasia or physician-assisted suicide, even if the patient requests this.”

We would ask that you take this fundamental ethical point on board in the further work on this paper.

Other areas of the paper where we believe more thought is needed, and where you may want to consider including some more information, are:

- Advance care planning on page 20. In our view, access for everyone to a range of advance care planning options is vital to achieving the fundamental ethical issue of meeting the person’s needs and upholding their care preferences.

It is unethical to have a system that works to assist people articulate their wishes, and thus raise expectations that these wishes will be honoured by the health system, but then fails to take steps to manage resources to enable these wishes to be realised.

Ethical issues associated with failure to include systems for full engagement include discussions with family members and significant others, and the role of proxy decision makers.

I attach the PCA position statement on *Advance care planning*.

- Culturally and linguistically diverse issues on page 19. I attach PCA’s interim position statement on *Palliative care and culturally and linguistically diverse communities*. I ask that in your use of this interim position statement, you recognise that it is currently undergoing consultation.
- Aboriginal and Torres Strait Islander issues, also on page 19. I attach PCA’s interim position statement on *Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians*. I ask

that in your use of this interim position statement, you recognise that it is currently undergoing consultation.

- Pædiatric palliative care, which you deal with briefly in the definitions section on pages 31 and 35.

PCA supports the concerns raised by Dr Jenny Hynson, the Chair of the Australian and New Zealand Pædiatric Palliative Care Reference Group, that the scope of the Discussion Paper is largely limited to adults, and does not attempt to deal with the complexity of ethical issues for children and their families.

The NHMRC could either acknowledge that the Discussion Paper deals with adult issues, or alternatively do the additional work to fully explore these challenges.

In terms of the questions posed by the Discussion Paper, rather than go through each of the questions posed in the discussion paper, I attach another PCA document, *Asking questions can help*, for your information and use. This 2007 booklet was developed by Dr Josephine Clayton as principal author, as part of her doctoral thesis, supported by an NHMRC Medical Postgraduate Scholarship. PCA is currently having this invaluable booklet translated into 20 community languages.

Next steps

PCA warmly welcomes this initiative by the NHMRC and looks forward to its further development. We would support the further development of this paper into guidelines, and, as the peak body, would be pleased to work with the NHMRC towards achieving this end.

A national forum was recently held in Canberra under the auspices of Palliative Care Australia, to discuss end-of-life issues and, in particular, to review how well health reform is meeting the reality that death is inevitable for everybody and our health system must allow good care for dying people and those around them.

The goal of this national forum is to develop a framework that can lead to better quality care at the end of life for all Australians. I attach *Australians dying badly*, a media release by PCA on 5 November 2009, which was also the communiqué arising from the first meeting of the national forum. This poses some questions you will find useful.

I believe that there are important synergies between this work and the work of the NHMRC on the ethical issues. I hope you will agree that we could work together in at least some of the important issues. I will be contacting you shortly to seek a meeting to explore these possibilities.

Yours sincerely



Donna Daniell
Chief Executive Officer