CONVERSATIONS
Choice in End of Life Care
Helping patients have control over their own care
Today, like every other day in Australia:

One Australian will die every 3 minutes and 27 seconds

404 people will die in total, 106 will be Victorians

323 deaths will be due to natural causes (involving more than one disease)

202 of the deaths were expected (and a palliative approach warranted)

220 will die hospital

198 wanted to die at home
Australian Centre for Health Research (ACHR)

ACHR is a leading independent, not-for-profit public policy research institute who address challenges in performance, policy and productivity across health and ageing sectors.

Throughout our work, we look for emerging trends and innovative, new ways to meet our nation’s performance, policy and productivity challenges across the health and ageing sectors. We investigate novel approaches promising solutions being employed in other parts of the world that may have exciting ramifications here at home. We collaborate within and beyond the field of health, seeking new relationships and fresh thinking that may accelerate progress.

VISION FOR END OF LIFE CARE
Every person’s wishes for End of Life Care are expressed and respected

OUR APPROACH

Current activities include investigations of effective interventions, service delivery and funding models, social change projects, health promotion tools and community engagement workshops to address the unmet demand and delivery needs in End of Life Care:

- Citizen and Stakeholder Panels
- End of Life Care Economic Analysis and Funding Models (with Palliative Care Australia)
- End of Life Care National Action Plan / Strategy
- The Australian Conversation Project: Death Over Dinner and Difficult Conversations
- Clinical and translational research projects (in Partnership Monash University)
Submission and Scope

We are grateful for the opportunity to contribute to the committee’s consideration and deliberation of the issues on End of Life Care choices.

For patients and their loved ones, no care decisions are more profound than those made near the end of life. Unfortunately, the experience of dying in Australia often involves fragmented care, invasive and intensive medical interventions that are often not desired by patients, inadequate treatment of distressing symptoms, numerous hospitalisations, frequent transitions among care settings, poorly coordinated programs increasing risks to patients and enormous care responsibilities for families.

We know that too many Victorians still do not receive good quality care which meets their individual needs and preference. At the same time the challenge of delivering consistently good experiences and outcomes for people at the end of their lives is growing. Each year around 39 000 people die in Victoria. The total number of deaths each year is expected to more than double over the next 25 years.

The Legal and Social Issues Committee has been asked to inquire into, consider and report, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should

1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care.

2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and

3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

We believe enabling choice in End of Life Care should mean:

• practical help at an individual level that will help every person express their preferences, should they wish to do so
• a commitment to involve those important to the individual in discussions about the dying person’s care and preferences, to the extent that the dying person has agreed
• support for staff and organisations whose responsibility it is to deliver high quality, compassionate care and implement the preferences and decisions people have articulated
• action, from Government and statutory agencies, in response to the specific recommendations in this report, to create an environment where people are informed and empowered to express their preferences and these preferences can be met as far as possible and
• recognition that good End of Life Care is not delivered in isolation – it depends on support and awareness in communities and in wider society.

A clear message from the existing evidence, along with feedback from our preliminary community engagement exercise, is that people want to have control and involvement in decisions about their End of
Life Care. The extent of this control and involvement varies but, at the very least, people wanted to choose how involved they would like to be.

We have presented eight recommendations for your consideration.

We believe widespread adoption of competent and improved choice for End of Life Care greatly removes the perceived need for assisted suicide / euthanasia at the end of life.

We are pleased to nominate two representatives to address the committee should you wish to draw on our experience or require further information about our recommendations.

Yours sincerely,

Rebecca Bartel
Executive Director
The Australian Centre for Health Research (ACHR)

Alan Castleman
Chairman
The Australian Centre for Health Research (ACHR)
Recommendations

How we want to die, represents the most important and costly conversation Australia isn’t having.

As a primary focus we seek the Victorian State Government’s support to further develop End of Life conversation tools (based on successful international models) to support The Australian Conversation Project:

1) Tools to help the community have discussions about their End of Life Care wishes openly in the family setting

2) Tools and training to help health professionals to start meaningful conversations about End of Life Care wishes with patients

Recommendation 1: Public Awareness – Community & Professional Conversations
Support ACHR to invest in community initiatives that enable the discussion of End of Life Care wishes openly in the family setting and to build on this work to produce an End of Life Care learning module for healthcare professionals to assist them with ‘difficult conversations’ (CME points from RACGP and other accrediting bodies). Whilst we have some funding to develop these projects, any additional support or resources would boost the development and implementation of The Australian Conversation Project:
- Death Over Dinner: community conversation engagement campaign
- Difficult Conversations: medical practitioner ‘difficult conversation’ campaign

Recommendation 2: State-wide / Nation-wide Public Awareness Campaign
Work with ACHR, and stakeholders, as well as Commonwealth, state and territory ministerial counterparts to actively support the development and implementation of a national public awareness campaign, based on elements of successful international community engagement campaigns, as soon as practical to increase community understanding of:
- death as a normal part of living
- encourage conversations about end of life wishes
- awareness of End of Life Care and palliative care options
- the importance of advance care planning to facilitate choices about care
- increase the uptake of advance care panning and advance care directives.
Recommendation 3: Recognise Annual Dying to Know Day (D2KD) - 8 August
Support community initiatives that support and enable the discussion of End of Life Care wishes openly in the family setting. D2KD as an official annual day of action dedicated to bringing to life conversations and community actions around death, dying and bereavement. This global initiative is designed to encourage and educate people to start end of life conversations and take action on advanced care planning.

Recommendation 4: New MBS item to Fund ACP Conversations
Write to, and lobby, the Commonwealth Minister for Health to create a new MBS item number to appropriately reduce unnecessary hospitalisations and remunerate Australian GPs for having advanced care planning conversations with Australians at the 75-year-old health assessment, patients with newly diagnosed dementia and those residing in residential aged care facilities.

Recommendation 6: Report on Funding
The Minister for Health ensure that the Victorian Department of Health and Human Services report on palliative care service provision and expenditure as part of its annual reporting, including a breakdown of funding sources.

Recommendation 7: National Palliative Care Strategy
Write to the Commonwealth Minister for Health to provide jurisdictional support for the refreshing / updating of the National Palliative Care Strategy 2010- 2015, so it can evolve into a National Action plan for End of Life Care and Palliative Care 2015 - 2020.

Recommendation 8: State-wide Palliative Care Framework
The Minister for Health ensures the state-wide palliative care framework is developed as soon as possible to guide the development of End of Life Care strategy, planning, funding, development of specialist services, and improvement in the capacity of primary health and generalist health and care services to implement an End of Life Care approach to care.
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Choice in End of Life Care: the challenge

Victoria is a leader in End of Life Care provision in Australia and The Department of Health & Human Services (DHHS) has set an ambitious agenda for the palliative care sector (Auditor General, April 2015). However, healthcare delivery demands and preferences of people nearing the end of life is changing markedly.

There is evidence of an increasing burden of unmet need for End of Life Care and palliative services. Changes in demographics, disease patterns, community expectations and patient preferences indicate that the future will see an ongoing and growing need for End of Life Care and palliative care as well as a need for greater diversity in its provision. At the same time States will have to balance these demands with limited resources, increasing cost pressures and workforce capacity challenges.

The key factors driving higher levels of need for End of Life Care are:

1. **Increasing demand**
   - Dying is part of the life cycle and can occur at any age, although more than half of all deaths in Victoria occur at or after 80 years of age.
   - Approximately 39,000 people die every year in Victoria, or around 106 per day. 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).
   - Between 2007 and 2012 Victoria reported the highest average annual increase in palliative care-related separations in all hospitals (8.8 per cent), with comparable increases in both public and private hospitals (AIHW, 2014).
   - Current availability of palliative care services and primary health care services is unable to keep pace with the 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. Based on Australian research estimating 50 – 90 per cent of all people could benefit from access to palliative care services (Rosenwax LK M. B., 2005), it can be estimated that between 19,500 – 35,100 Victorians may currently benefit from access to palliative services this year alone.
Changing demographics

In 2015, Victoria’s population was over 5.9 million and had an average growth rate of 1.7 per cent. Victoria’s population growth rate continues to be higher than the national average (1.4 per cent). According to VIF2015, the projected Victorian population will be 10 million in 2051, with 2.2 million living in Victoria’s regions (Victorian Govt, 2015).

Australians will live 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).

In line with the national trend, Victoria’s population is ageing as a result of sustained low fertility (despite an increase in births in recent years), increasing life expectancy and movement of the large baby boomer cohort (born 1946 - 1965) into older age groups. The number of people aged 65 years and over in Victoria is expected to triple from 2011 to 2051 as the large population currently aged 45 to 65 ages with increasing life expectancies. The number of people aged 18 to 64 years is projected to increase, though as a proportion of the total population this age group is expected to decrease (Victorian Govt, 2015).

Changing disease patterns (case mix and trajectory changes)

While the population is growing and ageing, the incidence of chronic disease is increasing. This is due in part to the ageing of the population, but also to medical advances in disease treatment and management.

People are living longer with higher rates of chronic disease and are more likely to die from advanced chronic illness rather than acute illness or injury as in the past. The leading causes of death in Australia are mainly cardiac, respiratory, neurological and renal conditions (Burgess TA, 2013). In 2007, chronic diseases were the cause of 83 per cent of all premature deaths (i.e., deaths under the age of 75) (AIHW, Australia’s Health 2012, 2012). While cancer is the most common principal diagnosis related to palliative care provision in hospitals (60 per cent), within the non-cancer diagnoses, heart failure (HF) and chronic pulmonary disease (COPD) were the most frequently reported diagnoses.

Palliative care is no longer just ‘cancer care’. While palliative care originated from the care of people with cancer, increased incidence of chronic disease and longer survival times means that approximately 40 per cent of people who receive palliative care in Victoria are now those with chronic disease. Generally, the palliative care ‘trajectory’ experienced by cancer patients has been a short period of evident decline. In contrast, chronic diseases, such as those relating to the heart and lung, have a different trajectory, with patients experiencing long-term limitations and ‘intermittent serious episodes of decline’. In the case of frailty and dementia and conditions associated with ageing, there is a different palliative care trajectory again, that of prolonged decline. Even well understood cancer end of life trajectories are requiring adjustment as new treatment options prolong life while increasing chronic (complex and severe) symptoms.

Different end of life trajectories mean that patients need to access and use End of Life Care and palliative care services in different ways, creating a different pattern of demand for the future. Variations in
palliative care trajectories make the planning, funding and management of palliative care even more complex. Services will need to respond to patients with non-malignant diagnoses and more chronic and complex health problems - including those with some combination of frailty, significant physical and cognitive disabilities, multiple chronic illnesses requiring polypharmacy, and functional limitations.

Palliative care is no longer just relevant in the last days or weeks of life. There is an increasing need for clearer transitions to end of life and concurrent care, where End of Life Care services are available concurrently with, or independent of, curative or life-prolonging care (Burgess TA, 2013).

These changes increase the need for palliative care services and change patterns of demand across current acute, primary, aged and community care settings.

**Rising expectations and patient preferences**

The current palliative care process is unable to meet patient choice with respect to both access of services and preferred place of death. Services are fragmented, difficult to navigate and are a source of anxiety for both patients and carers.

Access to palliative care is inequitable and is still largely based on diagnosis, age or geography rather than individual assessment. You are more likely to access services if you have a diagnosis of cancer, live in the city and are male.

When directly asked, most Australians wish to die at home. They want to be kept pain-free and avoid heroic, and often futile, measures to keep them alive (Hillman, 2010). Sadly, most will die in institutional settings like hospitals and nursing homes, and 20 per cent die in intensive care units (ICU).

However like most Australians, the Victorian community are demanding more and have higher expectations of service provision at the end of life. To meet the choice agenda, the community want to reorientate End of Life Care so it is less hospital focussed. They have expectations that their individual needs and preferences will be met. The appropriateness of care, preferred places of care and death, as well as equity of access to care are becoming increasingly important and people wish to be involved in decision making about their End of Life Care (AIHW, 2011).

**Groups with diverse needs**

There are some groups in the community who have special needs in relation to End of Life Care who either do not currently receive care, or receive inadequate care due to current service models and arrangements. These include people with dementia, people living in rural and regional areas, indigenous Australians and those from different cultural, religious or linguistic backgrounds. These difficulties will be compounded by the ageing of these communities.

End of Life Care services need to be sufficiently flexible to meet the needs of groups that may have different values or needs around death and dying. Significantly more will need to be done to provide for
the diversity of people coming into aged and palliative care. It is important that governments ensure that the needs of all palliative care service recipients are addressed sensitively and equitably.

Palliative care in residential aged facilities

Older people and, in particular, those older people living in residential aged care facilities (RACFs), are a significant group for whom palliative care needs are still not adequately met. Residential aged care services face unique difficulties in administering palliative care, with residents often having dementia and/or communication difficulties and comorbidities.

It is generally agreed that people with life limiting illnesses living in RACFs should be afforded quality of life by being provided with palliative care from diagnosis, as their illness progresses and the final days when they are approaching end of life.

Building increased capacity for End of Life Care and palliative care to be provided ‘in place’ and reducing 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 costs.

Rocketing health expenditure and capacity challenges

Australian Government real health expenditure per person is projected to more than double over the next 40 years, from around $2,800 to around $6,500. Overall the health expenditure is projected to increase from 4.2 per cent of GDP in 2014-15 to 5.5 per cent of GDP in 2054-55 (Commonwealth of Australia, 2015). At the same time, there will be fewer people in the available workforce and a proportionally lower tax base to fund and support increasing demand.

State government expenditure is also expected to be significantly higher. Spending on health, primarily hospitals, is about 25 per cent of state recurrent expenditure. Health spending as a share of state taxation revenue has increased from about 18 per cent in 2002 to 28 per cent in 2012. The states have been sharing more and more of the hospital cost burden. In 2000-2001 the state share of public hospital costs was 51%. By 2012-13 it had risen to 59%. The cutting of state hospital revenues, as in 2014 Commonwealth budget, exacerbates the pressure state governments already face.

States can no longer afford to impair health service capacity with wasteful and costly systemic problems, inappropriate funding models, including perverse financial incentives, fragmented care delivery systems, time pressures that limit communication and poor service coordination across programs.

This unprecedented financial challenge needs to be met with new ways of funding and delivering services so that they can keep on improving and innovating.
Choice in End of Life Care: pre-conditions that underpin choice driven End of Life Care

Death and dying are inevitable. Palliative and End of Life Care must be a priority. The quality and accessibility of this care will affect all of us and it must be made consistently better for all of us. The needs of people of all ages who are experiencing dying, death and bereavement, their families, carers and communities must be addressed, taking into account their priorities, preferences and wishes.

We believe there are ten minimum pre-conditions for delivering choice-driven, quality End of Life Care:

1. Person, carer and family centred care
   End of Life Care should be personalised. Person centred care focuses on collaboration between health workers, the person and their family or carer, and is centred on respecting the person’s wishes and needs (Department of Human Services, 2006). Person centred care supports people to participate in decisions about their healthcare through client–clinician collaboration.

   All patients in all situations are entitled to be treated as unique individuals and afforded fair and non-discriminatory assessment of their condition. Patients, carers and families are treated with dignity and respect and become active partners, playing a key role in contributing to all aspects of care (including care
planning and setting holistic goals of care). The care delivered is responsive to the preferences, needs and values of patients, carers and family members.

Effective systems for person centred care encompass systematic ways of reaching people who are approaching the end of life, effective assessment as well as effective decision making support, care coordination, care planning, and care delivery.

Person centred approaches can reduce anxiety, improve quality of life and improve chronic disease management by ensuring the person’s concerns and needs are met (Temel JS., 2010).

Good palliative and End of Life Care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people.

2. Needs based care

As people approach the end of life, interventions and assistance based on accurately identified needs is central to delivering person centred care. Needs based care ensures patients, carers and families have equitable access to services based on effective assessment rather than on the basis of diagnosis, age or geography.

People increasingly associate good care at the end of life with personalisation, preference and control. Some (but not all) people are increasingly well informed about what they want from care and have higher expectations about the care they should receive. For many people, high quality, compassionate care at the end of life means care that actively involves the dying person, allowing them the space and time to express their needs, wishes and preferences and for these to be met wherever possible. Frequent opportunities must also be available for patients, families and carers to describe their changing needs over time and to reassess care plans and goals of care.

Providers support the ‘whole person’, and responsively address 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.

3. Integrated, coordinated care

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 (Spehar AM, 2005).

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<th>The right care</th>
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<td>high quality, flexible, needs based and person centred, sensitive to individual and cultural differences</td>
<td>accessible to all and delivered in the home and community, and across general and specialist areas of the health system</td>
<td>provided early enough in a person’s disease trajectory that care can be planned and the person’s quality of life is maximised</td>
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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 was an overwhelming appeal from our engagement activities for better co-ordinated care: joined up services and systems, care planning, shared care records, integrated IT systems, better co-ordination and communication between healthcare professionals, community services, and family involvement.

To achieve 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 (ACP)

Advance Care Planning (ACP) is the gateway to personalisation of care and choice driven service provision for End of Life Care. Planning helps each person set out their personal decisions and preferences. ACP supports patient self-determination, including the development of advance care directives (ACD) and the identification of surrogate decision-makers. Although participation must be voluntary, the opportunity for informed discussion and planning should be universal. Every Australian and every Victorian should be given the opportunity to participate in an ACP discussion around future health care choices.

Advance care planning has benefits for the person and their family, the health practitioner and the broader health service system. These include:

- supporting better patient outcomes;
- assisting clinicians to provide person centred care; and
- optimising the use of health resources e.g. reductions in hospitalisation of 40 – 80 per cent have been shown, in randomised controlled trials, when nursing home residents express their wishes through an ACP process (Levy C, 2008).

Experience with ACP in the aged care sector in Victoria has shown that less than 3 per cent of residents in aged care facilities that were approached about an ACD declined it, and 90% of those who completed an ACD died in the facility while receiving palliation rather than in hospital, compared with only 50% of those who had not completed an ACD (Productivity Commission, 2007). ACP leads to fewer futile and unnecessary medical interventions on frail and dying patients.

The elements of an ACP should be broad, offering tailored personal support to develop the confidence and competence for effective self-management. They need to be easy to understand and written from a consumer perspective rather than from a service provider perspective, removing the legal jargon and making it user friendly. The planning process should allow people to express their preferences for care and set personal goals for the time they have left. ACP interventions involving multiple conversations and planning tools over time may be more effective in meeting patients’ preferences than written documents alone (Brinkman-Stoppelenburg A, 2014).
Personal preferences for death and dying must be regularly reviewed. Patients must be able to change and update any documentation themselves as their condition changes or views about end of life evolve. Subject to that person’s consent, or, if they lack mental capacity, in their best interests, the plan should also be shared with those who may be involved in their care.

In Victoria, and across Australia, there is strong support for ACP from both health professionals and the general community. However, despite widespread professional and public endorsement, and supporting legislation in every Australian jurisdiction, uptake of ACP is low (Rhee JJ, 2012) (Scott IA, 2013).

5. Equitable 24/7 access

Dying, death and bereavement affects everyone, so everyone must be able to access care that works for them personally, for their family and carers and for their communities. Currently in Victoria, and across Australia, access to palliative care is often determined by a person’s location, diagnosis, the education of the health professional, cultural background and age.

Every person at the end of life should have access to 24/7 services as needed as a matter of course. The distress of uncontrolled pain and symptoms cannot wait for ‘opening hours’. This is a necessary system-wide expectation and good End of Life Care cannot be achieved without it. This should be equally available for patients in hospital, home care residents and those who are in their own homes. Insufficient access to 24-hour care can result in inappropriate emergency hospital admissions and unnecessary burdens on emergency systems.

Timely referral to palliative care minimises the patient’s and care giver’s distress, ensures quality of life and appropriate measures at the End of Life Care (Devi PS, 2011). The impact of delayed referral to palliative care is significant. The adverse consequences of a late referral to End of Life Care include the following (Temel JS., 2010) (Wright AA, 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 final costs of treatment.

Innovative models of End of Life Care services are required in rural and remote areas. There is a disparity in health service provision between urban and rural areas. Trends toward centralisation of services affect access to healthcare for up to one-third of the Australian population who live in rural areas and the additional half a million people who live in remote regions. Some patients travel to major centres for treatment, for example, for oncology treatment or dialysis. They may remain in that centre, away from family, during the terminal phase of their illness, contributing to increased costs and isolation.

Access to services in rural and remote areas may be increased with effective use of telehealth and videoconferencing with 24-hour clinical advice. In addition there is potential to improve access to services by developing the capacity of regional and remote health service providers to provide care using a
palliative approach. Specialist palliative care services that have the capacity to provide training in a palliative approach can be encouraged to deliver training in ways that are accessible to rural and remote service providers. Supporting the capacity of carers to provide home care is also critical to enabling people in rural and remote areas to remain at home, if that is their wish.

6. Ensuring everyone matters

Ensuring individual choice relies on End of Life Care responding effectively to the widest range of difficulties people experience, and an awareness of the need for anticipatory and pro-active care. Local systems of care have to encompass the needs of dying children and young adults, people who are frail including in older age, and people living with dementia and learning or physical disabilities.

Ensuring that people have equitable care at the end of life also requires an awareness and commitment to deliver culturally appropriate palliative care. Delivering culturally appropriate care should also be founded on mutual trust, respect of the patient’s nationality, culture, age, gender and political and religious beliefs (Clark K, 2012).

The importance of providing culturally safe and appropriate End of Life Care services to Aboriginal and Torres Strait Islander people is paramount (McGrath P H. H., 2006). Guiding principles have been identified by Queensland Health in guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying. The four guiding principles for care for Aboriginal and Torres Strait Islander people and their family, faced with death are: cultural respect and recognition; communication; relationships and partnerships; and capacity building. (Queensland Health, 2011)

In Australia, over 300 languages are spoken, more than 100 religions and beliefs are practised 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 palliative 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).

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.

To improve collaboration and co-operation between community, disability and health services, case management is essential for service planning and resourcing. 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 patient, 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. Shared records

Care records for all people living with a long-term condition must encompass their needs and their preferences as they approach the end of life. With the person’s consent, these records should be shared with all those involved in their care.

To ensure a person centred approach, shared records have to be available to that person, so that they can review, change and update it themselves. Subject to that person’s consent, or, if they lack mental capacity, in their best interests, the plan should also be shared with all those who may be involved in their care.

All electronic systems for sharing health related preferences must encompass the recording and sharing of preferences at the end of life. There should be ambitious local targets for the rollout of systems for sharing digital records. The widespread use of electronic systems should be encouraged across health and social care providers in the statutory, voluntary and private sector. This will require support for, and investment in, the use of information technology.
9. Research and Evidence

Building the research and evidence base for End of Life Care is crucial to improving patient choice, service delivery and quality of interventions.

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. It is the responsibility of investigators and research sponsors to identify, develop, and rigorously test care interventions so they can offer guidance as political and cultural tolerance increasingly encourages people to make End of Life Care choices and permits implementation of End of Life Care programs. Whilst the evidence base underpinning a number of programs is actively developing both locally and globally, End of Life Care needs to be prioritised on Australia's research (basic, clinical and translational) agenda, with appropriate funds and targeted research programs.

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 required.

Developing interventions that are most likely to work will require elucidating how patients, family members and clinicians actually make decisions about which care plans to pursue. New research is showing how end of life choices are driven by nuances of choice architecture (Halpern SD, 2013). Such insights may guide interventions that redirect the potentially pernicious effects of the ways in which clinicians and advance directive forms frame options, helping to motivate choices that better serve patients' goals.

Those who fund research 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, RACFs and specialist palliative care units.

Increased openness to experimentation by governments, health systems, insurers, and other risk-bearing entities is key. Academics are increasingly interested in partnering with large organisations to test interventions developed in narrower settings, and research sponsors encourage such collaboration.

10. Education and training

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. 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.
Choice in End of Life Care: conversations – the critical difference

Good End of Life Care enables people to live in as much comfort as possible until they pass away, and to make choices about their care. It means providing support that meets the needs of both the person who is dying and the people close to them, and includes management of symptoms, as well as provision of psychological, social, spiritual and practical support.

Unfortunately, too many Australians do not have access to good End of Life Care and are dying in a way they wouldn’t choose, leaving many of their loved ones feeling bereaved, remorseful and uncertain.

Having personal preferences, needs and wishes ignored, misunderstood or overridden is a deeply rooted fear for those who are dying, their families, carers, as well as those who have been bereaved (The Choice in End of Life Care Programme Board, 2015).

While people expect to be in control of decisions about their own care throughout their lives, numerous factors can work against realising that desire. Many, nearing the end of life, are not physically or cognitively able to make their own care decisions. Communicating preferences and advanced care planning is critical for those who want to maintain their preferences, voice and control.

Honest conversations about death and dying

Everybody should have the opportunity for honest, sensitive and well-informed conversations about dying, death and bereavement, whether they are the person dying, their family, their carers or those important to them. We need to support all individuals to make their voices heard and their preferences known.

Despite the uncertainty and difficulty that can be associated with talking about death, people want repeated opportunities to engage in honest conversations about their future. Where possible these conversations should be early enough to enable people to reflect on their circumstances, to adapt and to plan.

Numerous studies show that when these end of life conversations occur, there is:

- greater alignment between patient preferences and the care they receive; (Institute of Medicine, 2014);
- higher patient quality of life (Temel JS., 2010);
- improved patient satisfaction (Morss S, 2008);
- less use of aggressive or non-beneficial life-sustaining treatments (Temel JS., 2010);
- greater use of hospice care (Productivity Commission, 2007);
- increased likelihood that people will die at home or in a comfortable setting (Wright AA, 2010);
- reduced family distress, anxiety and depression (Lautrette A, 2007) (Detering KM, 2010);
- reduced stress among doctors, nurses and other caregivers (Oberle K, 2001) (Detering KM, 2010);
- reduced medical errors (Slort W, 2011); and
- improved resource use and costs efficiencies (Ahrens T, 2003) (Institute of Medicine, 2014).
Making a Difference

A comparison of 123 advanced cancer patients who had received end-of-life counseling and 209 who hadn’t

- Preferences and planning

<table>
<thead>
<tr>
<th></th>
<th>Had counseling</th>
<th>No counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepts illness is terminal</td>
<td>53%</td>
<td>29%</td>
</tr>
<tr>
<td>Wants to know life expectancy</td>
<td>84%</td>
<td>67%</td>
</tr>
<tr>
<td>Values comfort over life extension</td>
<td>85%</td>
<td>70%</td>
</tr>
<tr>
<td>Against death in intensive-care unit</td>
<td>49%</td>
<td>28%</td>
</tr>
<tr>
<td>Completed do-not-resuscitate order</td>
<td>63%</td>
<td>29%</td>
</tr>
<tr>
<td>Completed living will, durable power of attorney or health-care proxy</td>
<td>72%</td>
<td>46%</td>
</tr>
</tbody>
</table>

- Care received in the last week of life

<table>
<thead>
<tr>
<th></th>
<th>Had counseling</th>
<th>No counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICU admission</td>
<td>4.1%</td>
<td>12%</td>
</tr>
<tr>
<td>Ventilator use</td>
<td>1.6</td>
<td>11%</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>0.8</td>
<td>6.7</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>4.1</td>
<td>6.7</td>
</tr>
<tr>
<td>Feeding tube</td>
<td>8.9</td>
<td>7.3</td>
</tr>
<tr>
<td>Outpatient hospice used</td>
<td>76%</td>
<td>57%</td>
</tr>
<tr>
<td>Outpatient hospice of a week or more</td>
<td>66%</td>
<td>45%</td>
</tr>
</tbody>
</table>


We believe that asking everyone a single question (“what’s important to you?”) can open the gateway to conversations that ensure people have choices and care that are focused around their needs. 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.
Conversations help patients have control over their care

End of life conversations is about defining your values. It focusses on what matters to you, not what’s that matter with you. Conversations about End of Life Care choices ensure that patients are able to understand their expected prognosis, define their goals, make decisions about the treatments they want and don’t want, identify levels of function they find tolerable, and explore acceptable and unacceptable trade-offs to achieve care goals, even if they are not able to speak for themselves in the moment.

Data from the UK, and preliminary engagement data from Australia indicate, care and preferences at the end of life are deeply personal. Most want choice over their place of care and death, others want control and involvement over aspects of their care, such as pain management and involvement of family and those close to them (Choice in End of Life Care, 2015) (ACHR, 2015). The extent of this control and involvement varies but, at the very least, people want to choose how involved they would like to be. The following themes, in particular, have been identified as relating to greater involvement in care:

- timely access to information, with support;
- involvement in decision-making, feeling in control over treatment choices (including treatment refusal); and
- honest communication and conversations.

People need to feel empowered to make decisions and to express themselves. They need to know that they will be listened to, and be able to make informed, meaningful choices about treatment or intervention at different stages of care. They also want to feel confident and clear about their power to refuse treatment and, in particular, to be able to tell medical staff to cease treatment intended to prolong life in favour of improving quality of life.

Sensitive, appropriate, honest, timely and two-way conversations with a high degree of awareness of people’s particular needs and circumstances are central to enabling choices and good care. People value the role and importance of advocates, where appropriate, to speak on their behalf and ensure that their wishes are upheld.

With people understanding their preferences, care can be designed around these wishes and preferences. Discussing End of Life Care preferences as early as possible, documenting and sharing them is considered an essential enabler of choice. This is in line with recent guidance on the use of advance care planning to document preferences and increase the likelihood that those preferences will be met (Department of Health, 2014).

Taking the lead on meaningful conversations

Although most people say they are open to having end of life conversations with loved ones, only 27% actually do, according to surveys conducted by the Conversation Project (IHI, 2013).

Some people avoid these conversations out of fear, while others think they will have time to do it later. Often conversations do not take place because patients, family members, carers and health professionals each wait for the other to initiate them.
In some places, doctors are taught to take the lead in initiating and guiding discussions about End of Life Care. Elsewhere, doctors leave it up to patients to take the lead. But 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 A, 2008).

The overall quality of communication between healthcare professionals and patients with advanced illness is poor, particularly with respect to discussing prognosis, dealing with emotional and spiritual concerns, and finding the right balance between hoping for the best and preparing for the worst (Institute of Medicine, 2014). Evidence shows there are structural and financial disincentives for having these conversations. In the absence of adequate documented advance care planning, the default decision is to treat a disease or condition, no matter how hopeless or painful. This may mean more intensive treatment, as well as more negative impacts on patients and family members.

**Timing and triggers matter**

End of life conversations are ongoing conversations about a person’s values, preferences and priorities. They should happen throughout life, not just in our final days.

Although participation must be voluntary, the opportunity for informed conversation and planning should be universal. Every Victorian (and Australian) should be given the opportunity to participate in a conversation around future health care choices.

Because it can be difficult for both patients and families to think clearly once a health crisis hits, conversations should be initiated while a person is well, and revisited periodically. There are different life stages when a person might complete a conversation or an advance care plan. Studies suggest that 10% of people are near death, 30% are chronically ill and 60% are well (Working Group of the Clinical, Technical, and Ethical Principal Committe, 2011). Many complete their personalised plan in stages, feeling confident to appoint a substitute decision-maker while they are healthy. Potential trigger points for initiation include:

<table>
<thead>
<tr>
<th>Primary Care</th>
<th>Acute Care</th>
<th>Aged Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Flu shot</td>
<td>* Medical clinic patient with a new diagnosis or deterioration of cancer or chronic disease or requiring referral to acute service e.g. renal referral for diabetes</td>
<td>* Making a will</td>
</tr>
<tr>
<td>* &gt;70 years age check up</td>
<td>* Pre-admission clinic for high risk surgery patients</td>
<td>* Requesting a seniors card</td>
</tr>
<tr>
<td>* Electronic Health Record</td>
<td>* Specific in-hospital support team for potential medical futility decision-making</td>
<td>* Commencement of long term organ support e.g. dialysis, home oxygen</td>
</tr>
<tr>
<td>* Taking out a private health insurance plan</td>
<td>* ACD status included in discharge summaries.</td>
<td>* Disability support pension application</td>
</tr>
<tr>
<td>* PBS safety net</td>
<td></td>
<td>* Commencement of home support services</td>
</tr>
<tr>
<td>* Registering for organ donation</td>
<td></td>
<td>* Admission to nursing home.</td>
</tr>
<tr>
<td>* Turning 75</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Conversations and plans should be incorporated into medical practice in the same way that patients are counselled on smoking, obesity and vaccines. They should be revisited when the diagnosis of a disease has been made, as a disease progresses, and before a risky procedure or surgery.

**Driving awareness and understanding**

The need to improve awareness and understanding of End of Life Care and of death as part of life is well recognised and acknowledged by governments, palliative care community, patients and carers.

Greater awareness and open conversation about dying, death and palliative care can facilitate planning and enable people to make better End of Life Care choices about where and how they want to be treated at the end of life. Improving public education is also necessary to encourage advance care planning and increase the use of Advance Care Directives.

The National Palliative Care Strategy 2010 - 2015 was endorsed by the Australian Health Ministers’ Conference in 2010 to guide palliative care policy development and service delivery (Commonwealth of Australia, 2010). Improving awareness and understanding is one area for action. The strategy states that better understanding will support improved access to End of Life Care services:

> There is a need to significantly enhance the understanding of dying, death, grief, bereavement and loss in Australia, including in health professionals and carers, to support better access to appropriate, timely services across the end of life continuum.

The two goals in the National Strategy to improve understanding were to:

1. significantly improve the appreciation of dying and death as a normal part of life; and
2. enhance community and professional awareness of the scope and benefits of timely and appropriate access to palliative care services.

These goals have not been achieved. While five years has passed since the strategy was written, the need for public education and engagement concerning End of Life Care has not abated, and it is manifest at several levels:

- **at the societal level**, to build support for constructive public policy related to the organisation and financing of End of Life Care and for institutional and provider practices that ensure that this care is high-quality and sustainable
- **at the community and family levels**, to raise public awareness of care options in the final phase of life, the needs of caregivers, and the hallmarks of high-quality care, and
- **at the individual level**, to motivate and facilitate advance care planning and meaningful conversations with family, caregivers, and clinicians about values, goals, and informed preferences for care.

More than one-quarter of all adults, including those aged 75 and older, have given little or no thought to their end of life wishes, and even fewer have captured these wishes in writing or through conversation (Institute of Medicine, 2014).
Expecting people to understand or have meaningful conversations about End of Life Care issues presumes a common vocabulary, however, surveys from the UK, US and Australia show people do not understand what palliative care is or what role it plays near the end of life, and do not have a clear concept of ‘caregiver’ (Institute of Medicine, 2014). Even some health professionals mistakenly confuse palliative care (care oriented toward quality of life for people with serious illnesses) with hospice (a model for delivering palliative care for people in their last months of life).

Improving communication and engagement

In the past there was a political and cultural inertia surrounding issues around death and dying. In 2015, there appears to be a cultural shift, creating an improved climate for conversations around death and dying.

Improving communication about End of Life Care has become a central mission for many healthcare institutions and a growing number of independent organisations internationally. The Institute of Medicine’s (IOM) recent report, Dying in America (Institute of Medicine, 2014) devotes a chapter to end of life communication, engagement and planning.

The relevance and potential of engaging communities has been recognised in the End of Life Care literature for over a decade (Kellehear A, 1999), and increasingly in international policy (Department of Health, 2008) (Scottish Government, 2008) (Paleri AK, 2008). 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 A, 2013).

A spectrum of community engagement in End of Life Care is presented in Figure 2. This spectrum employs a hierarchical model to place emphasis on the progressive development of community capacity, quality of care, and health and wellbeing.

Figure 2. Spectrum of engagement in end-of-life care: developing community capacity
The spectrum of engagement provides a framework through which the emerging and diverse field of community engagement in End of Life Care can be understood.

Conflicts of values related to End of Life Care can be expected in a heterogeneous societies such as UK, US, Canada and Australia. People’s views on serious illness and the end of life, bereavement and loss, and the duties of caregivers are deeply held and vary widely among individuals. While people may differ in their opinions, it is important to disseminate accurate information and evidence so that those opinions are based, to the extent possible, on the facts as they are known.

The movement for community engagement, social action and cultural change is accelerating across the UK, EU and the US (See Appendix). Two of the most successful not-for-profit community engagement projects are:

1. **Dying Matters (UK)**
   Dying Matters is a broad-based and inclusive national coalition with 30,000 members to date which aims to change public knowledge, attitudes and behaviours towards death, dying and bereavement.

   Members include organisations from across the NHS, voluntary and independent health and care sectors (including hospices, care homes, aged care charities, children and bereavement); social care and housing sectors; a wide range of religious organisations; community organisations; schools and colleges; academic bodies; trade unions; the legal profession and the funeral sector.

   The way society views dying and death frequently has a negative impact on the experience of people who are dying and bereaved. This lack of openness affects the quality and range of support and care services available to patients and families. It has also affected our ability to die where or how we would wish.

   The Dying Matters Coalition is working to address this by encouraging people to talk about their wishes towards the end of their lives, including where they want to die and their funeral plans with friends, family and loved ones.

2. **The Conversation Project (US)**
   The Conversation Project, co-founded by Pulitzer Prize winner Ellen Goodman and Dr. Atul Gawande (advisor), 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.

   Too many people die in a manner they would not choose, so The Conversation Project offers people the tools, guidance and resources they need to begin talking with their loved ones, around the kitchen table, about their wishes and preferences.

   The Conversation Project is not about promoting any specific preference for End of Life Care; instead, it seeks to encourage and support people in expressing their end of life wishes for care.
Launched in collaboration with the Institute for Healthcare Improvement (IHI), The Conversation Project’s cornerstone is a website that offers visitors a Conversation Starter Kit, and asks people to submit their personal stories to be shared on website and via YouTube, Twitter, and Facebook.

IHI and the Cambia Health Foundation strongly support the work of The Conversation Project, believing that the successful transformation of the health care system requires the engagement of patients, families, and the general public. End of life care is something that every human will face. As a leader in health care improvement, IHI is committed to bringing the public into the conversation.

By sparking cultural change at the kitchen table, not in the intensive care unit, The Conversation Project hopes it will become easier for people to communicate end of life wishes that can be expressed in advance and respected at the end.

The Australian Conversation Project
How we want to die, represents the most important and costly conversation Australia isn’t having.

The Australian Centre for Health Research (ACHR) aims to combine the best of both these social movements, and expand the campaigns across Australia, to undertake The Australian Conversation Project – ‘Death Over Dinner’ and ‘Difficult Conversations’

Death Over Dinner
Community focussed program

Informed by medical and palliative care leaders, Death Over Dinner (DOD) is an uplifting interactive adventure that transforms this seemingly difficult conversation into one of deep engagement, insight and empowerment.

As an extension of The Conversation Project, DOD is a grass roots campaign dedicated to helping people talk about their wishes for End of Life Care. The goal is 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.

The public campaign spans both traditional and new media to change our culture, share the way we want to live at the end of our lives and prevent people dying in a way they would not choose. This will be supported with additional tools, guidance, and resources to facilitate the process and will link with existing end of life projects and programs across Australia.

We believe that the place for this conversation to begin is at the kitchen table, not in the intensive care unit, with the people we love, before it’s too late. We aim to make the difficult conversations easier and make sure that our own wishes and those of our loved ones are expressed and respected.

We are currently forming alliances with political leaders, public health and other governmental agencies, community-based organisations, religious organisations, consumer groups, health care delivery...
organisations, funders, employers, and professional societies to partner and engage their constituents to encourage national conversations about End of Life Care, advance care planning and informed choice based on the needs and values of individuals.

We will unite with a range of Australian and international community and medical stakeholder groups to support Annual Dying to Know Day (D2KD). This is an official day of action dedicated to bringing to life conversations and community actions around death, dying and bereavement. This global initiative is designed to encourage and educate people to start end of life conversations and take action on advanced care planning.

The program is being developed with ACHR, Ceutica Medical Communications and Death Over Dinner (The Conversation Project, US).

**Difficult Conversations**

**Healthcare professional focussed program**

This program extends Death Over Dinner in to a training course (online and face-to-face) designed to teach and support health care professionals to have difficult conversations with patients and aged care residents.

The program is being developed with ACHR, Professor Don Campbell from Monash University, Ceutica Medical Communications. We are in discussions with Palliative Care Australia to partner on the program, and the RACGP about obtaining endorsement and CME points for General Practitioners.

**Medicare reimbursements of conversations**

In July 2015, the US announced that the Centers for Medicare and Medicaid Services (CMS) will reimburse physicians for engaging patients in advance care planning conversations. This decision was based on the valid premise that skilled communication among patients, family members, and clinicians about patients' values and goals is an important way to improve End of Life Care.

Despite the increasing demand for community End of Life Care and the critical importance of the general practitioners (GPs) role in End of Life Care broadly, and in palliative care specifically, there is no Medicare item specific to palliative care-related treatment provided by general practitioners (GPs). The MBS includes specific items for palliative medicine specialist services (delivered by palliative medicine specialists) for which it will reimburse a proportion of the MBS fee however, there are no equivalent palliative care-specific items that can be used by GPs. This means that GPs are likely to be using other MBS items, such as those for chronic disease management, when providing patients with palliative care support. This effects data collection, and is a disincentive for GPs to undertake conversations about End of Life Care or develop ACPs.

We recommend that an MBS item number is created to appropriately remunerate Australian GPs for having advanced care planning conversations with Australians at the 75-year-old health assessment, patients with newly diagnosed dementia and those residing in residential aged care facilities.
By talking more openly about dying, death and bereavement and discussing your end of life wishes, and the wishes of those close to you, you can make a difference. Healthcare is important, but we all have a responsibility to support each other in times of crisis and loss. We encourage you to initiate timely conversations with honesty and openness.
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.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Collaboration with the Institute for Healthcare Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>USA</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://theconversationproject.org/">http://theconversationproject.org/</a></td>
</tr>
<tr>
<td>Outcomes</td>
<td>Not publically available</td>
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</tbody>
</table>

Death Over Dinner
"*We need to have these conversations at the kitchen table, before we are in the ICU*"

Extension of The Conversation Project, this grass roots campaign is designed to share the way we want to live at the end of our lives. How we want to die – represents the most important and costly conversation America isn’t having. Informed by medical and wellness leaders, they have created an uplifting interactive adventure that transforms this seemingly difficult conversation into one of deep engagement, insight and empowerment.

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

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Collaborative – Michael Hebb, Institute for Healthcare Improvement, The Conversation Project, leading health practitioners, journalists, legal advisers, media experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>USA</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://deathoverdinner.org/">http://deathoverdinner.org/</a></td>
</tr>
<tr>
<td>Outcomes</td>
<td>100,000 dinners since 2013</td>
</tr>
</tbody>
</table>

Death Over Dinner (Downunder)
"*We need to have these conversations at the kitchen table, before we are in the ICU*"
ACHR have formed an alliance with the US collaborative to bring death over dinner to Australia. This model is currently being reviewed by Australian medical practitioners, the palliative care community and the broader Australian community. This grass roots campaign is designed to share the way we want to live at the end of our lives. How we want to die – represents the most important and costly conversation Australia isn’t having.

| Organisation | Australian Centre for Health Research (ACHR)  
Collaborators: Palliative Care Australia, The Groundswell Project |
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<th></th>
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<tbody>
<tr>
<td>Country</td>
<td>Australia</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://deathoverdinner.org.au">http://deathoverdinner.org.au</a></td>
</tr>
<tr>
<td>Outcomes</td>
<td>Launching 2016</td>
</tr>
</tbody>
</table>

**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. |
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<tbody>
<tr>
<td>Country</td>
<td>Europe, North America and Australasia</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://deathcafe.com/">http://deathcafe.com/</a></td>
</tr>
</tbody>
</table>
| 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 |
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<tbody>
<tr>
<td>Country</td>
<td>UK</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.conversationsforlife.co.uk/">http://www.conversationsforlife.co.uk/</a></td>
</tr>
<tr>
<td>Outcomes</td>
<td>Not publically available</td>
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</table>

**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.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Common Practice</th>
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<tbody>
<tr>
<td>Country</td>
<td>USA</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://mygiftofgrace.com/">http://mygiftofgrace.com/</a></td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>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</td>
</tr>
</tbody>
</table>

**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.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Ageing with dignity</th>
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<tbody>
<tr>
<td>Country</td>
<td>USA</td>
</tr>
<tr>
<td>Website</td>
<td><a href="https://agingwithdignity.org">https://agingwithdignity.org</a></td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>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.</td>
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</tbody>
</table>

**Death Wise – Wise Conversations**
Committed to helping people talk about, make decisions and plan for the end of their lives.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Death Wise and California Healthcare Foundation</th>
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<tbody>
<tr>
<td>Country</td>
<td>USA</td>
</tr>
<tr>
<td>Website</td>
<td>https://www_deathwise.org</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
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</tr>
</tbody>
</table>
### Health Promotion: social action and cultural change projects

**Dying Matters**  
Raising awareness of dying, death and bereavement.  

<table>
<thead>
<tr>
<th>Organisation</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>UK</td>
</tr>
</tbody>
</table>

**Good Life, Good Death, Good Grief**  
Working to make Scotland a place where there is more openness about death, dying and bereavement.  

<table>
<thead>
<tr>
<th>Organisation</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>Scotland</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.goodlifedeatghgrief.org.uk/">http://www.goodlifedeatghgrief.org.uk/</a></td>
</tr>
</tbody>
</table>

**Developing Compassionate Communities**  
The Compassionate Cities model 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. |
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Country</td>
<td>Global</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.phpci.info/">http://www.phpci.info/</a></td>
</tr>
</tbody>
</table>

**Tracks we Leave**  
A WHO demonstration project that is now a WHO Centre for excellence in palliative care.  

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Institute of Palliative Medicine, WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>Global</td>
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</tbody>
</table>
### 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.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Groundswell</th>
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</thead>
<tbody>
<tr>
<td>Country</td>
<td>Australia</td>
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</table>

### 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.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>USA</td>
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</table>

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

<table>
<thead>
<tr>
<th>Organisation</th>
<th>University of Western Sydney</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>Australia</td>
</tr>
<tr>
<td>Website</td>
<td><a href="https://caringatendoflife.wordpress.com/">https://caringatendoflife.wordpress.com/</a></td>
</tr>
</tbody>
</table>

### 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.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>The Lien Foundation – Radical philanthropy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country</td>
<td>Global / Asia Pacific</td>
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</table>
C. Definitions: Palliative and End of Life Care

End of life

Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. The term ‘approaching the end of life’ also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

Palliative care

The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient’s illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.
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