



**Palliative
Care
Australia**

Suite 4, 37 Geils Court, Deakin ACT 2600 PO Box 24, Deakin West ACT 2600
Phone: +612 6232 4433 Fax: +61 2 6232 4434 Email: bruce@palliativecare.org.au
Web: www.palliativecare.org.au ABN: 85 363 187 904

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Project Officer - Living within Limits
Health & Research Ethics Section
Quality & Regulation Branch
National Health and Medical Research Council
GPO Box 1421
CANBERRA ACT 2601

Consultation comments:

Living Within Limits: Ethical issues for those ageing with chronic illness

Thank you for the opportunity to comment on the draft issues paper on the ethical issues that arise in the context of ageing with chronic illnesses, and for the extension of time.

Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.

PCA welcomes this consideration of the ethics of ageing with chronic illness, and offer the following specific comments, ideas and suggestions. I will broadly structure these within the structure of the issues paper, and provide references.

An ethical issue dealing with chronic conditions is the appropriate consideration of end of life. PCA would recommend the use of the language and the definitions in our recently published *Glossary of Terms* available on our web site at <http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%2008%20LR.PDF>

A. Aims and scope of the project

The basic aims and scope are fine, though from the perspective of the peak body representing end of life issues, we would offer our services to assist you in refining the Issues Paper towards the preparation of the two Issues papers as part of the public consultation phase, for health professionals, and consumers respectively.

B. Phase one: Issues Paper

PCA would suggest that the structure of the paper needs to be re-thought to help make the key issues jump out as issues demanding attention.

For example, advance care planning is a key means by which the wishes of people with chronic conditions can identify, in an ethical way in which they control, the type of care and treatment they would like to receive in the different stages of a chronic condition. And yet this is only introduced, and very quietly, in section H, the 8th of 10 sections. (Though it is touched on in section G).

By and large, the paper identifies many of the relevant and appropriate ethical issues.

In this response, PCA suggests a number of additional points for consideration. Perhaps the key overriding ethical issue that needs to be included relates to how we as a society deal with changing perceptions – and realities - of viable treatment options as a chronic condition moves towards a terminal condition. We deal with this under section C under the sub-heading *‘No surprises’ policy*.

C. The current context

It is estimated that approximately 100,000 deaths in Australia each year are ‘expected.’¹ Before their death, these Australians currently undergo a range of experiences that do not consistently and equitably deliver the quality of care people and their families should reasonably expect. As their death is no surprise, there is some time for much better planning and coordination of resources.

‘No surprises’ policy

An international expert who is leading thinking about how health systems can better treat people who are dying from a wide range of chronic conditions is Professor Scott Murray who heads the Primary Palliative Care Research Group at the University of Edinburgh in Scotland.

We agree with Professor Murray and his associates’ findings that health, social, and palliative care services are continuing to fail many people with progressive chronic illnesses in whom death may be approaching. This reflects a failure to think proactively and holistically about their care. Murray describes this situation as “prognostic paralysis”, whereby clinicians of patients with uncertain illness trajectories prevaricate when considering end of life issues.²

Murray advocates a ‘no surprises’ policy: if it would be no surprise if the patient were to die in the next 12 months, then the patient requires assessment of scenarios and planning to meet their needs for end of life care.³

In other words, end of life care is required at any time where death in the next year would not come as a surprise. For this population group, death is expected and as a consequence an opportunity is presented to understand and anticipate its needs and better plan to meet the promise of delivery.

This will involve a change to the underlying attitudes: what Murray describes as the “need to move from prognostic paralysis to active total care.”⁴

D. Why *ethical* issues?

What your current list of questions under this heading do not address include the issue of what sorts of medical treatment are:

- viable

¹ This estimate is based on a basic analysis of ABS cause of death data for 2006 and subtraction of all assumed deaths that were accidental, resulted from suicide or could potentially be from acute illness. This figure is expected to be an under-estimation.

² *ibid*, further citing:

- Murray SA, Boyd K, Kendall M, Worth A, Benton TF. ‘Dying of lung cancer or cardiac failure; prospective qualitative interview study of patients and their carers in the community.’ *BMJ* 2002;325:929-32; and
- Stewart S, McMurray JJV. ‘Palliative care for heart failure.’ *BMJ* 2002;325:915-6.

³ Murray SA, Boyd K, Sheikh A, Thomas K, Higginson I. ‘Developing primary palliative care: people with terminal conditions should be able to die at home with dignity.’ *BMJ* 329; 1056-1057.

⁴ Murray SA, Boyd K, Sheikh A. ‘Palliative care in chronic illness.’ *BMJ* 2005;330:611-612. Downloaded from bmj.com on 15 May 2008.

- appropriate
- accessible
- available

as well as expensive.

These issues relate very much to the need for more seamless treatment and care options, as well as to the underlying philosophical questions posed under the *'No surprises' policy* sub-heading under section C.

E. General ethical principles and standards

PCA suggests that this section needs to be broadened, including along the lines outlined below.

Place of care

Hospitalisation is often not the most appropriate care setting for people with chronic conditions.

Because of resource limitations, many people receive poor palliative care in hospitals. In addition, the principles of chronic care are not always transported across into caring for patients in acute care hospital settings.⁵

This is particularly true for people with dementia as their cognitive impairment may pose additional difficulties for all parties in acute care settings.

In many cases, therefore, adequate care can be more effectively and efficiently provided in the place of residence, without the health risks implicit in hospitalisation.

Moreover, even at the terminal stage, while some people prefer the security provided by hospitalisation, most people when asked, express a preference to die in their home, whatever that may be.⁶

Yet in Australia there are real barriers to providing meaningful choice in care location at the end of life. Limitations in access to quality care for those at home or in residential aged care too frequently results in emergency department visits and hospital stays. Barriers confronting the sustained provision of care in people's places of residence include:

- workforce shortages that inhibit access to quality care in the home from members of an appropriate multi-disciplinary team;
- limited access to general practitioners and other primary care providers required to ensure pain and symptom relief is administered in a timely manner, particularly in residential aged care facilities;
- limited access to needs-based specialist palliative care practitioners in all settings, including in community care and in residential aged care facilities;
- carer fatigue and limitations in access to respite for carers;

⁵ Australia and New Zealand Society of Palliative Medicine. *Caring for People at the End of Life*. Submission to NHHRC, citing Hardy J, Haberecht J, Maresco-Pennisi D, and Yates P. Audit of the care of the dying in a network of hospitals and institutions in Queensland. *Internal Medicine Journal* 2007; 37:315-319.

⁶ LM Foreman et al. (2006) 'Factors predictive of preferred place of death in the general population of South Australia.' *Palliat Med* 20; 447- 453

- limitations in Medicare Benefits Schedule (MBS) items that restrict affordable, in-home access to a multidisciplinary team of care providers;
- limitations imposed by Pharmaceutical Benefits Scheme (PBS) prescribing criteria to general practitioners and other primary care providers prescribing appropriate, affordable pain and symptom management drugs in a timely manner, including medicines which have demonstrated efficacy for palliative care not being listed on the PBS for palliative care indications; and
- reluctance by many private health insurance funds to offer non-hospital-based palliative care options which make it difficult for private hospitals and health service providers to develop and offer integrated services incorporating end of life care.

Respecting people's preferences in care location at the end of life is expected to promote resource-efficiency and reduce unnecessary hospitalisations. However it will require a re-prioritising in resource distribution to support enhanced coordination of service provision through community care and to support aged care facilities to work towards policies of adequately resourced dying in-place.

PCA strongly submits that these are all ethical issues relevant to this project.

F. Ethically based questions

This is an important concept which we broach in section C under the sub-heading '*No surprises*' policy.

G. Key ethical issues

Advance care planning offers everyone, and especially people living with a terminal chronic condition, their families and significant others, the ultimate ethical opportunity to take control of decisions which affect their care.

The capacity to promote and support advance care planning and end of life care discussions rests within a broad social context in which the community, as well as health professionals, lawyers, individual patients, their families, significant others, and carers, all have a role to play.

Broader application and implementation of advance care planning will require greater awareness and knowledge among treating practitioners to support the development of advance care plans if these do not already exist, greater coordination across and among service providers to support the effective implementation of advance care plans, and enhanced community understanding of advance care plans.

H. Ethical issues for individuals who are ageing with a chronic illness

The provision of care that accords with people's preferences should be acknowledged as a shared goal across the health system. The realisation of this goal is too often hindered by failure to discuss and capture a person's considered preferences. Advance care planning provides the opportunity for people's care preferences to be clearly articulated and to enhance their choices and control over their care at the end of life. However, advance care plans are currently poorly understood by the general public and for many patients, whether or not they are even aware of this option, is dependent on their care location and care provider.

PCA will shortly be publishing a position statement on Advance Care Planning.

I. Ethical issues for those caring for individuals and/or loved ones who are ageing with a chronic illness

Planning for future care is best done in a considered way involving the patient as far as they are able, their care team and, optimally, their families, loved ones, and carers. Facilitating respect for people's care preferences is a vital ethical aspect of individual choice.

Carers must be recognised as both key partners in the care team and as recipients of care.

J. Ethical issues for healthcare professionals caring for individuals who are ageing with a chronic illness

Advances in health care have improved, both life expectancy and health expectancy. However, the ethical issue remains in defining a balance between these expectations and the exposure to increased and perhaps prolonged suffering.

End of life care has been identified as a particular issue for people with dementia and their family carers.⁷ Issues like communication difficulties, nutrition/hydration approaches and under-recognition of pain may be particularly problematic. In a 2003 US white paper, Professor Joann Lynn points to the 40 per cent of deaths attributable to 'dementia or generalized frailty of multiple body systems.'⁸ Currently dementia affects around 25 per cent of people aged 85 or older. The number of people with dementia is projected to increase from 227,360 in 2008 to 465,460 in 2030 and 731,030 by 2050.

There is growing international evidence and support for the view that getting end of life care right would be a significant step in reform of health care delivery overall. For example the results of a recent BMJ (British Medical Journal) Group "Making a Difference" international poll has [found that "palliative care for all would make the greatest difference to health care."](#)⁹

People's care needs as they move towards end of life should be met by services that are aligned with those needs. Providing services that are aligned to people's needs rather than to their diagnosis or prognosis or geographic location promises to more effectively and efficiently meet real needs. The end of life population is not a homogeneous population group and a commitment to needs-based service delivery must meet each person's level of need, which may be varyingly done through generalist and/or specialist health care providers.

Overall comment

PCA would welcome the opportunity to be more closely involved in the development of this important project.

Bruce Shaw
National Policy Director

⁷ Alzheimer's Australia (2006), 'Palliative care and dementia' Downloaded from <http://www.alzheimers.org.au/upload/PalliativeCare.pdf> on 17 June 2008.

⁸ Joanne Lynn, David M. Adamson (2003), Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age', Rand Health White Paper WP-137. Downloaded from <http://www.medicaring.org/whitepaper/> on 17 June 2008.

⁹ <http://makingadifference.bmj.com/>