

# BACKGROUND BRIEF



Palliative  
Care  
Australia

## Palliative Care Australia

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### Preventable pain

Why is there no outrage that some people at the end of life continue to suffer from pain that can be prevented? Is it because people, vulnerable at this stage of their lives are not knowledgeable about what to expect and where to go to get their questions answered?

Why, despite the funding and the promise of health reform, is the health care system unable to meet the needs of all people at the end of life? Is it because we are yet to reconcile the difference between where people choose to receive care at the end of life and the actual care options?

Whilst great advances have been made in the delivery of quality specialist palliative care, in general, health and other care services do not always perform well for people who are dying. We need to get it right to ensure people receive the care they need when they need it.

Despite the existence of very good pain medicines, patients continue to suffer from preventable pain – pain that quite simply and unforgivably is under-treated and generates a significant reduction in a person's quality of life.<sup>1</sup>

In Australia, it remains a reality that between 30 and 50 percent of people will experience physical pain that is under-treated at the end of life. This means, the chance of experiencing pain – that could be prevented – is very high.<sup>2</sup>

Inadequately treated pain has major physiological, psychological, economic, and social ramifications for patients, their families, and society.<sup>3</sup>

Pain remains poorly treated for a number of reasons:

- limited knowledge or lack of application of existing knowledge by health care professionals
- misconceptions about the dangers of addiction and side effects of pain relieving medicines
- consumer misunderstanding
- unreliable access to medicines
- cultural reasons.

Care setting also has a big impact on access to pain relieving medicines. Some very effective medicines for treating pain are not listed on the PBS for pain relief. This means patients have to pay the full price of the drug unless they can be admitted to a public hospital to receive it.

Furthermore, access to adequate pain relief can be problematic in aged care homes where suitably qualified staff are not always available to administer pain medication, particularly in relation to breakthrough pain. This means patients are often unnecessarily transported to hospital to receive necessary medication.

But, pain is not just physical – addressing emotional pain and the pain of grief is equally important. The impact of the loss of a loved one can cause physical changes. A recent study found the risk of heart attack increased six-fold for those who have lost a partner or child. People can suffer from higher blood pressure, increased heart rate and changes to immune system.<sup>4</sup>

As a health system, and as a society, we can do better for people at the end of life.

<sup>1</sup> Associate Professor Richard Chye, Director of Palliative Care, Sacred Heart Palliative Care Services, in *EoL – Towards quality care at the end of life*, Winter 2009, vol. 1, no. 1, p. 4.

<sup>2</sup> *EoL – Towards quality care at the end of life*, Winter 2009, vol. 1, no. 1, p. 3.

<sup>3</sup> F Brennan, D Carr & M Cousins, 'Pain management: A fundamental human right', *Anesthesia & Analgesia*, vol. 105, no. 1, July 2007, pp. 205-221

<sup>4</sup> T Buckley et. al. 'Prospective study of early bereavement on psychological and behavioural cardiac risk factors', *Internal Medicine Journal*, Vol. 29, 2009, pp.370-378.

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### Is access to quality care at the end of life equitable?

As Australians, we like to think we're all equal, but in reality our access to quality care at the end of life is not equal.

To be Aboriginal, elderly, living in a rural or remote area and to be socially disadvantaged, lessens one's chance of receiving appropriate, and apparently cost effective, services in the last weeks and months of life.<sup>5</sup> We know people dying with cancer are significantly more likely to access specialist palliative care services than those dying with non-malignant conditions such as cardiac or respiratory failure.

A significant proportion of people who require access to specialist palliative and end-of-life care do not receive it. This potentially results in unnecessary pain and suffering at the end of life which has implications not only for the patient, but also their family, carers and communities.

Historically, palliative and end-of-life care planning and evaluation has been based almost entirely on disease-based projections, for example cancer, or broader mortality rates per 100,000 population. Models of care have not accounted for regional or service level variations in the wider determinants of health, for example rates of chronic disease, socio-economic disadvantage, education or ethnicity.<sup>6</sup>

Quality palliative and end-of-life care must be available regardless of: location, age, income, diagnosis or prognosis, and social and cultural background. But this is not the reality today in Australia.

Despite a clear preference to die at home, many people will spend their last few days in intensive care surrounded by strangers in an often futile attempt to prolong life by a few more days. The fact that over ninety percent of deaths in the intensive care unit are as a result of withdrawing and withholding treatment may indicate that the intensive care unit has become the hospital's palliative care unit. This is not only expensive for our society, but can be a cruel way to spend one's last few days.<sup>7</sup>

Older people are less likely to receive good palliative and end-of-life care because of general age discrimination and because they have conditions that are not well embedded in current palliative care practice. While many residential aged care facilities try to provide palliative care, lack of standards, training, and support as part of a multidisciplinary team prevent many from achieving their goal.<sup>8</sup>

A new publication from Palliative Care Australia, *EoL – Towards quality care at the end of life*, identifies access blocks to palliative and end-of-life care for people from lower socio-economic backgrounds, people in acute care settings, rural and regional populations, people from culturally and linguistically diverse backgrounds, children, and people with MND and Parkinson's disease.

The National Health and Hospitals Reform Commission's final report recognised the importance of embedding end-of-life care across the health sector, reflecting PCA's position that end-of-life care is everyone's business. The report stated, 'we recommend building the capacity and competence of primary health care services ... to provide generalist palliative care support for their dying patients'.

Importantly, the report also recognised the need for additional investment in specialist palliative care services to ensure they are more available to people in the community who require them.

As a health system, and as a society, we can do better for people at the end of life.

<sup>5</sup> B McNamara, L Rosenwax, C D'Arcy Holman, E Nightingale, *Who receives specialist palliative care in Western Australia – and who misses out*, 2004, University of Western Australia, Perth.

<sup>6</sup> J Glover & S Hanson, 'Access – does socio-economic background make a difference?', *EoL- Towards quality care at the end of life*, Vol 1, No 1, Spring 2009, pp. 4-5.

<sup>7</sup> K Hillman, 'The conveyor belt of acute care – what should happen', *EoL- Towards quality care at the end of life*, Vol 1, No 1, Spring 2009, pp.6-7.

<sup>8</sup> L Yen & R Wells, 'Too little too late – care for older Australians', *EoL- Towards quality care at the end of life*, Vol 1, No 1, Spring 2009, pp. 18-19.