CONVERSATIONS
Creating Choice in End of Life Care

ACHR
AUSTRALIAN CENTRE FOR HEALTH RESEARCH

#dyingtotalk

- A good death gives people dignity, choice and support to address their physical, personal, psychological, social and spiritual needs.

- Around 70% of Australians would prefer to die at home, but only 14% actually do.

- Deaths for younger people are now rare; about two-thirds of Australians die between the ages of 75 and 95. Most of these deaths are expected, yet we are not taking the opportunity to help people plan to die well.

- When asked, most people have clear preferences for the care they want at the end of their life. But rarely do we have open, systematic conversations that lead to effective End of Life Care plans. Most people do not discuss the support they would like as they die.

- It is clear that sharing our preferences for what we'd like at the end of our life is the most important – and costly – conversation that Australia is not having.

Executive Summary

What is the Challenge?

The way people are cared for when they are dying is important.

End of Life Care impacts everyone, at every age - the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not limited to a particular group or section of the community.

When it comes to death the statistics are clear. We will all die.

We assume that we will always have control of our care decisions. However, many people nearing the end of life are not physically or cognitively able to make their own care decisions, and their choices and wishes remain unknown. This means too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain.

The care most Australians receive at the end of life often does not reflect their values, goals, or informed choices.

The majority of Australians say they would prefer to die at home, however most will die in a care institution, such as a hospital intensive care unit. Dying has become institutionalised, and evidence shows there is a significant mismatch between what people most often say they want (supportive services) and the services they actually get (acute care). Acute health systems are focused on providing treatment and cure - increasing survival and reducing mortality. For patients who are at the end of life, this can result in the delivery of care that is inappropriate, inadequate or futile. People frequently endure unwanted aggressive, costly treatments and suffer from insufficient management of symptoms such as pain and shortness of breath.

Reports and investigations too frequently identify poor End of Life Care. Access to care is largely determined by age, diagnosis and geography rather than individual need. It is often characterised by fragmented care systems; poor communication among doctors, patients, and families; and enormous strains on family caregiver and support systems. It can create significant moral distress for health professionals working in these systems, especially for those who recognise that the care they provide in some cases is not what they would want for themselves or for their families.

There is, however, a simple yet significant way to improve this care. The road map to reform starts with a conversation.

End of Life conversations improve End of Life Care, patient and family satisfaction and reduce stress, anxiety and depression in surviving relatives. These conversations offer people the opportunity to define their goals and expectations for the personal, medical, emotional and spiritual care they want to receive at the end of their life. Conversations emphasising patient choice, including treatment preferences, are a powerful determinant of care. Patients are more likely to receive care that is consistent with their choices when they have had the opportunity to discuss their choices for End of Life Care with their loved ones as well as a health professional. Patient conversations with health professionals are a better predictor of patients' End of Life Care outcomes than the place they are being treated.

Not everyone will want to talk about the end of their life, but the 'right conversations, with the right people, at the right time' can enable a patient and their loved ones to make the best use of the time that is left and prepare for what lies ahead.

Overwhelmingly, there is recognition that open conversations about death, dying and bereavement play a fundamental role in the:

- Changing of attitudes towards death and dying

- Successful planning and delivery of person-centred choice in End of Life Care

- Quality of End of Life Care

- Availability of support for the bereaved, and the

- Long-term health and well-being of individuals and communities.

Public awareness, engagement and community development work on dying, death, and End of Life Care are increasingly identified as priorities in government health strategies and policies worldwide. Policymakers, health systems and palliative care services are seeing conversations as important areas of action to improve end of life experiences. Countries such as England, Scotland, Ireland, Canada and the US are implementing public awareness campaigns to promote End of Life Care conversations so that people are aware of ways to better live with death, dying and bereavement.

End of Life Care has a low profile in Australia. It is not recognised as a public health concern, and we lack the national awareness and engagement programs evident in other countries. Our impressive global record of health promotion and public education is not being matched in the process of dying, death or bereavement.

Unless we take personal, professional, and political action, we will not be able to afford to die with dignity in the future. For multiple reasons that include an ageing population, escalating healthcare spending, and an approach to End of Life Care that often does not conform to the wishes of patients, we cannot delay action.

The Australian Centre for Health Research (ACHR) seeks to transform End of Life Care through a conventional research and practice development program, as well as innovative community awareness initiatives that help people have conversations about their end of life choices.

We present eight simple, cost effective recommendations to transform End of Life Care in Australia by creating choice through conversations.

Key Messages

What:
It's time to transform our culture so we shift from not talking about dying to talking about it. It's time to share the way we want to live at the end of our lives. And it's time to communicate about the kind of care we want and don't want for ourselves and our loved ones.

Why:
1. Currently, too many Australians experience pain and suffering in the final months and days of their lives, and die in a way they would not choose. These outcomes ripple out beyond the dying person to their families, loved ones, caregivers, and communities.

2. As a nation we are paying a high price for care we don't want, in a place we don't want it.

3. Caring for the dying is a fundamental responsibility of all societies and good stewardship of national resources requires an evidence-based approach to meet the ever-increasing and insupportable demands on hospital facilities, health professionals and ineffective resource utilisation.

How:
The pathway to reform starts with one simple step – conversation.

Conversations increase public awareness that End of Life Care can be guided in ways that responded to patients' choice. When it comes to End of Life Care, one conversation can make all the difference.

A Roadmap for Action
End of Life Care is Everyone's Responsibility

1. **People** to talk about their wishes for End of Life Care with family and loved ones at the kitchen table – not in the intensive care unit when it's too late. Encourage people to document their choices of care and initiate a conversation with their health professional.

2. **Communities** to build capacity to become compassionate and support people to live well and die well in partnership with health professionals through a health promoting approach to End of Life Care.

3. **Health providers** to initiate honest, timely and culturally-sensitive conversations with patients so they are a routine part of healthcare delivery. Establish a dedicated Medicare reimbursement system to facilitate of End of Life Care conversations and planning.

4. **Universities, colleges and training organisations** to help health professionals, across all chronic care and complex care specialities, have difficult conversations and improve end of life communication with patients, families, and colleagues.

5. **Policy makers** to acknowledge End of Life Care as a national health priority, promote public awareness programs and fund End of Life Care conversations with dedicated medicare item numbers.

6. **Employers** to better support staff who are living with an advanced illness, carer responsibilities or grief, and help them have conversations about their options and choices.

7. **Media** to demystify dying and help normalise the experience for the general public. Greater public discussions about the limits of healthcare as end of life approaches informs the public about their options and helps them translate these into personal choices.

8. **Researchers** to conduct randomised trials examining new approaches and models for enhancing conversations. These trials would include measures of the frequency and quality of end of life discussions, perceived control, quality of life, and pain / symptom management. Combined with a cost-benefit analysis, provide the data needed for a reimbursable End of Life Care management strategy.

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1 End of Life Care:
Meeting the Challenge

The Global Picture

Advancements in healthcare have been responsible for the most significant 'quality of life' gains in the recent past. Humans are, on average, living longer and are healthier than ever. But 'quality of death' is another matter.

The World Health Organization (WHO) regards End of Life Care as a human right in high demand (WHO, 2014). Worldwide over 40 million people would benefit from End of Life Care (20 million of these being at the end of life). However, less than 10 per cent of the need for palliative care is currently being met (WHPCA, 2015).

In 2014, the WHO and the Worldwide Palliative Care Alliance released the *Global Atlas of Palliative Care at the End of Life* - a tool to advocate for including palliative care in the global, regional and national health agenda

> " No one should be invisible. There are 'hidden patients' with 'hidden lives' for whom the need for End of Life Care is not recognised.

(WHO, 2014). In May 2014, the World Health Assembly unanimously passed a resolution to strengthen End of Life Care as a component of comprehensive care throughout the life course.

The Australian Challenge

Australia is recognised globally for the quality of its End of Life Care services. Australia was recently ranked second behind the United Kingdom, the gold standard, in the global 2015 'Quality of Death' Index (EIU, 2015).

This high ranking is largely achieved through the nations relative wealth, advanced infrastructure and recognition of the importance of developing national healthcare strategies.

However, Australia's End of Life Care system is confronting urgent and significant challenges. Australia is rated less highly for public understanding of End of Life Care and palliative care services. Australia struggles to provide adequate End of Life Care for all citizens, especially those in rural and regional areas, and funding is not equitably distributed. Australia's system of allocating the responsibility of healthcare to the states leads to inconsistencies in care delivery, serviceability and complex funding models.

On top of these immediate challenges, there is growing recognition that the way we approach End of Life Care in Australia is unsustainable.

The growing and ageing population, combined with the prevalence of chronic progressive disease and people's preferences about care, is increasing demand for End of Life Care services. At the same time the Commonwealth and States have to balance these demands with diminishing resources, cost pressures and workforce capacity challenges.

The Key Factors Driving Higher Levels of Need for End of Life Care

1. Changing Demographics, Population Growth

2. Service and Capacity Demands

3. Disease Pattern Complexity

4. Preferences and Expectation

5. Unmet Population Needs

6. Growth of Residents in Care Facilities

7. Workforce and Resources

8. Rocketing Health Expenditures

1. Changing Demographics and Growth

The population is changing in unprecedented ways. In March 2015, Australia's population reached over 23.7 million and had an average growth rate of 1.4 per cent (ABS, 2015). Over the next 40 years, the rate of population growth is expected to slow to 1.2 per cent on average per annum. This reflects a broadly stable fertility rate of 1.9 births per woman and continuation of net overseas migration at an average annual rate of 0.6 per cent of the total population - the same rate as over the last 40 years.

Based on these trends Australia's population is projected to reach 35.9 million in 2050 (Treasury, Australia, 2010).

In addition to the population growth, Australians are living longer and continue to have one of the longest life expectancies in the world. In 2054-55, life expectancy at birth is projected to be 95.1 years for men and 96.6 years for women, compared with 91.5 and 93.6 years today (Commonwealth of Australia, 2015).

Population ageing is a notable demographic. The number of people aged 65 years and over is projected to exceed the number of children aged 0-14 years by 2030 (ABS, 2014). Over the next 40 years, the number of people aged 85 years and over is expected to increase four-fold. Of this cohort, it is estimated that up to 85% will die as a result of a chronic illness, creating a growing demand for appropriate End of Life Care.

2. Service and Capacity Demands

Approximately 153 500 people die every year in Australia, or around 420 per day (ABS, 2015). The total number of deaths each year is expected to more than double over the next 25 years, with the most rapid increase in deaths coming between 2027 and 2037 (ABS, 2009).

Dying is part of the life cycle and can occur at any age, although more than half of all deaths in Australia occur at or after the age of 75 years (AIHW, 2013).

In 2012-13 there were 61 596 palliative care-related hospitalisations in Australian hospitals. Just under half (42 per cent) of all people who died as an admitted patient received palliative care. Palliative care-related hospitalisations have risen by 52 per cent over the last decade. Over the last 5 years Medicare Benefits Schedule payments for all palliative medicine specialist services rose by an average of 17 per cent each year.

Although palliative care focused initially on patients dying from cancer, the patient population that may benefit from care has expanded considerably (Kelley, 2015).

While the patient populations that benefit most from referral to specialist-level palliative care and the appropriate timing of such referral is still being defined by empirical research, consensus recommendations from the US support referral at the time of diagnosis for patients with the following (Kelley, 2015):

- advanced cancer, neurologic disease, or organ damage;

- multiple coexisting conditions, frailty, or advanced cognitive impairment;

- a high symptom or iatrogenic-treatment burden (e.g., those who have received a bone marrow transplant for acute leukaemia); and

- people onerous family or caregiver needs regardless of prognosis.

Based on Australian research, it is estimated that as many as 50 – 90 per cent of all people could benefit from access to palliative care services (Rosenwax, 2005). The current system is unable to meet this estimated or future demand.

New service delivery approaches, workforce and funding models are required to better respond to changing service demand. Care that was only relevant in the last days or weeks of life is now required to sustain long-term concurrent care, where End of Life Care services are available concurrently with, or independent of, curative or life-prolonging care (Burgess, 2013).

Current availability of palliative care specialist services and primary health care services is unable to keep pace with this growing demand. There will need to be significant changes to the organisation and delivery of healthcare to continue to provide care even at the current level.

3. Disease Pattern Complexity

Adding to this difficult situation is the reality that the prevalence of catastrophic diseases that once killed swiftly (e.g., pneumonia, cholera, massive heart attacks) have been replaced by chronic, complex and, often, degenerative diseases.

Coronary heart disease is now the leading underlying cause of death in Australia, followed by dementia and Alzheimer disease, then cerebrovascular diseases (which includes stroke). Lung cancer and chronic obstructive pulmonary disease (COPD) make up the top five leading underlying causes of death in Australia in 2013, for males and females of all ages combined (AIHW, 2013).

This means extending appropriate care and services for patients who are dying from non-malignant diseases is now a significant priority.

The failure to provide End of Life Care to much of the

broader non-malignant disease population is likely due to a complexity of reasons, including prognostic accuracy for chronic diseases, a curative culture, lack of communication, funding and reimbursement issues, lack of appropriate assessment tools and time constraints.

A new approach to End of Life Care must better manage advanced chronic illness, with multiple non-malignant diagnoses and more complex health problems, including those with some combination of frailty, physical and cognitive disabilities, polypharmacy, and functional limitations.

4. Preferences and Expectations

The healthcare system is experiencing unprecedented pressures, particularly in respect of the use of accident and emergency services and hospital services. We know that most people do not wish to die in hospital; surveys consistently show that between 60 to 70 per cent of Australians would prefer to die at home with a focus on comfort (Foreman, 2006).

But dying is now highly institutionalised. Over the past century, the proportion of home deaths declined and the rate of deaths in hospitals and residential aged care has increased.

The recent Auditor-General report into Victorian palliative care highlighted that while the majority of people who are terminally ill wish to die at home, only 14 per cent do (Auditor General, 2015). Fifty-four per cent die in hospitals (with 20 per cent dying in intensive care units (ICUs)) and 32 per cent in residential care (Broad, 2013). In Australia, home deaths occur at half the rate achieved in New Zealand, the United States, Ireland and France (Broad, 2013).

When a person is in the hospital, they are faced with a seemingly unstoppable momentum of medical treatment. However, the default medical position 'to do everything to save life, no matter what' addresses the wishes of only a minority. In a large survey, only 7 per cent of Australians 75 years and over wanted all possible medical intervention compared to 61 per cent who strongly opposed any intervention that prolonged life in poor health or resulted in a poor quality of life (Corke, 2015). Australians generally rejected burdensome treatment, especially in the presence of dementia.

When a person understands their prognosis, the realistic options available, and the likely outcomes of various treatment modalities, they rarely select aggressive medical interventions. Most want to be kept pain-free

and avoid heroic, and often futile, measures to keep them alive (Hillman, 2010). Health professionals need to ensure that attempts at curative or life-prolonging treatments - i.e. tube feeding, IVs, ventilator breathing, or resuscitation - are wanted, necessary and that there is clear communication about the probabilities and consequences of any interventions.

Overall, there is significant concern that we have lost the notion of death as a normal part of life (Smith, 2000; Kelleher, 2009). In The Australian Best Care of the Dying Project, Professor JR Hardy wrote,

> *"...the quality of dying in today's society is often poor. With the recent rapid advances in medical knowledge and technology and the explosion of new drugs, death is seen as a failure within many medical models. Death is no longer acknowledged as an inevitable part of life, but has been 'medicalised, professionalised and sanitised'. As a consequence, many patients still die alone, frightened and without dignity, having lost all control, feeling abandoned by health care professionals."*
> (Smith, 2000; Hardy, 2005).

Care at the end of life is clinically focused, episodic, fragmented, difficult to navigate and a source of additional anxiety and distress for patients, families and carers. Inequities and inconsistencies in access to care can lead to avoidable hospitalisations or lead to the inability of people to access what they want most, appropriate pain and symptom relief.

5. Unmet Population Needs

While access to care should be determined solely by need, access to End of Life Care is largely determined by diagnosis, geography, ethnic or cultural background and age. Irrespective of income, current services fail to reach increasing numbers of people with the care they need, particularly those living in rural and regional areas; Aboriginal and Torres Strait Islander groups; and those from different religious, cultural and linguistic backgrounds (CALD).

Rural and regional areas are made up of many diverse settlements including pastoral, farming, mining, tourism and Aboriginal and Torres Strait Islander communities, which have different social and economic determinants of health. The population is generally older, the levels of

Everyone deserves care that works for them at the end of their lives.

"For many people, regardless of income level, quality End of Life Care is simply not available.

health risks higher along with rates of disease, chronic disease and injury. People living in these areas generally have less access to health services with shortages of almost all health professions and health-related infrastructure.

Aboriginal and Torres Strait Islander people have poorer health outcomes and their culture demonstrates a clear resistance to accessing mainstream health services which are viewed as isolating and not relevant to their culture, way of life, family and belief systems. Currently Aboriginal people tend to not access palliative care services in mainstream facilities; and there is very little data on Aboriginal admissions to palliative care centres.

Similarly, for CALD individuals, the current care models are further exacerbated by language barriers and different cultural perspectives on death, dying and grief, reducing access to palliative care in a timely and effective way.

Each person in each community is unique, models of care need to be flexible and responsive to both individual and broader community need.

6. Growth of Residents in Care Facilities

Older people living in residential aged care facilities (RACFs) or disability facilities, are a significant group for whom End of Life Care needs are not adequately met.

As the number of persons living with severe, debilitating illnesses increases over the coming decades, so too will the numbers who will require residential aged care. The population of RACFs is expected to increase by 70 per cent in the next 30 years (Giles, 2003).

Currently, almost one-third of people who are admitted to a RACF as a high care resident will die within six months of admission, and 61 per cent will die within one year. By 2020, half of all deaths are expected to occur in RACFs (National EoL Framework Forum, 2010). There is a significant need for End of Life Care to be recognised as part of the normal scope of practice of residential aged care, recognising that RACFs are home for an increasing number of people at the end of life.

Residential aged and disability care services face unique difficulties in administering End of Life Care, with residents often having dementia and/or communication difficulties and co-morbidities. End of Life Care needs to be considered a core competency for aged care and disability workers. Building increased capacity for End of Life Care and palliative services so it can be provided 'in place' and reduce unnecessary transfers to acute hospital care will improve outcomes for older patients, reduce burdens on

hospital emergency departments and acute beds, as well as assist in constraining acute care resources.

7. Workforce and Resources

The palliative care workforce is characterised by a variety of health professionals, including specialist palliative medicine physicians, nurses, GPs, pharmacists, medical specialists such as oncologists and geriatricians, as well as other health workers, support staff and volunteers.

Across generalist, primary care and specialist workforces there remains significant challenges in both workforce size and competency to address community needs.

Based on 2012 estimates, there are 148 specialist palliative medicine physicians in Australia. There is a significant gap between the current and ideal workforce numbers (Australasian Chapter of Palliative Medicine Workforce Report, 2007). There are 0.5 FTE Palliative Medicine Specialists per 100,000 population in Australia. However, a minimum number of specialists required for a reasonable provision of service is 1.0 FTE (ANZSPM, 2012). The limited availability of the specialist palliative care workforce is acute in rural and regional areas. Currently, nine out of 10 specialists work mainly in major cities (AIHW, 2014).

The demand for palliative services and specialists will continue to increase as the population ages, the number of patients with non-malignant disease increases, and the scope of End of Life Care expands. While it will be impossible for palliative care services to be the sole dis-cipline involved in all patients with these illnesses, most of those patients would benefit from the advice and guidance of palliative care specialists.

The capacity of the specialist palliative nursing workforce is similarly under-resourced and is ageing. Nationally, nurses are concentrated in inner regional areas and spread most thinly in remote and very remote areas (AIHW, 2014). Providing support to the palliative work-force, particularly in rural areas is essential to allow nurses to deliver nursing care. Support in the form of social workers would free up the time nurses spend on facilitation of services to deliver nursing care.

A critical issue in the provision of End of Life Care is the historic fact that generations of doctors have received little or no education in palliative care and the care of the dying (ANZSPM, 2012)and many are inadequately equipped to deal with these issues. Education, there-fore, at all levels from undergraduate to post-graduate is crucial to the provision of End of Life Care in Australia. All

General Practice training should include a component of some time spent in Palliative Care. In regional and rural areas, there is currently no opportunity to access training in palliative care.

Unavailability and inequitable access to GPs providing palliative care services has been well documented as a barrier to receiving End of Life Care at home (NSW ACI, 2014).In addition, limited availability, education and training for primary care workers, allied health practitioners and community support workers does, and will, continue to challenge attempts to establish primary care led models of care.

Volunteers are vital, core members of the interdisciplinary palliative care team, yet very little palliative care volunteer workforce development has been undertaken in Australia. Education and training is limited and little data collection is available to measure this workforce (Luxford, 2012).

Some of these workforce challenges are a subset of the broader challenges of developing a sustainable, skilled and adaptable workforce to meet the health needs of the Australian community. However there is also a need to look at new and innovative End of Life Care workforce models that might be sustainable, address future demand and better and support the needs of patients, their families and carers.

8. Rocketing Health Expenditures

Australia is facing critical economic challenges. Real health expenditure per person is projected to more than double in the next 40 years, from around $2 800 to $6 500. Overall, health expenditure is projected to increase from 4.2 per cent of GDP in 2014-15 to 5.5 per cent in 2054-55 (Commonwealth of Australia, 2015). At the same time, a proportionally lower tax base will need to fund and support increasing demand.

Spending on health, primarily hospitals, is 25 per cent of state recurrent expenditure. Health spending as a share of state taxation revenue has increased from 18 per cent in 2002 to 28 per cent in 2012 (AIHW, 2014). In 2000-2001 the state share of public hospital costs was 51%. By 2012-13 it had risen to 59%.

In 2011 - 12, $2.4 billion was spent on hospital care for people aged 65 or older in their last year of life. A majority, over 70 per cent, of End of Life Care funding is spent in hospitals. Compared to quality home care, Palliative Care Australia estimates the cost of caring for a chronically or terminally ill person in hospital is between

40 and 300 per cent higher for the taxpayer (PCA, 2015). Other emerging evidence suggests high-quality, patient focused and compassionate End of Life Care may lower health costs, mainly by reducing hospitalisations at the end of life (Smith, 2014).

The way we support people to live and die well requires smart investment and foremost, helping Australians to receive care, and die, in their place of choice. This requires a rearranging of current expenditures into community-based care as a viable alternative to hospital care. It requires addressing of waste within the system, a review of inappropriate funding models and financial incentives, and improving the fragmented care delivery systems and time pressures that limit communication and poor service coordination across programs.

> " **Palliation is hard for many doctors because they like to fix things. They like cures. They are excellent at saving lives, but struggle to accept they cannot save everyone. But death is natural. Death in old, frail people is very natural. We aren't supposed to live forever and having a peaceful death with family present is a wonderful thing. A good death is as important as a successful resuscitation.**
>
> **Dr. Ashleigh Witt**
> **A doctor training to be a geriatrician**
> **Western Health, Melbourne, VIC.**

"Around 70% of Australians would prefer to die at home, but only 14% actually do.

Auditor General. Palliative Care. 2015

2 End of Life Care: Preconditions for Choice

The way people are cared for when they are dying is important. End of Life Care is care that impacts everyone, at every age, the living, the dying and the bereaved. It is not a response to a particular illness or condition. It is not limited to a particular group or section of the community.

When it comes to death the statistics are clear. We will all die. Reports and investigations too frequently identify poor End of Life Care. We have a collective responsibility to do better. Many things are necessary for good End of Life Care, including ten minimum preconditions for delivering choice-driven, quality care.

Preconditions for Delivering Choice-Driven, Quality Care

1. Person, Carer and Family Centred Care

2. Needs Based Care

3. Integrated, Coordinated Care

6. Ensuring Everyone Matters

4. Advance Care Planning

5. Equitable Access

7. Collaborative, Case-Managed Services

10. Education and Training

8. Health Information Technology

9. Research and Evidence

1. Person, Carer and Family Centred Care

Genuine choice allows people to make informed decisions about their End of Life Care and receive meaningful information and support that is consistent with their preferences and values.

Person centred care focuses on collaboration between health workers, the person and their family, carer and those who are important to the dying person (DHHS, 2006). Patients, family and carers are treated with dignity and respect. Person centred approaches reduce anxiety and improve quality of life by ensuring individual concerns and needs are addressed (Temel, 2010).

When people are at the centre of their care, they become active in their care, better manage symptoms and make health decisions with the support of their care team. They play a key role in contributing to all aspects of care-including care planning, care coordination and setting holistic goals of care.

A significant issue is the explicit need for recognition of the role of family, carers and surrogates both as informal carers and as an integral part of an individual's care team, particularly in the context of support in community settings (O'Connor, 2009). The presence of carers is fundamental to the ability of patients to have a choice at the end of life. There is also an increasing recognition that there is an inextricable relationship between the wellbeing of carers and patients and that in some cases the needs of the carers may exceed that of patients (Higginson, 1990).

Carers need psychological support, help with personal, nursing and medical care of the patient, out of hours support, respite, clear communication with the care team, domestic and financial help. Support encompasses good bereavement and pre-bereavement care, including for children and young people. It is also important to recognise that carers have their own unique needs and concerns.

Familes and carers also need information about the illness, prognosis, symptoms, treatment and care needs of the person for whom they are caring.

2. Needs Based Care

Providing care on the basis of need ensures patients, carers and families have equitable access to services based on choice and effective assessment rather than diagnosis, age or geography.

Needs based care supports the 'whole person', and responsively addresses practical and social needs (such as literacy; language barriers; access to food, transportation and safe housing; and mental and behavioural health issues) that may undermine effective care.

A needs based service delivery model acknowledges that patients have different needs that may change over time. It allows people the space and time to express their needs, wishes and preferences and provides frequent opportunities to describe their changing needs and to reassess care plans and goals of care.

3. Integrated, Coordinated Care

Choice is achieved when person-centred care management effectively bridges acute, post-acute, and long-term care settings, treatment and time.

Integrated care is seamless care. It enables patients, carers and families to be central to their own care planning and to receive the right care, in the right place, at the right time (**Table 1**) (Spehar, 2005).

The delivery of care to people who are dying is essential in all types of care settings including acute wards, emergency departments, hospices, nursing homes and home care. However many of the problems associated with the provision of complex cases of End of Life Care relate to barriers that occur at the interfaces between these settings as well as between services and healthcare professionals. Transitions between hospitals, hospices, nursing homes and home care are potentially high-risk events when those transitions between sites of care are poorly managed. Many of the problems associated with the effective provision of End of Life Care relate to

TABLE 1: INTEGRATED CO-ORDINATED CARE

THE RIGHT CARE	THE RIGHT PLACE	THE RIGHT TIME
high quality, flexible, needs based and person centred, sensitive to individual and cultural differences	accessible to all and delivered in the home and community, and across general and specialist areas of the health system	provided early enough in a person's disease trajectory that care can be planned and the person's quality of life is maximised

barriers that occur at the interfaces between settings, services and healthcare professionals.

Patient outcomes depend just as much on well-coordinated, integrated teams as they do on technically skilled clinicians. Teams of clinicians deliver far better results than autonomous specialists, each doing their own thing.

There is high demand for engagement activities and funding models to better coordinate care to seamlessly link services and systems, allow shared-care with access to electronic records, integrated delivery, monitoring systems and improved communication channels between healthcare professionals, community services, patients, carers and families.

Achieving this will require systems of care coordination that adds to the effectiveness and speed of service delivery, rather than inhibiting or restricting responsiveness by adding extra layers of process to the delivery of care.

4. Advance Care Planning

Normalising advance care planning through counseling, and meaningful discussion of prognosis, goals of care, personal values and treatment preferences will improve choice.

Many people, whether through old age or being at the end stage of chronic disease or a progressive neurological disorder, will have limited decision-making capacity for a period of time before they die and may not be able to communicate their wishes or preferences for care. This can result in continued treatment that may cause physical and emotional discomfort, or treatment that a person may not have chosen if they were able to communicate their preferences directly.

Advance care planning helps each person set out their personal end of life wishes, treatment preferences and goals of care. The process offers effective communications between healthcare providers and patients and families. Planning has been shown to improve quality of care at the end of life and increase the likelihood of a person's wishes being known and respected (Detering, 2010).

Individuals and their families report being more satisfied with the End of Life Care provided when an advance care plan (ACP) is in place. Symptoms of anxiety, depression and post-traumatic stress in surviving family members are often reduced as a result (Detering, 2010).

Planning interventions involving multiple conversations and planning tools over time appear to be more effective in meeting patients' preferences than written documents alone (Brinkman-Stoppelenburg, 2014). Whether the goals of care are verbal or written, they need to be regularly reviewed and should be easy to update if conditions change or views about end of life evolve. Subject to that person's consent, or, if they lack mental capacity, wishes and preferences should also be shared with loved ones and those who may be involved in their care.

From a broader perspective, advance care processes support better patient outcomes, assists clinicians to provide person centred care and optimises the use of health resources. Reductions in unnecessary hospitalisation of 40 – 80 per cent have been shown, in randomised controlled trials, when nursing home residents express their wishes through an advance care planning process (Levy, 2008).

Although participation must be voluntary, the opportunity for informed discussion and planning must be universal. Every Australian should be given the opportunity to participate in a discussion around their future health care choices and goals of care.

Across Australia, there is strong support for advance care planning from both health professionals and the general community. Despite the widespread endorsement and supporting legislation in every Australian jurisdiction, uptake is low (Rhee, 2012; Scott, 2013).

5. Equitable Access

Access is a critical factor to achieve choice in End of Life Care. The importance of access is stressed, not only to care services, information and expertise, but also to spiritual and emotional support and to hospice type care across all settings.

Accessibility to End of Life Care services should be equitable and based on needs of all people who require care, regardless of their diagnosis, prognosis, age, culture, geography, socio-economic status or care setting (PCA, 2005).

Access to 24/7 care services is a necessary system-wide expectation and good care cannot be achieved without it. The distress of uncontrolled pain and symptoms cannot wait for 'opening hours'. Emerging evidence shows that the provision of 24/7 services can avoid unnecessary hospital admissions and can enable more people at the end of their life to live and die in the place of their choice (Department of Health NHS, 2008).

Early access to End of Life Care leads to significant improvements in both quality of life and mood, as well as minimising patient distress (Devi, 2011; Temel, 2010). As compared with patients receiving standard care, patients receiving early referral had less aggressive care at the end of life and longer survival (Temel, 2010).

Conversely, the adverse consequences of a late referral to End of Life Care includes (Temel, 2010; Wright, 2010):

- reduced survival;

- increased psychological distress;

- medical treatments inconsistent with personal preferences;

- increased utilisation of aggressive health care resources of little therapeutic benefit;

- a more difficult bereavement for families and carers; and

- increased costs of treatment.

Options for quality End of Life Care must be equally accessible for patients in hospital, residential care or those who are in their own homes.

Population based admission rates to palliative care services are 30–50 per cent lower in regional and remote locations than in metropolitan areas (National EOL Framework Forum, 2010) due largely to geography, cost and service availability. The evidence suggests a population-based approach to service development, based on local need and capacity, is the most appropriate framework for the delivery of effective and efficient End of Life Care in rural and regional areas (Phillips, 2006). While provision of services in rural and remote areas will always have challenges, the goal should be to change those aspects of service delivery and funding models that block rather than facilitate access to care.

The fundamental principle should be that people who would benefit from care at the end of life should have access to services that match their need.

6. Ensuring Everyone Matters

End of Life Care must respond to the diversity of the Australian community, including the needs and values of older people, people living in rural and regional areas, people from culturally and linguistically (CALD) diverse backgrounds, Aboriginal people, and aged and disability residents.

Ensuring that people have equitable care at the end of life also requires an awareness and commitment to deliver culturally appropriate care founded on mutual trust, respect for an individual's nationality, culture, age, gender or religious beliefs (Clark, 2012).

Contemporary models of palliative and End of Life Care in Australia, are dominated by western traditions and the biomedical paradigm.

Aboriginal and Torres Strait Islander people require culturally safe and appropriate End of Life Care services, and the development of strategies and programs that respect and accommodate their spiritual and cultural beliefs (Queensland Health, 2011; Mc Prior, 2009; Grath, 2006).

In Australia, over 300 languages are spoken, more than 100 religions and beliefs are practiced and many of the world's ethnic groups are represented from over 230 different countries (PCA, 2010). Because culture- and religion-based responses may vary within a cultural or religious group, taking the time to understand each patient's unique needs, values and beliefs is the most respectful way of delivering care and facilitating a dignified death.

Local services should also anticipate and support those who will have to live with loss. Too often these needs are considered peripheral to the response required for people living with more predictable illness.

7. Collaborative, Case-Managed Services

An integrated care pathway for End of Life Care requires a commitment and connection between health (acute, primary, aged care), disability and community care services, with a coordinated collaborative approach to promote shared care responsibility. Care must be timely and anticipated, and supported by multidisciplinary team to guide and support the patient progressively through the end of life experience and decrease unnecessary utilisation of acute services (Bandolier, 2001).

The current barriers preventing collaborative, co-ordinated services and delivery of person centred care include:

- the complexity of the service system;

- funding arrangements;

- organisational 'silos';

- absence of a single medical and care record;

- inadequate discharge planning;

- communication barriers; and

- limited resources for co-ordination and case management.

Patients often receive care from a range of organisations with different systems, roles and approaches to managing End of Life Care. Unless there is an identified person who takes overall responsibility for coordinating care and ensuring effective communication and collaboration, patients can receive fragmented and disjointed care along with discordant information. Lack of coordination can cause significant distress and is a source of frustration and anxiety for the dying person and for all those important to them. Carers often testify to the difficulties of multiple professionals and organisations working with little awareness of each other.

All patients need a medical home. The case management role may be undertaken by a GP, a community care service provider, a specialist palliative care service, or another health or care provider. The case manager acts as a bridge between acute and community care, having the dual effect of ensuring that much of the care is appropriate and appropriately sited within the community and, at the same time, providing ongoing education to care providers so that the care of the wider community is enhanced over time.

The interdisciplinary team need to respect and appropriately use each other's expertise, and that of the dying person, family and carers. For effective team work, roles and responsibilities need to be clear and processes need to be in place for the organisation and exchange of information. The patient's goals of care, and the treatment plan, need to be clear to all members of the care team so that care can be effectively coordinated.

8. Health Information Technology

Health information technologies (HIT) that promote advance care planning documentation and effective information sharing across time, place and provider with appropriate safeguards for privacy is critical for patient choice.

A comprehensive shared eHealth record holds great promise in providing that individual's goals of care and wishes are known and accessible in real-time. They also play a key role in ensuring quality, efficient delivery systems for individuals needing End of Life Care.

Health record sharing, and having access to documentation, can be particularly beneficial for patients with serious and life-limiting conditions as emotions are often high during appointments in which multiple issues are addressed and treatment plans formulated. Easy to update End of Life Care preferences will help ensure patients can maintain a single source of truth for advance care planning documentation.

Successful health record systems will improve communication among individuals and providers as well as emergency, inpatient, home and community-based services. This is expected to improve efficient integration and coordination of care delivery among silos of services, improve the quality and safety of care, and reduce unwanted and unnecessary interventions which may result from poor communication, especially during periods of care transitions and handovers.

HIT efforts must also include the development of standards, protocols and incentives to ensure quality and efficacy across settings and providers, privacy and the protection of individually identifiable health information.

Significant cost savings are anticipated with HIT. Assuming full participation, the Australian Government has estimated a fully functioning national eHealth system could save taxpayers $2.5 billion per year within a decade, with an additional $1.6 billion in annual savings also delivered to the states (Commonwealth of Australia, 2015).

9. Research and Evidence

Supporting expanded evidence-based research as a key tool to improve care delivery practices and strengthen quality standards for individuals and families facing end of life is essential for choice.

One of the most sobering facts is that little current policy or practice designed to improve End of Life Care for thousands of dying Australians is backed by robust evidence. There is little systematic data available about patient's experiences and the outcomes of End of Life Care (Halpern, 2015). Without timely information, it is not possible to undertake informed decision making about service delivery or assess the impact of any efforts at improvement.

Whilst the evidence base underpinning a number of initiatives is actively developing locally and globally, End of Life Care needs to be prioritised in Australia's

research (basic, clinical and translational) agenda, with appropriate funds and targeted research protocols.

Palliative and End of Life Care organisations need to take data seriously, become data literate and invest in collecting and using data to inform judgements about the quality of interventions, the accessibility of services, and support productivity improvements. Formalised information-sharing and networks of clinicians and researchers are essential.

Further, as broad health system reform calls for care centred around each individual person, improving care requires that we develop systems that support and enable high-quality, safe care of individual patients.

Clarity is required on the longitudinal nature of the needs of older adults with serious illness and their care-givers. In particular, the complex care needs of people with multiple coexisting conditions must be investigated (Kelley, 2015). The population at risk must be defined beyond traditional disease-specific or prognosis-based

> **" When a person has reached the end of life, clear communication and collective decision-making are as important as any clinical intervention.**

> **" Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not.**
>
> **Claire Henry**
> **London J Prim Care, 2009**

definitions. We need a better understanding of the multi-year needs of individuals and their caregivers in order to develop targeted care models and, given an inadequate workforce, to deploy the workforce efficiently.

It is the responsibility of investigators and sponsors to identify, develop, and rigorously test interventions so they can offer guidance as political and cultural tolerance increasingly encourages people to make End of Life Care choices and encourages implementation of programs.

Increased openness to calculated experimentation by governments, health systems, insurers, and other risk-bearing entities is key. Research funders must be cognisant of the need for strengthening the evidence base for palliative and End of Life Care.

State and Federal governments, along with institutions such as the National Health and Medical Research Council (NHMRC) and other funding bodies need to support multidisciplinary research teams that consist of researchers, clinicians, economists, policy makers, patients and families. Process and cost effectiveness outcomes must not be ignored in any future research. To ensure generalisability, studies should stratify participants according to different care settings, including general acute care, emergency departments, cancer care units, hospices, RACFs and specialist palliative care units.

10. Education and Training

Real choice relies on building a healthcare workforce educated and equipped with the clinical and social skills to enable people, their families and caregivers to navigate their treatment, care, and support options according to their values and preferences.

Every professional needs to be competent and up to date in the knowledge and practice that enable them to play their part in good End of Life Care. The core palliative care competencies of communication, recognition of end of life, pain and symptom management, and psychosocial assessment need to be a larger part of medical school and residency training programs.

An increasing body of evidence suggests that these skills (particularly communication skills) can be effectively learned and developed and are associated with improved outcomes (Au, 2012; Tulsky, 2011). Strategies to expand specialist-level palliative care training and generalist training in core palliative care knowledge and skills are needed.

It is vital that every locality and every profession has a

framework for their education, training and continuing professional development, to achieve and maintain this competence. That framework must allow expertise and professionalism to flourish in the culture of every organisation and every caring contact. It should offer practical examples of how care can be delivered in a way that is tailored to the person.

There are a number of workforce changes occurring to the skill mix of health professionals caused by new team based and shared care models. Additional training and education for healthcare workers in areas such as professional resistance and poor interpersonal relationships can address inherent barriers to teamwork.

The growing complexity of care provided in the community also requires education and training of students and health professionals to be better incorporated at all levels, in appropriately resourced, interdisciplinary, community based settings.

> " More work is needed at all levels - to protect patients' rights to choose care options, to improve the quality of clinical care and clinicians' responsiveness to patients and families, and to create well-functioning healthcare finance and delivery systems that make high-quality care genuinely available.
>
> Susan Wolf
> NEMJ, 2015

" The art of living well and dying well are one.

Epicurus
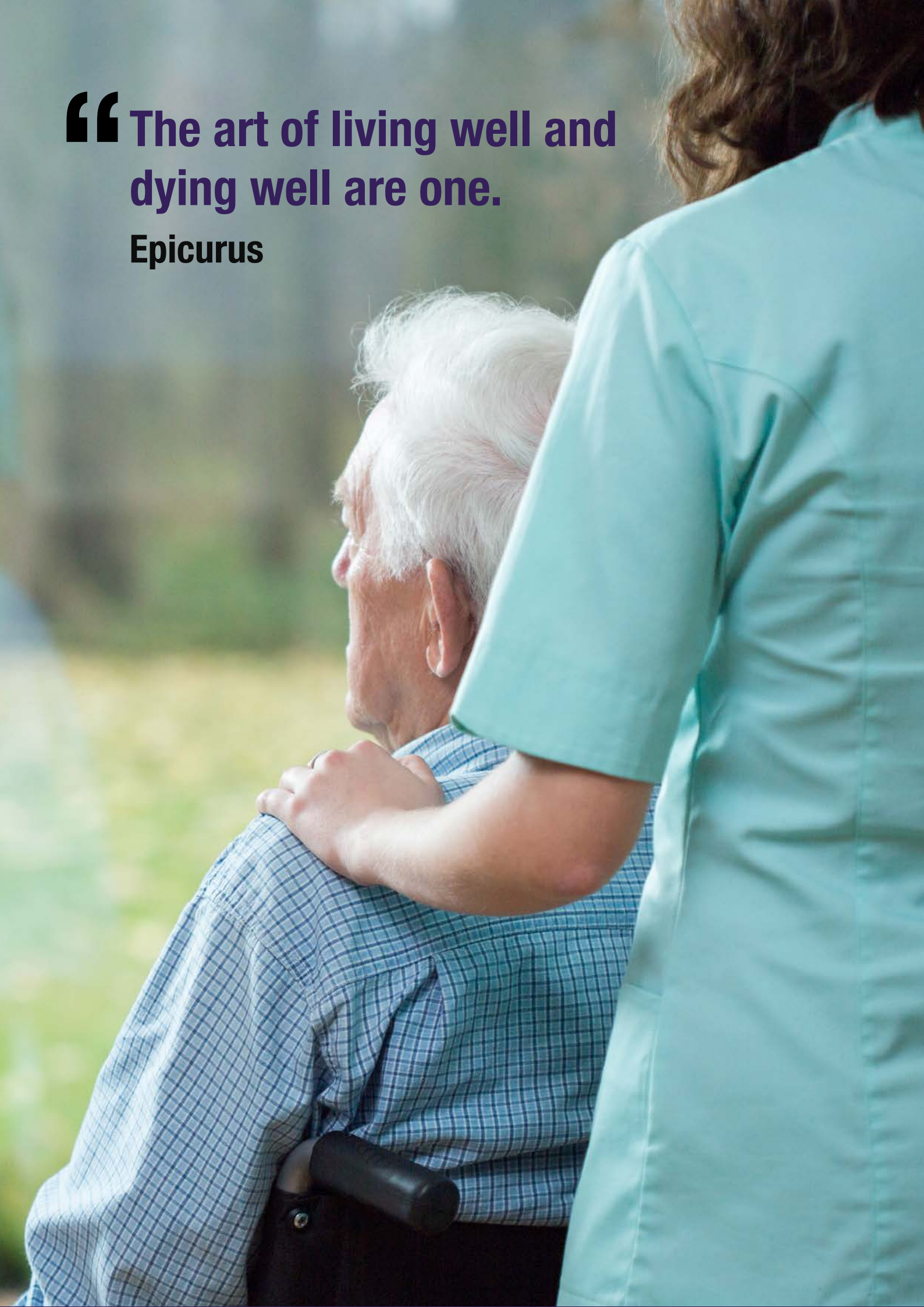
Life and Death Decisions

Sometimes it is just too late.

A medical crisis or an intensive care unit (ICU) admission due to a protracted downward trajectory of an illness may be irreversible.

By the time a person is admitted to an ICU most cannot hold a meaningful conversation either because of their critical condition or sedating medications.

Often family members or other surrogates have to speak for them. In decisions regarding the withdrawal of life support, the main determinants reviewed by a doctor are (Cook, 2003):

- A very low probability of survival;

- A very high probability of severely impaired cognitive function; and

- Recognition that patients would not want to continue life support in such circumstances if they could speak for themselves

Without an understanding of the patient's choices, either communicated directly by a family member, advocate or a written advance care plan, doctors do not know how aggressively to treat a patient or if they want to receive basic or advanced life support.

If the patient is 21 years old, they will usually receive more aggressive treatment. If the patient is 101 years old, comfort will likely be a priority. Most patients, however, fall somewhere in between.

If their heart stops, cardiopulmonary resuscitation (CPR) can be performed. This causes trauma to a frail person's chest. In the process, ribs are broken and final moments are traumatic. They are surrounded by doctors, not their children. That is not necessarily 'a good' or dignified death.

In specific circumstances, people can elect to 'do everything' and maximise medical intervention or they may choose palliation - preferring comfort care including pain relief and symptom control, even their favourite foods.

The latter option means not worrying about cholesterol or blood pressure medications. It means making sure the important people are by their bedside. It means calling spiritual or emotional support if that's wanted. It means everyone getting a chance to say goodbye.

3 End of Life Care: Critical Conversations

A National Health Priority

Responsible societies ensure that everyone is able to live well until they die. Like birth, death is a part of life. How we care for the dying is a litmus test of a good health system and a responsible society – to be judged by the dignity and respect given to all people of all ages in all settings at the end of their lives.

For many of the 56 million people who die each year worldwide, death is associated with substantial but preventable suffering. When death is managed badly it leaves a scar that runs deep in our collective psyche and reinforces the tendency to turn away from any reminder of death.

During the 1990s 'a bad death' was largely defined by an observational study of patients dying in a hospital in Scotland (Mills, 1994). Disturbing scenes of neglect and poor care of people dying on busy medical wards were described. This was followed by the largest study of End of Life Care ever conducted, the SUPPORT Project. This study highlighted short-comings in the care of people with life-limiting illnesses. These included issues of poor communication, continuation of inappropriate treatment, high rates of pain, and ignorance of patients' end of life choices (SUPPORT, 1995).

Subsequently, defining 'a good death' became critical. People throughout the world share core ideals of 'a good death' (Smith 2000; Seymour, 2009). This includes being free of pain and other symptoms, being with friends and family, not being a burden, being listened to, being able to decide about medical treatments (Rietjens, 2006) and being treated with respect. In some studies 'having one's affairs in order' was highlighted as important, while religion or spirituality was important to some people (Steinhauser, 2000). Many people would like to be cared for at home during their final illness (Gott, 2004; Lloyd-Williams, 2007; Gomes, 2012).

Globally, the importance of 'a good death' is gaining momentum. Whilst there remain distinguishable national cultures of End of Life Care, with differences in meaning, priorities, and expertise in each country, there is an increased focus on the quality of death and dying. Some governments have introduced End of Life Care strategies, and are embracing the reality of an ever-expanding ageing population who, thanks to medical advances, live longer but whose final years with multiple long-term conditions increasingly challenge health systems.

Countries such as the UK, US, and Canada, are undergoing fundamental shifts of emphasis to ensure rigorous assessment of new End of Life Care services that improve quality and choice, train and educate health professionals, and explore the best use of resources to maximise outcomes and value (Ellershaw, 2010).

Changing government policy is only one step in making care of the dying a priority for all. Quality End of Life Care must also be built from the ground up. Addressing attitudinal barriers to the provision of excellent End of Life Care means eradicating ignorance among policy makers, health professionals, patients, and the public about what can be achieved with modern palliative care and with careful proactive planning.

Overwhelmingly, there is recognition that open conversations about death, dying and bereavement play a fundamental role in the:

- Changing of attitudes towards death and dying

- Successful planning and delivery of person-centred choice in End of Life Care;

- Quality of End of Life Care;

- Availability of support for the bereaved; and the

- Long-term health and well-being of individuals and communities;

Hope is Not a Plan

End of Life conversations offer people the opportunity to define their goals and expectations for the personal, medical, emotional and spiritual care they want to receive at the end of their life.

Because death is ultimately a deeply personal human experience it evokes different reactions, emotions, and perceptions from individuals, families, and communities throughout life. The perception of death is different for children, adults seen to be in the prime of life, and those in the later years of life, but it is also highly subjective and deeply personal irrespective of when it occurs along the life journey.

Perceptions and views about death are also influenced by a wide array of social, cultural, economic, geographic, spiritual, and religious beliefs and experiences. While most people have given thought to how they would like to die, many have found it difficult to communicate those views and choices to family and loved ones, and in many cases, family and loved ones have their own perceptions and views about death that can influence discussions about dying.

As much as we want and expect to be in control of decisions about their own care throughout their lives, numerous factors can work against realising that desire. Rather than having a conversation and planning to ensure the care we want, we tend to just hope for the best. It's understandable, but hope is not a plan.

US data shows more than one-quarter of all adults, including those aged 75 and older, have given little or no thought to their end of life choices, and even fewer have captured these wishes in writing or through conversation (IOM, 2014). It is assumed the numbers are lower in Australia.

For certain patient populations, having the conversation and undertaking advance care planning is particularly important. The risk of harm is elevated and more apparent in patients with serious illness or older age. As a consequence of their conditions, these patients have an increased risk of death, and may also have an increased risk of potentially harmful events such as hospitalisation, loss of capacity, loss of independence, or loss of identity. In these populations, failure to conduct appropriate conversations and planning could result in unnecessary suffering and harm.

Families can also often bear the brunt of delaying or avoiding a conversations about end of life choices. In one study, nearly half the carers for critically ill patients reported having moderate or high levels of decisional

conflict because they were forced to make decisions without knowing what their loved one would have wanted (Chiarchiaro, 2015). Families are left feeling bereaved, guilty and uncertain about the decisions they made, or that medical professionals made for them. Those who had conversations with their loved ones had less decisional conflict, suggesting that the benefit of end of life conversations and advance care planning extends beyond respecting patients' choices to also ameliorating the burden on patients' loved ones (Chiarchiaro, 2015).

Although participation must be voluntary, the opportunity for informed end of life conversations and planning should be universal. Every Australian should be given the opportunity to participate in a conversation around future healthcare and well-being choices.

Benefits of End of Life Conversations

While these conversations mean confronting the reality that life is finite, end of life conversations have cascading benefits for both patients, families and their carers.

Among patients with advanced illness or older age, conversations about end of life choices are an essential element of good care. Numerous studies and analyses (Burge, 2015; Bernacki, 2014; IOM, 2014; Slort, 2011, Detering, 2010; Temel, 2010; Wright, 2010; Wright, 2008; Morss, 2008; Productivity Commission, 2007; Lautrette, 2007; Ahrens, 2003; Oberle, 2001) show that when conversations occur there is:

- Greater alignment between patient preferences and the care they receive;

- Higher patient quality of life;

- Improved patient satisfaction;

- Less use of aggressive or non-beneficial life-sustaining treatments;

- Greater use of hospice care;

- Increased likelihood that people will die at home or in a comfortable setting;

- Reduced family distress, anxiety and depression;

- Reduced stress among doctors, nurses and other caregivers;

- Reduced medical errors; and

- Improved resource use and efficiencies.

Conversations emphasising patient choice, including treatment preferences, are a powerful determinant of care. Patients are more likely to receive care that is consistent with their choices when they have had the opportunity to discuss their choices for end of life care with a health professional. Patient conversations with health professionals are a better predictor of patients' End of Life Care outcomes than the place they are being treated (Wright, 2010).

The association between conversations and patients' preference for less aggressive care is noteworthy. Honest conversations make patients more realistic about the benefits of aggressive therapies, and thereby reduce the likelihood that they receive unwanted or futile intensive treatments near death.

Figure 1 shows patients who had conversations during counselling had less aggressive medical interventions, were better prepared and were more likely to receive hospice services for more than one week (Wright, 2008). Less aggressive care and earlier hospice referrals were associated with better patient care near death. Aggressive care was associated with worse patient care and worse bereavement adjustment for families.

There no evidence to support that end of life conversations are associated with increased emotional distress, terror or psychiatric disorders. Instead, the worst outcomes were seen in people who did not report end of life conversations.

Given the adverse outcomes associated with not having conversations there appears to be a need to increase the frequency of these conversations. By acknowledging that the end of life is near, patients, caregivers, and health professionals can focus on clarifying patients' priorities and improving pain and symptom management.

> **When treating a patient who has reached the end of life, clear communication and collective decision-making are as important as any clinical intervention.**

Conversations increase hospice use, reduce admissions and unwanted or futile aggressive medical interventions

Figure 1: A comparison of 123 advanced cancer patients who received end of life counselling and 209 who did not

⊕ Preferences and planning

	Had Counselling	No Counselling
Accepts illness is terminal	53%	29%
Wants to know life expectancy	84%	67%
Values comfort over life extension	85%	70%
Against death in intensive-care unit	49%	28%
Completed do-not-resuscitate order	63%	29%
Completed living will, durable power of attorney or healthcare proxy	72%	46%
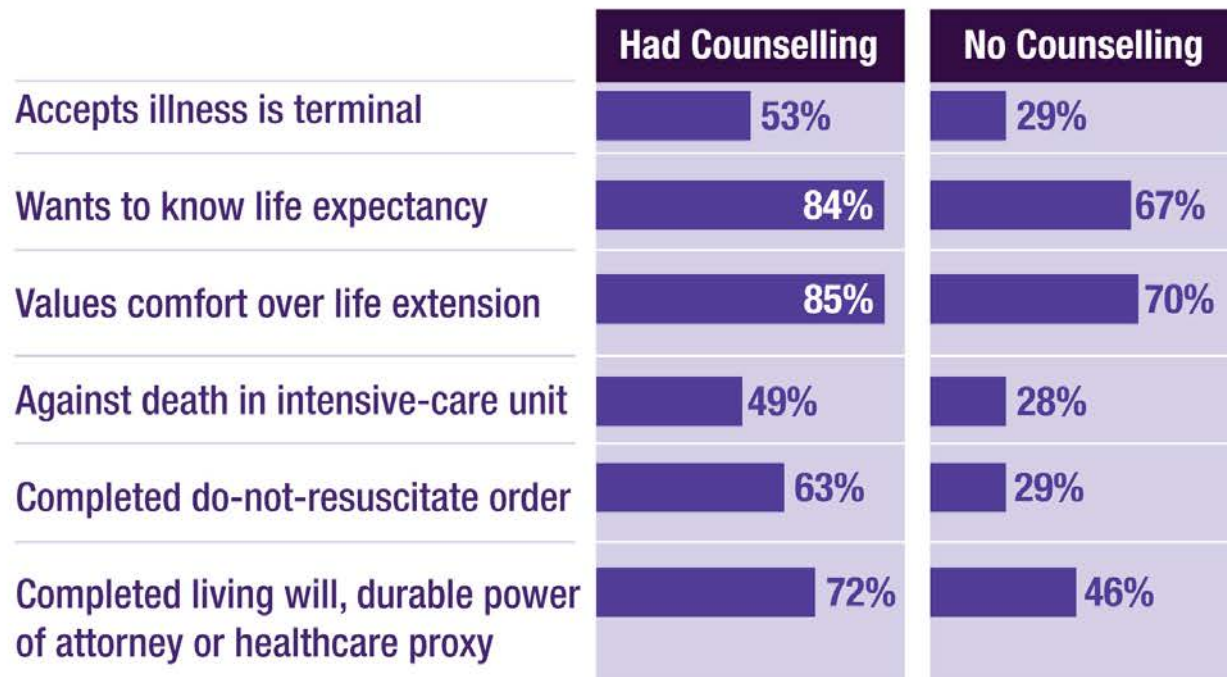
⊕ Care received in the last week of life

	Had Counselling	No Counselling
ICU admission	4.1%	12%
Ventilator use	1.6%	11%
Resuscitation	0.8%	6.7%
Chemotherapy	4.1%	6.7%
Feeding tube	8.9%	7.3%
Outpatient hospice used	76%	57%
Outpatient hospice of a week or more	66%	45%
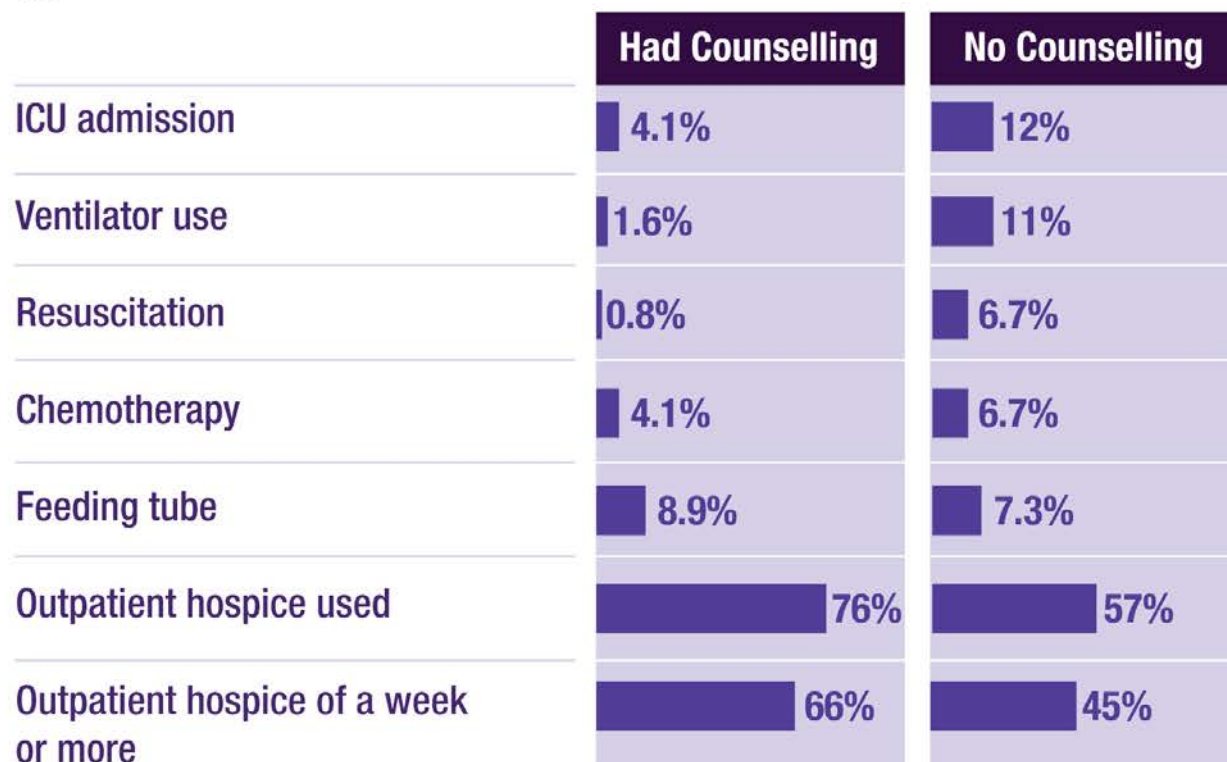
Source: Wright AA, et al. JAMA, Oct 8, 2008

Ongoing Conversations

End of life conversations are ongoing conversations about a person's values, preferences and priorities (IOM, 2014). Because choices evolve with changing circumstances, such conversations must be regularly reviewed, revisited and revised.

These conversations should happen throughout life, not just in the final days of life (Klugman, 2015). It can be difficult for people and their loved ones to think clearly in a health crisis and many, nearing the end of life, are not physically or cognitively able to make their own care decisions. For these reasons conversations should be initiated while a person is well.

In Australia, of the people considering completing an advance care directive (ACD) - a formal document recognised by common law, to make their wishes and preferences for future healthcare management clear and known (Australian Health Ministers' Advisory Council, 2011):

- 10 per cent are near death;
- 30 per cent are chronically ill; and
- 60 per cent are well.

This suggests that many individuals who are engaging in end of life conversations are not experiencing advanced illness or disability (Australian Health Ministers' Advisory Council, 2011). Many complete their personalised plan in stages, feeling confident to appoint a substitute decision maker while they are healthy.

When people understand their preferences and priorities, goals of care can be designed to support them to live to the end the best way they can. Asking everyone a single question, "what's important to you?", can open the gateway to conversations that will help facilitate their care. People can also be asked to reflect on whether they have any strongly held values and beliefs that might influence how decisions should be made (IHI, 2014).

Ideally, advance care conversations and plans are discussed with family and friends. They also should be incorporated into medical practice in the same way that patients are counselled on smoking, and obesity. They should be revisited when circumstances change, if a diagnosis of a disease has been made, if a disease progresses, and before a risky procedure or surgery.

Discussing End of Life Care wishes as early as possible, documenting, and then sharing them, is considered an essential enabler of choice.

What Matters Most

Before advanced illness develops, patients' perceptions about what matters most for high quality End of Life Care varies, but human connections are key.

Three main themes have been identified that relate to the involvement people generally want in their care. These also reflect patients' highest ranked attributes of 'a good death' (The Choice in End of Life Care Programme Board, 2015; ACHR, 2015; Heyland, 2006; Steinhauser, 2000) (**Table 2**).

TABLE 2: WHAT MATTERS MOST IN END OF LIFE CARE

HONEST COMMUNICATION & CONVERSATIONS	Have someone who will listen Know what to expect about your physical condition Have a person who cares and can discuss fears Know that your doctor is comfortable talking about death and dying'
TIMELY ACCESS TO INFORMATION AND SUPPORT	Involvement of family and those close to them Trust and feel comfortable with the health professionals Able to maximise comfort and well-being Access to pain and symptom relief Religious, spiritual or emotional support Continuity of care
INVOLVEMENT IN DECISION-MAKING	Feel in control over treatment choices Choice over the place of care and death Avoidance of unwanted life support Feel prepared to die - life completion

Patient Experience and Satisfaction

Effective communication as well as enabling patients and their carers to understand what is happening, and adjust to their new situation, are key components of good End of Life Care.

From a serious conversation with a health professional, patients expect a sensitive, appropriate, honest, timely two-way conversation with a high degree of awareness of their specific needs and circumstances.

Unfortunately, many doctors do not do this and patients often report being unsatisfied with their experiences (Singer, 1999; Quill, 2000). The clinical focus of many health professionals emphasises the physical self, and often does not align with broader psychosocial and spiritual components that are usually more important to patients and families (Zimmermann, 2007). This can create barriers to open communication about end of life issues and impending death.

When faced with life-threatening illness, health professionals often feel that they must choose between hoping for disease remission and preparing the patient for death. Hoping for a cure and preparing for potential death need not be mutually exclusive (Back, 2003). Although it may seem contradictory, hoping for the best while at the same time preparing for the worst can be a useful strategy for approaching patients with potentially life-limiting illness. By acknowledging all the possible outcomes, patients and their doctors can expand their clinical perspective to include disease modifying and symptomatic treatments and attend to underlying psychological, spiritual, and existential issues.

In addition to communication issues, a recent review of patient experience identified health professionals still used incomprehensible language, lacked the skills to deliver bad news, and patients and families viewed them as being too busy to be available to talk (Robinson 2014; Caswell, 2015).

Poor communication between hospital staff and family carers can cause significant distress and dissatisfaction, and is a common topic of complaint (Caswell, 2015). Common problems for the family most often relate to information about the patient's overall condition, and guidance about the family's role.

The power of effective communication also includes the power of silence (Lilly, 2007), family satisfaction with meetings about End of Life Care in hospitals is greater when health professionals talk less and listen more (McDonagh, 2004).

Conversation Barriers and Facilitators

Most people state that they want to have End of Life Care conversations with their loved ones or a health professional. There is, however, a significant gap between intent and the translation to action. Data consistently shows, around 90 per cent of people say that talking with a loved one about End of Life Care is important, however only 27 per cent actually do (IHI, 2013).

The common patient barriers to, and facilitators of, End of Life Care conversations, including frail and older people who had no main overriding diagnosis, are (De Vleminck, 2014; Sharp, 2013; Barclay, 2009):

1. Families

The most frequently identified barrier to discussions are the families of older people. Often they were unwilling to have discussions, to accept that their relative is near the end of their life or wish to protect their loved one from upsetting conversations. Breakdown in family relationships and lack of close family were further obstacles identified.

2. Professional or Time Limitations

Concerns over healthcare professionals' proficiency and willingness for conversations; as well as perceived lack of continuity of care and support are identified as barriers.

3. Reluctance to Discuss

A small but significant minority of older individuals were unwilling to discuss their End of Life Care, not wanting to talk about 'upsetting' or 'negative' issues; not feeling 'ready to do it'; or wanting to put off discussions to a time 'if I ever have a terminal illness'. They sometimes saw End of Life Care discussions as the responsibility of others, commonly family members. Those who had a life-limiting diagnosis estimated their prognosis to be excellent, reported quality of life to be good and did not desire active involvement in decision making (Hoffman, 1997). Some reported feeling content to leave such matters 'in God's hands', or that 'my doctor will decide for me'.

4. Difficulty Planning for an Uncertain Future

The problems of unforeseen medical scenarios and the difficulty of making well-informed decisions before illness occurs were felt to inhibit conversations and planning. Cognitive impairment and a lack of decision making capacity were felt to be important barriers to

> **" I encourage you to hope for and expect the best, but it is also wise to prepare for the worst.**
>
> Anthony Back
> Annals of Internal Medicine, 2003

planning. The onset of dementia was identified as a prompt for early planning.

5. Administrative Barriers

A lack of information, inadequate time to consider decisions and the legalistic paperwork involved in completing advance care plans were all felt to be off-putting.

Existing barriers, and a lack of facilitators, result in missed opportunities to hold conversations about end of life choices. Studies show that of the elderly people, over 70 per cent lack the capacity to make those decisions for them-selves or to communicate them to others (Silveira, 2010).

Health Professionals and Difficult Conversations

Today we expect health organisations and professionals, responsible for the care of dying, to be actively promoting end of life conversations and breaking barriers on how dying, death and bereavement are discussed. On the contrary, time demands, lack of training, and clinical focus can often be a significant impediment to the conversation process. This can create significant moral distress for health professionals working in these systems, especially for those who recognise that the care they provide in some cases is not what they would want for themselves or for their families.

Lack of Skills

We assume health professionals are skilled in talking about difficult subjects, even when patients may not be able to. However, research shows the overall quality of communication between health professionals and patients with serious illness is poor, particularly with respect to discussing prognosis and dealing with emotional or spiritual concerns (IOM, 2014). Some health professionals describe being uncomfortable with the 'paradox of promoting health and discussing its inevitable failure' and finding the right balance between hoping for the best and preparing for the worst (IOM, 2014).

A good rapport with the patient, experience in dealing with End of Life Care matters, adequate training in breaking bad news and specialist knowledge are important for facilitating difficult conversations (Momen, 2012).

Avoiding Conversations

The tendency of medical professionals to avoid conversations with patients about their care options is common and a significant barrier to overcome (Lamont, 2001).

In one recent study, 86 per cent of doctors stated that conducting end of life conversations with patients was challenging, especially with ethnic minority patients and their families (Periyakoil, 2015). Individual, interactional, and system-level factors perpetuate the culture of avoidance (Pavlish, 2015; Buiting, 2011). These include the intellectual and emotional toll of addressing ethics; differences in moral perspectives; fear of harming relationships or destroying hope; ignorance of patients' cultural beliefs, values and practices; lack of continuity in care; emphasis on efficiency; and lack of shared decision making.

This avoidance has a serious impact for patients. It can give false hope or, conversely, increase anxiety by raising suspicions that doctors are withholding potentially frightening information (Gattellari, 2002; Fallowfield, 2002). Arguably, the most serious impact is that it denies patients the opportunity to prepare and plan for their end of life.

Uncomfortable Initiating Discussions

While some health professionals may believe that patients are not willing or able to face discussions around death and dying, most patients expect their GP to initiate conversations and would prefer to talk with a GP who they know and trust than a stranger or designated 'advance care plan professional' in the hospital following admission (Cartwright, 2004).

Many doctors find conversations initiated by patients easier but admit to feeling uncomfortable even when patients ask about End of Life Care directly (Sullivan,1996; Crawford, 2010). In some places, doctors are taught to

take the lead in initiating discussions about End of Life Care. Elsewhere, doctors leave it up to patients to take the lead. World Health Organization (WHO) experts agree that a shared approach is best, with patients laying out their preferences and priorities, and doctors helping them understand the risks and benefits associated with them (Coulter, 2008).

Patient Preferences and Values

Health professionals are rarely able to predict individuals' End of Life Care preferences (Pfeifer, 1999), including preferences for discussions. Research suggests as few as 14 per cent of doctors know patients' preferences regarding pain management or place of death (Desharnais, 2007) and many patients receiving palliative chemotherapy do not understand its non-curative intent (Weeks, 2012).

In a study of family conferences for patients at high risk of death across five US intensive care units (ICUs), patient treatment preferences and values were discussed by clinicians and carers in only 37 per cent of all conferences. In more than 88 per cent of conferences, there was no conversation about the patient's values regarding autonomy and independence, emotional

well-being and relationships, physical function, cognitive function, or spirituality (Scheunemann, 2015). On average, only 3.8 per cent (SD, 4.3; range, 0-16%) of words spoken pertained to patient preferences or values.

Defining Responsibility

Defining which health professionals should be responsible for conversations can be problematic.

In a recent systematic literature review on End of Life Care conversations in chronic obstructive pulmonary disease (COPD), no single group of health professionals felt that their role, relationship with patients, or work setting made them the most appropriate professional to have a conversation about the end of life. This was despite 74 per cent of people hospitalised with an exacerbation seeing their general practitioner in the month before admission, 31 per cent three or more times (Momen, 2012).

The chronic disease management strategies that emphasise importance of multidisciplinary involvement, and that all healthcare professionals have a 'collective responsibility', leads to the danger that no health professional takes the responsibility.

Funding for Conversations

In Australia, there are significant time and financial disincentives for health professionals to have conversations with patients and deliver care that aligns with stated goals, values, and informed preferences.

Published, peer-reviewed research shows that advance care conversations and planning lead to better care, higher patient and family satisfaction, fewer unwanted hospitalisations, and lower rates of caregiver distress, depression and lost productivity. Adequate funding of these conversations deserves priority attention.

Reimbursing these essential services would remove significant obstacles to making sure that people actually have conversations and receive advance care planning. It will also signal to clinicians that these conversations are valuable and will empower Australians to demand and expect this necessary, but often neglected, service.

There are several options for improving the efficiency and effectiveness of End of Life Care (advance care) conversations and delivering palliative and end of life care services:

1. Funding for General Practitioners (GPs)

In Australia there is currently no dedicated Medicare Benefits Schedule (MBS) item for advance care conversations or planning. A series of non-specific item numbers are often muddled together.

GPs play an important role in the care of patients as they approach the end of their life. Conversations and advance care planning requires commitment of time specific to that activity with the patient (30 - 90 minutes), with additional consults to review and update plans.

In the US, the value of advance care conversations and planning has been officially recognised and this represents a significant turning point for End of Life Care. From 1 January 2016, the Medicare physician fee schedule
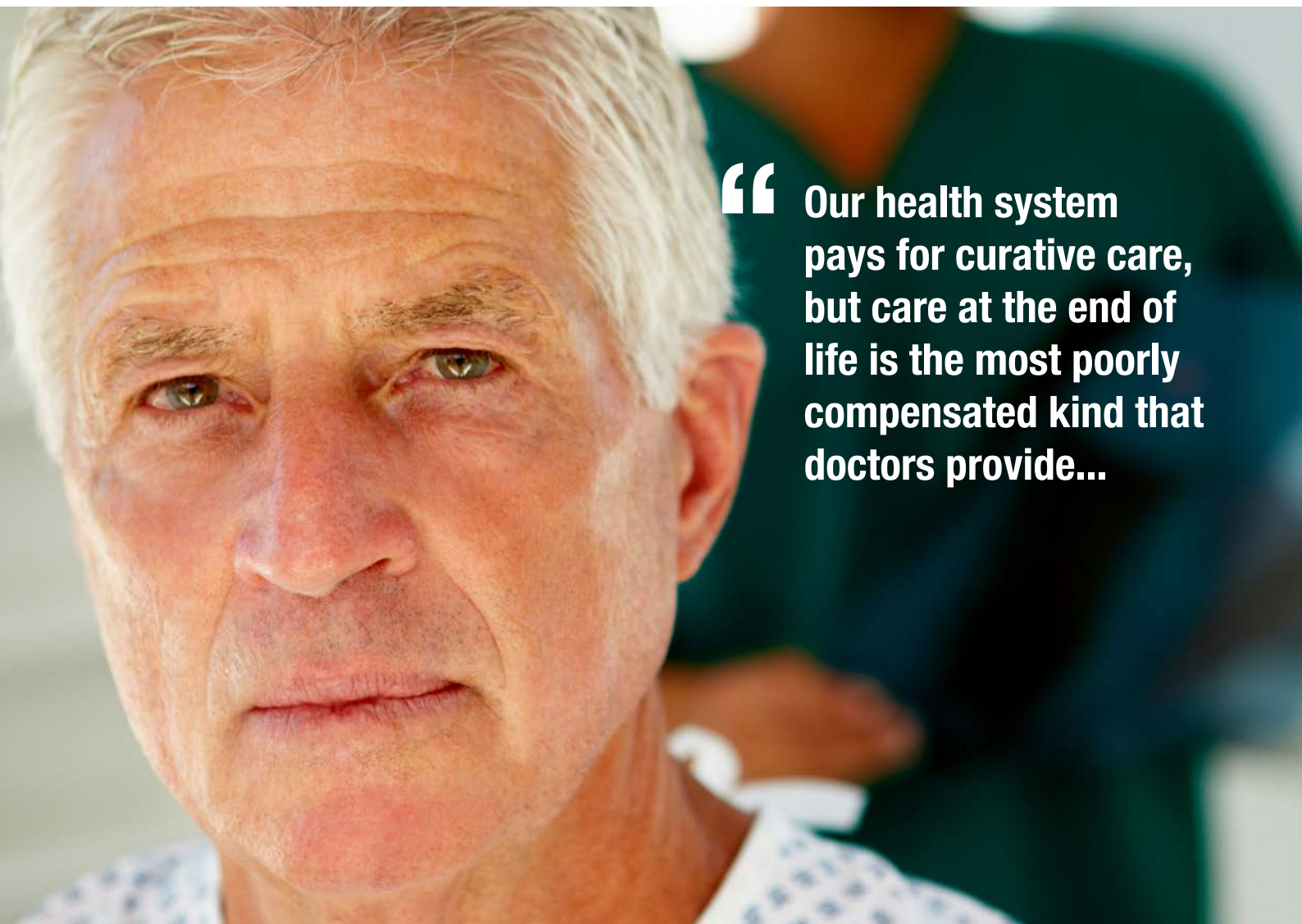
> **"** Our health system pays for curative care, but care at the end of life is the most poorly compensated kind that doctors provide...

(covering up to US$161.00) provides access to voluntary services and provides individuals with an important and often timely opportunity to establish and document their goals of care and preferences in the event of a serious illness. Focus now being placed on the next steps includes helping to ensure that advance care plans for all US patients are easily accessible and updated frequently, and that doctors are trained to have these difficult conversations.

Adopting a similar funding policy in Australia, and creating specific MBS item for End of Life Care conversations in Australia would make the provision of this important service more visible to GPs and enable greater promotion of the GP role and responsibility in advance care planning and management.

This item number should include the development and review of advance care plans by GPs (of similar time and value to those Items for chronic disease management) as well as the ability to refer to allied health professionals subsidised by the MBS.

This GP focus would also allow non-cancer patients to gain better access to services where discomforts may be more uncertain, particularly for disorders such as neurodegenerative disorders, congestive heart failure, liver disease, COPD or failed organ transplant, which are difficult to track and predict.

2. Better Funding for Community, Residential Aged Care and Rural Care

Ensuring GPs and palliative care nurse practitioners are reimbursed to provide care and have end of life conversations in the community is critical.

While there are existing items to support a home visit, there are no items relating to conversations and coordination of palliative care within a residential aged care facilities (RACF). Reimbursement needs to consider the earnings lost from GPs not being available for consultations in their practice or to support GPs making visits to RACFs to have conversations, develop advance care plans and provide palliative care.

We promote the exploration of options for using the Aged Care Funding Instrument to have conversations and better achieve access to quality palliative and End of Life Care in RACFs.

The Commonwealth needs to recognise the additional costs of rural and remote service provision, where financial and social welfare issues are more prevalent.

3. Reimbursement for Family Conferences

We lack MBS items that can facilitate health professional engagement with the families that could help health professionals better understand care needs, and help everyone agree on the goals of care for each patient. Funding of family meetings would reduce the time required when there are disagreements about the goals of care, and would potentially lead to a reduction in provision of futile and unnecessary care.

5. Funding for Essential Services

There are also a number of essential services that do not attract Medicare benefits, including issue of death certificates, cremation certificates and counselling of relatives. In addition, the federal government should require public reporting on quality measures, outcomes, and costs regarding end of life conversations for programs it funds or administers (e.g., Medicare, health insurance, the Department of Veterans Affairs [DVA], Centrelink and other social service benefits paid).

> "
> **In Australia there is no dedicated MBS item for End of Life Care, advance care conversations or planning.**
>
> **Significant investment in health infrastructure and services is necessary for improvements in End of Life Care, and for greater patient choice.**

4 End of Life Care: Everyone's Responsibility

A New Approach: Everyone's Responsibility

Evidence suggests there is currently a significant mismatch between the services readily available to people near the end of life (acute care) and what they most often say they want (supportive services) (Gruneir, 2007). There is increasing pressure on the system at every level:

- Health professionals are struggling to meet the complex needs of the people they care for;

- We are all paying a high financial price for care, which includes costs for medical interventions that many do not want or that are futile;

- Many believe the health system no longer meets their needs at the end of life, preferring better access to community-based services.

We all have a stake in improving care for people nearing the end of life. For people with a life-limiting illness and their families, that stake is immediate and personal, and no care decisions are more profound. For those who work in health and community care it is a matter of professional commitment and responsibility. Funders and policy makers also have a professional stake in the provision of End of Life Care, and must ensure that is not only high quality but also affordable and sustainable.
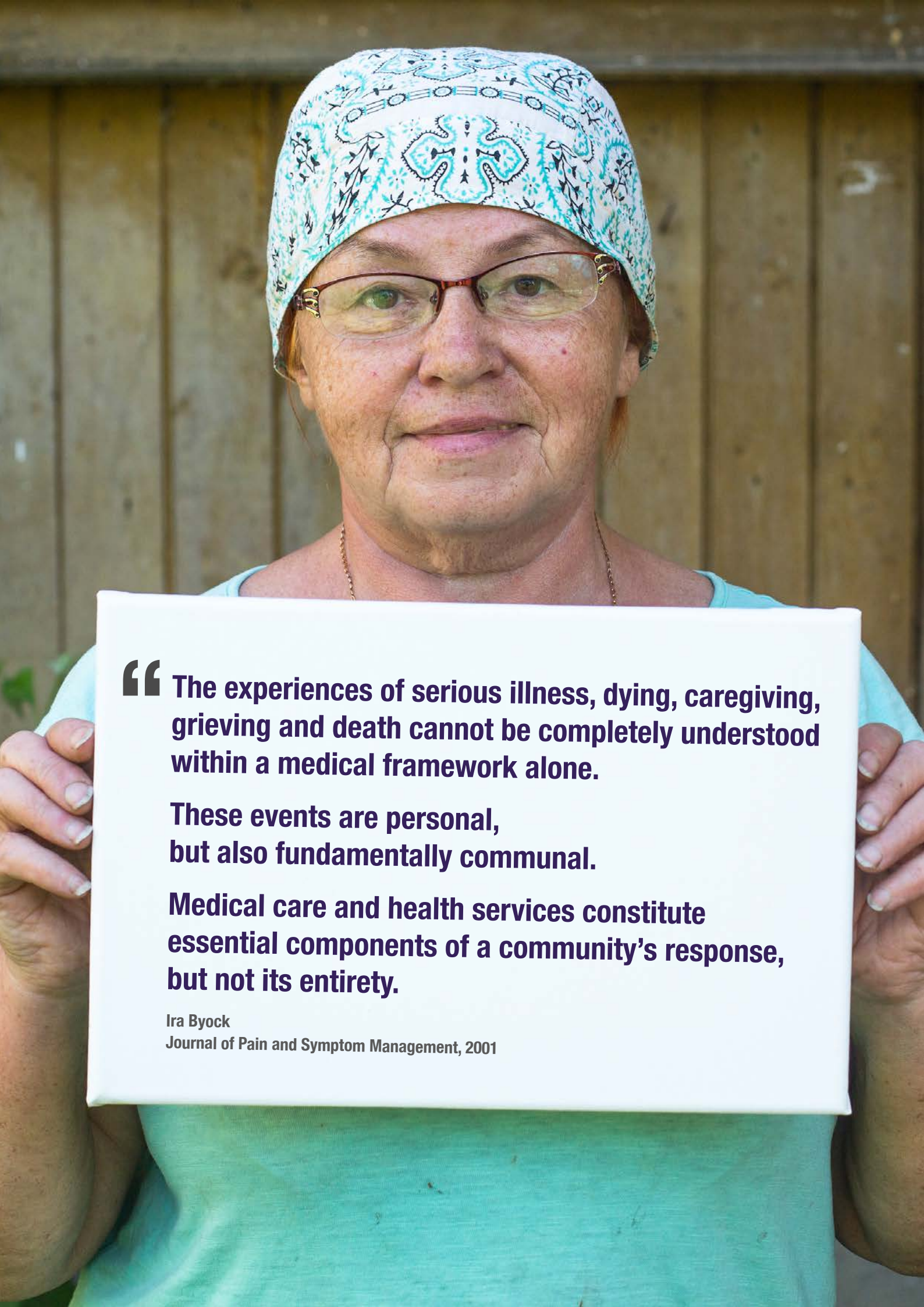
The issues that contribute to this sub-optimal care gap at end of life include a lack of open communication, difficulties in accurate prognostication and a lack of planning of End of Life Care (Edmonds, 2003). Because they effect us all, efforts to improve End of Life Care and decision making need to focus on greater individual and societal approaches if established practices are to be changed (SUPPORT, 1995).

Amongst the many innovative and inspiring examples of societal approaches to End of Life Care from around the world, Professor Allan Kellehear, an Australian Public Health academic, has developed a rationale that focusses on extending and changing the model of professionalised End of Life Care into one that sees the end of life as part and parcel of life as a whole. He sees a need for professional service and communities to work in partnership (Kellehear, 1999; Kellehear, 2005), making health, dying and death everyone's responsibility.

Commonly, people who live with a life-limiting illness also encounter anxiety, depression, social isolation, social stigma, social rejection, family breakdown, premature job loss, financial strain, spiritual dilemmas or crises, among other concerns. These are key determinants of quality of life for the dying, their carers and the bereaved. They are not easily addressed by health, palliative care services or acute care facilities, even less so in the last days of life or to follow up the bereaved after a death (Kellehear, 2013). However, these determinants are amenable to prevention, harm reduction and early intervention by enlisting the community and increasing the effectiveness of End of Life Care as a public health goal (Kellehear, 2013).

Kellehear's *Compassionate Communities* (Kellehear, 2005) are whole communities that decide to promote the health and well-being of their population in a systematic and holistic way. They recognise that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities.

The Compassionate Communities model calls for the reconfiguration of services where the wider community supports those at the end of life, working in partnership

"The experiences of serious illness, dying, caregiving, grieving and death cannot be completely understood within a medical framework alone.

These events are personal, but also fundamentally communal.

Medical care and health services constitute essential components of a community's response, but not its entirety.

Ira Byock
Journal of Pain and Symptom Management, 2001

with health professionals through a 'health promoting' approach, where:

- Death, dying and bereavement cease to be taboo subjects and become normalised;

- People's expectations of death and dying change, along with the management of death; and

- Palliative care and community support work together. Palliative care re-orientates, supporting health and care teams to work with the community in providing care to those at the end of life, and their loved ones.

In this community model, End of Life Care is often initiated by hospices or GPs, and co-ordinated through local government or regional areas. The model employs teams of naturally occurring supportive networks enhanced by making best use of families, friends, neighbours, local government and businesses, as well as community members and supported by health and community care professionals looking after people in their communities. Some of the work carried out by palliative care professionals is performed by working with communities and volunteers, making the experiences more meaningful to both caregivers and patients.

Decreasing the current workload of palliative care professionals offers the opportunity for service redesign. Identification of people with life-limiting illness is easier for professionals when they know that there is some-thing extra that can be done to improve the quality of their remaining life.

A very successful example of this can be found in the project developed at Severn Hospice in the UK (Wegleit-ner, 2015; Severn Hospice, 2016). Their initial goal was to support frail people and those living with long term illness to remain active members of the community and reduce social isolation. There was wide interest from community volunteers. The hospice provided support with initial community engagement, volunteer support, training and advice, and provided working procedures and practices for groups to adopt and adapt to their needs. GP surgeries were able to identify with ease their 35 most vulnerable, frail patients. This is already nearly half of the people who are likely to die within a year for an average GP practice size of 10 000 patients. The outcomes showed significant reductions in use of unscheduled health services through GP phone calls and appointments, a reduction in emergency and unplanned admissions following six

months support from a volunteer.

Freeing up workforce then gives the possibility of extending services to all people who have terminal illnesses irrespective of diagnosis. Teams of carers, families, friends, neighbours and volunteers working directly in localities with palliative care nurses to provide support in multiple ways for the last phases of life. Health and community care professionals are also part of this team. The freeing of resources means that the most vulnerable and those most at need can use the limited availability of professional caring services.

These developments and community models mark a significant shift in thinking about End of Life Care and highlight the appreciation of new public health ideas such as health promotion, community development, death education and literacy, as well as engagement into a field that was previously focused on inpatient, outpatient, day care, and home care services.

Health Promoting End of Life Care

The health promoting approach to End of Life Care has gained literature, policy and practice focus globally. Examples published from India, Australia and the UK have subsequently described the role community engagement has played in both increasing access to services and improving the holistic nature of care (Wegleitner, 2015; Abel, 2011; Horsfall, 2011; Rosenberg, 2011; Kellehear, 2007; Kellehear, 2008; Kumar, 2007). Policy documents are recognising the significance of this type of community involvement (National Palliative and End of Life Care Partnership, 2015; NHS Department of Health, 2008; Scottish Government, 2008; Paleri, 2008). The critical role of health promotion, education and engagement has also has been emphasised in the ground-breaking Institute of Medicine's report, *Dying in America* (IOM, 2014), which devotes a chapter to end of life communication, engagement and planning.

These national positions, campaigns and policy initiatives are important because they provide a critical framework, legitimacy, focus and resources for public awareness work, and top-down leadership is essential for funding. However, to maximise impact and uptake, both top-down and bottom-up activities are needed. Communities need to be invested, committed, and aligned to campaign and policy goals. Ultimately, it takes real and committed engagement of individuals and organisations working across a community that holds the wisdom, skills,

connections and experience required to effect change where people live.

The emergent field of the Compassionate Communities approach to End of Life Care (Matthiesen, 2014; Haraldsdottir, 2013; Rosenberg, 2010; Kellehear, 2005) offers a way to reframe and expand national campaigns beyond the health focused context. It supports professionals and local communities to work together to build broad integrated, sustainable approaches to end of life conversations to match needs with service provision and care requirements.

Through this program capacity building in End of Life Care is becoming a central mission for many hospices and care institutions focussed on working from the bottom-up. Health promotion approaches to End of Life Care are now a priority for many palliative care services in the UK, with services actively undertaking community initiatives (Paul, 2013). Their work is developing around three central focal points to advance this change:

1. Community Development - Circles of Care

Promoting community development restores the ability of families and communities to better support those who are dying (Abel, 2013; Rosenberg, 2011; Earle, 2009). To achieve this, end of life services are enhancing family and community capacity through development initiatives that follow three principles (Abel, 2013):

- **The subsidiarity principle** - decision making by those most affected by outcomes of the decision;

- **The empowerment principle** - personal empowerment and control by individual citizens over their own life; and

- **The structural principle** - developing ongoing structures and processes by which groups can meet their own needs.

Professional and technical expertise remain vital, regaining its rightful place as a well-resourced servant rather than a master trying to do everything and too often failing (Abel, 2013).

2. Death Literacy and Education

Many are actively working to improve death education and death literacy. Just as health education has been crucial to the prevention and harm reduction strategies of those working in cancer care (sun screens, anti-smoking campaigns etc.), sexual health (condom use, sex education etc.) or in trauma medicine (bike helmets, car seat belts etc.) so too education in death normalises and equips communities to better prepare for death, dying and loss (Kellehear, 2008). It combats the stigma of dying and promotes open awareness of death as a normal part of life.

High levels of death literacy, defined as a set of knowledge and skills that make it possible to understand and act upon End of Life Care options, provides people and communities with context-specific knowledge about the death system and the ability to put that knowledge into practice (Noonan, 2015). Positioned within a public health framework, death literacy is considered an outcome of people's experiences of and learnings about, death and dying. High levels of death literacy also act as an ongoing resource that individuals and communities can use for their own benefit strengthening their capacity for future caring.
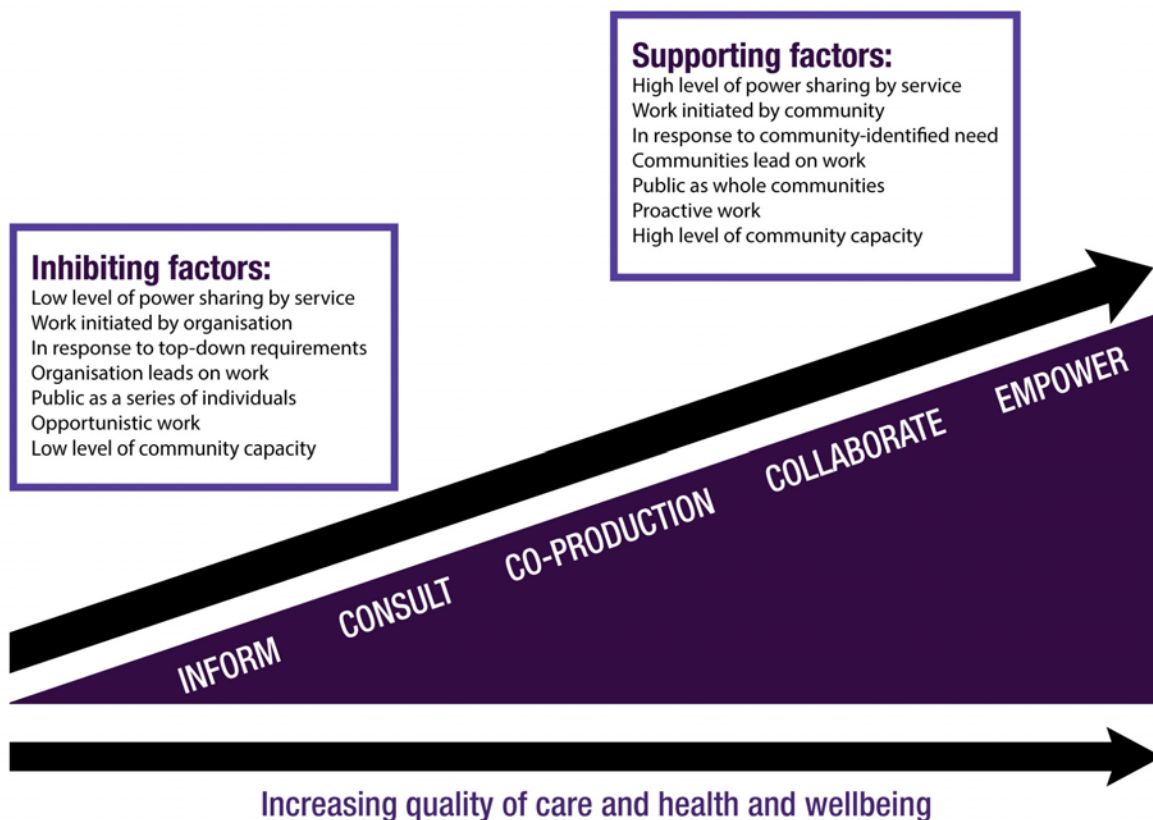
3. Community Engagement & Support

A health promotion approach to End of Life Care requires engagement in, and support of, community wide activities to undertake community development and promote death education at the end of life.

Community engagement exists on a spectrum that extends from informing at one end to empowerment at the other, distinguished by the extent to which power is shared with the community. A spectrum of community engagement in End of Life Care is presented in **Figure 2** (Sallnow, 2014). It provides a framework through which the emerging and diverse field of community engagement in End of Life Care can be understood. At one end of the spectrum, approaches that work to promote public openness around death, dying and loss can tackle the stigma that can surround these issues. Approaches that focus on empowering people, families and communities allow them to draw on their own resources and community supports to adapt and cope.

Engaging communities in their own care has important public health impacts. Services designed and implemented in partnership with communities are more likely to meet the needs of those communities and to be accessed by larger numbers of users; those with ongoing community involvement are more likely to be responsive to changing need and to be sustainable; and the skills developed within a community when working on such projects can have a wider impact, including building community capacity, changing health behaviours, tackling the social determinants of health, improving well-being and developing social capital (NICE, 2008; O'Mara-Eves, 2013).

FIGURE 2: A SPECTRUM OF ENGAGEMENT IN END OF LIFE CARE - DEVELOPING COMMUNITY CAPACITY

Supporting factors:
High level of power sharing by service
Work initiated by community
In response to community-identified need
Communities lead on work
Public as whole communities
Proactive work
High level of community capacity

Inhibiting factors:
Low level of power sharing by service
Work initiated by organisation
In response to top-down requirements
Organisation leads on work
Public as a series of individuals
Opportunistic work
Low level of community capacity

INFORM CONSULT CO-PRODUCTION COLLABORATE EMPOWER

Increasing quality of care and health and wellbeing

Source: Sallnow, L. Critical Public Health, 2015

Conversations to Build Compassionate Communities - Globally

Public awareness, engagement and community development work on dying, death, and End of Life Care are identified priorities in strategies and policies worldwide. There is increasing recognition that these are important areas of action to improve the end of life experiences for people and their families by policymakers, health systems and palliative care services (Sallnow 2013).

Most developed nations recognise the need to raise the profile of End of Life Care and to change attitudes to death and dying in society (**Table 3, See Appendix**).

ENGLAND

In England, this has led to a national coalition 'Dying Matters' being established in 2009 under the auspices of the National Council for Palliative Care and the promotion of an annual Dying Matter's week and the development of extensive information material and community education initiatives.

SCOTLAND

'Good Life, Good Death, Good Grief' is working to make Scotland a place where there is more openness so that people are aware of ways to live with death, dying and bereavement.

IRELAND

The Irish Hospice Foundation (IHF) is a national charity dedicated to all matters relating to dying, death and bereavement in Ireland. Their community awareness program, 'Think Ahead', guides people to discuss and record their care preferences in the event of an accident, advanced illness or death.

UNITED STATES

In the US, 'The Conversation Project' is a public engagement campaign with a goal that is both simple and transformative to make sure that every person's wishes for End of Life Care are expressed and respected. 'The Conversation Project' offer people the tools, guidance and resources they need to begin talking with their loved ones, around the kitchen table, about their wishes and preferences.

CANADA

The 'Speak Up' Campaign is part of a larger initiative, Advance Care Planning in Canada, and is overseen by a National Advance Care Planning Task Group comprised of individuals representing a spectrum of disciplines, including health care, law, ethics, research and national non-profit organisations.

TABLE 3: INTERNATIONAL EXAMPLES OF NATIONAL PUBLIC AWARENESS ACTIVITY

COUNTRY	ACTIVITY	DATE STARTED	WEBSITE
ENGLAND	• Dying Matters national coalition led by National Council for Palliative Care • Annual public campaign Dying Matters week • Over 27 000 members (individuals and organisations)	2009	www.dyingmatters.org
SCOTLAND	• Good Life, Good Death, Good Grief • Annual public campaign week • Under auspices of Scottish Partnership for Palliative Care	2011	www.goodlifedeathgrief.org.uk
IRELAND	• Think Ahead campaign - Arose from Forum on End of Life in Ireland, 2009 Pilot Think Ahead projects started in 2011	2011	www.hospicefoundation.ie
CANADA	• National Speak Up Campaign • National ACP Day (April) • Under auspices of Canadian Hospice Palliative Care Association	2011	www.advancecareplanning.ca
USA	• National Campaign: The Conversation Project • National Health Decisions Day • State-wide coalitions	2013 2008	www.theconversationproject.org www.nhdd.org
Adapted from Matthiesen 2014			

> **"Death and dying is everyone's business. It takes a village to raise a child and it takes a community to support death, dying and bereavement.**
>
> Julian Abel
> British Medical Journal, 2016

Advancing Australian Conversations on End of Life Care

End of Life Care has a low profile in Australia. It is not recognised as a public health concern, and we lack the national awareness and engagement programs evident in many other countries. Our impressive global record of health promotion and public education is not being matched in the process of dying, death or bereavement.

As death has become less common in our daily lives, it has become harder to consider our own mortality or that of those close to us. Lack of public openness about death has negative consequences for the quality of care provided to the dying and bereaved - including fear of the process of dying, lack of knowledge about how to request and access services, lack of openness between close family members, and isolation of the bereaved. Eradicating ignorance about what can be achieved with modern palliative care and encouraging dialogue about End of Life Care issues are important means of changing attitudes.

The view that we can cope better or less well with death and dying is relatively new to our culture. In the past, coping with advanced illness and dying has typically been viewed as a crisis that overwhelms normal coping processes and precludes notions of 'manageability.' This shift in perspective, combined with public and community awareness efforts presenting a different image of dying, is an essential element in the evolution of end of life conversations.

Perhaps unsurprisingly, relatively uniform opinions are found about the elements comprising quality of care at the end of life, reflecting widespread concerns about the process of dying. Research indicates that most Australians want: to be at home, with family and friends; to have their pain managed and controlled; their spiritual wishes and needs to be respected and honoured; and to be assured that those who love them are not emotionally and financially devastated in the process.

But all too often, that's not what our health system and our society provide. There is a large gap between the kind of care and treatment people say they want when the end is near and what our society, health and aged care systems currently provide. The quality of care is variable, fragmented and often low or inaccessible. This problem is compounded by a low awareness of many of the common and complex problems that individuals, families and caregivers face during end of life and the subsequent lack of conversations and planning to prepare for those situations.

Not everyone will want to talk about the end of their life, but "the right conversations with the right people at the right time can enable a patient and their loved ones to make the best use of the time that is left and prepare for what lies ahead,"(Barclay, 2010).

Mirroring populations of other developed countries, 90 per cent of Australians say it's important to talk about their End of Life Care wishes, yet less than 30 per cent of people have actually had that conversation. Facilitating conversations, building public engagement to help people make informed decisions and supporting changes in care delivery and policy is essential to transforming End of Life Care in Australia.

Evidence from social marketing shows that 'bottom up' approaches focusing on value to the user provide a framework for designing programs to raise public awareness of issues related to death and behaviour change (French, 2009). A number of important national and regional initiatives are at work (e.g., ACHR's DeathOverDinner.org.au ; The Groundswell Project ; Palliative Care Australia program; and Compassionate Communities) supporting the public will for change and empowering people to have informed conversations, plan and make decisions for End of Life Care. These initiatives encourage families and individuals to think about anticipated life course changes and challenges, document those discussions before emergencies occur, and broadly educate people about specific care options along the advanced illness continuum.

Dying, death and bereavement needs to be accepted as a natural part of everybody's life cycle. End of Life Care impacts everyone, at every age, the living, the dying and

the bereaved. It is not a response to a particular illness or condition. It is not limited to a particular group or section of the community. Eventually, everyone dies. Because dying is a universal experience, nearly everyone has a story about a good death or a hard death among those they love. The difference between these experiences often rests on whether we have shared our wishes for how we want to live at the end.

The Roadmap to Reform Starts with Conversation

Australians are beginning to be engaged in an important debate and discussion involving the end of life and how to die well. Among the factors prompting increased attention include the ageing of the population - each week in Australia, 2 000 people turn 65 years old and more than 1 000 turn 85 years old; the increasing recognition that doing everything possible to prolong life, such as intensive care or chemotherapy for patients with terminal illness, is not always appropriate or desirable; the growing awareness of the importance of advance care planning, advance directives and self-determination about End of Life Care decision making; and data that indicates health spending during the last year of life represents a significant amount of healthcare costs and accounts for a substantial proportion of total Medicare expenditures, with typically more money spent on medical care during a patient's last year of life than in any other year.

The climate has changed, and discussions about End of Life Care conversations are more honest and well informed.

The majority of Australians will face advancing, life-limiting illness and they need to be prepared and cared for. There must be encouragement and opportunities to talk openly about death and dying, discuss care preferences with family or friends, and be supported by professionals who are not reluctant to initiate conversations with patients but instead offer timely, sensitive, patient-led conversations. These conversations must transform from being accidental and transactional to becoming part of a well thought-out, informed, longer range plan.

The Australian Centre for Health Research (ACHR) seeks to transform End of Life Care through a conventional research and practice development program, as well as innovative community awareness initiatives that help people have conversations about their end of life choices.

For ACHR, raising public awareness is regarded as just as vital as the policy and practice developments needed to address seemingly intractable problems in the care of the dying in Australia.

ACHR is committed to encouraging people to talk about death and dying – in thousands of kitchens, living rooms, coffee shops and restaurants across the country. ACHR believe that conversations about End of Life Care shouldn't always start with doctors, governments, insurance companies, or in intensive care units (ICUs) when people are overwhelmed; they should start with family and friends while breaking bread, and well in advance of an accident or an emergency.

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Appendix A
Health Promotion: talking about death and conversation projects

The Conversation Project

"When it comes to end of life, one conversation can make the world of difference"
Dedicated to helping people talk about their wishes for end-of-life care. The goal: to make it easier to initiate conversations about dying, and to encourage people to talk now and as often as necessary so that their wishes are known when the time comes. A vision emerged for a grassroots public campaign spanning both traditional and new media that would change our culture. Too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. It's time to transform our culture so we shift from not talking about dying to talking about it. It's time to share the way we want to live at the end of our lives. And it's time to communicate about the kind of care we want and don't want for ourselves. The Conversation Project emphasises having a conversation on values - what matters to you, not what's the matter with you.

Organisation	Collaboration with the Institute for Healthcare Improvement
Country	USA
Website	http://theconversationproject.org/
Outcomes	Not publicly available

Death Over Dinner

Death Over Dinner is an interactive website and cultural movement dedicated to giving people the permission and the tools to powerfully discuss their choices and thoughts on end of life and End of Life Care with their friends and loved ones. It has already inspired over 100,000 people to break bread and explore the many aspects of mortality, ageing, and the choices we face at the end of our lives. Designed for both intimacy and accessibility, Death Over Dinner leverages the physical dinner table as its centre piece, and provides additional opportunities for interactive engagement online.

Death Over Dinner is being used to train doctors, HMO staff and palliative care communities how to have end of life discussions with patients.

Lead Organisation Collaborators	Michael Hebb (Founder) Institute for Healthcare Improvement (IHI), The Conversation Project, leading health practitioners, journalists, legal advisers, media experts
Country	USA
Website	http://deathoverdinner.org/
Outcomes	100,000 dinners since 2013

Death Over Dinner (Australia)

In Australia 'how we want to die' represents the most important and costly conversation Australia isn't having. To address this, the Death Over Dinner movement becomes international and launches in Australia in 2016. Informed by local medical and community leaders, this is an uplifting interactive adventure that transforms this seemingly difficult conversation into one of deep engagement, insight and empowerment, catering to an Australian audience. The Australian Centre for Health Research (ACHR) is committed to changing our national culture from not talking about End of Life Care to talking about it – in thousands of kitchens, living rooms, coffee shops and restaurants across the country. Michael Hebb will continue to be involved with this project expansion.

Lead Organisation Collaborators	Australian Centre for Health Research (ACHR) Monash University, Deakin University, University of Melbourne, leading health practitioners, journalists, legal advisers, media experts
Country	Australia
Website	http://deathoverdinner.org.au/
Outcomes	Launching in 2016

Death Cafe

At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death. Their objective is 'to increase awareness of death with a view to helping people make the most of their (finite) lives'.

Organisation	Developed by Jon Underwood and Sue Barsky Reid. Based on the ideas of Bernard Crettaz. Run by volunteers.
Country	Europe, North America and Australasia
Website	http://deathcafe.com/
Outcomes	2361 registered events since 2011. If 10 people came to each one that would be 23610 participants.

Conversations for Life

A proprietary program and workshop series offering tools and inspiration for families, professionals, communities to talk about end of life.

Organisation	Mary Matthiessen, Nicola Rudge Start-Up funder: The Department of Health Social Enterprise Investment Fund
Collaborators	Dying Matters Coalition, Lancaster University
Country	UK
Website	http://www.conversationsforlife.co.uk/
Outcomes	Not publicly available

My Gift of Grace

My Gift of Grace is the cornerstone of Common Practice, a platform of proprietary products and services that help organisations improve end of life conversations for staff, patients, families, and communities.

Lead Organisation	Common Practice
Country	USA
Website	http://mygiftofgrace.com/
Outcomes	74% of people who played My Gift of Grace went on to perform an advance care planning activity. 90% of participants advanced in stage of change and/or performed an advance care planning activity. Reading JM. et al. 2015, Van Scoy LJ, et al. 2015

Five Wishes

Changing the way people talk about and plan for care at the end of life. They have a mission to safeguard the human dignity of people as they age or face serious illness.   Today we are a trusted resource for people who want to plan for care in advance of a health crisis. This document is the most widely used advance directive or living will in America. It is often called the "living will with a heart and soul" because it includes the things that matter the most.

Lead Organisation	Ageing with Dignity
Country	USA
Website	https://agingwithdignity.org
Outcomes	Over 20 years, they have touched the lives of more than 23 million people and their families. Worked with more than 40,000 organisations across America that distribute the Five Wishes document. Resources available in 27 different languages.

ACP Decisions Video Support Tools and Decision Aides

Video support tools are carefully crafted after undergoing rigorous review by leading experts in medicine, geriatrics, oncology, cardiology, ethics, and decision-making. Today, multiple healthcare systems use video support tools to empower patients and families.

Lead Organisation	ACP Decisions
Country	USA
Website	https://www.acpdecisions.org
Outcomes	A number of peer-reviewed publications show that when compared to the verbal arm, subjects in the video arm had • had more accurate knowledge about CPR and intubation • were more knowledgeable and certain of their end of life decisions and goals of care • were more knowledgeable about advanced dementia and goals of care preferences.

Death Wise – Wise Conversations

Committed to helping people talk about, make decisions and plan for the end of their lives.

Lead Organisation	Death Wise and California Healthcare Foundation
Country	USA
Website	https://www.deathwise.org
Outcomes	Not publicly available

Appendix B
Health Promotion: social action and cultural change projects

Dying Matters

Raising awareness of dying, death and bereavement.

Organisation	Set up by the National Council for Palliative Care (NCPC), Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.
Country	UK
Website	http://dyingmatters.org/

Good Life, Good Death, Good Grief

Working to make Scotland a place where there is more openness about death, dying and bereavement.

Organisation	Scottish Partnership for Palliative Care is an umbrella and representative organisation which, through a collaborative approach, supports and contributes to the development and strategic direction of palliative care in Scotland.
Country	Scotland
Website	http://www.goodlifedeathgrief.org.uk/

Think Ahead

A public awareness initiative aimed at guiding people in discussing and recording their care preferences in the event of an accident or other emergency, serious illness or death – when they may well be unable to speak for themselves. It comprises a detailed form divided into six sections: (1) Key Information; (2) Care Preferences; (3) Legal Matters; (4) Financial Matters; (5) When I Die; and (6) Sharing Information.

Organisation	Irish Hospice Foundation
Country	Ireland
Website	http://hospicefoundation.ie/supporting/wayswesupport/think-ahead-planning-for-death-dying/

Advance Care Planning Canada / Speak Up

Advance Care Planning in Canada was created in 2008 to raise awareness of the importance of advance care planning and to equip Canadians with the tools they need to effectively engage in the process. The Initiative also has a goal is to provide professionals/health care providers with the tools they need so they can facilitate and engage in the process of advance care planning with their clients. Along with a National Framework, the Initiative has developed the Speak Up campaign to provide tools and resources to patients and families, health professionals and community organisations.

Organisation	Advance Care Planning Canada
Country	Canada
Website	http://www.myspeakupplan.ca/

Compassionate Communities

The Compassionate Cities model and charter provides a broader framework within which end of life issues in general can be addressed, not merely those that fall within the more specialised interests of palliative care. Attention turns to developing communities in which citizens living with dying and loss can continue to participate in meaningful ways.

Organisation	Public Health and Palliative Care International (PHPCI) An association to communicate the importance of public health ideas and approaches in palliative care at a global level.
Country	Global
Website	http://www.phpci.info/

Tracks we Leave

A WHO demonstration project that is now a WHO Centre for excellence in palliative care.

Organisation	Institute of Palliative Medicine, WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care.
Country	Global
Website	http://www.tracksweleave.org/

Ten things / Dying to Know

To develop innovative arts and health programs that create cultural change about death and dying, while championing others to do the same.

Organisation	Groundswell
Country	Australia
Website	http://www.thegroundswellproject.com/

Order of the Good Death

The Order is about making death a part of your life. Staring down your death fears - whether it be your own death, the death of those you love, the pain of dying, the afterlife (or lack thereof), grief, corpses, bodily decomposition, or all of the above. Accepting that death itself is natural, but the death anxiety of modern culture is not.

Lead Organisation	The Order of the Good Death is a group of funeral industry professionals, academics, and artists exploring ways to prepare a death phobic culture for their inevitable mortality.
Country	USA
Website	http://www.orderofthegooddeath.com/

Caring at End of Life

Understanding the nature and effect of informal community care networks for people dying at home.

Lead Organisation	University of Western Sydney
Country	Australia
Website	https://caringatendoflife.wordpress.com/

Life Before Death

The elderly and sick often suffer in silence every single day as death approaches them but really, they shouldn't have to. Radically innovate the delivery of eldercare and push for better and more open conversations about something that is inevitable because we have to face it sooner or later.

Lead Organisation	The Lien Foundation – Radical philanthropy
Country	Global / Asia Pacific
Website	http://www.lienfoundation.org/ http://www.lifebeforedeath.com/

Appendix C
Definitions

Below is a list of common terms and their meanings in the context of this document adapted from Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015.

Advance Care Directive

A type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care, and appoint a substitute decision-maker to make decisions about health care and personal life management. In some states, these are known as advance health directives.

Advance Care Plan

An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care, and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.

Advance Care Planning

A process of planning for future health and personal care, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.

End of Life

The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.

End of Life Care

Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next
12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in
- their condition
- life-threatening acute conditions caused by sudden catastrophic events.

Palliative Care or Palliative Approach

An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).

Resuscitation Orders / Plans

Not for resuscitation (NFR) and do not attempt resuscitation (DNAR) orders relate solely and specifically to decisions to not perform cardiopulmonary resuscitation if the patient has a cardiac or respiratory arrest. In some organisations, decisions about other specific limitations of medical treatment may also be listed as part of a resuscitation plan (e.g. decisions to call a medical emergency team or transfer a patient to intensive care if they deteriorate).

The Australian Centre for Health Research (ACHR)

The Australian Centre for Health Research (ACHR) is an independent, health research institute focused on accelerating evidence-based solutions to improve the quality and lower the costs of care.

Concentrating on the creation, translation and advocacy of health systems knowledge, ACHR transforms evidence on high-quality, high-value care into policy and practice.

ACHR is engaged with health policy makers, health and care agencies, academic institutes and clinicians to facilitate the use of research findings in the development of health policy and practice.

By combining best-practice with the collective vision of our multi-sector membership - spanning the non-profit, mutual and private sectors - ACHR cuts across traditional silos to effect real change, develop policy frameworks, ignite community-wide debate, and develop new thinking in health, disability and aged care.

Opening the door to solutions that impact health, care delivery, as well as social and economic well-being, ACHR contributes to the overall societal and economic prosperity of Australia.

Our unique structure is designed to break down barriers that impede innovation and serves to bring researchers and knowledge users together from across disciplines, professions, sectors and geographic borders to find solutions to Australia's most complex health challenges.

- **Achieving research excellence through knowledge creation, translation and advocacy**

- **Using health service research outcomes to contribute to the development of health policy and practice**

- **Promoting expert debate and informing public discussion**

> " Whether it comes to changing our lives or changing the world... it all begins with a conversation.