

*Victorian Councils: Supporting Communities Around End of Life  
Project*

Starting.....  
'end of life' conversations within  
your council

Information/ communication kit (#1) to support  
local government staff progress the end of life  
concept and ideas across council.

August 2017

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## 1. Introduction

The *Victorian Councils: Supporting Communities Around End of Life Project* (the project) is a new collaboration between La Trobe University Palliative Care Unit (LTUPCU) and the Municipal Association of Victoria (MAV). The project is funded (2017-2019) by the Department of Health and Human Services.

The overall aim of the *Victorian Councils: Supporting Communities Around End of Life Project* is to explore how local government can be involved in building the capacity of communities to actively participate in caring and supporting people in their community around dying, death and bereavement.

This information/communication kit provides factual information, ideas and resources to support council staff in beginning the journey of communicating and discussing 'end of life' across all of council.

It is envisaged that this kit will be the first in a series of tools developed by the project to assist council work in this new area.

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For further information and resources for councils on the *Victorian Councils: Supporting Communities Around End of Life Project* go to the Municipal Association of Victoria.

<http://www.mav.asn.au/policy-services/social-community/ageing-disability/end-of-life-project/Pages/default.aspx>

## 2. Terms/definitions

An array of terms, references and expressions are used to describe or discuss end of life. End of life can refer to different things depending on the setting in which it is used. For example, End of Life Care or End of Life Care Planning is commonly used in palliative care and residential care settings when discussing care in the last few months of a person's life.

End of life for others can mean that period of time when a person is approaching death, while in other settings it refers to anyone living with a life-threatening illness. Many people may also associate end of life with voluntary euthanasia but this is not the focus of this project or the work councils will become involved with.

The *Victorian Councils: Supporting Communities Around End of Life Project* applies a broad definition of end of life.

For the purposes of this project the following terms and definitions are also used.

### **End of life**

**End of Life** refers to the period of time around dying and death and the impacts this has on the dying person, their family and their wider social and community networks. This definition focuses beyond the 'care' a person receives at their end of life to include individual, family, carer, and community experiences of dying, death and bereavement.

### **Community development**

The project is applying a community development approach with councils as the facilitators of this approach. Community development refers to a process where community members come together to generate solutions and take collective action to addresses common problems or to advance common strengths in the community. Community wellbeing often emerges from this type of collective action.

### **Compassionate communities**

The Compassionate Communities Network is an international movement that aims to build community capacity to support people approaching the end of their lives.

*'A compassionate community is a community that cares for and supports one another, particularly individuals at end of life and their families and carers. This approach relies on strong partnerships between the dying person, their families and carers, friends, local community, service providers, volunteers, community organisations and government and non-government agencies.'* (Compassionate Communities – A Tasmanian Palliative Care Policy Framework 2017-2021)

### **Life-limiting illness**

*'A person with a life-limiting illness may die prematurely. The term is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades.'* (Victoria's end of life and palliative care framework June 2016)

### **Life-threatening illness**

*'This refers to a person with a life-limiting illness who is likely to die prematurely. Often used when referring to children or adults who have an illness with poor prognosis and their life span may be considerably shortened.'* (Victoria's end of life and palliative care framework June 2016)

### **Palliative care**

‘Palliative care is: an approach that improves the quality of life of patients and their families facing the problems 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.’ (World Health Organisation 2014)

### **Person-centred care**

Person centred care means that the client is involved in all planning and decision making and care is aligned with their priorities.

### **Social determinants of health and wellbeing**

‘The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. The determinants of health include: the social and economic environment, the physical environment and the person’s individual characteristics and behavior’. (World Health Organization)

### **Advanced Care Planning**

‘Advanced care planning is the process whereby patients discuss their values, beliefs and personal care preferences. This then guides clinical decision making in the future when the patient can no longer communicate their wishes.

In 2014 the Victorian Government developed and launched a new *strategy Advanced care planning: have the conversation: A strategy for Victorian health services 2014-2018* to assist health workers discuss these issues with and ensure the wishes of patients are honoured. Advanced care planning is supported within Victoria’s current legal framework, primarily through four acts that give people rights when it comes to medical treatment.

On 24 November 2016 the *Medical Treatment Planning and Decisions Bill 2016* was passed by the Parliament. The Act will give statutory recognition to advanced care directives and will simplify and contemporise laws relating to medical treatment decision making for people without decision making capacity.’ (Victorian Government)

### **Recent developments in Victoria to voluntary assisted dying**

‘Following the Parliamentary Enquiry into end of life choices, the Government appointed a Ministerial Advisory Panel to develop voluntary assisted dying legislation for introduction into parliament in 2017.

The Panel – which consists of the best clinical, legal, consumer, palliative care and health experts – has undertaken extensive consultation, engaging with more than 300 stakeholders. The Panel’s final report includes 66 recommendations to Government covering eligibility for the scheme, how requests to access voluntary assisted dying are made and assessed, oversight, and the protections in place.

In July 2017, the Andrews Labor Government announced it will incorporate all 66 recommendations from the Ministerial Advisory Panel’s final report on Voluntary Assisted Dying into a Bill to be introduced into the Parliament in coming months.’(Victorian Government)

### 3. Project context

The broad context of the *Victorian Councils: Supporting Communities Around End of Life Project* includes:

#### A shift in societies approach to dying, death and bereavement

The project sits within a broader context of working towards a society where end of life is embraced as a part of community life and is supported by the community. Internationally, the Compassionate Communities movement has been gaining momentum, building compassion and capacity in communities to support people during dying, death and bereavement. Compassionate communities emphasise the importance of keeping people who are ageing or living with and life-limiting illness connected with family, friends and community.

#### A public health approach to dying and death

The social, economic and physical environments that impact on living well also impact on dying well. The public health approach to end-of-life recognises that while clinical support for people with a life limiting condition may be vital for many, ensuring their comfort, their care and their wellbeing depends on the community.

#### Victoria's palliative care framework

*Victoria's end of life and palliative care framework*, (June 2016) reports that community expectations around end of life and palliative care have shifted, and we can no longer rely on traditional approaches to palliative care to meet these expectations. The framework priorities include a greater emphasis on engaging communities and strengthening community capacity to support individuals, families, and carers during the period around end of life. The framework provides an overarching State-wide direction under which the project sits.

#### The need for a 'new way of thinking' about end of life

Research indicates that in many societies, communities or families, dying, death and bereavement can be 'taboo' subjects or difficult areas to have conversations.

Research also shows that many people, as they approach their end of life, wish to remain connected with family, friends and community. Respecting individual choice is embodied in person-centred approaches and upheld by policy and service directions now commonly in place across health and other community services.

A further driver behind the need for a new way of thinking is the unsustainability of current palliative and care service models to accommodate an increasing ageing population and corresponding increase in deaths. 'Demand for end of life and palliative care in Victoria is increasing at an average annual rate of four percent. Current service models are unsustainable and will not be able to meet future demand, expectations or needs.'<sup>1</sup>

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<sup>1</sup> Victoria's end of life and palliative care framework June 2016

## 4. Project overview

The *Victorian Councils: Supporting Communities Around End of Life Project* approach is based on community development principles accepting the role of local government as a key leader and facilitator of inclusive and connected local communities.

In the first instance the project aims to explore the potential role and engagement of local government around end of life – as a communicator, facilitator, networker and leader in building strengths and social capital in local communities.

As the project progresses over the three-year time frame it is anticipated that, with the support of the project partners, individual councils will start on a journey of building organisational capacity where end of life is understood and embraced across all relevant areas of council business. The potential of including end of life in Municipal Health and Wellbeing Plans, Age-friendly/Positive Ageing Strategies, intergenerational approaches and seniors' festivals, for example, are potential areas of local government involvement.

Importantly, the project is not about local government becoming a service deliverer of end of life care, but is more about utilising councils position and links in the community (with residents, community groups and service providers) to promote a new way of thinking about end of life in the community setting.

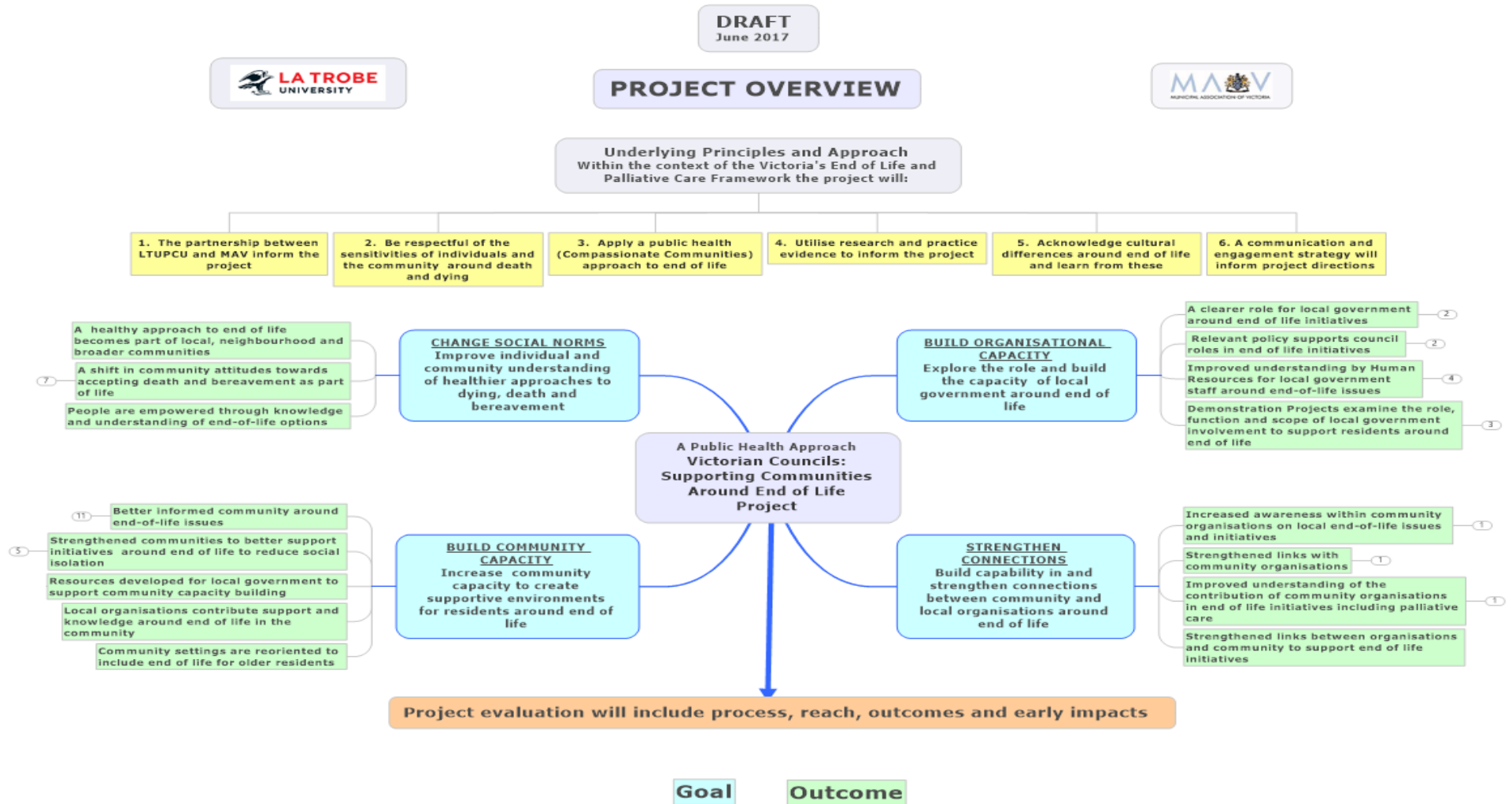
Promoting this new way of thinking about end of life is embedded in the project approach. A long term goal of the project is to contribute to the 'normalisation' of dying, death and bereavement as part of everyday community life. A starting point for this is to encourage conversations, compassion and the 'normalisation' of end of life within local communities. It is anticipated that early steps in the project will seek opportunities for councils to link with community organisations, groups and residents to facilitate end of life conversations.

As a new area for local government, two demonstration projects will be funded to further inform the potential role of councils in this space and to explore potential strategies, actions and processes. Councils will be able to access relevant end of life resources and support through the MAV intranet and a dedicated (part-time) position for an end of life project worker. LTUPCU will provide expert advice and undertake an evaluation which will track project progress and inform ongoing project developments.

The Project is guided by a reference group comprised of representatives from the MAV, LTUPCU, Department of Health and Human Services, (DHHS) metropolitan and rural Councils, Council on the Ageing Victoria (COTA Vic), Palliative Care Victoria, Health Issues Centre, State Trustees, Victorian Primary Health Network and Alliance, Victorian Aboriginal Community Controlled Health Organisation (VACCHO).

The following diagram provides an overview of the project's principles, goals, outcomes and strategic actions over the three years.

## 5. Project overview diagram





## 6. Key project directions

- The overall aim of the project is to explore how local government can play a role in building the capacity of communities to better accept that dying is a part of life and encourage more Victorians to actively participate in caring and supporting people at the end of their lives at home and in their community.
- The project is designed to start a process of change within the community with a focus on older age groups (with the intention that over time, the whole community can be involved).
- The project seeks to contribute to an increase in community knowledge, skills and involvement around the social dimensions of dying, death, loss and bereavement.
- The project will apply a community development approach to generate local responses to end of life by communities for communities. The role of local government is to stimulate, facilitate, coordinate and provide opportunities for communities to come together around end of life issues.
- The project will build on existing formal and informal care networks to improve end of life outcomes for Victorians. Councils can draw on their existing and extensive networks, particularly with community organisations and their ageing communities, to support development of local end-of-life initiatives.
- The project sits comfortably with an age-friendly communities approach and with existing council commitments to their ageing communities through positive ageing initiatives and support for people in their homes.
- The project will take into account the diversity of communities within each local government area.
- Councils may consider a range of approaches with a primary focus on creating sustainable, community-led, community development initiatives.
- Becoming involved in end of life issues offers opportunities for councils to contribute to new partnerships and connections that will expand the reach of end-of-life initiatives across Victoria.

## 7. Potential role of local government in end of life

Local government over the last two decades has increasingly taken a leadership role in building healthy, inclusive, cohesive and sustainable municipalities. As the level of government 'closest to the people', Councils are both an organisation in the community as well as an organisation for the community. Council jurisdiction embraces birth to death and everything in between.

The rationale for local government to become involved in end of life sits within the need for a shift in dying, death and bereavement from primarily a medical approach to a social community approach and as an expected part of life. This new thinking reflects the learnings from the social determinants of health and wellbeing approach, where it is now clearly understood that factors such as income, housing, community inclusion and purposeful lives have an impact on individual and community health and wellbeing.

Inclusion of end of life as an essential part of health and wellbeing brings attention to the influences that social and physical environments have on people dealing with dying, death and bereavement. It also provides a focus for how individuals, communities, community organisations and services can better support people in their communities around end of life.

Local government has been identified as being in a unique position to advance this new thinking within a public health context. With roles in health and wellbeing (Municipal Health and Wellbeing Plans), healthy and active ageing, (Age-friendly Strategies, Positive Ageing Strategies, Seniors Festivals,) community visioning and planning (Council Plans, Community plans) and service planning and delivery (aged care) to name a few, councils are in a pivotal position to facilitate the building of community strengths to support people in their community around end of life and so create more compassionate communities.

'Dying in Australia is more institutionalised than in the rest of the world. Community and medical attitudes plus a lack of funds for formal community care mean that about half of Australians die in hospital, and about a third in residential care. Often they have impersonal, lingering and lonely deaths; many feel disempowered. Seventy per cent of people want to die at home, yet only about 14 per cent do so. People are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France.'<sup>2</sup>

### Potential roles for local government around end of life could include:

- Inclusion of end of life in council plans/documents – to help provide a community vision where people, families, carers and or friends experiencing end of life continue to be included as part of community life.
- Information dissemination – a conduit of information for residents, community organisations and service providers to raise awareness and responses around end of life.
- Linking and networking – facilitate links within and between community groups and residents to encourage community responses to support people, families and communities around end of life.

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<sup>2</sup> Swerissen, H and Duckett, S., 2014, Dying Well. Grattan Institute

- Leading by example through development of supportive and relevant HR policies and actions across council

#### Potential initial actions for councils could include:

- Inclusion of end of life discussions at staff/departmental meetings
- Presentations on end of life to managers/councillors
- Applying an end of life lens to council policies, plans and strategies
- Promoting information around end of life at council events, festivals, internal opportunities within council and to community via social media
- Inclusion of end of life information/presentations/conversations at Seniors Clubs and in Seniors newsletters
- Holding an end of life conversation event (for example Dying to Know Day, Before I Die Board) in a local community
- Supporting community development initiatives responding to end of life in the municipality (information dissemination, venue support, administration assistance)
- Map/ establish a data base on end of life activities, and actions taking place in the local community.

As the project progresses and through the project's two demonstration projects, further support and resources will become available to support councils undertaking this work.

#### How the project/councils role relates to Palliative Care

The focus of this project – strengthening community support around end of life in the community by the community, is not the same as palliative care. Community-based palliative care supports people to die in place, particularly if they want to die at home and is based on a service intervention.

This project, although sharing some of the same goals as community based palliative care, is concerned with how communities can be strengthened to socially and emotionally support people approaching the end of their life, to remain in the community and if that is their wish, to die at home.

The project philosophy is based on the premise that within any community there is individual and collective capacity and skills to support others as they and their families experience dying, death and bereavement.

## 8. Understanding dying, death and bereavement in your community

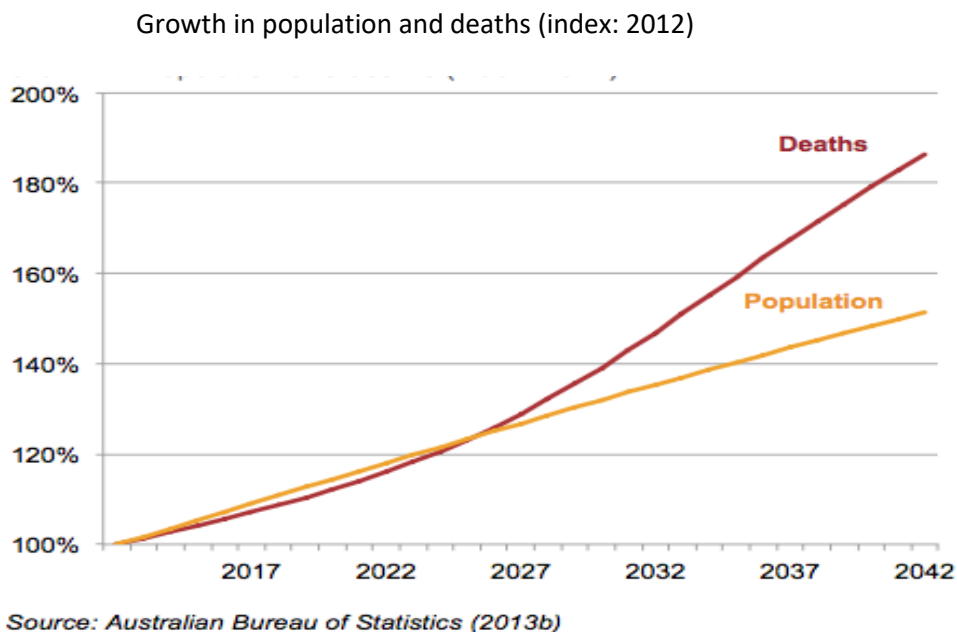
The following information and statistics are from *Dying Well*<sup>3</sup> the Grattan report from 2014. They are presented here to provide some helpful information to support the project approach and to convey the rationale for the project.

### Changing patterns and preferences for dying

- Dying has dramatically changed over the past century in Australia. Death is now more predictable and takes longer. About 70 per cent of deaths are expected and many people know when they are likely to die in the near future. Most people dying have chronic diseases and disabilities at the end of their lives.
- Surveys consistently show that between 60 and 70 percent of Australians would prefer to die at home however, in 2014 only about 14 percent of people died at home.
- Death is increasingly an institutionalised and medicalised experience. For older age groups hospitalisations have increased significantly in number. In the decade from 2001/2 to 2011/12 the hospitalisation rate for those aged over 85 increased by 35 per cent for women and 48 percent for men.

### Change in demand

- The number of deaths will grow faster than the population in the future as reported in the graph below.



<sup>3</sup> All information in this section is from Swerissen, H and Duckett, S., 2014, *Dying Well*. Grattan Institute

- The baby boomers are growing old, and in the next 25 years the number of Australians who die each year will double. As the number of people dying each year increases, pressure to improve quality of dying is also likely to grow. In addition, for each person who has died, there are greater numbers of people who are bereaved who can benefit from better social and community support.
- Choice is a critical issue for people, particularly for the ageing baby boomer generation. Currently it can be difficult to have the choice to die at home either because support services are inadequate or because people have not had a chance to articulate, plan and implement their choice.

### Economics of dying

- Despite widespread assumptions about the cost of end-of-life care, only about \$5 billion a year of a health budget of \$100 billion is spent on the last year of life for older people. But only about \$100 million is spent on helping people to die at home. A change in focus will create some savings but will help more people to die well.
- Each year over \$2 billion is spent on older people who die in hospital. Costs are highest for those who die as acute in-patients. About a third of all people who die in hospital have only one admission – the one in which they die. The average cost of that admission for those aged 50 and over is about \$19,000.

## 9. Diversity and different cultural beliefs and approaches to end of life

Within any one municipality there will be a diversity of beliefs, practices, processes and paths followed around end of life. Some familiarity and understanding of these different approaches within your municipality will be valuable starting points when preparing to engage with residents, community and community organisations around end of life.

There is wealth of research material around cultural differences in regard to dying, death and bereavement. Although the main focus of the research material is on assisting professionals to practice cultural sensitivities and competence in delivering end of life care, this information could be of assistance to understanding the diversity within your municipality.

A few links to resources are provided below to give an insight into the possible different approaches to end of life that are likely to exist within your municipality. It is important to reiterate the diversity across, within and between individuals, cultures, beliefs, practices and communities.

- ***Sad News Sorry Business Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2)*** - Queensland Health December 2015

‘Aboriginal cultural protocols following death generally have two purposes:

- sending the spirit onto the next world, and
- identifying the cause of death.

Many Aboriginal tribal groups share the belief that this life is only part of a longer journey. When a person passes away, the spirit leaves the body. The spirit must be sent along its journey; otherwise it will stay and disturb the family.

There are two significant practices that occur following death that assists with the journey of the spirit.

- The name of the deceased is not mentioned for a long period of time, from several months to years. This is to ensure that the spirit is not held back or recalled to this world.
  - A smoking ceremony is conducted. The smoking of the deceased person’s belongings and residence also assists with encouraging the departure of the spirit.
  - Some Aboriginal groups also practice means of identifying causes of death. These are practiced by Elders who hold the cultural authority to do so, and the causes in question are usually of a spiritual nature. The ceremonies are likened to an autopsy of Western practice.

These practices may be sacred in nature and therefore not discussed openly.’

[https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0023/151736/sorry\\_business.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0023/151736/sorry_business.pdf)

- ***An Outline of Different Cultural Beliefs At The Time of Death*** - Loddon Mallee Regional Palliative Care Consortium September 2011

‘When faced with a life-threatening illness and the possible or subsequent death of a family member or friend, religious practices, rituals and beliefs may resume an important place.

This report covers 13 different cultural and religious groups including Buddhists, Catholic, Greek Orthodox, Hindu, Seventh Day Adventists and provides a summary of beliefs, preparing, funerals, burials and after. It is intended as a resource to help understand different cultural approaches to end of life whilst emphasising that all individuals across all cultures and beliefs practice individual approaches, practices and paths.'

<http://lmrpcc.org.au/admin/wp-content/uploads/2011/07/Customs-Beliefs-Death-Dying.pdf>

- ***Death and Dying Rites and Rituals*** - COASIT

'After the funeral, family and friends will generally gather at the family's home for coffee and something to eat. Close family members will cook and take the food to the family home. As the family is considered to be in mourning they are not expected to cook and enough food is prepared to last them for at least a week. Thirty days after the funeral, it is usual to commemorate the passing of a loved one with a Mass specifically dedicated to them. Thereafter there is a Memorial Mass for the first anniversary.'

<http://coasitagedcare.org.au/lifestyle-italian-australians/death-and-dying-rites-and-rituals/>

- ***Mourning around the world*** Elizabeth Berg -Originally published in KidSpirit Magazine's Change & Loss issue

'Different traditions in Christianity have different rules for mourning. The tradition of wearing black during mourning dates back to Roman times or earlier. In 1969, the Roman Catholic Church changed the acceptable liturgical colors to be worn for the Mass for the Dead to violet, black or white.

Greek Orthodox Christians believe that death is when the soul separates from the body. As soon as someone dies, they begin experiencing partial judgment, which is when they first experience heaven and hell. During this time, the behavior and faith of the deceased are judged. The family holds a funeral service that is an hour or less and is not part of a larger service. Almost every Greek Orthodox funeral involves an open casket that the mourners bow in front of. A religious icon is usually placed on the deceased's body, and the mourners kiss the icon. During the burial there is a short prayer service, which is followed by a memorial service which takes place on the Sunday closest to the fortieth day after the death.'

[http://www.huffingtonpost.com/kidspirit/mourning-around-the-world\\_b\\_1542935.html](http://www.huffingtonpost.com/kidspirit/mourning-around-the-world_b_1542935.html)

- ***Funeral Customs around the world*** - SBS 12 April 2016

'Death is one of life's inevitabilities, but the traditions around it are not, thanks to the influence of culture and religion on the rituals we call on when a person dies. The differences in funerary customs around the world are fascinating, but even more interesting are the surprising similarities that unite us at the end of life.'

<http://www.sbs.com.au/topics/life/culture/explainer/funeral-customs-around-world>



## 10. Some potential activities with your community

### Before I die

*Before I Die* is a global art project that invites people to contemplate death and reflect on their lives. Originally created by the artist Candy Chang on an abandoned house in New Orleans after she lost someone she loved, there are now over 2,000 walls around the world.

The following images from <http://beforeidie.city/the-walls> provide an insight into what is happening around the world.



Flinders Island, Australia



Geraldton, Australia



Townsville, Australia



Austin, Texas



Nalia, Malaysia



Quincy, Illinois



Sheffield, UK



Adelaide, Australia



## Dying to Know Day (August 8<sup>th</sup>)

Dying To Know Day is an annual day of action dedicated to bringing to life conversations and community actions around death, dying and bereavement.

D2KDay launched in 2013 and has seen 285 registered events and has sparked thousands of conversations about death, dying and bereavement.

Dying to Know Day is an initiative of the GroundSwell Project.

Go to the Dying to Know Day website for events and more information:

[www.dyingtoknowday.org](http://www.dyingtoknowday.org)



Dying To  
Know *day*  
8th August  
[www.dyingtoknowday.org](http://www.dyingtoknowday.org)