

MEDIA RELEASE



**Palliative
Care
Australia**

Palliative Care Australia

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5 November 2009

Australians dying badly

Have **you** prepared for the end of **your** life? Whether healthy or ill, an individual, a family, a carer, a healthcare practitioner or a health system reform authority, we **all** need to talk about dying – because too many people in Australia **unnecessarily** experience a **bad death**.

Have you asked yourself:

- How would I want to live in the last few months of my life?
- What do I need to arrange to make my wishes happen?
- What decisions should I make now about my health care at the end of my life?

If you haven't prepared, then chances are that when your time comes no-one else will ask for your answers to these questions either! This means that your last months, weeks or days may not go the way that you would wish them to. You could miss out on the right care.

Why do so many Australians unnecessarily experience a bad death? A bad death can mean different things to different people:

- experiencing pain or other symptoms that could have been prevented
- not having cultural or spiritual wishes honoured
- not obtaining honest, open discussion about conditions and treatments
- not being afforded choice in available evidence-based treatment options
- not being where they want to be or having things done the way they would wish
- not having an opportunity for a quality of life that means something to them

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.

Professor Megan-Jane Johnstone, Professor of Nursing at Deakin University noted that 'Forum members reached consensus that a key step to building an effective health system is a change in culture and attitudes: better planning, better support for the right care options and better resources to enable access to that care'.

Primary care expert Dr Stephen Phillips said 'Forum members urged planners and politicians to undertake this consultation and related research **before** committing to premature and potentially inappropriate health system reforms'.

Professor Colleen Cartwright, Director of the Aged Services Learning and Research Centre at Southern Cross University said 'Consumers and their care networks want and need a framework for advance care planning that allows them to express and document their preferences for the type of care and support they want at the end of life'.

Consumer and community representative Mr Noel Muller noted 'Forum members believe 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'.

GP Dr Richard Kidd stated that 'Dying should be seen as a whole-of-community issue – not a 100% health issue. Taking the opportunity to redress current imbalances will create huge benefits for our health system and for the strength and maturity of our community in general. People want to talk about these issues'.

Professor Ian Olver, CEO of Cancer Council Australia concluded 'In an era of increasingly complex medical technologies and consequent choices, it's time to refocus the debate on the right, and indeed the necessity, to provide high quality palliative and end-of-life care for all Australians – regardless of their diagnosis or prognosis, location, age, income, and social and cultural background'.

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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

Patron: Her Excellency Ms Quentin Bryce AC Governor-General of the Commonwealth of Australia

Background on the National End-of-Life Framework Forum

Current health reform has rightly identified the need to strengthen specialist palliative care services and improve the skills and support for primary care practitioners providing quality end-of-life care. This is important.

But this is only part of the task. This approach isolates health reform and delivery from the people at the centre of the matter – consumers.

It is important we ask people what *they* think is important before planning care for the dying. We need to do things differently if people in need are to have better deaths. Australia needs to get this right.

This is a big issue: each year, more than 135,000 Australians die. Because our population is ageing the total number of deaths every year is growing. By 2026, 175,500 people will die each year, by 2036, more than 224,000.

Now is the time for a considerable investment in consultation and discussion about dying well.

Many Australians are unsure what to expect at the end of their life. People rarely know what they need to do when faced with dying and death, what they can expect from others, where they can find information and support, and importantly, what they can do to plan in advance.

In our society, this uncertainty has led to a disproportionate focus on options such as euthanasia and physician-assisted suicide, because people do not have awareness of, or access to, care at the end of life which we know can provide good quality of living and a better death. Forum members called for action to improve people's understanding of these issues and the information resources available to them. All Australians have a part to play in this important conversation.

The goal of the National End-of-Life Framework Forum is to develop a framework that can lead to better quality care at the end of life for all Australians. The participants come from across the health and consumer sectors.

Members

Dr Andrew Boyden – Heart Foundation

Dr Will Cairns – Director of Palliative Care Services, The Townsville Hospital

Professor Colleen Cartwright – Aged Services Learning and Research Centre, Southern Cross University

Peter Cleasby – Head, NSW Central Coast Palliative Care Services

Professor Patricia Davidson – Professor of Cardiovascular and Chronic Care, Curtin University

Professor Philip Davies – Professor of Health Systems and Policy, University of Queensland

Peter Downing – Community Pharmacist

Sara Fleming – Paediatric Palliative Care Nurse Practitioner, Adelaide Children, Youth and Women's Health Services

Professor Megan-Jane Johnstone, Professor of Nursing, Deakin University

Professor Jenny Keating, Professor of Physiotherapy, Monash University

Dr Richard Kidd – General Practice; Board Member GP Partners; AMA Queensland Chair, Council General Practice

Anne Matyear – Registered Nurse in Primary Health Care

Dr Roderick McRae – Anaesthetist and Intensive Care Specialist, Monash Medical Centre

Nick Mersiades – Senior Advisor Aged Care, Catholic Health Australia

Dr Maureen Mitchell – Acting Director of Northern Territory Palliative Care

Noel Muller – Consumer/Community Representative

Professor Ian Olver – CEO, Cancer Council Australia

Associate Professor Deborah Parker – UQ/Blue Care Research and Practice Development Centre

Dr Stephen Phillips – General Practice

Mary Reid – Carers Australia

Dr David Stephenson – Palliative Care Clinical Practice Consultant

Dr Jane Tolman – Geriatrician – Royal Hobart Hospital