



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

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**Research Report 34**

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# Contents

Executive Summary .....	1
Introduction.....	3
What is palliative care and how can it make life better? .....	5
Ageing Australia—caring for the baby boomers and beyond . .....	7
The changing experience of health, ageing, illness and death for older Australians .....	8
Box 1: Services are already under strain .....	10
Preferential treatment—more palliative care for cancer patients .....	11
Even less palliative care for chronic disease sufferers .....	12
The palliative care gap in Australia fosters myths about death .....	13
Box 2: Medicare’s Structural Flaws and the Palliative Care Gap.....	13
Box 3: The 70% myth .....	14
The lack of access to palliative care .....	15
Palliative care in Australian hospitals .....	15
Palliative care in residential aged care facilities .....	16
Another challenge: the funding of palliative care in Australia .....	17
Box 4: The variety of funding .....	18
Box 5: The palliative care workforce; underfunded and understaffed .....	19
Palliative Policy—perfect on paper but inadequate in practice .....	20
How to improve life before death? Policy makers, doctors and society.....	21
The medical profession must do better.....	21
The Australian public deserve better .....	21
Conclusion.....	23
Endnotes.....	24

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All errors are the author's responsibility.



## Executive Summary

Old age and death are humbling phenomena that make equals of us all. Yet for too many older Australians, the experience lacks the autonomy, dignity, and compassion that palliative care can provide.

Most Australians don't receive palliative care in approaching death, and too many elderly Australians don't even live well before they die. Some estimates are that as many as 130,000 Australians should have received palliative care last year, but approximately only 14,300 did. Other estimates are that at least 20% of hospital patients would benefit from palliative care, but the majority who would benefit do not receive palliative care services.

Palliative care—properly defined—prevents and relieves the suffering of patients associated with chronic or incurable illness through early identification, comprehensive assessment and treatment of pain and other psychosocial or spiritual needs. Palliative care involves the delivery of coordinated, person-centred 'team care' to ensure that patients are empowered and receive the care they want and need.

The term general 'palliative care' is used when this care is delivered by any treating doctor. 'Specialist palliative care' is when palliative care is delivered by a doctor (or other health professional) who has undertaken speciality training. Throughout this paper I refer to general palliative care unless otherwise specified. 'End-of-life' care refers to care provided by any doctor at the terminal phase of life. Treating doctors who are unable to provide adequate palliative care should seek the expertise of a

specialist palliative care doctor. Palliative care can be provided years, weeks, months, days or just hours from death. It does not have to be a continuing service ending in death but can be consultative supportive care as well.

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

Due to more accurate estimates of cancer mortality, and the clinical culture and funding of oncology services, patients dying from cancer are more likely (up to eight times more likely according to some estimates) to receive palliative care. Cancer patients (though still under-serviced overall) are therefore more able to live as actively as possible in the period leading up to terminal decline, and thereafter receive quality end-of-life care based on their values— as per the clinical ethics and principles that guide the discipline of palliative care.

However, this is the exception to the rule. Access to palliative care in Australia is suboptimal, and is limited or non-existent for the majority of Australians who do not die from cancer but from 'diseases of ageing' each year. Patchy provision of palliative care, and inadequate access based on location, diagnosis, background,

and doctor, is due to a range of historical cultural and institutional barriers within the health system, the medical profession, and in the community and across government, including persistent workforce and funding challenges.

Ironically, inadequate provision of palliative care is also attributable to the inappropriate application of the 'treat, cure, repeat' model of *acute* 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.

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 the achievements of modern medicine, the typical experience of death today is very different to decades ago when heart disease or stroke killed quickly at younger ages; with the majority of Australians now dying at very old ages from *chronic* diseases.

The projected 4 million Australians aged 65 and older in 2021 will — based on current trends — have on average 4 diagnosed chronic diseases and visit the GP roughly 10 times a year; using twice as many health resources as the younger Australian. Today's 65-year-old can expect to live to 87 years of age.

For the average 65-year-old, this means another 22 years at least of dependency on their GP and eventually dependency on family, friends, volunteers, hospitals, ambulances and residential aged care facilities. The majority of these 22 years will be spent in good health thanks to improvements in disease management and treatment. But the trajectory for many patients will inevitably involve gradual deterioration, loss of independence, health crises, exacerbations, frailty, and finally death.

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, with an overall lack of acknowledgement of impending death.

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, whereas most deaths in Australia actually occur in a hospital. However, this statistic is unreliable: it is based on a survey of people as young as 15 years old conducted in a single Australian state (South Australia). When asked where they would like to be cared for, *and* where they would prefer to die, the answers from patients with chronic illnesses and their carers indicate that most would prefer to be cared for at home until death is imminent, and then access a more supported environment in which to die.

The notion that the problems associated with death and dying can be solved by allowing 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.

Almost 50% of Australians die in hospital today, and the reality is that most Australians are likely to continue to die in hospital. The focus of the debate about death and dying therefore needs to be broadened beyond the question of where patients die; because 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.

Australian Governments need to provide leadership to address the dual ethical and economic challenges of promoting access to cost-effective and quality of life-enhancing palliative care services. This report proposes an 'investment approach' to palliative care that would ensure Australia finally sees implementation of the recommendations of the innumerable reports and reviews calling for expanded provision of palliative care.

Actuarial assessment of the lifetime costs to government of existing unintegrated, reactionary 'end of life' care across the existing fragmented health and aged care systems should be conducted to drive and inform service and funding redesigns that support palliative care. This could drive a national approach to palliative care, encompassing even a joint federal-state funding instrument. Investment in evidence-based palliative care services should also ideally occur in a consumer-centred way, potentially through a commissioning-based approach to drive the reorientation of the health system away from simply reactive, life-protracting care towards holistic, person-centred care.

Expanding access to palliative services will also require leadership from the Australian medical profession. This must entail altering the current scope of clinical practices that erect barriers to access by making doctors disinclined to discuss patient's end-of-life preferences, and identify and refer patients, or practise palliative care themselves. The medical profession's engagement with the task of repositioning palliative care in the health system and placing the focus on life before death should be driven by an awareness of the pressing ethical challenges associated with death and dying. The alternative prospect, by default, of radical changes to clinical ethics and practice will place an already under-serviced and undervalued 'old and dying' population at greater vulnerability.

Closing the 'palliative care gap' between supply and demand will also require greater community awareness of the benefits of palliative care. Informing more Australians about what palliative care is and what it can do — and how it can fix the deficiencies in the health system that foster the fear of a 'horrible death' — is also crucial to drive overdue policy change.



## Introduction

The Australian health system is struggling to deliver high quality healthcare for all Australians in an affordable way, in the face of well-known and mounting challenges. The rising cost of health — which already consumes 10% of GDP annually — is being largely driven by the impact of the ageing of the population on demand for health services. Paradoxically, these challenges have arisen due to how successful modern medicine has been in prolonging average lifespans over the past 60 years.

Health systems such as Australia's that operate around the model of 'treat and cure' excel at delivering effective short-term treatment for short-term acute illnesses. But ageing Australians ultimately develop incurable chronic conditions. This incongruence — between the needs of the community and the type of medicine supplied — highlights how the health system is struggling to deal with the number one health challenge facing the nation: the effective treatment and management of the rising burden of chronic disease in the twenty-first century.<sup>1</sup>

The consequences of keeping more people with chronic disease alive for longer, with a system not fit for this purpose, has not gone unnoticed. "The patient experience of care receives little focus as a goal of the system. Notwithstanding the massive burden of chronic illness, its prevention and proper management is still in its infancy."<sup>2</sup> The Harper competition and policy review suggested that "without fundamental change to the

health and aged care systems, the ageing of Australia's population will mean a future of greater government-managed care and increased rationing of health services."

Chronic disease sufferers need to receive integrated or coordinated, person-centred care that will allow them access to all necessary multidisciplinary care in the lowest cost setting, and prevent inefficiencies such as avoidable hospital admissions. Palliative care upholds these characteristics and has been identified as a priority area for reform. The Productivity Commission's 2016 review of Australia's human services suggested there be an increase in user choice about the setting, timing and availability of care in light of the fact that currently there is substantial variation in the quality of palliative care services across Australia.<sup>3</sup>

The most recent Inquiry Report similarly argued that "the system primarily responds to patient crisis. In areas where patient choice is critical — an exemplar being end-of-life care — many people are disempowered because they do not get adequate access to end-of-life care at home, but are instead treated in a hospital setting." The NSW Auditor similarly concluded that "NSW Health has a limited understanding of the quantity and quality of palliative care services across the state, and at a district level planning is ad hoc and accountability for performance is unclear".<sup>4</sup>

Palliative care is often misunderstood as purely end-of-life care. In fact, palliative care—properly defined—is a form of chronic disease management that can help address the wider challenges facing the health system. Expanding access to palliative care services in Australia would ensure that patients with incurable chronic conditions receive person-centred and cost-effective care—not only in the terminal stage, but earlier—to improve the quality of their lives in the period well before death.

Palliative medicine is a branch of medicine that is driven by patient values. Its focus is as much on how patients live before death as it is on how a patient dies. It is concerned with symptomatology and the daily experience of life—palliative care is cost effective, as it directs care away from being curative and reactionary to being holistic and supportive. Palliative care enables people to live at home for longer, prevents hospitalisations or within hospital prevents invasive and misdirected medical care which is usually expensive. Although palliative care is for patients of all ages, this report specifically focuses on older Australians.

As the population grows to older and older ages with increasing frailty, comorbidities and expectations the need for more palliative care increases. Most older Australians have multiple chronic diseases and rely heavily on the health system. By facilitating and enabling such conditions to become chronic, the health system has rendered a population dependent on its ongoing involvement in managing their diseases. As such, the way Australians live and die has evolved, heart disease and stroke are less responsible for causing immediate death and more likely to form a collection of chronic conditions. Whilst medicine is to be commended for providing such unprecedented longevity, the lived experience of these conditions is that they have a high symptom burden with frequent exacerbations, often requiring hospitalisation—and eventually cause a death which is unpredicted, prolonged and most often ill-managed and expensive.

To date, the health system has been largely unable to adapt from its curative reactionary model of care to the holistic supportive care these conditions require particularly in the latter and last stages of life. The structural problems of the health system are driven by outdated funding incentives borne of a time when chronic disease wasn't the most important health issue and contribute to the inherent rigidity of the health system, so that death in Australia has become over medicalised, and shrouded with misplaced concern regarding where people die. Myths and horror stories about death in the Australian health system has fostered the belief that 'natural' death, with all the apparently inevitable interventions and complications, represents the antithesis of a dignified ending. Not surprisingly, these assumptions are of great concern to increasing numbers of dependent and vulnerable older Australians, who want a much better experience of life and death.

This is also fostering interest and support for more radical end-of-life options. What is missing in this debate is an appreciation of the role of palliative care, and the need to address the rigidities in the health system that currently limit the availability of palliative services. Greater access to palliative care provides the best answer—ethically and financially—for improving the way elderly Australians experience life before death as well as death itself.

The Harper review specifically suggested that the ageing population—beyond aged care arrangements—will demand “new competitive and innovative services to meet a widening array of needs and preferences.”<sup>5</sup> The Productivity Commission concluded that “fundamental change must revolve around the greater adoption of market economy ideals including a focus on consumer, rather than producer.”

This report explores the changing nature of disease and death in contemporary Australia, which is largely evidenced by the increasing longevity we are witnessing in the baby boomer generation and beyond. The report will describe how chronic disease has arisen and subsequently how death has evolved—to become the result of an interplay of chronic disease, frailty and medicine. Not surprisingly, most Australians die in hospital and without palliative care.

Palliative care will be more fully explored; specifically the benefits of palliative care, including the evidence-based improvement in quality of life and cost effectiveness. Current access to palliative care will be examined, including the preferential provision for patients suffering from cancer, and the significant limitations in accessing palliative care amongst particular groups—including those with non-malignant disease, as well as those in hospital and residential aged care facilities.

The current challenges preventing greater access to palliative care will be discussed. These are steeped in policy limitations, funding arrangements (related to the structure of Medicare), workforce issues as well as cultural obstacles. The cultures of the medical profession and the wider Australian community in regards to palliative care will be explored both as barriers to access and as harbouring possible opportunities for solutions.

The policy solutions suggested include more targeted funding to increase workforce capabilities. Recommendations canvassed will include proposing a consumer-centred and commissioning-based approach to the provision of palliative care services. State and federal governments will also be advised to investigate an 'investment approach' to calculate the economic (on top of the ethical) benefits of investment in cost-effective palliative care, and drive the systemic changes needed to reorientate the health system's focus away from purely reactive care towards holistic, person-centred care.



## What is palliative care and how can it make life better?

Palliative care offers quality care directed by patient values that aims to ensure life before death is based on what patients and their families want and need. Palliative care upholds the values of autonomy and individuality by creating a partnership with patients. It delivers holistic care by collaborating with patients, families and carers in addressing spiritual and psychosocial as well as physical concerns. It provides effective pain and symptom management, improved quality of life, improved mood, and greater patient and family satisfaction with care.<sup>6</sup>

Palliative care offers support for patients to live as actively as possible until death, by using an interdisciplinary team approach that acknowledges dying as a normal process, but affirms life. Notably, palliative care should not start with death, and does not end with death—as care is extended to those left bereaved.

The WHO definition of palliative care is widely used in Australia:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>7</sup>

Through a variety of services and professionals, palliative care ensures that the life patients experience before death is lived actively to the greatest capacity that can be afforded, and is dependent on patient's values. Interestingly, the United States (US) health system has taken an even broader definition. In the US, palliative care extends into a patient's life when death is not even expected; that is, patients do not have a terminal condition but rather have multiple chronic conditions with an increasing symptom burden—much like Australia's ageing population. The US palliative care team advocates for patients by communicating patient wishes with their treating specialists.<sup>8</sup>

The American Centre to Advance Palliative Care<sup>9</sup> claims palliative care as the answer to the increasing burden placed on US Medicare by a small percentage of seriously unwell patients who have multiple chronic diseases but are not predictably dying and have ongoing acute and long-term care requirements. These patients benefit from palliative care as they define it:

Palliative medicine is specialized medical care for people with serious illnesses. It focuses on providing relief from the pain, symptoms and distress of serious illness. It is a team-based approach to care involving specialty-trained doctors, nurses, social workers and other specialists focused on improving quality of

life. By determining patients' goals of care through skilled communication, treating distressing symptoms and coordinating care, palliative care teams meet patients' needs and help them avoid unwanted and expensive crisis care. Unlike hospice care, palliative care can be provided at the same time as curative treatments; it is appropriate at any age and at any stage of a serious illness.<sup>10</sup>

Arguably, the definition of palliative care within Australia—while holistic—is not as applicable across a patient's lifespan as in the US, where palliative care is considered a solution to the changing demographic and health of the population. There is significant danger in Australia of palliative care being reduced to care provided at the terminal phase—underestimating the benefits that can be had for patients and their families in their lives before death.

Importantly, palliative care is not practised under a belief that death is an event to be feared. Its purpose is not to avoid death or even to prevent a 'horrible' death. The myth that death is a terrifying experience, full of pain and to be avoided at all costs, is refuted in the experience of death under palliative care.

Most patients who receive palliative care are not in pain when they die, most patients do not request to hasten death, and most patients are not fearful.<sup>11</sup> The rare but prevalent desire to hasten death has a multifactorial aetiology and is mostly seen as a severe emotional response to an overwhelming situation. Throughout the literature, pain is cited as a reason to request death in 22–36% of patients.<sup>12</sup> More commonly, patients seek

death when they have concerns regarding autonomy, dignity and dependency. Many patients in this situation, with a seeming loss of life's meaning, are likely to be suffering depression.<sup>13</sup> However, a palliative care approach results in a reduction in the desire to hasten death.<sup>14</sup> In Australia, less than 1% of patients receiving inpatient palliative care had a sustained request to hasten their death.<sup>15</sup>

The terms 'end-of-life care', 'specialist palliative care' and 'palliative care' are confusingly used interchangeably in Australia. End-of-life care often refers to care provided during the terminal phase of dying, while palliative care can be considered a broader approach applied to the last period of one's life which may range from days, weeks, months to years.

Moreover, palliative care is a type of medicine that can be practised by any doctor, including subspecialists such as cardiologists and general practitioners, as well as nurses, allied health, family and even volunteers. Specialist palliative care is provided by palliative care physicians or nurses and other allied health professionals who have explicitly specialised in palliative care. A palliative medicine specialist is a medical specialist who is a Fellow of the Royal Australasian College of Physicians and has completed the College's training program in palliative medicine or a Fellow of the Australasian Chapter of Palliative Medicine, or both.<sup>16</sup>

All clinicians should be able to provide palliative care and end-of-life care and refer to palliative medicine specialists for more complex and difficult cases. However, the reality is many clinicians cannot and do not provide it, despite the increasing need for access to palliative services in an ageing Australia.



## Ageing Australia — caring for the baby boomers and beyond

The average Australian woman who is currently 65 years of age can expect to live to 87 years and the average current 85-year-old now will live to 92.<sup>17</sup> The life expectancy at birth is currently 91 years for men and 93 years for women.<sup>18</sup> This is projected to increase to 95 years for men and 96 years for women by 2054.<sup>19</sup> Predictions are that the number of centenarians in 2034 will be 15,700, compared to 4,600 in 2014.<sup>20</sup>

The ageing Australian population is partly a product of continued low fertility rates,<sup>21</sup> combined with the ageing of the baby boomer generation—the large cohort of the population born between 1946 and 1964—and compounded by the impact of improvements in medicine (including public health) that have increased longevity and reduced death rates. The baby boomers' effect on the age structure of the population will peak in 2021. However, the nation will continue to experience unprecedented population ageing as the proportion of older people increases well beyond the life spans of the baby boomer generation.<sup>22</sup>

In 2021, 17.6% of Australians (4 million people)—the peak of the ageing Baby Boomers—will be aged 65 years and over, compared to 1997's 12% of the population (2.2 million). By 2051, of the total expected population of 26 million, 24% or 6.3 million Australians will be aged 65

and over.<sup>23</sup> The number of 'very old' Australians—aged 85 and over—is also forecast to rise from 2% of the population to 5% by 2061.<sup>24</sup> Median population age is another measure of population ageing. Historically a population is considered old if its median age is over 30.<sup>25</sup> The median age of Australia in 2016 was 37; in 2021, it is forecast to be 41, and rise to 46 in 2051.<sup>26</sup>

The increased longevity of the population that is attributable to improvements in health, and to the changing nature of disease, is in turn changing the way people die. The median age at death has increased to 78.9 for men and 85 for women across Australia.<sup>27</sup> It is as high as 80.1 for men and 85.9 for women in South Australia. The majority of deaths occur among those aged 65 or over. The age-standardised death rate in Australia has actually fallen throughout the twentieth century, contributing to longevity.<sup>28</sup> Today it is steady at around 5.5 per 1000 population. However, a greater number of older people means an increase in the crude number of deaths per year; in 2015 there were 159,052 deaths. This is expected to increase to up to 352,100 by 2061 and beyond.<sup>29</sup> The leading cause of death for older Australians has been cardiovascular or heart disease for most of the twentieth century; however, this is likely to be overtaken by dementia—a degenerative disease inextricably linked to ageing.<sup>30</sup>

## The changing experience of health, ageing, illness and death for older Australians

That more Australians will eventually die from a 'disease of ageing' is one example of how longevity has changed the experience of death. Dementia, not even appropriately recognised or recorded prior to 1979 when the death rate was 2.35 per 100,000 population, is now the second leading cause of death.<sup>31</sup>

Greater longevity has fortunately meant in general a greater number of years lived without disability; and this is despite people living with several chronic health issues, as these are managed with modern medicine.

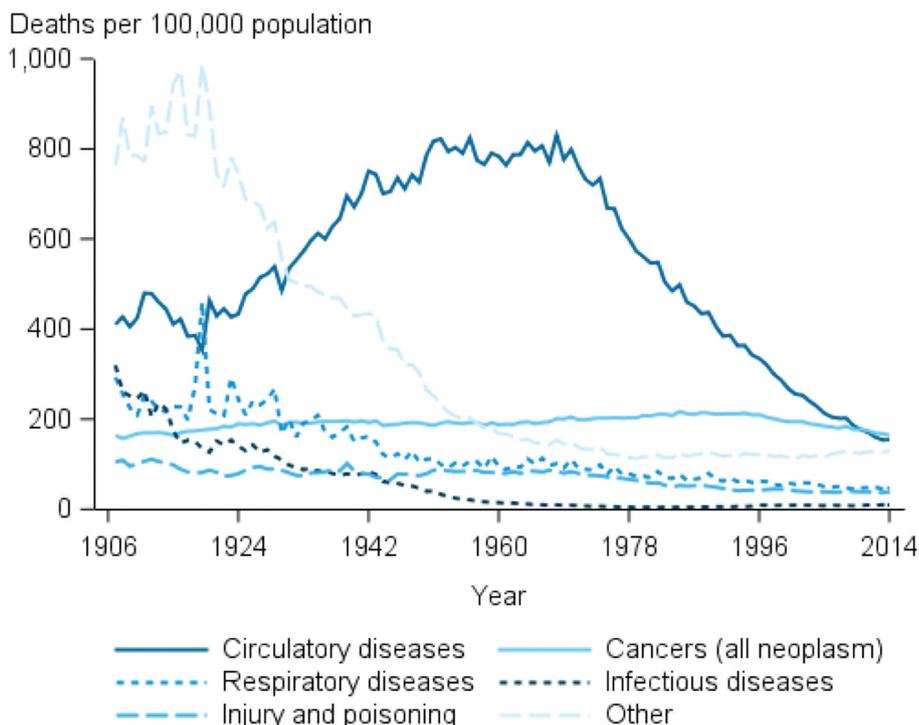
This increased period of active ageing, with chronic disease, is largely attributable to public health, medical sub specialisation and treatment. There are currently 85 specialist titles recognised by the Medical Board of Australia, which doesn't include sub specialisation e.g. interventional cardiologist or subspecialisation e.g. advanced heart failure and transplant cardiology.<sup>32</sup> In the 1970s, there were 20 medical specialties. Specialisation has allowed us to treat diseases so well that the way they impact life, and eventually cause death, has changed. It is an irony that the experience of death (from chronic disease) for many Australians has changed for the worse, despite living longer. Chronic diseases are incurable, co-exist, persist and contribute to a gradual deterioration

of health, symptom burden, loss of independence and ultimately, at increasingly greater ages, death.<sup>33</sup>

Causes of death over the last century tell the story of how Australians have a changed experience of health and death. Circulatory diseases—including cerebrovascular disease (mainly stroke) and ischemic heart disease—experienced a great rise as the dominant cause of death during the twentieth century. However, improved treatments meant the death rates fell; for example from 1,020 male deaths per 100,000 in 1968 to 319 per 100,000 in 2000. Cardiovascular disease still remains the leading cause of death, however the age at which death occurs has changed so that the cumulative number of deaths from circulatory disease began to peak by the age of 45 in 1970, but by the year 2000 it was 85.<sup>34</sup>

Death rates from respiratory diseases, including pneumonia, influenza and chronic obstructive pulmonary disease (COPD), also peaked and then fell collectively over the century. Within the group, COPD has increased relative to pneumonia, which has declined dramatically as a cause of death. Death rates from infectious diseases were around 7 deaths per 100,000 population for females in 2000—a far cry from 230 per 100,000

**Figure 1: Age-standardised death rates, by broad cause of death, 1907-2014**



Source: AIHW GRIM books (Data tables)<sup>35</sup>

in 1907. Tuberculosis was the leading cause of death in women in 1907. Now it is ischemic heart disease, cerebrovascular disease, other heart disease and dementia. However, in the very old age group—those over 85—death from septicaemia has increased since the 1980s, probably because more people are reaching this age and we have increasing antibiotics resistance.

Death rates from cancer at the beginning of the twentieth century were initially half that of circulatory disease. The all cancer death rate then peaked for men in 1980 at 290 deaths per 100,000 population; it has since declined to 234.4 per 100,000 in 2003. Among this category, deaths from lung cancer have continued to rise as a hangover from the previous popularity of smoking. Smoking cessation is also attributable to the reduced death rates from ischemic heart disease, and other cancers over the course of the twentieth century. See Figure 1.

The increase in longevity and rise in the chronic disease burden due to improved treatments is reflected in the typical Australian over 65 having four chronic diseases and visiting the GP roughly 10 times a year—using twice as many health resources as the average Australian.<sup>36</sup> Older people are the largest per capita consumers of medications. GPs prescribe around 120 medications per 100 encounters with those aged over 65<sup>37</sup> who are estimated to account for two thirds of prescriptions filled under the PBS and roughly half the PBS's total expenditure—which is projected to reach over 15 billion dollars by 2023.<sup>38</sup> The amount of polypharmacy, as defined by five or more medications, is increasing proportional to the ageing population and increasing comorbidity of chronic diseases.<sup>39</sup>

Due to medical intervention—that of specialists, GPs and medications—cancer, stroke, ischemic heart disease and respiratory disease have become chronic conditions. Patients need significant support to maintain 'health' until death. It is testament to our health system that most older Australians, rate their health as 'good', confirming the success of medicine in managing chronic diseases and delaying disability.<sup>40</sup> Women aged 65 can expect to live another 9.5 years free of disability, 6.7 years with a disability but no severe or profound core activity limitation, and 5.8 years with a severe core activity limitation such as always needing assistance with either self-care, mobilising, or communication (8.7, 6.7, and 3.7 years for men, respectively). This corresponds to around 86% of Australians aged over 85 requiring some form of assistance compared to 32% of those aged 65–74 years.<sup>41</sup>

Decline and dependence is inevitable, but is now occurring at greater ages with increasing frailty. Older Australians are relying on the medical profession and the health system to keep them well—but prevention and treatment can only do so much before the deterioration into disability and death. However, it is at this time that many Australians will be let down by the health system, doctors and society.

The pattern of life in the months before death is usually evidenced by ongoing exacerbations, readmissions, interventions until an unexpected death in hospital. A study of over 7000 Australian decedents who died from cancer and non-cancer causes found that in the last six months of life, the mean number of hospitalisations per person was 3.1, and these increased—together with emergency department presentations—in the last month of life. The average total cost of health care per decedent in the last six months of life was AUD \$30,001 in the cohort who died from cancer and \$26,131 in the non-cancer comparison cohort. The majority in both cohorts died in hospital.<sup>42</sup>

In 2013–2014 and 2015–2016, almost 50% of Australians died in hospital. Even within the 108 specialist palliative care services, who submitted data to the Palliative Care Outcomes Collaboration (PCOC) in the year 2016, 72% of patients died in hospital.<sup>43</sup> The remaining 50% of Australians likely die in RACFs, or at home, however there is a lack of data clearly demonstrating where Australians die.

Elderly patients with chronic diseases experiencing back-to-back readmissions are rarely given the opportunity to receive care based on their values and choices; such as staying at home rather than living longer with curative intent. Instead, many end up dying suddenly in an emergency department, or after lingering for days, weeks, months or even years in a hospital ward or intensive care bed—to the distress of both the patient and their family.

These experiences demonstrate how the current health system is not fit for purpose in managing older Australians with chronic disease. The doctor-directed model of treatment seems aimed at prolonging life irrespective of costs. Often, a variety of specialists across multiple settings deliver reactionary care in response to specific clinical indications, which are delivered through a prism of 'treat and cure', rather than holistic goal-orientated care that is centred around the needs of the 'whole patient'.

This model is unsuited to managing the changing trajectory of disease, ageing and death among an ever-growing population of older Australians. These people had previously lived well, but eventually succumb to deteriorating episodes of illness as multiple interacting chronic diseases progress. Both patient and health professional expectations—presently blinded by success at keeping people well—mean inevitable crises are managed poorly and without a comprehensive focus on quality of life.

For example, for most Australians quality of life means growing old at home.<sup>44</sup> Already Australians are facing shortages of aged care places, in-home assistance, palliative care and family support. Staying at home will become even more difficult to ensure as a smaller proportion of the population is available to provide and pay for aged care services in an ageing Australia. The

way we care for elderly Australians currently drains services that are already under strain (See Box 1).

As such, the health system—despite being at breaking point in providing care to thousands of older Australians—isn't providing the care they want and need, especially in the last years and months of people's lives. It is an unfortunate response that in light of the

limitations of the health system, many Australians have come to fear 'natural' death and even fear ageing itself. It is even more unfortunate that palliative care, which can provide the holistic value-driven care Australians want at an efficient price, is not widely recognised or widely available—except for the exception to the rule, in the case of cancer patients.

### **Box 1: Services are already under strain**

- In 2015 there were already an estimated 2.86 million people—mostly women aged 55-65 years—providing informal care in Australia. They provided roughly 1.9 billion hours worth of care, the replacement value of which is estimated to be \$60.3 billion.<sup>45</sup>
- The capacity to provide home care will be limited by declining family sizes, increasing rates of divorce and subsequently greater numbers of Australians living alone.<sup>46</sup> The number of people aged over 65 relative to the number of people of traditional working age will almost double, so that for 10 working age people there were 2 people over 65 in 2007 (20%), compared to 4 people over 65 for every 10 working age people (42%) in 2047. This will not only seriously compromise the ability to provide formal care for older Australians, but will undermine the capacity to raise taxes to fund these services.<sup>47</sup>
- It is projected that by 85 years of age, 62% of women and almost 50% of men will require residential aged care.<sup>48</sup> This leads to estimates that 337,500 aged care places will be needed by 2020, increasing to 464,000 places by 2030.<sup>49</sup> In 2015 there were 192,000 aged care places, meaning a 75% increase is required over 8 years.<sup>50</sup>
- An aged care bed costs on average \$73,000 a year and is mostly subsidised by the Commonwealth.<sup>51</sup> Aged care funding is expected to double by 2055 as the per-person aged care expenditure increases from \$620 to \$2,000.<sup>52</sup>
- Increased longevity not only drives demand for supportive services and long term residential care, but also for shorter-term, emergency and inpatient medical care. The number of emergency department (ED) presentations across Australia increased by 6.5% from 2004-05 to 2013-14 for those 65 years and older.<sup>53</sup> This increase was even greater in the 85 years and older population, with an 8.3% increase in presentations.<sup>54</sup>
- A corollary of increasing ED presentations are increased hospital admissions, as elderly patients are more likely to be admitted and have a greater length of stay.<sup>55</sup> Public hospital expenditure is already on average four times greater in the 85 years and older group versus the average across all ages.<sup>56</sup> By 2050, the number of annual hospital bed days is expected to rise by 150% for those aged 60 and over and by 320% for Australians 85 years and over.<sup>57</sup>



## Preferential treatment – more palliative care for cancer patients

For over a decade, there has been domestic and international evidence that cancer patients are overrepresented in receiving and accessing hospital and community palliative care services.<sup>58</sup> In Western Australia, 68% of people dying with cancer accessed specialised palliative care, compared to 8% of people dying from a non-cancer condition.<sup>59</sup> This is despite evidence that non-cancer patients are just as likely – if not more likely – to benefit from palliative care.

Due to advances in medicine and technology, many malignancies have transformed from being rapidly and devastatingly aggressive to chronic conditions. The 5-year survival in Australia from all cancers increased from 48% in 1984–1988 to 68% in 2009–2013.<sup>60</sup> Palliative care has worked hard to form an allegiance with oncology. There is a wealth of evidence to suggest that palliative care for cancer patients and their families improves outcomes including symptom control, anxiety and reduced hospitalisations.<sup>61</sup> Perhaps most influentially, a study comparing palliative care to standard care in patients with metastatic terminal lung cancer determined that those receiving palliative care

not only had a better quality of life with less depression but survived longer, despite receiving less aggressive treatment.<sup>62</sup>

Cancer, unlike lung disease is far more likely to induce thoughts of mortality in patients and doctors – which has arguably led to the increased prescription of palliative care in these groups. There are a myriad of calculators, studies and guidelines pertaining to specific malignancies and the likelihood of five- and ten-year survival on the basis of numerous factors, such as patient age and the stage. Staging of malignancy is an established practice enabling doctors to recommend evidence informed therapy based on survival predictions.

As such, at diagnosis, prognosis is more likely to be discussed and this discussion is facilitated by a series of well-researched prognostic indicators. Early and more accurate prognostication presumably enables clinicians, patients and their families to have a more open discussion about the future and make informed decisions regarding palliation, life and death.

## Even less palliative care for chronic disease sufferers

Despite being more prevalent, patients dying from non-malignant chronic conditions are less likely to have conversations with their doctors about their prognosis and survival, in part because their deaths are more unpredictable.<sup>63</sup> For example, using a mortality tool on a cohort of heart failure patients, the predicted median survival was two years while the actual median survival time was 21 days.<sup>64</sup>

Benefits have been shown for palliative care for patients suffering from a wide range of illnesses; including COPD, cystic fibrosis, pancreatitis, heart failure, osteoarthritis, end stage renal disease, HIV, and neurological conditions including stroke.<sup>65</sup> A study comparing various patients found that in the last three months of life, those suffering COPD were the least likely to be referred for palliative care (20%), after heart failure (34%), severe dementia (37%) and cancer (60%).<sup>66</sup> In a West Australian study of 1071 people who died in 2005-2006, 61% died in hospital and of these a greater proportion had a non-cancer diagnosis, and were from rural areas—demonstrating the characteristics pertaining to reduced access to palliative care.<sup>67</sup> The Victorian government estimates that at least 50% of people dying from diseases such as heart failure would benefit from palliative care.<sup>68</sup>

Heart failure has a complex and varied prognosis, in which patients are likely to experience a high burden of symptoms that progress with time e.g. breathlessness, anxiety and fatigue. It is a life-limiting illness and the population experiencing these symptoms is increasing—the lifetime risk of developing heart failure is around 20% for all adults and the mortality rate is higher than most cancers.<sup>69</sup> Studies suggest that many of these patients suffer poor quality of life exacerbated by frequent hospital admissions and would prefer their care to focus on 'comfort'.<sup>70</sup>

There are limited data demonstrating how many Australians with heart failure access palliative care. However, research suggests the experience of patients with heart failure is one of ignorance of their condition, poor communication with physicians, a focus predominately on curative treatment, poor end-of-life planning and symptom burden.<sup>71</sup> A study comparing

patients with heart failure to those with cancer found those with non-malignant disease had more concerns around medications, social isolation and progressive loss, while receiving less palliative care and less co-ordinated care. This led researchers to conclude that "care for people with advanced progressive illnesses is currently prioritised by diagnosis rather than need."<sup>72</sup>

Arguably, nephrologists should have greater links with palliative care as cessation of dialysis is a common occurrence. However, even this doesn't always lead to a palliative care referral. Within Australia there are increasing numbers of elderly, nursing home patients with chronic co-morbidities and end stage kidney disease (ESKD) beginning dialysis.<sup>73</sup> Some evidence suggests there may be little value in terms of survival and quality of life for frail patients; indeed, the trajectory of dialysis for older patients is marked with frequent hospital presentations and dialysis-related complications. This raises question of its benefit as the extension of life may be offset by poorer quality of life.<sup>74</sup> Moreover, mortality among the elderly continues to be high even with renal replacement therapy.<sup>75</sup>

There is limited ability to predict the likelihood of benefit from dialysis. As such, whether patients are making a truly informed decision to take on dialysis rather than conservative treatment is being questioned. One study has called for the inclusion of palliative care into ESKD guidelines to ensure that palliative options are considered—and most importantly, discussed with patients and their families—before dialysis has begun.<sup>76</sup> All sub-specialities should be able to provide palliative care, have palliative care based guidelines, and ensure patients make informed decisions about life prolonging treatments.

However, throughout Australia the provision of palliative care for chronic disease sufferers is patchy at best. Patients with cancer are more likely to receive and benefit from this care. Even among this population, palliative care is still arguably insufficient and untimely—however it is vastly superior to the care provided for non-cancer patients.

## The palliative care gap in Australia fosters myths about death

Murtagh et al. (2011) determined that in high income countries up to 82% of people who die need palliative care. Last year, 159,000 people died in Australia. Applying Murtagh's statistic this equates to roughly 130,300 people requiring palliative care. In 2015-2016 only 14,300 patients received an MBS-subsidised palliative care medicine specialist service in Australia.<sup>77</sup>

Clearly there is a gaping chasm between the supply of, and the real demand for, palliative care in Australia. Lack of access to palliative care is a symptom of the larger structural problems in the Medicare system, which result in service gaps for chronic care, including palliative care. (See Box 2)

However, calls for more palliative care services are often based on the belief that too many Australians die in hospital. This applies a narrow definition of palliative

care as purely 'end-of-life care', and distorts the broader benefits that good palliative care can provide for patients.

Palliative care is often simplistically seen as the answer to the problem posed by the survey finding that up to 70% of Australians would prefer to die at home, rather than in a hospital.<sup>79</sup> However, the veracity of this statistic has been questioned by a number of studies. Agar et al. (2008) in an Australian longitudinal study made sure to delineate between asking patients and their carers where they would prefer to be 'cared for' and where they would prefer to die. This is an important distinction—not made in most studies of death preferences. Together with missing data and the exclusion of patients with 'no preference', caution should be exercised when interpreting data suggesting

### Box 2: Medicare's Structural Flaws and the Palliative Care Gap

- It is well recognised within the Australian health policy debate that the chief systemic barrier to better outcomes and patient-centred care is the fragmentation of health services owing to the structural flaws in the complex funding and service arrangements that distinguish the Medicare system and the federal-state split in health responsibilities.<sup>78</sup>
- The federal government runs and funds the primary care part of Medicare. This oversees the Medical Benefits Scheme (MBS), the principal function of which is to pay benefits to meet or assist in covering the cost of fees mainly for GP care, medical imaging and diagnostic services, and other specialist ambulatory and inpatient attendances and procedures on a fee-for-service, on-demand, and open-ended basis. The federal government also gives state and territory governments a fixed amount of money each year to partially fund the operation of public hospitals. Federal hospital funding is provided on condition that all Australians are entitled to receive 'free' public hospital care; but otherwise state and territory governments are responsible for hospital governance and administration.
- Jurisdictional complexity—with the result being that neither level of government is solely accountable for the entire healthcare needs of patients—distorts responsibilities and incentives in ways that partially account for the service gaps for chronic patients. Medicare provides access to separate sets of acute care services. It does not provide access to the full range of medical, pharmaceutical and allied healthcare that might ensure chronic conditions are properly managed to stop patients ending up in hospital. The fragmented and 'siloe'd' services patients receive is accentuated by the fact that aged care services are provided under yet another separate, federally-funded program.
- Palliative care is an important example of how there is no room within the current health (and aged care) system and its funding arrangement for flexible, innovative, integrated and comprehensive care. Instead these services are lost in the gap between what the federal government pays for and the state government funds. Such service gaps are also caused by the way current funding arrangements reward separate occasions of hospitalisation and GP activity over integrated community based multidisciplinary care – of which palliative care is an example.
- Hence the lack of access to palliative care services in Australia is a demonstration of how Medicare is not really a comprehensive health system but rather a doctor and hospital centric system. The biggest gaps exist when patients leave hospital or aren't in a GP clinic, i.e. where community based multidisciplinary palliative care should exist. However, in a fee-for-service system that rewards activity rather than outcomes, and is distinguished by siloe'd funding for hospital and non-hospital services, there is no incentive or funding available to provide truly patient-centred services. Palliative care is the square peg that doesn't fit into the round hole that is the Medicare system.
- Closing the palliative care 'gap' therefore requires addressing the inherent problems within Medicare, which rewards a rigid set of proscribed medical and hospital activity, rather than the delivery of holistic integrated care for dying Australians.

most patients wish to die at home, when in fact many patients and their families ultimately prefer death not to occur at home.<sup>80</sup> (See Box 3)

Certainly, most Australians wish to *age* at home and the holistic approach of palliative care can facilitate this.<sup>85</sup> However, the majority of Australians are likely to continue to die in hospital, and in residential aged care facilities (RACFs). Death in hospital or a RACF is not the problem—death without palliative care is the real problem. Hospitals must be equipped to provide this type of care both in terms of workforce, culture and environment. Similarly, palliative care should

be readily available to thousands of elderly in RACFs. Demonising the idea of death occurring outside the home is an oversimplification of a bigger problem and unhelpfully adds to the growing premise that natural death in a hospital or RACF is undesirable. The current provision of palliative care—as properly defined as care encompassing quality of life before death—in Australian hospitals and among residential aged care facilities is insufficient. Improved palliative care in these settings will not only contribute to better patient experiences and quality of life but will improve cost effectiveness both by preventing hospital admissions and also within hospitals by preventing unwanted interventions.

### **Box 3: The 70% myth**

- The original statistic comes from a 2006 South Australian study that asked 2,652 individuals over the age of 15 “if they were dying of a terminal illness such as cancer or emphysema” where they would prefer to die<sup>81</sup>
- Agar et al (2008) also found that preferences for place of care and place of death not only differed between patients and caregivers but changed for both—and not synchronously—over time. Their findings suggest a trend from home being the preferred place of care to an inpatient setting as death approaches.
- Agar et al (2008) concluded that asking patients ‘where they want to die’ is not sufficient in determining the nuances that exist as patients live before death, deteriorate and death becomes more acute.
- Previous studies have concluded that relative to other considerations such as being pain free, place of death is a low priority for those who are dying.<sup>82</sup>
- Other studies have also considered caregiver perspectives and found that preference for home care reduced as death became more imminent (from 92% to 42%), for patients there was a similar decline (90% to 50%) in the last week of life.<sup>83</sup>
- There are numerous reasons for this change of mind; such as lack of carer or family resources, concerns about symptom control and comfort, the ability of family to provide care, concerns from patients about being a burden, as well as unexpected medical events or deteriorations.<sup>84</sup>



## The lack of access to palliative care

The overwhelming majority of patients with a life-threatening illness do not receive specialist palliative care. There is unequitable access across the country and at present the likelihood of receiving palliative care is “nothing short of a lottery” and depends on your “location, diagnosis, cultural background, age, and (your) health professionals’ education”.<sup>86</sup> Many continue to miss out, and this includes not only patients but families so in need of bereavement support. It is ironic that the two places where most Australians die are arguably two places you are least likely to receive palliative care, acute hospitals and RACF.

### Palliative care in Australian hospitals

Studies have identified that at least one fifth of hospitalised patients at any given time have needs that would benefit from palliative care.<sup>87</sup> Of hospital deaths, some data suggests up to 46% receive palliative care while other sources highlight as little as 3% receive palliative care.<sup>88</sup> However, the current hospital system does not readily enable this model of care to be delivered. Firstly, because treating clinicians do not consider, or are reluctant to refer to, palliative care—as seen in both metropolitan Melbourne and Sydney hospitals, where most patients in need were not referred for palliative care.<sup>89</sup> Secondly, even when palliative care is considered, there are barriers—sterile rooms, high turnover of busy staff, noisy atmosphere, restrictions on visitors,

overcrowding and inadequate clinical training—to the provision of genuine, timely, considered care that incorporates a patient’s family, their surroundings, their symptoms, and concerns.

Virdun et al (2015) identified that for palliative patients, the main themes of need were; maintenance of sense of self, expert care, effective communication and shared decision-making, respectful and compassionate care, adequate environment for care and family involvement. While for families, the themes were as follows: maintenance of patient safety, preparation for death, care extending to the family after patient death and enabling patient choice at the end of life.<sup>90</sup> It is not surprising that not all dying inpatients receive palliative care and that even when they do it is often not best practice from a specialised palliative care team.<sup>91</sup>

Inpatient specialist palliative care not only ensures a more comfortable period of living for patients and their families before death, but is also more cost effective. An Australian study corroborated by international findings suggests that palliative care associated cost reduction in mean total cost for an episode of terminal care was \$6,662 for cancer patients and \$7,477 for other patients. There were also savings in private hospitals, although they provided less palliative care.<sup>92</sup> These savings largely came about due to a reduction in ICU admissions and operative procedures. In the US, similar cost savings have been found and it is estimated that

\$84 million to \$252 million could be saved annually in New York State alone if all hospitals with more than 150 beds had a specialist palliative care service—and their services were utilised.<sup>93</sup>

## Palliative care in residential aged care facilities

Access to palliative care for residents in aged care facilities has been shown to increase the likelihood of dying at home rather than hospital.<sup>94</sup> However, older Australians without cancer from aged care facilities are the least likely to receive palliative care.<sup>95</sup> In Australia (2015-16), only 9,144 aged care residents had an Aged Care Funding Instrument (ACFI) assessment that indicated the need for palliative care—this corresponds to roughly 4% of residents being assessed as requiring palliative care. This must be a gross underestimate and demonstrates a failure to recognise the needs of residents, especially given that over a third of residents die within a year of admission.<sup>96</sup> Previous studies have determined that palliative care in Australian RACFs is sub optimal—contributing to poor pain management, unwarranted hospital admissions, and resident and family upset.<sup>97</sup>

Experts speculate the ACFI is misrepresentative because the addition of palliative care needs for some residents does not add to their overall remuneration. Additionally, the requirements for a RACF to claim for palliative care may be unachievable, as care must be provided by a capable Registered Nurse (RN) usually under direction from a GP or palliative care specialist.<sup>98</sup> There is a higher proportion of ACFIs claiming for palliative care in inner regional RACFs (69 per 100,000) compared to the outer regional (38) demonstrating varying access to these specialists.<sup>99</sup> Moreover, RACFs are encouraged to claim for palliative care when a patient is terminal; however, the benefits patients and families glean from palliative care can be seen much earlier in a patient's life than the last few hours or days.

In Australia, the emergency transfer of elderly patients and residents from aged care homes is frequently cited as a cause for concern and a source of waste. Ambulance Victoria's metropolitan emergency transportation data shows the crude rate for emergency transfers has increased by 55% since 1990 and this increase is being disproportionately driven by those over 85 years of age.<sup>100</sup> However, considering the current system—a lack of community and residential palliative care, inadequate numbers of RNs, a paucity of medical and family planning, these transfers are often warranted. Up to 95% of residents experience an emergency transfer each year.<sup>101</sup> On presenting to ED, these patients are usually unwell with multiple complex comorbidities, and are at a high risk of firstly being admitted but then suffering

in-hospital complications including pressure ulcers and delirium.<sup>102</sup> Up to 80% experience invasive interventions and 34% die in hospital.<sup>103</sup> It is not only the emergency transfer of these patients that should be questioned; it is the care available to them in the community and RACFs, as well as their admission to hospital and the type of care they receive in hospital.

There is evidence that some emergency department presentations and hospital admissions are the direct result of a lack of community palliative care resources.<sup>104</sup> Having expressed a wish to die at home, having a palliative 'treatment goal' and receiving palliative care by a GP, reduces the likelihood of being hospitalised in the last three months of life.<sup>105</sup> Patients who are either unable to access palliative care services at home or unable to access services acutely i.e. after hours, are more likely to be transferred by ambulance to hospital.<sup>106</sup>

Hospitalisations account for the significantly higher health care costs per person in the last six months of life. Patients with cancer who have not received palliative care are more likely to utilise the health system. In a recent study of decedents from NSW with and without cancer in their last six months of life, decedents with cancer visited the ED once, had three hospital admissions, participated in 90 clinician visits/procedures and were prescribed 41 medications at an average cost of \$30 001 per decedent, roughly \$4000 more on average than patients without cancer.<sup>107</sup> Worryingly only 10% of the cohort (total = 4271) dying from cancer and 1% of the comparison non cancer cohort (total = 3072) received a palliative care service whilst they were in hospital. Persons who died outside of a hospital had at least 42% lower overall costs compared to those who died in hospital.

A palliative care program, including an interdisciplinary approach to home based end-of-life care, provided to over 558 patients in the US, demonstrated fewer emergency department visits, days in hospital, and clinician visits than those in the control group. There was a 45% decrease in costs in the group receiving palliative care.<sup>108</sup> Community based in-home palliative care is more likely to be associated with significantly increased patient satisfaction and a reduction in the utilisation of medical services, lending itself to be both a valuable patient centred approach as well as a cost effective one.<sup>109</sup> However, access to in-house palliative care is also dependent largely on location, with lower socioeconomic areas being under serviced.<sup>110</sup> Of the palliative care related public hospital separations more people are from lower socioeconomic areas (26 per 100,000 population) than those living in higher socioeconomic areas (14 per 100,000 population)—suggesting higher socioeconomic patients are more likely to be receiving in home palliative care services and die at home.<sup>111</sup>



## Another challenge: the funding of palliative care in Australia

There is significant variability in the provision of palliative care across facilities and across the country. Patients with cancer are more likely to receive palliative care, but even this cohort is under-served. Access to palliative care is even more limited for marginalised groups such as Indigenous Australians, patients with a disability and those living rurally. As determined by the Grattan Institute report in 2014,<sup>112</sup> palliative care services in Australia are fragmented and inadequate in supply. This was corroborated this year by the Auditor General of NSW stating that “NSW Health has a limited understanding of the quantity and quality of palliative care services across the state, which reduces its ability to plan for future demand and the workforce needed to deliver it.”<sup>113</sup>

Even within a large tertiary hospital in Melbourne, less than half the patients requiring palliative care were referred for such services—despite the fact that when received, palliative care was associated with improved end-of-life medication orders, improved communication with patients and families, and increased cessation of futile treatment and interventions.<sup>114</sup>

In a 2010-2013, a parliamentary inquiry committee determined that there is much inconsistency in the standard of palliative care delivered in Australia and this is likely due to the complexity of the funding framework (See Box 3).<sup>115</sup> The funding of palliative care services is varied within states and across the country. In NSW, the Local Health Districts (LHDs) decide how to deliver services that meet local needs under service agreements with the Ministry of Health.

It is very difficult to grasp how much palliative care is being provided, to whom and at what cost. For example, in NSW the community palliative care services cannot provide care to patients ‘out of area’. So if you live just across the Parramatta river from Concord Hospital, for example, and you are admitted to Concord, you are not able to receive community palliative care from the Sydney Local Health District at home because you reside in the Northern Sydney Local Health District—and the types and amount of services between these two districts differs.

However, differences in service provision are difficult to describe, given the lack of data regarding access and outcomes of palliative care nationwide. The paucity of data to assess the provision of palliative care services extends to admitted patients and patients in the community and primary care settings. This contributes to a failure of accountability within the sector, an inability to plan for the future and has resulted in the ad hoc nature of service provision.<sup>116</sup> Over a decade ago, a study in England determined if patients who had non-malignant disease were provided with palliative care at the rate cancer patients were, it would mean a 79% increase in the caseload for palliative care services.<sup>117</sup> Meeting unmet needs for palliative care in Australia—including providing for marginal groups such as Aboriginal and Torres Strait Islanders—would certainly raise significant workforce issues (See Box 4).

## **Box 4: The variety of funding**

### **Hospital funding**

- The majority of palliative care is provided by the public hospital sector and can be funded under the Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP).<sup>118</sup>
- AN-SNAP was established as part of activity based funding in 2013 after the National Health Reform Agreement in 2011. The IHPA has recently released AN-SNAP Version 4 to better reflect current and evolving clinical practice in subacute services, and has introduced paediatric classes for palliative care.
- Some public hospitals use sub-acute funding to subsidise palliative care provided by staff specialists within the hospital. However, sub-acute funding is packaged, and it is up to the discretion of the state/hospital to determine how much is spent on palliative care. For example, in 2009-2010 "Of its \$39,973 sub-acute funding South Australia committed \$11,970 to palliative care. On the other hand, Queensland allocated none of the sub-acute funding to palliative care."<sup>119</sup>
- There have been calls to separate palliative care from the sub-acute funding, however this was recently rejected by the Australian government.
- Other inpatient services receive block funding to provide inpatient palliative care under the Health Services Act 1997 and service level agreements. Often these organisations also provide community care and in-reach services (e.g. to RACFs).

### **Specialist funding**

- Specialist palliative care physicians can claim under the Medicare Benefits Scheme. In 2015-2016 \$5.6 million was paid in benefits for palliative care specialist services for 74,300 occasions. This has increased by 60% over the past five years, reflecting the significant trend towards the increasing need for palliative care.<sup>120</sup>
- Importantly, palliative care can be provided—and should be provided—by other specialist clinicians such as geriatricians and oncologists. However, they are unable to claim care as a palliative care related service under the MBS.

### **General practice funding**

- There are no palliative care Medicare Benefit Schedule (MBS) specific items that can be used by GPs. Instead GPs use other items to deliver palliative care, such as a GP management plan. This remuneration likely underestimates the complexity of these patients and the time taken for appropriate care to be given to them and their families.
- It is consequently impossible to quantify the amount of palliative care being performed by general practitioners, or the associated costs. Not only does this make it difficult for policy makers to assess and predict the needs for the future, inadequate remuneration is a disincentive to providing this care.
- Providing palliative care is an essential skill for GPs and the need for this will only increase. GPs should be encouraged to upskill and deliver this essential care by at the very least having an identifiable and separate MBS items to claim for this care.

### **RACF funding**

- RACFs claim for palliative care under the ACFI, which likely underrepresents the real need for palliative care.
- The paucity of palliative care services in RACFs under the current funding model may well be due to the inadequacy of GPs and a lack of access to specialists including nurses. Registered nurses (RNs) are essential to the delivery of palliative care with RACFs.
- Many RACFs cannot provide palliative care because of GP skill and a lack of RNs. In 2016, RNs made up 15% of the residential aged care workforce—down from 21% in 2003 despite an increase in the number of residents. One does not have to look far to appreciate how understaffed RACFs are.
- All RACFs should be capable of providing palliative care.

### **Informal care**

- Informal carers do not receive training or supervision and are estimated to provide at least \$6.5 billion worth of care in Australia per year.<sup>121</sup>
- Carers are often spouses—who may be older than the patients themselves—or other family, friends and neighbours. Most are co-resident, spending 24 hours a day with the patient. Even if people do not die at home, 90% of palliative care patients spend the majority of their time living before death at home supported by a carer.<sup>122</sup> The needs of carers cannot be overestimated—physically, economically, socially and psychologically—in light of the fact that the person they are investing so much time, energy and emotion in will ultimately pass away.
- The cost of paying for 24 hours' worth of active care in NSW is roughly \$1,332.00 per 24hrs, not including weekend or public holiday rates, adding up to \$9,324 per week.<sup>123</sup>
- There are increasing numbers of older adults living alone, and—together with reduced family sizes and increasing work place commitments—there is little likelihood that the amount of this informal care will continue to meet the needs of our ageing population.

### **Box 5: The palliative care workforce; underfunded and understaffed**

- In 2015, specialist palliative care physicians made up around 1 in 140 (0.7%) of the employed medical specialists in Australia.<sup>124</sup> This corresponds to around 213 palliative care specialists working in Australia, compared to 1,040 cardiologists and 511 geriatricians. There were 85 doctors in palliative care training in 2015 compared to 177 cardiology trainees.<sup>125</sup>
- In 2015, the majority of palliative care physicians were female and worked in major city hospitals. Across Australia there were 0.9 FTE specialist palliative physicians per 100,000 population and this ranged from none in the ACT to 1.8 in Tasmania.<sup>126</sup> There has been a roughly 50% increase in the number of specialist palliative care physicians since 2012. Nationally, there were 12.0 FTE palliative care nurses per 100,000 population in 2015 making up 1.1% of employed nurses.<sup>127</sup>
- In 2003 Palliative Care Australia (PCA) recommended 1.5 FTE palliative care physicians per 100,000 population for the reasonable provision of palliative care services nationwide. 14 years later, the gap is ongoing.
- One solution is a greater emphasis being placed on palliative care throughout the academic life of a doctor. Unfortunately, there is still inadequacy in palliative care training reported by physicians, surgeons, medical students and advanced trainees.<sup>128</sup>
- But it is not only doctors who provide palliative care. To face the challenges of a declining workforce combined with an ageing population, health professionals are going to need to step beyond the traditional boundaries of their disciplines.
- A recent proposition for nurse practitioners to prescribe palliative care medications was 'supported in principle' but is ultimately under the jurisdiction of the Australian Health Practitioner Regulation Agency (AHPRA) and likely to be a difficult reform.

## Palliative Policy – perfect on paper but inadequate in practice

Palliative care policy in Australia is supposedly guided by *The National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life*. This replaced the first National Palliative Care Strategy: *A National Framework for Palliative Care Service Development 2000* which began in 1998. The more recent strategy is actioned by the National Palliative Care Projects (NPCP). These projects are unique, ranging across Australia from small local projects to multi-institutional collaborations. Each received an array of government funding as they were seen to align with the goals identified in the 2010 Strategy.

A recent review of the strategy and the associated NPCPs revealed some successes and significant limitations.<sup>129</sup> Pointedly, the strategy itself was often not actually identified among local- and state-based professionals or plans—leading to duplication, misalignment and diffusion of responsibility. For example, in NSW the Agency for Clinical Innovation Palliative Care Network was established in 2012 to “drive continuous improvement in palliative and end-of-life care for all people approaching or reaching the end of their life in NSW” as instructed by the *NSW Government plan to increase access to palliative care 2012-2016* with \$35 million worth of funding.

This strategy is yet to be successfully implemented, reviewed and critiqued. The Clinical Excellence Commission also in NSW has an end of life program, and similarly most other states and territories have their own palliative care plan. Whether or not any of these plans or programs have been comprehensively realised remains to be seen, and likely contributes to the variation in services.

The variability of care provided by a wide range of professionals calls into question the consistency in quality of care. Currently, the only national standards for providing palliative care have been created and published by the non-government organisation Palliative Care Australia (PCA) in 2005. It describes 13 national standards.

The Australian Commission on Safety and Quality in Health Care (ACSQHC) is responsible for developing the National Safety and Quality Health Service (NSQHS) Standards. These apply to palliative services. However, palliative care has not been specifically addressed in the standards. The Commission is currently writing the National Safety and Quality Health Service (NSQHS)

Standards (second edition) which addresses the previous gaps noted in the provision of standards for palliative care within public hospitals.

There are no formal standards or accreditation benchmarks for the provision of community and NGO outpatient palliative care services. The Palliative Care Outcomes Collaboration (PCOC) is one project that has attempted to service the data gap required to assess and drive services. There are also no nationwide consistent requirements for advanced care directive documentation.

Advanced care plans demonstrate that conversations about end-of-life care result in better outcomes and improve clinician decision-making. Advanced care directives (ACD) are tangible documents that form part of advanced care planning—which involves conversations with families and clinicians. The laws underpinning ACDs differ across Australia.<sup>130</sup> A national survey found that 14% of the population has an ACD,<sup>131</sup> while other studies have revealed in NSW only 5% of residential aged care residents had an ACD.<sup>132</sup> There have been a number of attempts to increase the uptake of ACDs within Australia; including from the RACGP, various websites, interest groups and the NSW Health Advance Planning for Quality Care at End of Life Action Plan 2013–2018. However, their widespread implementation remains to be seen.

The use, understanding and legal framework of ACDs across the country are extraordinarily varied. The legal ramifications are poorly understood, and the directives themselves are often misplaced, clouded with uncertainty and poorly documented<sup>133</sup>. The government needs to take responsibility for creating a clear and comprehensive policy and legal framework on a national level regarding advanced care planning. However, in response to a senate inquiry this year, the government rejected the recommendation to create a uniform national model of legislation—claiming that the National Framework for Advance Care Directives (the Framework) commissioned in 2011 provides guidance on policy and best practice in relation to advance care directives for the states and territories. Clearly, six years later this is not enough.

A recent review of palliative care within NSW led to the recommendation that NSW Health needs an “integrated palliative and end-of-life care policy framework”. More importantly it needs to implement this framework.<sup>134</sup>

**Table 1: National Palliative Care Strategy 2010 Goals**

Goal area	Number	Goal
Awareness and Understanding	Goal 1	To significantly improve the appreciation of dying and death as a normal part of the life continuum.
	Goal 2	To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.
Appropriateness and Effectiveness	Goal 3	Appropriate and effective palliative care is available to all Australians based on need.
Leadership and Governance	Goal 4	To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.
Capacity and Capability	Goal 5	To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

## How to improve life before death? Policy makers, doctors and society

Policy makers must move on from paying lip service to palliative care and start by bolstering the workforce. Funding needs to be directed towards increasing the number of RNs and doctors in particular to provide this care nationwide. Seemingly a simple solution, the likelihood is this will have significant implications for the cost of the system as a whole going forward, given the cost effectiveness of a palliative care framework. The NSW Auditor General similarly recommended that there be a “workforce plan which supports the policy framework and is linked to the Health Professional Workforce Plan 2012–2022.”

State and federal governments should also consider adopting an ‘investment approach’ to palliative care provision. Undertaking a longitudinal actuarial study of the lifetime costs of chronic disease in the latter and last stages of life without palliative care will help inform decisions about service and funding redesigns that will lead to greater provision and access to cost-effective palliative services. Understanding the real costs of the existing fragmented health and aged care systems would help encourage rational policy responses from federal and state governments. This could drive a national approach to palliative care, encompassing even a joint federal-state funding instrument. State and federal governments should also think boldly about ways to ensure comprehensive access, integrated services, accountability and choice. This should involve exploring consumer-centred and commissioning-based models of palliative care that focus on “improving outcomes and delivering quality services, regardless of organisational boundaries and constraints”<sup>135</sup> with the interests of the patient and their families at the centre.

### The medical profession must do better

While the policy challenges are real and significant, the delivery of timely and quality palliative care will ultimately depend on the willingness and ability of the medical profession to identify and refer patients. It is an unfortunate reality that despite decades of research, policies, funding and public campaigns, the rest of the medical profession has been alarmingly reticent to discuss patient values and goals, and either provide palliative care or refer them for specialist palliative care in a timely manner. A study by the Royal Australian College of Physicians revealed “only 17 per cent of physicians believed doctors were always aware of their patients’ death-related preferences.”<sup>136</sup>

The majority of general practitioners completing a survey, mostly from metropolitan Melbourne (n=56), did not routinely discuss end-of-life care or advanced care planning with their patients. In providing palliative care, 31% did not feel confident in doing so and 63% identified poor correspondence from hospitals, a lack of palliative care guidelines (50%), lack of access to a specialist (38%) and lack of knowledge about local services (39%) as barriers to providing care for palliative

patients.<sup>137</sup> A 2016 study of 178 patients with advanced cancer discovered that only 9 (5%) had a completely accurate understanding of their illness.<sup>138</sup> Other studies have suggested that patients receive more information about their illness from other patients in the waiting room than from their doctor.

Doctors need to start ensuring care—for elderly patients, at the very least—is made in partnership with patients and their families with their overall goals in mind. All doctors should be capable of providing palliative care—even at the same time as curative care—and more need to be willing to refer patients for specialist services and do so before the terminal phase of life. Even studies demonstrating how few doctors discuss end of life preferences highlight the narrow-minded focus on death, instead of life before death. Doctors also need to change common colloquial terms such as ‘ceiling of care’ and ‘withdrawing care’ that unhelpfully imply an end to ‘caring’—and step away from the idea that when talking to patients about end of life you are offering a ‘medical’ point of view.

Palliative care must become integrated into subspecialty training. And, just as resuscitation skills are taught and mandated, the same should apply to having ‘difficult’ conversations with patients and their families. More needs to be done to alleviate the lack of confidence within the medical community to discuss an issue that should be core business. Having discussions about life and death will become imperative and doctors need to start fulfilling their individual and societal obligation to have these conversations and—more importantly—provide this care. This expertise must extend beyond the realm of oncology and metropolitan Sydney.

The palliative care profession itself needs to reclaim the alarmist provocations about death and dying. In doing so, it must reposition itself so as not to be seen as solely providing terminal care, but as clinicians who have a holistic view of care and provide care based on patient and family values. Palliative care ensures that, no matter how far or near death is, one’s life is led as actively as possible with autonomy and dignity. Palliative care in Australia should align itself as being complementary to active treatment as opposed to being mutually exclusive. There is already a move to rename palliative care as ‘palliative and supportive care’.

Palliative care is much more than ensuring a ‘good death’ and should be provided based on a patient’s symptomatology and their goals for life. This will require a significant shift in the thinking of much of the health profession—and it will also require a societal shift.

### The Australian public deserve better

In the US 90% of adults interviewed had no, or only limited, awareness of palliative care. However, when educated, more than 90% said they would want palliative care for themselves or for their families and

that it should be universally available.<sup>139</sup> Australians perceive that the experience of ageing, health and death is changing. However, despite the best attempts of a series of programs and lobby groups to encourage Australians to discuss ageing, death and dying, this domain has been overwhelmed by those pushing an agenda of fear and personal stories. In light of the limitations within the health system explored here, and the lack of palliative care, this message is dominating the minds of those approaching old age. Palliative care is a welcome solution to the visible deficiencies in the system but is unable to receive the attention it deserves.

There is hope however, that demand for improved quality of life and palliative care will come from the community. The current cohort of patients who think 'doctors know best' are being gradually replaced (much to the chagrin of doctors) by tech-savvy, information-seeking baby boomers who are far less passive about the kind of care they want and need. These patients want autonomy, they want to make informed decisions, they want data, they will seek second opinions and they arguably want quality of life over quantity. Most of all, they do not want to live or die the way their parents and grandparents did.

Doctors already wary of the increasingly informed patient must put their pride and pedestals away and be willing to engage with patients as partners. Together, there is much common ground to be found—and the more common this practice becomes the easier it will

be to make better decisions about patient care. As an American doctor forecasting the future of medicine put it:

The more patients and families become empowered, shaping their care, the better that care becomes, and the lower the costs. Clinicians, and those who train them, should learn how to ask less, "What is the matter with you?" and more, "What matters to you?"<sup>140</sup>

Due to defective policy in relation to palliative care and ACP, it will continue to fall to families to have conversations so that when the time comes to make value based decisions, they are made without hesitation based on patients' wishes; rather than being reactionary and chaotic because a piece of paper cannot be found or interpreted. This is imperative as more and more older Australians experience episodes of health crises and receive care that would have been unwanted.

Communities—and by extension, society—need to provide options for older people who seek supportive care to remain as active as possible. Whether that be by volunteering, engaging in work, being able to travel or contribute in some way. The common thought that one would 'rather die than be in a nursing home' (or pursue more radical alternatives to forestall natural death) should challenge policy makers and doctors to ensure more attractive options are available for an increasing number of older Australians die well & live better.



## Conclusion

Australians have for many years now experienced great improvements in health. We are living longer than ever before, and most of our lives are spent in good health. Conditions that used to kill more quickly, and at younger ages, have been replaced by chronic disease—and lower death rates show how we reach greater ages despite a greater burden of disease.

This progression in health and change in illness can be largely attributed to public health, subspecialisation and the advancements in modern medicine. However, this has meant a changed experience of death for many Australians and their families. After living well with chronic diseases for many years, they find themselves facing a downward trajectory in health. At this time, many are let down by the health system set in its 'treat and cure' ways. The experience for many Australians and their families is one of confusion, multiple visits to doctors, clinics, hospitals, ambulances with little in the way of holistic care. This eventually results more often than not in an acute hospital visit that leads to death without palliative care—and occasionally, without an awareness that one was even dying.

The health system's failure to adapt to the changing nature of ageing and death, and provide quality care to the elderly and dying, has meant this time of life has become shrouded in myths of desolation and indignity. The inability of the health system to provide palliative care generally has raised an unhelpful focus on where people die, rather than how they die and how they lived prior to death. These assumptions, together with a societal bent for youth and independence, has created a climate where old age and death is dreaded.

Palliative care is holistic value-driven care that is patient- and family-centred, pre-emptory and perfectly situated to support chronic disease sufferers in their later years of life. Palliative care is also cost-effective care that reduces hospital admissions, means patients live at home (including RACFs) longer, and in hospital prevents dissatisfaction and over-treatment. This amalgamates to palliative care being an efficient use of resources, especially in light of the pattern of disease among our ageing population. More so, it is better care—and care that older Australians want and deserve.

However, in Australia access to palliative care is limited. Oncology has formed a strong alliance with palliative care, and preferentially services are provided for patients dying of cancer. However, diagnosis should not dictate access to palliative care—and patients suffering from many types of chronic diseases including heart disease, dementia and lung disease all benefit from palliative care. Patients who live rurally, have a disability or are Indigenous have even less access to palliative care. However, alarmingly, so do those who die in hospital and in RACFs. Patients are likely to continue to die in hospital and RACFs from many other diseases apart from cancer, and these patients also warrant access to palliative care. At present, it's the lucky Australians who receive palliative care.

But there is hope yet. As the information gap between patients and doctors is eroded, baby boomers will demand a partnership from the medical profession. This should be met with open arms by enlightened doctors who see the value in palliative care and seek to understand patients' goals so collectively, sensible decisions about treatment, life and death can be made. These opportunities require multiple cultural barriers to be overcome in the medical profession and society.

A palliative care policy will also be required that ensures comprehensive access, integrated services, accountability and choice: this is a public health issue, as well as an ethical and economic issue. To close the palliative care gap between supply and demand, government should consider bold options. This must include exploring a consumer-centred or commissioning approach, as recommended by the Productivity Commission, to drive reform, improve access, and increase quality across the social services sector. Embracing an investment approach would also highlight the cost benefits of widespread palliative care in light of an ever increasing older population. Expanding access to palliative care in Australia will ensure that older Australians look forward to quality of life before death, and the choice of palliative care at the end of life, no matter where they die.

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# About the Author



## Jessica Borbasi

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Dr Jessica Borbasi is working as a Research Associate in the Health Innovative Program at The Centre for Independent Studies.

Jessica completed a Bachelor of Psychological Sciences with Honours at UQ and a Bachelor of Medicine and Bachelor of Surgery at Flinders University during which she spent time as a medical student in rural Australia. She has since worked as a clinician in South Australia, and NSW recently completing her Basic Physicians Training at Royal North Shore Hospital. These experiences sparked an interest in health policy, hospital administration and health economics for which she is currently undertaking a Masters of Public Health and Health Management at UNSW.

Together with some self-taught classical liberalism Jessica is always keen to discuss politics, health and what medicine may look like in the future.