



# RESEARCH REPORT SNAPSHOT



## Life Before Death: Improving Palliative Care for Older Australians

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### Death without indignity

For too many elderly Australians, the experience of death lacks the autonomy, dignity, and compassion that palliative care can provide by allowing people to die in a way, and in a place, that reflects their values or their choices.

Most Australians don't receive palliative care when they die, and too many elderly Australians don't even live well in the years, months, and weeks before they die.

Estimates are that as many as 130,000 Australians should have received palliative care last year, but only approximately 11% (around 14,300) did. Other estimates are that at least 20% of hospital patients would benefit from palliative care, but less than half of those patients receive palliative services.

The generally poor current experiences of death have given rise to the pervasive myth that it is always horrible, degrading and painful. Greater access to palliative care can alleviate these fears surrounding death, but access to palliative care services is limited due to historical, workforce, funding, policy and cultural obstacles.

### Patchy provision at best

Whether Australians receive palliative care or not is a lottery that currently depends on their postcode, diagnosis (cancer being preferable) and doctor.

The medical revolution of recent decades has yielded enormous successes in curative medicine in an array of disease sub-specialities that have prolonged life spans and

contributed significantly to the ageing of the population. As a consequence of these achievements, the typical experience of death today is very different to decades ago when heart disease or stroke killed quickly at younger ages. The majority of Australians now die at very old ages from chronic diseases—often after protracted periods (even years) of deteriorating health.

Ironically, inadequate provision of palliative care is also attributable to the inappropriate application of the 'treat, cure, repeat' model of health care that has successfully extended life—but which is not fit for purpose to deal with the new realities of modern death and dying at increasingly older ages.

In the absence of palliative care, patients in the latter and last stages of life are highly likely to receive disjointed, inflexible, reactionary, and non-holistic care, which will be determined by what doctors decide they can do to prolong life, rather than according to what patients and their families value in life.

In many cases, the over-medicalisation—and the depersonalisation and dehumanisation—of death will involve multiple and often lengthy hospital admissions, intensive 'curative' interventions, and with an overall lack of acknowledgement of impending death.

Improving palliative care is a great opportunity to challenge the inherent problems within the health system, which reward rigid activity based care rather than holistic integrated care which is more apt at meeting the challenges of chronic disease.

## The myth of dying at home

One of the myths that surrounds death and dying is that most Australians want to die at home and to avoid dying in hospital at all costs (See Box).

Almost 50% of Australians die in hospital today, and the reality is that this large proportion of hospital-sited deaths is likely to continue. The focus of the debate about death and dying therefore needs to be broadened beyond the question of where patients die.

The real problem is not dying in hospital, but death without palliative care. The challenge is to ensure that hospitals offer greater access to palliative care to improve the quality of *life before death* for more Australians.

## More than 'dying well'

Palliative care is *not* just about improving the experience of death or 'dying well' in the terminal phase, including managing pain effectively. A wealth of Australian and international evidence shows that palliative care improves quality of life for both patients and their families by supporting patients to be as active as possible prior to death. There is also extensive evidence demonstrating that palliative care is cost-effective in preventing hospitalisations, emergency transfers and unwarranted medical intervention in hospitals.

Palliative care — properly defined — prevents and relieves the suffering associated with chronic incurable illness through early identification and comprehensive assessment and treatment of symptoms.

Palliative care involves the delivery of coordinated, person-centred 'team care' across the spectrum of clinical need, and relies on building partnerships between palliative specialists, clinical teams and patients and their families to ensure that empowered patients receive the care they want and need.

Palliative care offers holistic support for patients to live as actively as possible until death by using an interdisciplinary approach that acknowledges dying as a normal process, but affirms life.

Palliative care should not start with death, it can be delivered for symptom management years, months, weeks and days prior to death. And it does not end with death, as care is extended to those left bereaved.

## An 'investment' approach to palliative care

To ensure that the recommendations of innumerable reports and reviews calling for expanded provision of palliative care are finally implemented, this report proposes an 'investment approach' to palliative care.

## Author

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## The 70% Myth

- One measure of the inadequacy of palliative care in Australia is the purported statistic that 70% of Australians would choose to die at home if they had a terminal illness.
- This statistic is unreliable: it is based on a survey of people aged as young as 15 conducted in a single Australian state (South Australia).
- When the question 'where would they like to be cared for, *and* where would they like to die', has been asked of patients with chronic illnesses and their carers, the results suggest that most would prefer to be cared for at home until death is imminent, and then access a more controlled and supported environment in which to die.
- The notion that the problems associated with death and dying can be solved by enabling more Australians to die at home is an oversimplification.
- Moreover, the myth that most people want to die at home, but don't, has also unhelpfully reinforced the popular fear that grim, distressing, painful and undignified 'natural death' in hospital should be avoided at all costs.
- These myths undermine the broader benefits that good palliative care can provide for patients.

Actuarial assessment of the lifetime costs to government of existing unintegrated, reactionary 'end of life' care should be conducted to drive and inform service and funding redesigns that support palliative care.

Expanding access to palliative care services will require leadership from the Australian medical profession, driven by an awareness of the pressing ethical challenges associated with death and dying. This must entail repositioning palliative care in the health system, and altering the current scope of clinical practices that erect barriers to access (by making doctors disinclined to discuss patient's end of life preferences, identify and refer patients, or practise palliative care themselves).

Australian governments must also provide leadership to address the dual ethical and economic challenges of promoting access to cost-effective and quality of life-enhancing palliative care services. Closing the 'palliative care gap' between supply and demand will also require greater community awareness of what palliative care really is and what it can truly do — and how it can fix deficiencies in the health system that foster fear of a 'horrible death'.