



Why include 'end of life' in local government health and wellbeing planning

A MAV discussion and ideas paper for the:

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

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A note about terminology

A number of terms, definitions and concepts are used when referring to dying, death and bereavement. End of life is commonly used, however different interpretations are applied.

For the purposes of *The Victorian Councils: Supporting Communities Around End of Life Project*, (the Project) a specific definition of end of life was developed to describe the project. It was important to convey that the project is not about assisted dying nor delivering palliative care services.

End of life is used in the Project to refer to:

‘the period of time around dying and death and the impacts of this on the dying person, their family and their wider social and community networks’.

The following concepts and understandings are used in this paper.

Dying

Dying is multidimensional involving physical, social, psychological and spiritual dimensions. It is a uniquely individual as well as a communal experience. This Project embraces the concept that dying is part of normal everyday life and is a social (not just a medical) event.

Palliative Care

The term ‘palliative care’ as identified in *Victoria’s end of life and palliative care framework*, describes an approach to care that improves the quality of life of people and their families who are facing the problems associated with a progressive illness. It does this by preventing and relieving suffering through early identification and assessment, by treating pain and other physical, psychosocial and spiritual problems and by addressing practical issues.

Palliative care is based on people’s needs rather than a diagnosis or possible time to death and is delivered by a range of health and community providers. Palliative care can be provided at the same time as other treatment intended to reverse or resolve particular conditions.¹

Public Health approach to dying, death and bereavement

Public health palliative care is becoming the accepted term used to encompass a variety of approaches that involve working with communities and the wider society to improve people’s experience of death, dying and bereavement.²

Health Promoting Palliative Care (HPPC)

Health Promoting Palliative Care (HPPC) frames death, dying and loss, as a societal experience that requires a societal response to build resilience in citizens and communities. HPPC has become synonymous with a social rather than a biomedical model of HPPC. Often referred to as the new public health approach.³

One of the first systematic attempts to link the health promotion and palliative care literatures was Allan Kellehear’s *Health Promoting Palliative Care* (1999). Kellehear took a new public health approach, encapsulated in the Ottawa Charter, and considered palliative care through this lens.⁴

¹ <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/palliative-care/end-of-life-and-palliative-care-framework>

² Scottish Partnership for Palliative Care

³ Scottish Public Health Care Network Palliative and end of life care in Scotland: The rationale for a public health approach Michelle Gillies February 2016 p.49

⁴ Health promoting palliative care and dying in old age Bruce Rumbold Chapter 7 Gott & Ingleton

The impact of a single death affects a wider network of carers, family, friends, employers and communities, and has a direct impact on population health⁵.

Introduction

A drive to change how society views and deals with dying, death and bereavement is gaining momentum across the globe. Driving factors behind this include an ageing population, the emergence of 'compassionate communities' and responses to the 'medicalisation' of death.

A growing wealth of research, resources and activities are feeding the momentum including government policy, plans and strategies, academic study, home-grown movements and the emergence of community groups, initiatives and activities. Conversations around the need to challenge death as a 'taboo' subject, the need to promote death as a 'normal' part of life and the need to address the fact that a substantial number of people do not die in their place of choice, have multiplied in recent years.

Governments and communities (in the United Kingdom in particular) have been concerned about the 'removal' of death from everyday life and a consequent reduced capacity in communities to understand, support and manage death. Over the past two decades in Australia, La Trobe University Palliative Care Unit (LTUPCU) has contributed significant leadership in this area as the initiator of public health approaches to palliative care.

In Victoria, at government and community levels there is an increasing focus on facilitating conversations about dying, death, and bereavement including a new State-wide framework for palliative care, promotion of Dying to Know Day, art events depicting death, 'before I die' community boards, death cafes and coffin clubs, to name just a few. At the same time the *Voluntary Assisted Dying Bill 2017* was passed into law by the Victorian Parliament, which has further drawn community attention to death.

The Municipal Association of Victoria (MAV) became aware of the public health approach to palliative care and the compassionate communities work being undertaken by LTUPCU. This led to engagement with council officers through the MAV Positive Ageing Network around the topic of death and the momentum for change in society. This collaboration with La Trobe University led to the development of the *Victorian Councils: Supporting Communities Around End of Life Project* (the Project).

The Project is a partnership project between the MAV & LTUPCU funded by the Department of Health and Human Services (DHHS) for three years (2017-2019). The overall aim of the Project is to explore how local government can be involved 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 LTUPCU is evaluating the project and provides expertise around end of life whilst the MAV is focusing on implementation of the project across local government.

The initial focus of the Project has been in the positive ageing area with the view of broadening this focus to other areas of local government.

⁵ Solutions Strategy Research Facilitation Ltd for Public Health England Developed with: PHE's Chief Knowledge Officer and Health and Wellbeing directorates © Crown copyright 2016

To date, the Project has been well received in the positive ageing area and many councils are developing initiatives and actions to engage with their community on dying, death and bereavement. A number of resources and training material have been developed to facilitate councils' work in this area which are available from the MAV website. Three councils, South Gippsland, Mansfield and Whittlesea received demonstration project funding to further explore local governments potential role in this new area.

As part of broadening its focus into the health and wellbeing area the MAV Project Team as a first step undertook a scoping exercise – to explore the rationale and opportunities for local government to include end of life (as defined in the Project) in health and wellbeing planning.

This discussion and ideas paper presents the findings of the scoping exercise and aims to facilitate discussion with councils. The discussion and ideas paper is an internal MAV document and is not intended as an academic or a research paper on health and wellbeing and end of life.

Key health and wellbeing considerations and questions that underpinned the scoping included:

- What is the connection/relationship between a 'preventative approach' to health and wellbeing and end of life?
- What are the health and wellbeing impacts of dying, death and bereavement on a community?
- What are the 'avoidable harms' impacting on individual and community associated with dying, death and bereavement?
- What are the social morbidities associated with end of life?
- What is the current status of end of life and health and wellbeing planning at State and local government levels?
- What are the opportunities for including end of life in health and wellbeing planning?
- What are the barriers/challenges for including end of life in health and wellbeing planning?

Victorian Councils: Supporting Communities Around End of Life Project
MAV Project Team
Jan Bruce & Katherine Wositzky

1. Project context

The local government context

The Victorian Councils: Supporting Communities Around End of Life Project is being implemented within a complex end of life environment involving a range of systems, services, businesses, care, individuals, families and communities. Local government to date has not had a direct role in this end of life service and system environment.

The Project is operating at a time when the concept, understanding and responses to end of life are being challenged with an increasing push for dealing with death as a social (not just a medical) event and a normal part of everyday life. Understanding death in a social context⁶ provides the overarching context for the Project and the rationale behind funding an end of life project in local government.

The Project is exploring opportunities and the potential role for local government to build capacity in their communities to support a more compassionate response to dying, death and bereavement. Building the capacity in communities and promoting a public health approach to death as a normal part of life, underpin the Project's aims.

A key challenge for the Project is to explore where and how local government might be involved around end of life in the public health and compassionate community sense, and how this role would work in with the complexities and range of systems and services that are concerned with end of life care.

The public health context

A public health approach to end of life promotes 'good health – good death' and is concerned with the health and wellbeing impact that dying, death and bereavement have on a person, a family and a community. The public health approach promotes death as occurring in a social context and brings together formal and informal support to provide care and support.

Medical advances have created a death denying culture. Over a number of decades the social context of death and dying has been lost: professionals in institutions have increasingly taken responsibility for managing death and dying – consequently there is a whole generation that has limited experience of supporting dying and bereaved. Limited experience of death, dying and loss affect informal community support.⁷

Public health approaches invite us to consider the place of death in human development: that is, in what sense can dying be seen as a healthy activity rather than capitulation to illness?⁸

⁶ An event that is not only a medical event but a social or societal event that occurs in the community, by the community

⁷ Scottish Public Health Care Network Palliative and end of life care in Scotland: The rationale for a public health approach Michelle Gillies February 2016 p.43

⁸ Palliative Care Lecture Series 2013, Compassionate Communities Bruce Rumbold, Palliative Care Unit, Department of Public Health, La Trobe University

The palliative care context

Palliative care is commonly understood and associated with end of life care however there are a number of different practices and approaches to palliative care.

Health Promoting Palliative Care (HPPC) began with the formation of the LTUPCU (1998) and has been discussed since the turn of the century. HPPC is important to understand as the philosophy or approach that underpins the aims of the Project. Importantly, HPPC promotes engagement with communities around dying, death and bereavement and building community capacity through conversations, activity, information provision, public education and awareness raising and community development.

The Victorian Palliative Care Framework 2016

The recently released Victorian Framework embraces a new approach and directions that reflect greater choices for people about the care they receive as they approach the end of life. The Framework:

- emphasises a person-centred approach
- promotes dying as part of life (a key principle guiding the Framework)
- promotes engaging with communities and embracing diversity as key priority areas, and
- includes local government agencies, clubs and organisations, to play a role in providing people with access to services and enhancing end of life awareness. This includes encouraging and facilitating people to have conversations about what matters to them to live well, to die well and to put plans in place for the future.

The *Victorian Councils: Supporting Communities Around End of Life Project* has been funded under priorities 1, 2 & 3 of the Framework.

2. Linking public health and end of life (as defined in the Project)

Public health and health promotion commonly focus on strategies for achieving good health and improved health and to date generally do not include references to (healthy) dying.

'Health promotion for the most part seems interested in death only as something to be avoided or postponed by health promoting practices. The discipline of palliative care, while having the goal of a good death, seldom talks about this as a health outcome'.⁹

The MAV scoping exercise found there are many public health definitions. The definition below however (John Last, Dictionary of Public Health 2006) includes references to dying.

'The mission of Public Health is to protect, preserve and promote the health of the public. Public health is the art and science of promoting and protecting good health, preventing disease, disability, and premature death, restoring health when it is impaired, and maximising the quality of life when health cannot be restored. Public health requires collective action by society; collaborative teamwork involving physicians, nurses, engineers, environmental scientists, health educators, social workers, nutritionists, administrators, and other specialised professional and technical workers; and an effective partnership with all levels of government.'

Under this definition of public health, links between public health and end of life could include:

- the health of the public – and the consideration for the impacts and effects of dying, death and bereavement on the community
- the requirement for collective action by society and others – and the essence of the compassionate community movement
- maximising quality of life when health cannot be restored – and the concern for a 'good death' or a 'healthy death'.

Discussion point – does this definition sit well with PH&WB Plans?

The social model of health and end of life

The scoping exercise also identified a relationship between the social model of health and end of life. The public health approach to end of life embraces a social model of health on a number of levels including:

- addressing the impact that the social and physical environment (of death, dying and bereavement) has on health and wellbeing
- empowering people to take greater control of their health and wellbeing (at the end of their life)
- putting the person at the centre of care, and
- recognising the strengths and capacity in communities to support wellbeing.

⁹ Health promoting palliative care and dying in old age Bruce Rumbold Chapter 7 Gott & Ingleton

Social morbidities and end of life

Public health and wellbeing is concerned at addressing the social, economic and physical environments that influence population health. Identifying the social morbidities associated with end of life in the scoping exercise found the following conditions are commonly associated with a person who is dying, their carers and their families. These conditions include:

- isolation
- loneliness
- poor mental health
- loss of identity (including after the caring role ceases), and
- loss of income.

Discussion point –
What are the impacts of social morbidities around end of life on population health?

'Many of the social morbidities associated with the end of life are amenable to traditional public health methods - health promotion, public education, or community development'.¹⁰

Public health and health promoting palliative care

A further link between public health and end of life can be demonstrated through the Health Promoting Palliative Care (HPPC) approach. As outlined earlier in this document, HPPC promotes engagement with communities around dying, death and bereavement and building community capacity through conversations, activity, information provision, public education and awareness raising and community development.

The following table¹¹ is provided to demonstrate connections between public health, end of life and HPPC using the core principles of the WHO Ottawa Charter, a concept first promoted through Kellehear's HPPC model.

Ottawa Charter	End of life /Health Promoting Palliative Care
Build Healthy Public Policy	⇒ Combat death denying health policies and attitudes in wider society
Create Supportive Environments	⇒ Provide social supports (individual and community) For example, this might involve establishing support groups for those facing death, dying, loss and care
Strengthen Community Actions	⇒ Healthcare should be participatory where professionals work with others, recognising the importance of social relationships and strengthening existing networks
Develop Personal Skills	⇒ Provide education and information for health, dying and death Include health and death education at all life stages
Reorient the Health Services	⇒ Encourage reorientation of palliative care services to better understand and appreciate the potential of HPPC

¹⁰ Public Health Approaches to End of Life Care – A toolkit The National Councils for Palliative Care Public Health England

¹¹ Developed by Allan Kellehear, Health Promoting Palliative Care: Developing a social model for practice 1999. This version has been adapted from a table in Identifying and changing attitudes toward palliative care: an exploratory study McLoughlin, K. 2012 National University of Ireland. Maynooth.

3. Public Health and Wellbeing Plans

The scoping exercise identified the need to establish the relationship between the 'prevention' focus of health and wellbeing planning and end of life. Progressing this concept involves thinking about dying as a normal part of life and bringing in the concept of a good death.

Where and how end of life could be included in public health and wellbeing planning was explored through analysing current State policy/plans¹² to establish inclusions around end of life.

This analysis found that the current Victorian Public Health and Wellbeing Plan and relevant planning documents do not include explicit references to end of life, dying, death or bereavement. In addition, ageing is not a priority area and people with life limiting illness are not a priority group.

Discussion point – what could be the connection between a preventative approach and end of life?

Potential areas for including end of life in health and wellbeing planning however were identified and are presented below as example areas of where end of life may be able to be placed in future health and wellbeing planning. The next State Plan will be released in September 2019 and consultation for this plan commenced in late 2018.

Current Policy/Plan	Elements of policy providing potential opportunities/relevance for inclusion of end of life
Victorian Public Health and Wellbeing Plan 2015-2019	'So that all Victorians can enjoy the highest attainable standards of health, wellbeing and participation at every age' 'Strategic direction – Active and healthy ageing'
Implementing the Victorian Public Health and Wellbeing Plan 2015-2019 Taking Action the first 2 years	'A life course approach' 'Action at every stage of life' 'Groups experiencing significant health and wellbeing inequalities ' 'Prevention is central to reducing inequalities - We are focusing on the unique strengths of communities and places to deliver solutions that are relevant, effective, efficient and sustainable'

Source:<https://www2.health.vic.gov.au/public-health/population-health-systems/municipal-public-health-and-wellbeing-planning/health-and-wellbeing-planning-guides>

Local Government Health and Wellbeing Planning

The Public Health and Wellbeing Act states that councils' health and wellbeing plans must have regard to State Public Health and Wellbeing Planning. The absence of end of life from the state plan means there is no direct reference point for local government to include it in health and wellbeing planning.

Despite there being no explicit references to end of life in the current State Plan, research undertaken by LTPCU as part of the Project identified five councils have included a reference to end of life in their health and wellbeing plans.

The next council public health and wellbeing plans will be for 2020-2024.

Discussion point – What will be helpful for councils to consider inclusion of end of life in their PH&WB Plans?

¹² Health 2040; Victorian Public Health and Wellbeing Plan 2015-2019; Victorian Public Health and Wellbeing Plan 2015-2019 Taking Action the First 2 years; Victorian Public health and Wellbeing Outcomes Framework 2016

'A new public health approach takes us beyond a health services perspective to consider not merely amended or added professionalised strategies near the end of life, but the settings in which life draws to a close, the resources with which people come to the end of life and – closely linked with both of these – the communities that shape these settings and resources. To put it another way, it invites us to reflect upon what health means over the life course: to develop an idea of a good life that can encapsulate the idea of a good death. Life and death may be binary opposites – but living and dying are not, and should be linked seamlessly in policies and practice.'¹³

The evidence base

Health and wellbeing planning is underpinned by an evidence base. The following data is listed as possible evidence/data that would support the inclusion of end of life in health and wellbeing planning.

- Population ageing data
- Deaths per municipality
- Social morbidities associated with death
- Gender differences around end of life
- MORT – Mortality over regions and time. LGA data by sex on recent deaths, median age at death, premature deaths, and leading causes of death. <https://www.aihw.gov.au/reports/life-expectancy-death/mort-books/contents/mort-books>
- Bereavement statistics (for example, in the UK it is estimated that around 5% of young people have been bereaved of at least one parent by the time they reach 16 years.)

Discussion point –
What other evidence/statistics / research could add to the evidence base?

¹³ Health promoting palliative care and dying in old age Bruce Rumbold Chapter 7 Gott & Ingleton

4. Influences of public health and wellbeing planning on 'end of life'

There are many influences on a person's experience of end of life including family, income, diversity, education, workplace, health and social care, information, media and community.

'Death is unpredictable. It can be slow, sudden, traumatic, expected – we all hope for a 'good death'. What that means very much depends not only on our definition but on our circumstance, our support networks and on the nature of our death'.¹⁴

A 'good death' or a 'healthy death' are reported to be hampered by a lack of conversation/understanding and/or acceptance of dying, in particular in western society. The momentum referred to earlier in this paper around changing how society deals with end of life includes the emergence of different approaches to bringing 'the conversation' into families and communities. How can local government help facilitate these conversations in the community has been a focal point of the Project so far.

The scoping exercise also identified the need to further understand and consider equity issues around public health and wellbeing and end of life. What is the impact of low socio-economic circumstances on quality of dying and death? Does a disadvantaged life result in a disadvantaged death? In what way could health and wellbeing planning improve experiences around end of life for people who are disadvantaged?

Considering a gender lens around public health and wellbeing and end of life is also important. The main caring role continues to be primarily undertaken by females. Alongside the new thinking of a need for greater compassion in our society to support people at the end of life, considerations of gender and equity issues need to be considered.

The scoping exercise identified some public health opportunities that could influence end of life. These opportunities include:

- addressing health inequalities and end of life of low socio-economic communities
- addressing gender issues around end of life
- addressing the community impacts from an ageing population and the growing number of deaths in all communities
- addressing the lack of capacity in the community to manage dying, death and bereavement well
- improving death literacy, so that community can better deal with dying and death, and
- improving death literacy for people with life limiting illness and their carers.

Discussion point –
What are the opportunities for local government to influence a 'good death'?

These opportunities require further understanding and discussion, however they also merit consideration for including in health and wellbeing planning.

In addition, under councils' role of shaping healthy, inclusive, cohesive and equitable municipalities, there are a number of policies, strategies and plans where 'end of life' has relevance and

¹⁴ Investing in Systemic Impacts to Improve End of Life Outcomes: Summary report The Australian Centre for Innovation

connections. For example, council's work in human rights, age-friendly, equity and socially just communities, have links with the new thinking around end of life outlined in the introduction.

'Death, dying and loss are universal experiences that have a major impact on health and wellbeing at a population level and are associated with significant burden and cost. Demographic, epidemiological and societal factors suggest that without action, this burden will increase'.¹⁵

¹⁵ Scottish Public Health Care Network Palliative and end of life care in Scotland: The rationale for a public health approach Michelle Gillies February 2016 p.49

5. Barriers & challenges

The MAV Project Team has met with a number of challenges in introducing the Project and the concept of end of life in local government. Further challenges with particular reference to health and wellbeing planning identified in the scoping exercise included:

- a need to have a clear language, terms and definitions when discussing end of life and health and wellbeing
- the State Public Health and Wellbeing Plan does not include explicit references to end of life
- there are relatively limited resources for council health and wellbeing planning and the implementation of actions
- the need to translate policy and theory around public health and end of life into practice, and
- the range of stakeholders and sectors involved with end of life.

Discussion point – Are there other barriers or challenges for councils?

6. The MAV Project Team – next steps

'End of life' is a new area for local government and the Project has been funded to explore a potential role for local government. The following opportunities and actions are suggested starting points for the MAV Project Team to begin to engage with local government health and wellbeing planners. Next steps include:

- engaging a 'think tank' of local government health and wellbeing planners to discuss this discussion and ideas paper.

And dependent on the outcomes of the above:

- contact local government health and wellbeing planners through existing networks to discuss end of life
- further explore the relevance of and availability of data that supports an evidence base around end of life and health and wellbeing
- consult with local government health and wellbeing planners to develop an example paragraph around end of life that may be inserted into councils Public Health and Wellbeing Plans, and
- engage with Public Health and Wellbeing Forums.

Discussion point – What other actions from the MAV Project Team would be helpful?

The scoping exercise confirmed the rationale for why end of life is of interest to local government health and wellbeing planning. The discussion and ideas paper is a starting point to assist local government discussions around considering end of life in their next health and wellbeing plans.

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Victorian Public Health and Wellbeing Plan 2015-2019 (and associated documents)

Acronyms

DHHS – Department of Health and Human Services

HPPC – Health Promoting Palliative Care

LGA – Local Government Area

LTUPCU – La Trobe University Palliative Care Unit

MAV – Municipal Association of Victoria

MORT – Mortality over regions and time

PH&WB plans – Public Health and Wellbeing Plans

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