



Final Report: Compassionate Communities Feasibility Study

Department of Health

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1 Executive Summary

Compassionate communities are a core part of public health approaches to palliative care, end of life care and bereavement. The term was first used by Australian experts in the mid-2000s to describe “community and neighbourhood networks which play a much stronger role in the care of people at end of life and their families and carers.”¹ It draws from the Compassionate City Charter, developed by Allan Kellehear to describe a city that “publicly encourages, facilitates, supports and celebrates care for one another during life’s most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care.”²

Public health approaches to palliative care, end of life care and bereavement, including compassionate communities, draw from the World Health Organization’s Ottawa Charter for Health Promotion (‘the Ottawa Charter’)³ to focus on “early intervention and a social approach to the problems and experiences of dying.” They encourage “service providers, family members, and the dying themselves to seek ways to promote emotional, social, and spiritual well-being, as well as physical health.”⁴ These approaches respond to the medicalisation of palliative care and the loss of community skills and activities in supporting people at end of life in many places. They also aim to address the social determinants that impact on people’s health and wellbeing at end of life and ensure equity of access to palliative care and other supports.

Compassionate communities play a key role in this public health approach. Abel et al argue that efforts to grow compassionate communities, along with public health reforms in three other areas – specialist palliative care, generalist palliative care and civic end of life care, are all essential to improve quality and continuity of care for people at end of life and address issues of access to care.⁵

Since the first compassionate communities emerged in Australia in the mid-2000s, the movement has grown both in Australia and overseas, particularly in recent years. Within this context, the Department of Health engaged Nous Group (Nous) to undertake a study on the evidence on compassionate communities and feasibility of implementing compassionate communities in Australia. This study involved a detailed literature review, stakeholder interviews and 12 case studies of compassionate communities and related approaches in Australia, the United Kingdom and New Zealand. As part of this study, the Department asked Nous to develop a principles-based implementation guide, which is provided alongside this report.

This final report presents the collective findings of the feasibility study. The study has found that compassionate communities are indeed feasible in Australia and, particularly when combined with broader public health approaches, deliver a range of benefits to people at end of life, their families and carers, communities and health systems. Compassionate communities can be created and grown through grassroots community activity and community development approaches. These approaches may be supported by community organisations, governments, civic institutions, researchers or service providers but must ultimately be owned and driven by the community.

In examining the case studies of national and international compassionate communities, this study found a range of views about the level of engagement between communities and health services that is optimal in the implementation of this approach. Some stakeholders believe that compassionate communities can only flourish without engagement from government or health services, while others see partnership as the key enabler for compassionate communities to thrive. This study has adopted a broad view of compassionate

¹ Abel, J, Kellehear, A and Karapliagou, A, ‘Palliative care – the new essentials’, *Annals of Palliative Medicine* 7(Suppl 2) (2018).

² Kellehear, A, *Compassionate Cities. Public Health and End of Life Care*, Routledge, London (2005).

³ World Health Organization, ‘Ottawa Charter for Health Promotion’ (2018); accessed at <http://www.who.int/healthpromotion/conferences/previous/ottawa/en>.

⁴ Kellehear, A, *Health Promoting Palliative Care*. Melbourne, Oxford University Press (1999).

⁵ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

communities, seeing benefit in not limiting the usefulness of compassionate communities to one specific model.

While compassionate communities are a core part of a public health approach to palliative care, the achievement of ongoing, sustainable outcomes at the individual, community and health system levels remains a significant challenge. An increase in the number of people dying at home and consequent reductions in the use of institutional beds will require a broad set of reforms across community and governments, including health services and systems, to deeply embed public health approaches to palliative care, end of life care and bereavement in health care and civic institutions. A growth in the development of compassionate communities across Australia will be an important step in such a transformation.

Key findings from this feasibility study are summarised in Table 1 below. These findings will inform the Department of Health’s broader work to improve policies and programs and create an enabling policy environment for public health approaches to palliative care, end of life care and bereavement.

Table 1 | Summary of findings

Section	Findings
Overview of compassionate communities	<p>Compassionate communities are part of the public health approach to palliative and end of life care. Many experts argue that to be most effective, compassionate communities need to be implemented as part of a more comprehensive public health approach involving palliative care, other health and non-health services, civic institutions and others.</p> <hr/> <p>Definitions of compassionate communities emphasise that they are communities where people care for each other across the full spectrum of illness, dying, death and bereavement. Compassionate communities are described by Abel et al. as ‘naturally occurring networks of support in neighbourhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement.’⁶ Compassionate communities usually involve people in the same geographic location but may be families, neighbourhoods, faith groups, local organisations, workplaces or groups of people that share similar experiences, such as Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD) and lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) communities.⁷</p> <hr/> <p>Compassionate communities complement the palliative care system. Compassionate communities emphasise the use of health promotion, community development and death education to provide a more holistic approach to end of life. They encourage palliative care professionals to support and empower communities to take a leading role in need identification and solution generation and delivery.⁸</p>

⁶ Ibid.

⁷ Sandwell Compassionate Communities, ‘What is a Compassionate Community’ (2018); accessed at <http://www.compassionatecommunities.org.uk/>.

⁸ Sallnow, L, Bunnin, A and Richardson, H, “Community development and hospices: a national UK perspective”, in Wegleitner, K, Heimerl, K and Kellehear, A eds. *Compassionate communities: case studies from Britain and Europe*. Routledge (2015): 1-14.

Section	Findings
	<p>There is no standard model for a compassionate community and they generally exist along a spectrum with related public health initiatives. Examples of compassionate communities vary greatly. They can generally be mapped along a spectrum (see figure below) based on who the activities and initiatives are initiated and led by (e.g. a formal health or non-health service, a civic institution or the community) and the level of engagement between health care services and the community. There are differences in opinion between some stakeholders on whether initiatives towards the left of the spectrum can be called a “compassionate community” or fall within the broader umbrella of public health approaches to palliative care.</p> 
<p>Costs and benefits of compassionate communities</p>	<p>Compassionate communities are feasible and deliver strong benefits to individuals, communities and health systems. There is a growing body of research and best practice – both in Australia and internationally – which shows that compassionate communities, when implemented with other public health approaches, deliver substantial benefits to people at end of life, their families and carers, communities and health systems. These benefits include improved quality of life, community cohesion and bereavement outcomes and reduced health care costs.</p> <p>The benefits and cost savings of compassionate communities are unlikely to be realised at the system-level without being part of a broader public health approach. Research and case studies examined for this study indicate that for benefits to be achieved at the system level and sustained, they must be accompanied by broader healthcare reform across specialist palliative care and generalist health services, civic change at the population level and cultural changes in the perception of death and dying.⁹ Studies that have shown reductions in emergency admissions and health care costs attribute these outcomes not just to compassionate communities but to broader efforts across local palliative care, health and community services.¹⁰</p> <p>Funding structures for compassionate communities vary considerably; while most aim to be self-sustaining they often rely on ongoing funding to be sustainable. Costs and funding structures of compassionate communities vary depending on who leads and implements the initiatives. They often involve an intense initial investment in community development activities to build the capacity of the community. The aspirational end goal is a compassionate community with no funding in which people organically care for each other, though in practice most examples studied for this review continued to depend on external funding.</p>
<p>Current status of compassionate communities in Australia</p>	<p>Compassionate communities are building momentum in Australia but some face challenges related to sustainability. Compassionate communities were pioneered in Australia in the mid-2000s. There are several well-established compassionate communities in Australia and a growing number of new initiatives with an accompanying body of research. There are also some successful models of community-based palliative care in Australia which have elements of compassionate communities. In recent years examples of and research on compassionate communities has grown considerably in Australia. Some Australian examples face challenges in being sustainable and some have folded after withdrawal of funding from an external source.</p>

⁹ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

¹⁰ Brown, M, ‘Compassionate Community Project,’ *Resurgence & Ecologist*, Iss 307.

Section	Findings
Implementation of compassionate communities in Australia	<p>There are five underpinning principles that can guide and direct implementation of compassionate communities. Nous has developed the following five principles for the implementation of compassionate communities based on the Ottawa Charter.¹¹ These are included in the principles-based implementation guide for compassionate communities which accompanies this report:</p> <ol style="list-style-type: none"> 1. Integrate community provision of palliative and end of life care into public health practice and policy 2. Draw on community strengths to create supportive environments and advocacy 3. Strengthen community development and action 4. Develop individual knowledge and skills about end of life 5. Re-orient services to work in partnership with sectors, organisations and communities. <hr/> <p>There are a number of success factors and challenges to implementation of compassionate communities. These span from an overall system and operating environment level, to understanding of the compassionate community model and interaction with service providers, through to the specific community and individuals in that community where implementation is taking place.</p> <p>Success factors identified in the case studies include listening and aligning to community needs, building capacity of the communities using community development approaches and connecting with GPs, palliative care services and other health services. Challenges include low existing community cohesion, difficulty in shifting mindsets away from medicalised views of care, and funding constraints.</p> <hr/> <p>Sustainability is a central goal, with several important considerations emerging. Compassionate communities need to be, in themselves, designed with an objective of long-term sustainability and minimal reliance on external funding sources. This is consistent with the community development principles of only supporting sustainable solutions and designing an exit strategy from the outset.¹²</p> <p>Key considerations for sustainability identified in the case studies include: using community development approaches to build local capacity with an exit strategy; ensuring resources and time dedicated to the first stages of initiatives are sufficient to generate a self-sustaining community; and aiming to embed compassionate communities approaches in the business as usual functions of community organisations, civic institutions and health and other services.</p> <hr/> <p>Case studies point to a number of learnings for implementation of compassionate community approaches. Australian and international case studies examined for this study identified a range of lessons, including the following:</p> <ul style="list-style-type: none"> • Invest in a community development approach but understand that it takes time. • Respect differences and diversity in the community. • Aim for community-led and -driven activities and initiatives where possible. • Invest in measuring outcomes and sharing learnings.

¹¹ World Health Organization, see n 3.

¹² Grindrod, A and Rumbold, B, Healthy End of Life Program (HELP): offering, asking for and accepting help. Creating an End of Life Collaborative Community Culture. La Trobe University Palliative Care Unit, Melbourne, Australia (2016).

2 Introduction

2.1 Background and context

Historically, the role of caring for people at end of life and their families was located in the community. Medical advances have seen the growth of palliative care services which have contributed to major improvements in medical care and quality of life for people at end of life. However, these medical advances have been accompanied by a reduction in community skills and activity in this area. While families continue to provide the vast majority of care for people at end of life, they often do so with limited or no support from their local community. People at end of life and their families and carers often experience isolation and fear of dying, and have low awareness of death and dying.¹³

In 1986 the World Health Organization released the Ottawa Charter, which provided a framework for the growth of public health globally. The Charter stipulates that “the responsibility for health promotion in health services is shared among individuals, community groups, health professionals, health service institutions and governments.” The Charter has a strong focus on health equity and emphasises that social determinants of health have a major impact on health outcomes.¹⁴

Public health approaches to all areas of health have grown considerably since the release of the Ottawa Charter, including in end of life care. In the late 1990s, Australian experts applied the Charter to develop a model for ‘health promoting palliative care.’¹⁵ According to Allan Kellehear, this model focuses on “early intervention and a social approach to the problems and experiences of dying... [It] encourages service providers, family members, and the dying themselves to seek ways to promote emotional, social, and spiritual well-being, as well as physical health.”¹⁶

Public health approaches to palliative care, end of life care and bereavement are growing in Australia and internationally. These approaches have been described as “initiatives from governments, their state institutions and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, caregiving and bereavement.”¹⁷ Public health approaches aim to address the social determinants that impact on people’s experiences at end of life as well as the barriers to access palliative care and other end of life care. This responds to evidence that marginalised populations, including people from lower socio-economic backgrounds, may be less likely to access palliative care services and other supports and more likely to experience poor outcomes at end of life.¹⁸

Compassionate communities are part of the public health approach. The term was coined by Allan Kellehear to describe community and neighbourhood networks which play a much stronger role in the care of people at end of life and their families and carers.¹⁹ Compassionate communities are most effective when accompanied by broader healthcare reform across specialist palliative care and generalist health services, civic change at the population level and cultural changes in the perception of death and dying.

¹³ GroundSwell, ‘Ageing well means being connected,’ The GroundSwell Project (2018) accessed at <http://www.thegroundswellproject.com/10k-ageing-well-means-being-connected>.

¹⁴ World Health Organization, see n 3.

¹⁵ Rumbold, B, ‘Public health approaches to palliative care in Australia,’ in Sallnow, L., Kumar, S. & Kellehear, A. (Eds.) *International perspectives on public health and palliative care* (pp. 52-68). London: Routledge (2012).

¹⁶ Kellehear, A, *Health Promoting Palliative Care*. Melbourne, Oxford University Press (1999).

¹⁷ Karapliagkou A, Kellehear A, ‘Public Health Approaches to End of Life Care: A Toolkit’ (2013), Middlesex University; accessed at [http://www.ncpc.org.uk/sites/default/files/Public Health Approaches To End of Life Care Toolkit WEB.pdf](http://www.ncpc.org.uk/sites/default/files/Public%20Health%20Approaches%20To%20End%20of%20Life%20Care%20Toolkit%20WEB.pdf).

¹⁸ Lewis, J, DiGiacomo, M, Currow, D C, Davidson, P M., ‘Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world,’ *Journal of Pain and Symptom Management*, 42(1): 105-118 (2011).

¹⁹ Abel, J, Kellehear, A and Karapliagou, A, ‘Palliative care – the new essentials’, *Annals of Palliative Medicine* 7(Suppl 2) (2018).

Compassionate communities draws from the Compassionate City Charter, developed by Allan Kellehear in 2005. This Charter describes 13 social changes to the key institutions and activities of cities to create a city which “publicly encourages, facilitates, supports and celebrates care for one another during life’s most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care.”²⁰ The Compassionate City Charter with these 13 changes is provided in Appendix D.

In Australia, there has been increasing interest in compassionate communities in recent years with a growing body of research and many new examples emerging across the country. While the term ‘compassionate communities’ is growing in use across the Australian health landscape, community approaches to caring for people at end of life and their families have existed for generations, both in Australia and internationally. According to Allan Kellehear, compassionate communities is a term that simply aims to describe these community-driven and public health approaches, and articulate what makes them effective, so that they can be better supported through formal and informal mechanisms.²¹

2.2 About the feasibility study

The Department of Health engaged Nous Group (Nous) to undertake a study of the evidence on compassionate communities and the feasibility of implementing compassionate communities in Australia.

A key requirement of the study was a principles-based implementation guide (provided alongside this report). Nous understands the purpose of this framework is to provide guidance to communities, service providers and other organisations in Australia on how to develop and implement compassionate communities. The framework was tested with key stakeholders, including academics, peak bodies and state and territory governments, and updated based on their feedback. Stakeholder feedback on the implementation guide also informed the development of this report.

Compassionate communities are widely recognised as part of broader public health approaches to palliative care, end of life care and bereavement. As such, this study also examined at a high level research and best practice in public health approaches to palliative and end of life care and how these approaches relate to the effective implementation of compassionate communities. This included investigation of approaches to palliative and end of life care that display many of the positive attributes of compassionate communities, such as in-home palliative care services that are delivered through strong partnerships with families and communities.

The feasibility study addressed four key lines of enquiry:

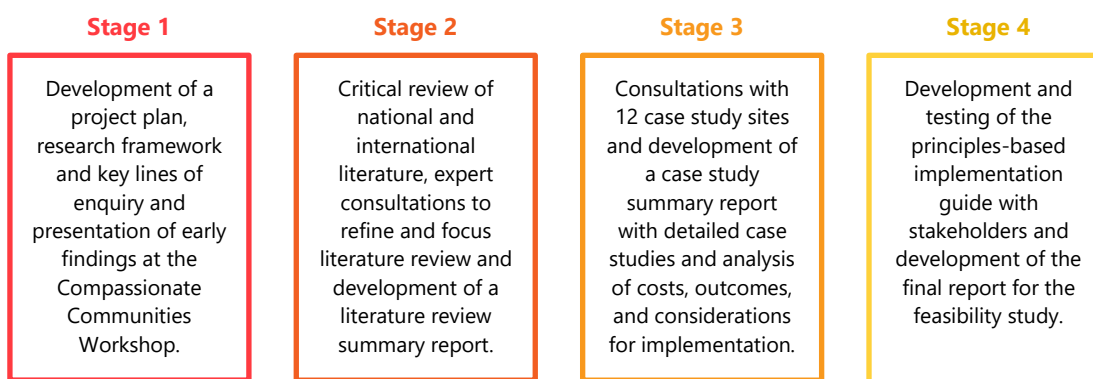
1. What is the potential role of compassionate communities in Australia?
2. How effective and efficient are compassionate communities’ activities at delivering outcomes?
3. How sustainable are the effects of investment in compassionate communities?
4. How can compassionate communities be successfully implemented in an Australian context?

The detailed methodology for the study is in Appendix A. It involved a four-stage approach which is summarised in Figure 1 (overleaf).

²⁰ Kellehear, A, see n 2.

²¹ Based on Nous interview with Allan Kellehear, April 2018.

Figure 1 | Stages of the feasibility study



2.3 About this report

This report presents the collective findings of the key deliverables for the feasibility study, including the literature review report, case study summary report (which presented the key themes from 12 case studies conducted as a part of this study) and the principles-based implementation guide.

The report is structured as follows:

- Sections 1 and 2 provide the executive summary, discuss the context and background for compassionate communities and provide an overview of the feasibility study.
- Section 3 provides an overview of the role and characteristics of compassionate communities and discusses examples from Australia and internationally.
- Section 4 summarises findings on evidence from the literature review and case study summary report, including benefits and outcomes, and costs and funding approaches.
- Section 5 briefly describes examples of initiatives which use compassionate communities and related approaches in Australia and outlines the status of these at a high level.
- Section 6 outlines the principles for implementing compassionate communities (as per the principles-based implementation guide that accompanies this report), the enablers and barriers for implementation, how sustainability should be considered, and lessons learned from the case studies.
- The appendices provide a summary of the methodology for the feasibility study (see Appendix A), literature review (see Appendix B), the 12 case studies from Australia, the United Kingdom and New Zealand (see Appendix C), and the Compassionate City Charter (see Appendix D).

Definitions of key terms in the report are provided in Table 2 (overleaf). These definitions are taken from those that are commonly used in the literature, however, it is important to note that some commentators may use different definitions for these concepts. Nous has taken a broad interpretation of these definitions in this feasibility study in order to cover a broader array of issues and evidence that relate to compassionate communities.

Table 2 | Definitions used in the feasibility study

Term	Definition
Palliative care	Palliative care is described by the World Health Organization as an approach that improves the quality of life of patients and their families facing 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, including physical, psychosocial and spiritual. ²² Definitions for palliative care may also be narrower (that is, focusing entirely on pain relief only); this report is also informed by these.
End of life care	End of life care is directed towards the care of persons who are nearing end of life. It aims to help people live as well as possible and to die with dignity. It also refers to treatment during this time and can include additional support, such as help with legal matters. End of life care continues for as long as the person, their family and carers need it. ²³
Public health approaches to palliative care, end of life care and bereavement	<p>Karapliagkou and Kellehear (2013) describe public health approaches to end of life care as “social efforts led by a coalition of initiatives from governments, their state institutions, and communities, often in partnerships with health and other social care organisations, to improve health in the face of life-threatening/limiting illnesses, caregiving and bereavement.”²⁴ This includes:</p> <ul style="list-style-type: none"> • public education • improvement of social capital (trust, empathy and cooperation) and community development • enactment of laws • partnerships with health services and their professionals • the creation of safe and sustainable social and physical environments.²⁵ <p>Public health approaches to palliative care involve the coordination and interaction of specialist palliative care, generalist palliative care, compassionate communities and civic end of life care.²⁶</p> <p>Public health approaches to bereavement adopt the same approaches used in public health approaches to palliative and end of life care. They support ‘everyday assets’ in the community who care for the majority of the bereaved, without the overreach from professional services.^{27 28}</p>
Health promoting palliative care	<p>The World Health Organization defines health promotion as “the process of enabling people to increase control over, and to improve, their health.”²⁹ Kellehear coined the term “Health promoting palliative care” to describe an approach that aims to:</p> <ul style="list-style-type: none"> • enhance a sense of control and support for those living with a life limiting illness • encourage interpersonal reorientation i.e. to assist, facilitate and enable those living with a life limiting illness to adjust to some lifestyle changes • build public policies that support dying, death, loss and grief • reorientate palliative care services, by linking with public health colleagues, utilising education opportunities, research activity, community and policy development • alter community attitudes to health, death, dying and be involved in dying, death and loss and care issues so that support for families is maximised beyond the simple provision of services.³⁰

²² World Health Organization, ‘WHO Definition of Palliative Care’ (2018): accessed at <http://www.who.int/cancer/palliative/definition/en/>.

²³ Ibid.

²⁴ Karapliagkou A, Kellehear A, ‘Public Health Approaches to End of Life Care: A Toolkit’ (2013), Middlesex University; accessed at http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf.

²⁵ Ibid.

²⁶ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

²⁷ Aoun SM, Breen L, Howting D, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. PLoS One; 10(3): e0121101. (2015).

²⁸ Aoun SM, Breen LJ, White I, Rumbold B, Kellehear A. What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the Compassionate Communities approach. Palliative Medicine. DOI: 10.1177/0269216318774995 (2018).

²⁹ World Health Organization, ‘Ottawa Charter for Health Promotion’ (2018): accessed at <http://www.who.int/healthpromotion/conferences/previous/ottawa/en>.

Term	Definition
Compassionate communities	<p>Compassionate communities are described by Abel et al. as 'naturally occurring networks of support in neighbourhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement.'³¹ They are communities where "citizens are encouraged to engage and become more informed about death, dying and care and adapt their practices and behaviour to be active in supporting those at end of life."³²</p> <p>Compassionate communities usually involve people in the same geographic location but may be families, neighbourhoods, faith groups, local organisations, workplaces or groups of people that share similar experiences, such as Aboriginal and Torres Strait Islander, CALD and LGBTIQ communities.³³ These communities:</p> <ul style="list-style-type: none"> • are informed about end of life and bereavement • are characterised by leadership embedded within the local community (non-expert leadership) rather than within palliative care or public health • work alongside service providers to support people at end of life and their family and carers through the experience of illness, dying and bereavement • are often created and grown through community development approaches. <p>Compassionate communities are responsive to local community needs. This means that how they evolve and how they provide support can vary significantly across different communities.</p>

³⁰ Kellehear, A, *Health Promoting Palliative Care*. Melbourne, Oxford University Press (1999).

³¹ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

³² GroundSwell Project, 'What is a Compassionate Community?' Compassionate Communities Hub (2018) accessed at <https://www.comcomhub.com/learn-more/>

³³ Sandwell Compassionate Communities, see n 7.

3 Overview of compassionate communities

This section provides an overview of the role and characteristics of compassionate communities and discusses examples from Australia and overseas.

3.1 Role and characteristics of compassionate communities

There are a number of emerging challenges for palliative and end of life care in Australia

In Australia there are growing pressures on the health and social care systems that support palliative and end of life care.³⁴ The number and proportion of older Australians is expected to continue and grow; by 2056, it is projected there will be 8.7 million older Australians (22 percent of the population).³⁵ There will be more people living with chronic and life-threatening conditions, including high levels of disability. This is predicted to create a significant burden on the health care system. Australia's expenditure on health in real time has grown at an average of 5.3 percent per year, compared with average real growth of gross domestic product (GDP) of 3.1 percent per year³⁶ - widely considered to be unsustainable. The National Health & Hospital Reform Commission concluded that evidence-based investment in strengthened health promotion was one of several potential strategies to help contain future growth in spending.³⁷

The social care needs of people at end of life are often not sufficiently met. Formal palliative and end of life care provides one part of all social supports provided to people at end of life. People at end of life and their carers and families commonly experience social isolation, stigma, depression, financial strain and spiritual dilemmas.³⁸ In one study, 71 percent of participants felt that their family life had been affected by the pressures of palliative and end of life care and 82 percent felt that their social life had been greatly affected.³⁹ Fifty-seven percent of the participants experienced tension quite a bit or very much, 43 percent experienced worry, 35 percent experienced irritability and 38 percent experienced depression. These feelings most often related to a sense of loss and were often connected to being unable to undertake roles that had once been an accepted part of life.⁴⁰ The healthcare workforce and volunteers working in hospice care were also subject to adverse effects, including compassion fatigue, secondary trauma and burnout.⁴¹

At the same time as people at the end of life often experiencing social isolation and stress, there has been an increasing trend of professionalisation and medicalisation of death and the dying process in Australia.⁴² Palliative and end of life care services have adopted a multi-professional model and include a variety of disciplines in care decision-making (e.g. doctors, nurses, physiotherapists, occupational therapists, social workers, spiritual care providers, art and music therapists and volunteer coordinators).⁴³ However this model remains dominated by professional and medical supports, with less focus on social and informal supports. In many instances, there is limited interaction with community efforts to provide support.

³⁴ Horsfall, D, Noonan, K and Leonard, R, "Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities." *Health Sociology Review* 21.4 (2012): 373-382.; Palliative Care Victoria, "Submission to the Senate Community Affairs Committee Inquiry into Palliative Care" (2012).

³⁵ Australian Bureau of Statistics (ABS) 2013, Population projections, Australia, 2012 (base) to 2101. ABS cat. no. 3222.0. Canberra: ABS.

³⁶ Palliative Care Victoria, "Submission to the Senate Community Affairs Committee Inquiry into Palliative Care" (2012).

³⁷ Ibid.

³⁸ Kellehear, A, "Compassionate Communities: end of life care as everyone's responsibility", *QJM: An International Journal of Medicine* 106.12 (2013): 1071-1075.

³⁹ Skilbeck, J et al, "Palliative care in chronic obstructive airways disease: a needs assessment", *Palliative Medicine* 12 (1998): 245-254.

⁴⁰ Ibid.

⁴¹ Slocum-Gori, S et al, "Understanding Compassion Satisfaction, Compassionate Fatigue and Burnout: A survey of the hospice palliative care workforce", *Palliative Medicine* 27(2) (2011): 172-178.

⁴² Horsfall, D, Noonan, K and Leonard, R, see n 34.

⁴³ Brown, L and Walter, T, "Towards a social model of end of life care", *The British Journal of Social Work* 44.8 (2013):2378-2390.

Compassionate communities respond to these challenges by caring for people across all phases of illness, dying, death and bereavement

As described in the definitions in Table 2, compassionate communities cover all phases of end of life, from illness through to bereavement for family, friends and carers of people who have died. Definitions provided in the literature and stakeholder consultations emphasise that compassionate communities are not a service, but rather they are a community in which people are activated and care for each. Through this care, compassionate communities address many of the gaps in formal palliative care services and support the medical, social, spiritual and emotional wellbeing of people at end of life and their families and carers.⁴⁴

Compassionate communities are part of the public health approach to palliative and end of life care

Compassionate communities emerged from the Ottawa Charter, World Health Organization's concept of 'Healthy Cities' or 'Healthy Communities' and subsequent literature on health promoting palliative care, public health palliative care approaches and Compassionate Cities. These approaches aim for population-wide change in health outcomes by addressing the social determinants of health and recognising the right of citizens to control their health and redress social determinants of health that negatively impact their lives.⁴⁵

The role of the community in public health was re-affirmed in the World Health Assembly Resolution 51.12 on Health Promotion (2012) which recognised the importance of health promotion to build healthy public policy, create supportive environments, strengthen community action, develop personal skills and reorient health services.⁴⁶ This resolution urged all member states to promote social responsibility for health, increase investments for health development, consolidate and expand partnerships for health, increase community capacity and empower the individual in matters of health, strengthen consideration of health requirements and promotion in all policies, and adopt an evidence-based approach to health promotion policy and practice.⁴⁷

Commentators generally agree that compassionate communities are a critical part of the public health approach to palliative and end of life care. Abel et al argue that in compassionate communities, the best outcomes are achieved when there is systemic change across multiple sectors and the whole community, for example through legislative reform, cultural changes in the perception of death and dying, and increased civic activity. Abel et al present compassionate communities as one of four essential elements within a public health model for palliative care (see Figure 2, overleaf). They argue that all four elements must be present to improve quality and continuity of palliative care and address barriers to access to care.⁴⁸

⁴⁴ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

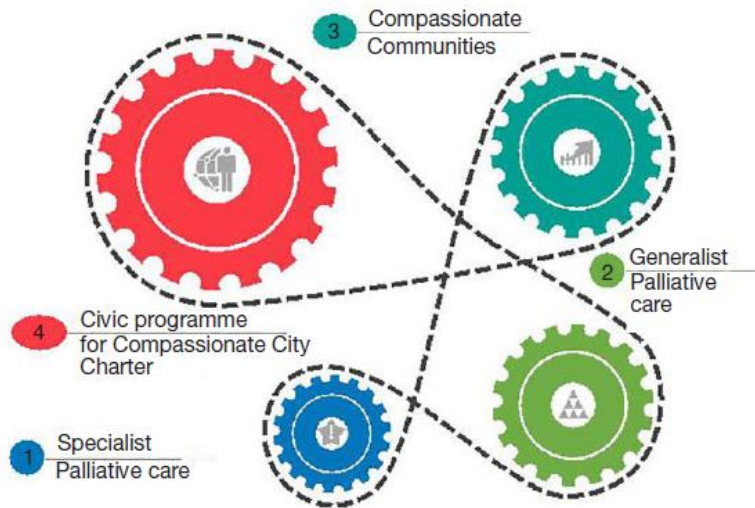
⁴⁵ Kellehear, A, 'Compassionate communities: End of life care as everyone's responsibility,' *QJM: An International Journal of Medicine*, 106. 12 (2013): 1071–1075.

⁴⁶ World Health Assembly, 'World Health Assembly Resolution WHA 51.12 – Health Promotion' (2012): accessed at <http://www.who.int/healthpromotion/wha51-12/en/>.

⁴⁷ Ibid.

⁴⁸ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

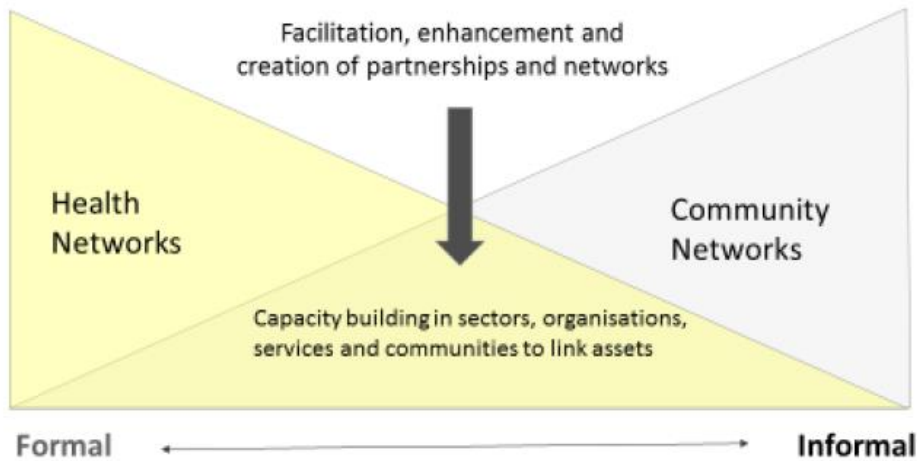
Figure 2 | Palliative care – the new essentials model by Abel et al⁴⁹



Grindrod and Rumbold similarly position compassionate communities as part of their public health palliative care framework. They argue that formal health networks and informal community networks are both required to improve the quality of end of life care and cannot exist in isolation.⁵⁰

Figure 3 | Public Health Palliative Care Framework by La Trobe University⁵¹

Connecting informal & informal networks to enable home based caring at the end of life



⁴⁹ Ibid.

⁵⁰ Grindrod, A and Rumbold, B, Public Health Palliative Care Model, La Trobe University Palliative Care Unit, Yet to be published (2018).

⁵¹ Ibid.

Compassionate communities complement the formal palliative care system

Compassionate communities emphasise the use of health promotion, community development and death education to provide a more holistic approach to end of life, in a field that previously had a clinical focus on physical symptoms.⁵² These approaches encourage palliative and end of life care professionals to support and empower communities to take a leading role in need identification and solution generation and delivery.⁵³ In doing so, they address three key challenges in palliative and end of life care:

1. the need to ease population-related burdens and a growing expenditure on health
2. addressing the unmet social care needs of people at end of life
3. de-professionalising and de-medicalising death and the dying process.⁵⁴

Communities may take on several roles, including providing companionship to the person at end of life, supporting caregivers in daily activities to avoid fatigue, promoting conversations on death and end of life planning and helping to identify resources for people at end of life and their loved ones.⁵⁵

Models of compassionate communities focus on community engagement and the range of actors that care for people

Commonly cited models for compassionate communities describe the type of community engagement that can occur and the relationship between people at end of life and those that care for them (see Figure 4, overleaf).

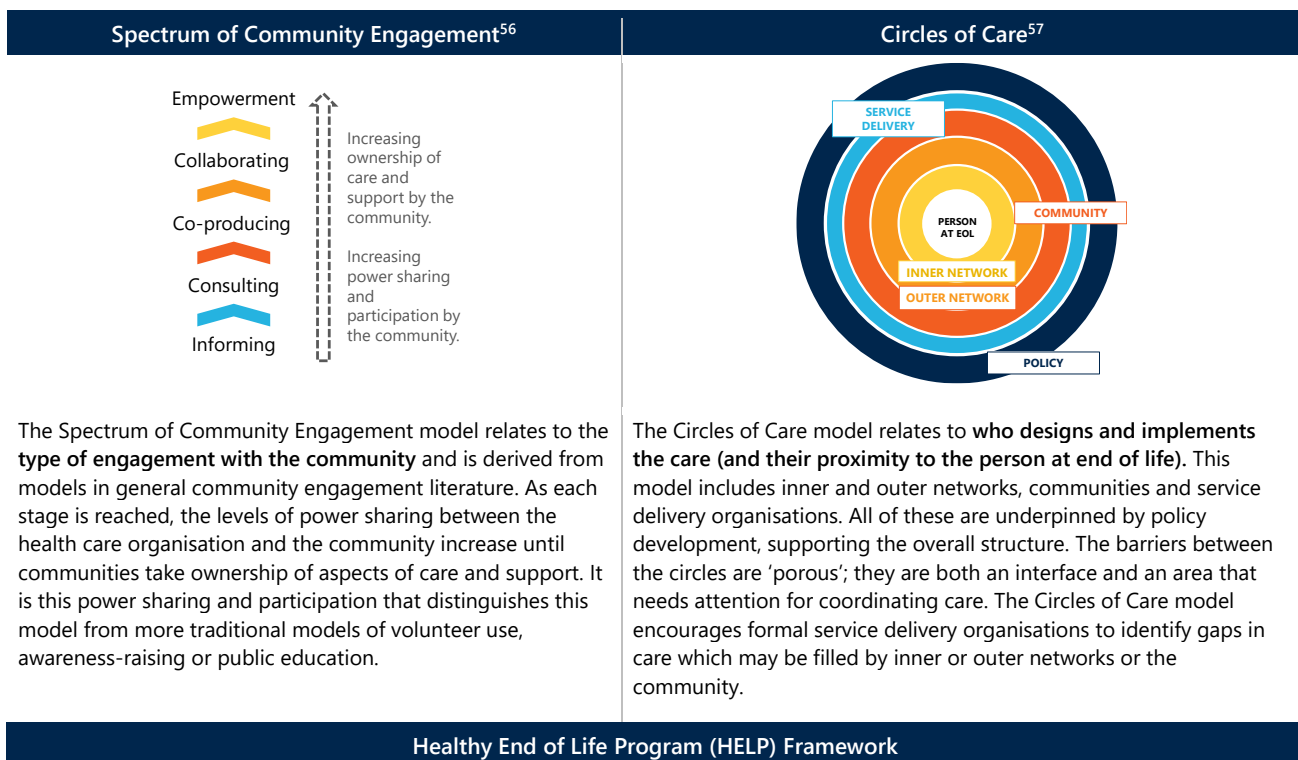
⁵² Kellehear, A, see n 3035.

⁵³ Sallnow, L, Bunnin, A and Richardson, H, "Community development and hospices: a national UK perspective", in Wegleitner, K, Heimerl, K and Kellehear, A eds. *Compassionate communities: case studies from Britain and Europe*. Routledge (2015): 1-14.

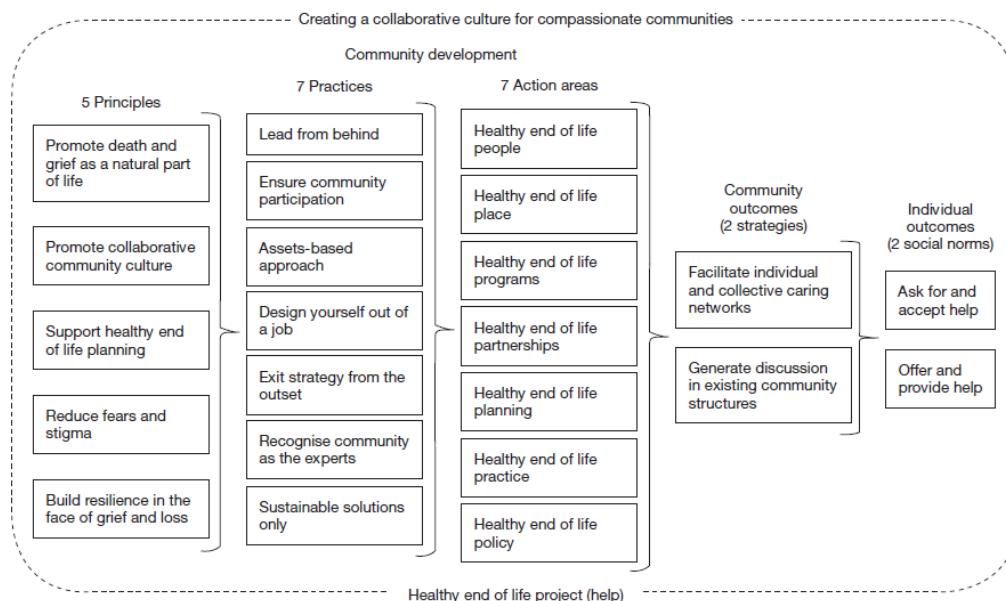
⁵⁴ Horsfall, D, Noonan, K and Leonard, R, see 31; Palliative Care Victoria, see n 34.

⁵⁵ Russell, C, "Compassionate Communities and their Role in End of life Care", *University of Ottawa Journal of Medicine* (2017)

Figure 4 | Commonly cited models that describe compassionate communities



Healthy End of Life Program (HELP) Framework



The HELP Framework is a research-informed initiative aimed at creating a collaborative community culture for palliative and end of life

⁵⁶ Sallow, L and Paul, S, "Understanding community engagement in end-of-life care: developing conceptual clarity", *Critical Public Health* 25.2 (2014): 231-238.

⁵⁷ Abel, J et al, "Circles of care: should community development redefine the practice of palliative care?", *BMJ Supportive & Palliative Care* 3 (2013).

care. It outlines a set of evidence-based and research informed **principles, practices, action areas, community outcomes (strategies) and individual outcomes (social norms)**.⁵⁸ The model aims to develop community capacity to care for people at end of life, work cooperatively with carers, family, friends and neighbours and lead compassionate communities' initiatives in their local area.

There is no standard model for compassionate communities and they generally exist along a spectrum with related public health initiatives

Examples of compassionate communities vary greatly, both in Australia and overseas. Some are purely community led initiatives with no external support while others are implemented through community development approaches involving partnerships between communities and other organisations, such as palliative care services, residential aged care facilities, universities and local governments. Two key factors in the delivery of compassionate communities to palliative and end of life care are:

1. Who the activities are initiated and led by (that is, a formal health care service, a non-health service organisation or the community)
2. The level of engagement or alignment which existed between health care services and the community.

The combination of these two factors can be used to create a spectrum (see Figure 5). Initiatives which use approaches towards the left of the spectrum are primarily driven and led by formal health care services, and either have a high level of engagement with communities or strive to align closely with perceived community needs. Initiatives which use approaches towards the right of the spectrum are primarily driven and led by communities and have minimal engagement with formal health care services. Initiatives in the middle may be community led but initiated through partnerships with other organisations, such as health services, non-health service or civic institutions,

Figure 5 | Spectrum of compassionate communities and related approaches



There are some common types of activities used in compassionate communities

There is no standard set of activities which need to occur when implementing compassionate communities, however activities used tend to fall into one or more of six categories. These are summarised in Figure 6.

⁵⁸ Grindrod, A and Rumbold, B, see n 12.

Figure 6 | Common types of activities used in compassionate communities

CARE & SUPPORT	COMMUNITY DEVELOPMENT	COMMUNITY PARTNERSHIPS	AWARENESS RAISING	COMMUNITY ACTIVATION	ADVOCACY & POLICY
Clinical, social, emotional and spiritual care and support for people, families and carers through illness, dying, death and bereavement. Ranges from in-home medical and psychosocial care to respite care, cooking meals, caring for children and assisting people to navigate health systems.	Activities to build on the skills and capabilities of communities to care for people and lead their own compassionate communities initiatives.	Developing networks, partnerships and other relationships with stakeholders in the community, such as schools, universities, and community groups and enhancing existing networks to care for people and raise awareness about death and dying.	Education and health promotion activities to increase death literacy and raise awareness about death, dying and services that are available to support people at end of life and their families.	Activities to recruit, train, coordinate, and support people from the community to care for each other and implement compassionate communities approaches. Includes network mapping and building social connections. Some compassionate communities refer to this as the development of volunteer networks.	Advocacy and policy development to shape dialogue and improve services and policies on palliative and end of life care.

3.2 Examples of compassionate communities

There are a variety of Australian and international examples of initiatives which use compassionate communities and related approaches to palliative and end of life care

Several examples of initiatives which use compassionate communities and related approaches to palliative and end of life care were identified through the literature review, case studies and in consultations. All examples listed adopted a tailored approach, working with their communities to identify their needs and preferences and then designing activities accordingly. There is considerable variance in the shape and size of initiatives.

Figure 7, Figure 8 (overleaf) and Figure 9 (overleaf) provide selected examples of initiatives which use compassionate communities and related approaches in Australia, the UK, the Republic of Ireland, Canada, Austria and India. Appendix C provides detailed case studies of 12 examples from Australia, the United Kingdom and New Zealand.

The examples provided in this report are not comprehensive and there are many other compassionate communities in Australia and other countries. These examples were chosen because they were commonly cited in the literature and stakeholder consultations.

Figure 7 | Examples of compassionate communities and related approaches in Australia

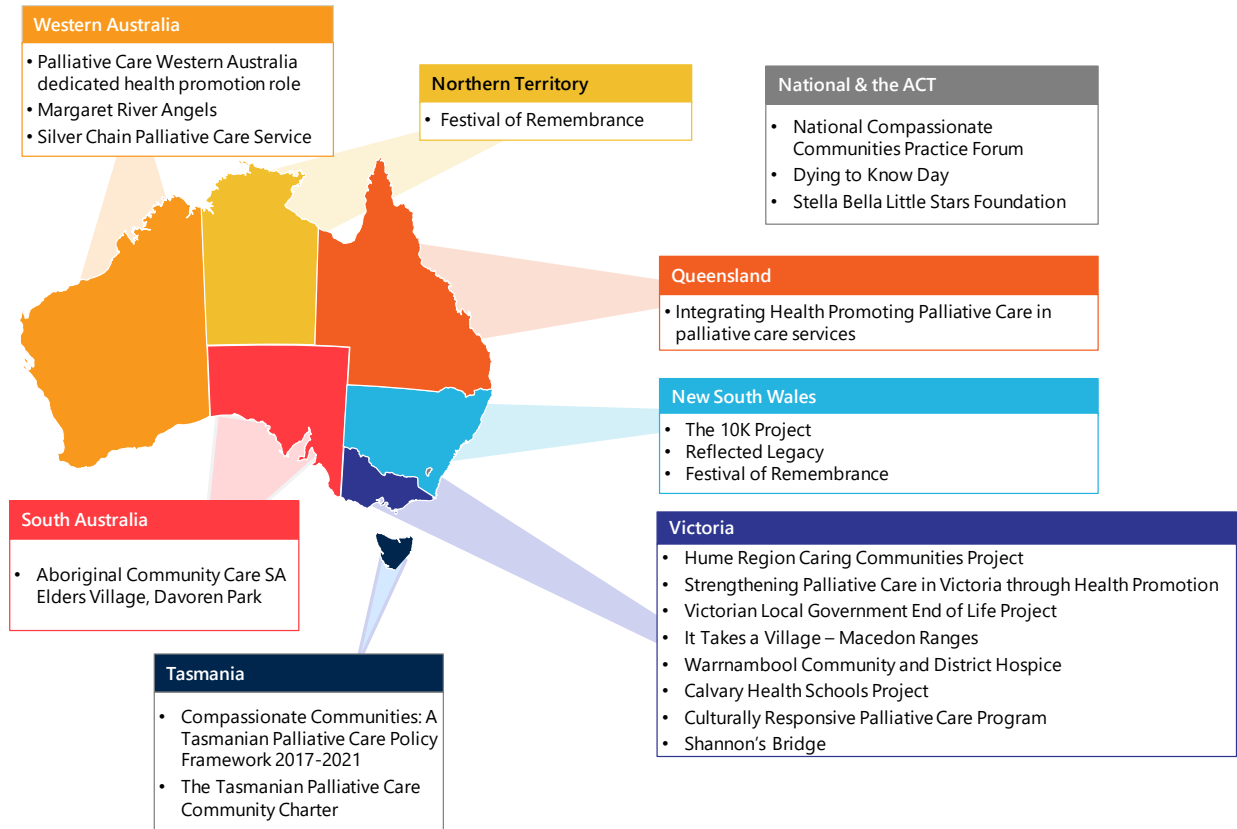


Figure 8 | Examples of compassionate communities and related approaches in the United Kingdom, Ireland and Canada

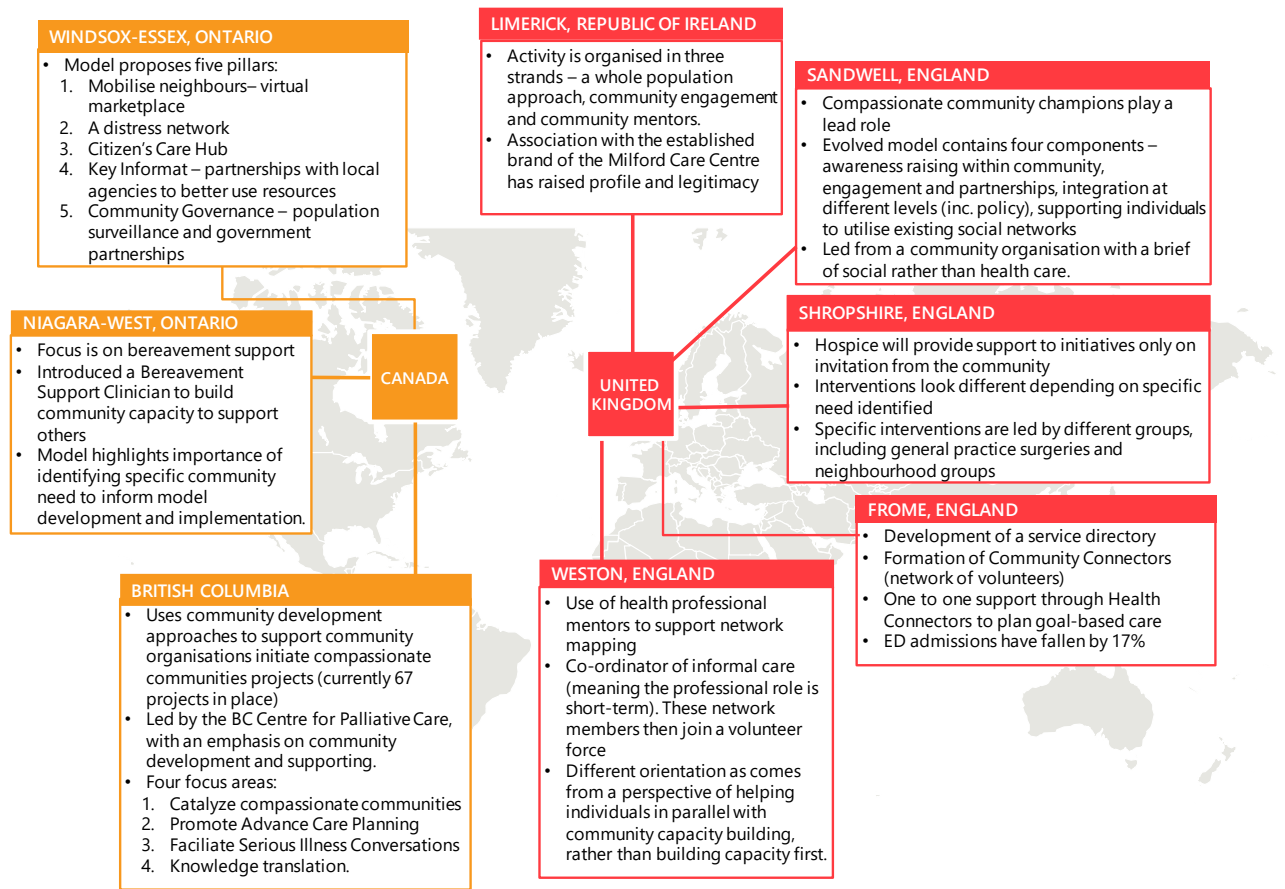
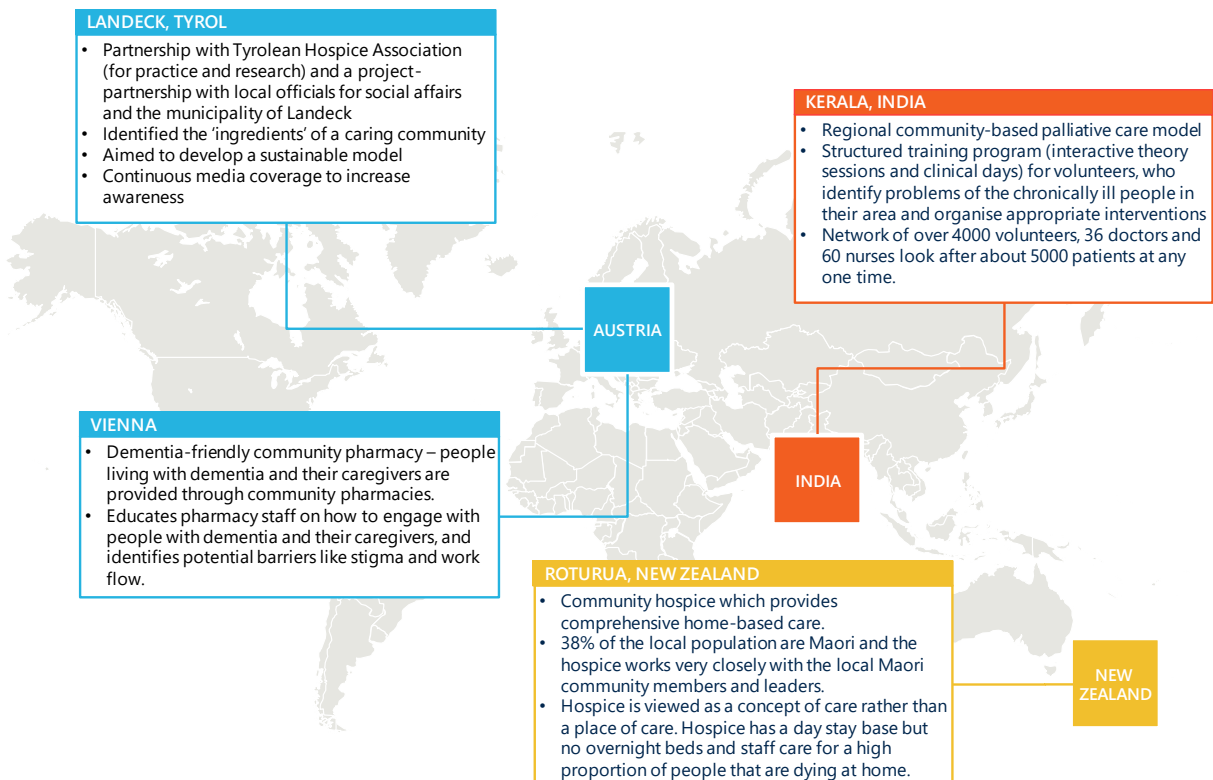


Figure 9 | Examples of compassionate communities and related approaches in Europe and Asia



4 Evidence on compassionate communities

This section summarises findings on evidence from the literature review and case study summary report, including benefits and outcomes, and costs and funding approaches.


4.1 Benefits and outcomes

Evidence indicates compassionate communities deliver a wide range of benefits

According to the literature, there are many potential benefits associated with compassionate communities. Benefits commonly cited include those experienced by people at end of life, their carers and their families, health and social care professionals, communities and the health and social care systems (see Table 3).

Intended outcomes of compassionate communities typically relate to improving the experiences of people at end of life and their families and carers and facilitating community development and capacity building.

Table 3 | Commonly cited benefits and outcomes of compassionate communities and related approaches in the literature and case studies

Stakeholders	Benefits and outcomes
 People at the end of life	<ul style="list-style-type: none"> ✓ Improved quality of life and wellbeing⁵⁹ ✓ Reduced stress and anxiety, which is linked to reduced experiences of pain⁶⁰ ✓ Reduced fatigue and feelings of isolation⁶¹ ✓ Increased death literacy and willingness to have conversations about death and dying⁶² ✓ Increased awareness of and access to palliative care and other services, including for marginalised populations⁶³ ✓ Increased confidence in asking for assistance and the ability to find resources⁶⁴ ✓ Reduced palliative care-related hospital admissions and reduced lengths of stay in hospital⁶⁵ ✓ Increased likelihood of being cared for and dying in place of choosing, including at home⁶⁶ ✓ Personal growth and learning, including greater appreciation of self and identity, and improved sense of belonging⁶⁷ ✓ Improved cultural responsiveness and appropriateness of care

⁵⁹ Rhatigan, J, "The Compassionate Communities Project", presentation at Living and Dying Well in the Community: The Future of Primary Palliative Care in Ireland (2014).

⁶⁰ Sallnow, L et al, "The impact of a new public health approach to end of life care: A systematic review", *Palliative Medicine* 30.3 (2016): 200-211.

⁶¹ Ibid.

⁶² Noonan, K et al, "Developing death literacy", *Progress in Palliative Care* 24.1 (2016): 31-35; Horsfall, D, Noonan, K and Leonard, R, "Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities." *Health Sociology Review* 21.4 (2012): 373-38.

⁶³ Paul, S, "Working with communities to develop resilience in end of life and bereavement care: Hospices, schools and health promoting palliative care", *Journal of Social Work Practice* 30.2 (2016); 187-201.

⁶⁴ Sallnow, L et al, see n 60.

⁶⁵ Compassionate Communities Symposium Working Group, *Compassionate Communities Communique* (2017): accessed at https://static1.squarespace.com/static/57e52fb237c5811bc06c8595/t/58dd977417bffcc368576f26/1490917266797/PCA016_CC+Communique+Booklet_F+Online.pdf.

⁶⁶ Downer, K, "It takes a compassionate community: Palliative Care is Everybody's Business", presentation to British Columbia Hospice Palliative Care Association (2016).

⁶⁷ Rosenberg, JP, Horsfall, D and Leonard, R, "Informal caring networks for people at end of life: building social capital in Australian communities", *Health Sociology Review* 24(1): 29-37.

Stakeholders	Benefits and outcomes
 <p>Families and carers of people at end of life</p>	<ul style="list-style-type: none"> ✓ Improved quality of life and wellbeing⁶⁸ ✓ Increased death literacy and willingness to have conversations about death and dying⁶⁹ ✓ Reduced stress and anxiety ✓ Reduced burden of care on informal caregivers through support in day-to-day tasks⁷⁰ ✓ Improved bereavement outcomes⁷¹ ✓ Less days off work or school due to caring responsibilities or bereavement issues
 <p>Communities</p>	<ul style="list-style-type: none"> ✓ Increased death literacy and willingness to have conversations about death and dying⁷² ✓ Growth of social capital and capacity building ✓ Growth of formal and informal partnerships ✓ Greater community self-sufficiency and sustainability through strengthened relationships⁷³ ✓ Improved access to resources,⁷⁴ including access to information and local services⁷⁵ ✓ Increased awareness of palliative care services⁷⁶ ✓ Development of a workable community development model which can be shared between different organisations and community groups ✓ Development of organisational structures and processes that promote ongoing involvement of people at end of life, their carers and their families⁷⁷ ✓ Increased sense of community inclusion and cohesion⁷⁸ ✓ Increased helping and caring behaviour by community members⁷⁹ ✓ Increased number of community-driven and -led activities⁸⁰ ✓ Increased support for groups who are often marginalised in service planning and provision
 <p>Health and social care professionals</p>	<ul style="list-style-type: none"> ✓ Management of the increasing demand on service providers, particularly in raising awareness and capacity-building in the community⁸¹ ✓ Reduced care burden on health and social care professionals⁸² ✓ Reduced likelihood of compassion fatigue and secondary traumatic stress of staff⁸³ ✓ Increased discussion about the non-clinical needs of a person at end of life⁸⁴

⁶⁸ Downer, K, see n 66.

⁶⁹ Noonan, K et al, see n 62.

⁷⁰ Mills, J, Roseberg, JP and McInerney, F, "Building community capacity for end of life: an investigation of community capacity and its implications for health-promoting palliative care in the Australian Capital Territory", *Critical Public Health* 25(2): 218-230; Horsfall, D et al, "Working together - apart: Exploring the relationships between formal and informal care networks for people dying at home", *Progress in Palliative Care* 21.6 (2013): 331-336.

⁷¹ Sallnow, L et al, see n 60.

⁷² Noonan, K et al, see n 62.

⁷³ Rosenberg, JP, Horsfall, D and Leonard, R, see n 57.

⁷⁴ Rhatigan, J, "The Compassionate Communities Project", presentation at Living and Dying Well in the Community: The Future of Primary Palliative Care in Ireland (2014).

⁷⁵ Rosenberg, JP, Horsfall, D and Leonard, R, see n 57.

⁷⁶ Paul, S, see n 63.

⁷⁷ Ibid.

⁷⁸ Ibid.

⁷⁹ Rosenberg, JP, Horsfall, D and Leonard, R, see n 67.

⁸⁰ Ibid.

⁸¹ Mills, J, Roseberg, JP and McInerney, F, *ibid.*

⁸² Crowther, J et al, "Compassion in health care – lessons from a qualitative study of the end of life care of people with dementia", *Journal of the Royal Society of Medicine* 106.12 (2013): 492-497.

⁸³ Ibid.

⁸⁴ Grindrod, A and Rumbold, B, Public Health Palliative Care Model, La Trobe University Palliative Care Unit, Yet to be published (2018).

Stakeholders	Benefits and outcomes
 <p data-bbox="217 423 360 533">Broader health, aged care and social care systems</p>	<ul style="list-style-type: none"> ✓ Promotion and development of evidence-based public health approaches to palliative and end of life care ⁸⁵ ✓ Development of an active and engaged palliative and aged care environment ✓ Growth of formal and sustainable partnerships ✓ Increased sustainability of care through addressing issues of access, equity and quality of palliative and end of life care⁸⁶ ✓ Reduced palliative-related hospital attendances and emergency admissions ✓ Reduced palliative-related length of stays in hospital ✓ Reduced costs of care per patient ✓ Reduced requests for formal palliative services and acute (hospital) services ✓ Increased organisational capacity in local government on end of life issues for the community

Few negative outcomes of compassionate communities are identified in the literature. One study warned they may lead to a decrease in manageability of care if the process of organising and managing a network of friends and community members involved more work and contributed a degree of stress.⁸⁷

There is a growing body of evidence on the benefits of compassionate communities to bereavement outcomes

As described in Table 2 above, compassionate communities also care for people during the bereavement phase of end of life care. Members of the local community networks that support a dying relative or friend continue to support each other during bereavement, unlike formal services where there is often a disjunction between the palliative care and bereavement care teams.⁸⁸

National bereavement survey data and other research indicates that the majority of bereaved people rely on family and friends for bereavement support: that is, on relationships that pre-date the end of life experience. Conversely, the professional sources were the least used by bereaved people, those who did use them reported the highest proportions of perceived unhelpfulness.⁸⁹ Case studies also reported anecdotally that compassionate communities had a large positive impact on bereavement outcomes for families, friends and carers.

Aoun et al (2015) advocate for a public health model of bereavement support that articulates the need to support ‘everyday assets’ in the community who care for the majority of the bereaved, and to limit the overreach of professional services. Under this model, professionalised services would be offered to those who would most benefit, while others would be supported within their natural support networks through compassionate communities approaches.⁹⁰

Compassionate communities must be part of a broader public health approach to achieve sustainable outcomes and cost savings

Research and case studies show that without a strong public health environment, the outcomes of compassionate communities are often limited to those individuals who give and receive care. The most successful examples of compassionate communities, such as Frome in the United Kingdom,⁹¹ involve a comprehensive public health approach to palliative and other areas of health care. Studies which have

⁸⁵ Rhatigan, J, see n 74.

⁸⁶ Downer, K, "It takes a compassionate community: Palliative Care is Everybody's Business", presentation to British Columbia Hospice Palliative Care Association (2016).

⁸⁷ Sallnow, L et al, see n 8.

⁸⁸ Aoun et al, see n 27; Aoun et al, see n 28.

⁸⁹ Ibid.

⁹⁰ Ibid.

⁹¹ Brown, M, see n 10.

shown a reduction in hospital admissions and costs to the health system attribute these results not to compassionate communities alone but to broader public health initiatives which may involve formal health and social services, civic institutions and communities. Studies show that to achieve outcomes at the individual, service and system levels, compassionate communities must be accompanied by broader public health reforms. Such reforms can lead to substantial benefits and cost-savings for individuals, communities and health systems.⁹²

For example, in Frome, emergency admissions to hospitals fell by 17 per cent between 2013-14 and 2016-17, with a 21 per cent reduction in costs (while, over the same period, emergency admissions to hospitals across Somerset increased by 29 per cent).⁹³ This cost saving represents 5 per cent of the total health budget in Frome. No other interventions have reduced emergency admissions across the population to the same extent. These results are not just attributed to compassionate communities but to a broad range of public health initiatives mostly led by local medical practices.

4.2 Costs and funding approaches

Compassionate communities aim to be self-sustaining but often rely on long-term funding

Given the variety of compassionate communities and related approaches to palliative and end of life care, it is not possible to identify a generic set of cost inputs. Cost inputs depend on the types of activities and initiatives underway. Based on examination of a small number of case studies for which specific inputs could be identified, costs can be grouped into several categories, including costs associated with:

- **non-clinical, practical support:** this may include daily living support for the person who is at the end of life and/or practical support for families and carers. It may also include the cost of time dedicated by community members, champions or others who provide support for families and carers
- **training:** this may include costs associated with training for staff and community members involved in the model to be better equipped to discuss life, death, loss and dying and to support patients/people to engage in future life planning
- **community engagement activities:** this may include public forums and meetings (aimed at increasing community capacity, resilience and future life planning) and other unspecified community engagement activities
- **collaboration activities:** this may include physical meetings, networking or conferences supporting the critical networks that underpin compassionate community models. Based on one study, these were seen as time consuming and costly if not carefully planned (compared to the use of web, social media and other links)⁹⁴
- **community development activities:** this may include costs associated with supporting the development of compassionate organisations or developing networks for listening and providing practical support
- **community development managers or 'connector' roles:** this can include the costs of employing community development managers (e.g. within an existing palliative care service) to strengthen links across the community and other organisations and/or the cost of specific positions funded to connect people and organisations (for example, connecting people in the community with general practitioners and other health, social or aged care organisations)

⁹² Grindrod, A and Rumbold, B, see n 12..

⁹³ Brown, M, see n 10.

⁹⁴ Barry, V and Patel, M, "An overview of compassionate communities in England", Murray Hall Community Trust and National Council for Palliative Care, Dying Matters Coalition (2013).

- **clinical services or linkages with clinical services:** this may include involvement of palliative and end of life care clinicians, nurses and allied health professionals who provide at home care
- **psychosocial support:** this may include psychosocial support provided by social workers, counsellors, pastoral care and allied health professionals.⁹⁵

Costs and funding structures vary considerably depending on who leads the initiatives

In the small number of case studies examined by Nous, there was a relationship between who initiated and led the initiatives in the case studies undertaken for this study, and the key costs incurred and funding structures used. This relationship is outlined in Table 4.

Table 4 | Typical costs and funding structures in the case studies

Initiated and led by	Typical costs	Typical funding structure
Formal health care services	Overall, these initiatives have more formal costs structures and higher administrative and staff costs. Costs mainly covered project administration staff and service delivery staff (including clinical, psychosocial and other practitioners). Other costs included medical equipment (for in-home services), community engagement activities and information resources.	These initiatives received ongoing funding from state or territory governments.
Formal partnerships between academic, peak bodies, not-for-profits or local government organisations	Overall, these initiatives had costs involved in administering community development activities and included staff (e.g. project managers and community development workers), capacity building events for communities, training for community members and information and education resources.	These initiatives typically received government grants, research grants, funds from service providers (e.g. residential aged care facilities), peak body funding, or philanthropic donations.
Community	Overall, these initiatives had lower administrative costs, with most funding going towards supports for people at end of life and their families, as well as training for community members.	These initiatives tended to rely on donations from individuals, businesses and charities in the community, although some had received seed funding from governments or peak bodies such as Palliative Care Australia.

⁹⁵The cost input categories were identified from the following sources: The National Council for Palliative Care, "Dying Well Community Charter Pathfinder Project: Evaluation Report", The National Council for Palliative Care (2016) and Silver Chain, "Silver Chain Group submission on the consultation paper on the pricing framework for Australia public hospital services 2016-17", Silver Chain (2015).

Funding structures for compassionate communities in the UK

Although many commentators consider compassionate communities a potentially 'sustainable model' working through existing structures, commentators recognise a need for financial, human and support resources, particularly in the early stages. Barry and Patel (2013) identify a range of funding sources for compassionate communities and public health approaches referenced in their scoping study, including:

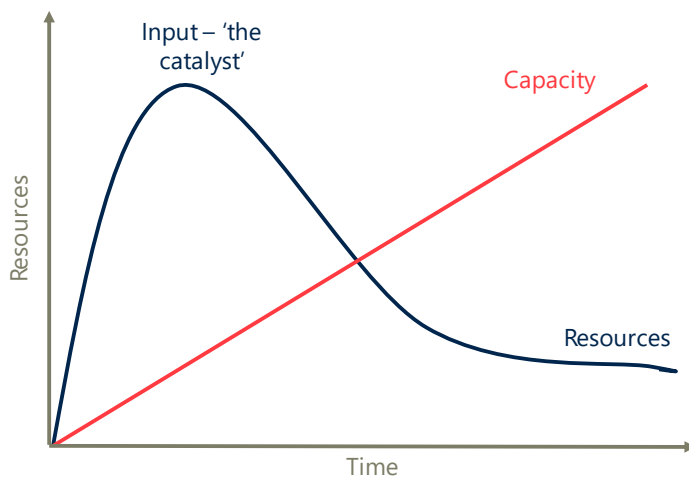
- Strategic Health Authorities and Clinical Commissioning Groups
- NHS Primary Care Trusts
- large national charities – including Macmillan Cancer Support and the Big Lottery 'Reaching Communities'
- council workforce development initiatives
- local partnership funds
- local charitable trusts
- university research funds
- self-funding from hospices
- independent community interest groups (operating from funds from sale of materials, workshop facilitation etc.).

In cases where funding is obtained from external sources, this is often directed to the employment of development or other community workers to play a lead role in establishment of compassionate communities, building networks and managing partnerships. In several cases where initiatives are centred around a hospice service, initial funding was provided, with hospices continuing support for the program once the initiative was established.

After an initial investment, compassionate communities may be able to become self-sustaining

One research study found that there is a need for an initial investment as the 'catalyst for change' and to accelerate achievements associated with a switch to a public health-based approach to palliative and end of life care (as shown in Figure 10). Over time, it is anticipated that initiatives become self-sustaining, as the community drives and implements initiatives and identifies and responds to changing needs and demand (eventually leading to embedding social change and reduced need for investment).⁹⁶

Figure 10 | Example of suggested investment pattern in community-based palliative care over time⁹⁷



⁹⁶The National Council for Palliative Care, "Dying Well Community Charter Pathfinder Project: Evaluation Report", The National Council for Palliative Care (2016).

⁹⁷Ibid.

5 Compassionate communities in Australia

This section briefly describes examples of initiatives which use compassionate communities and related approaches in Australia and outlines the status of these at a high level.

There are a variety of initiatives which use compassionate communities in Australia

Figure 7 in Section 3.2 and Appendix C provide range of examples of compassionate communities and related public health approaches to palliative and end of life care in Australia. These examples range from community members supporting their neighbours with day-to-day errands to campaigns to increase death literacy to embedding palliative and end of life care through local government policy. Many are managed by formal health care services, academic, peak bodies, not-for-profits or local government organisations, with a focus on empowering communities to lead their own initiatives through community development approaches. Others are generated through grassroots action by community members, with little involvement from formal health services.

Compassionate communities and related approaches are building momentum in Australia but can face challenges related to sustainability

From the literature, consultations and the case studies, the status of compassionate communities and related approaches in Australia can be summarised as follows:

- **Compassionate communities were pioneered in Australia in the mid-2000s.** The first examples emerged in Victoria, followed by New South Wales and Queensland. Australia is a world leader in the in this area and other countries drew on the early literature from Australia to grow their own compassionate communities.
- **There are several well-established compassionate communities in Australia and many more in the making.** There is considerable momentum building in the compassionate communities movement in Australia. In the past two to three years there has been a significant increase in the number of compassionate communities, largely as a result of initiatives led by La Trobe University, GroundSwell, Western Sydney University and some state and territory governments. These examples are in earlier stages of development and scale but early research indicates they have strong potential.
- **There are some successful models of community-based palliative care in Australia which have elements of compassionate communities and related approaches.** These models, led and driven by formal health care services, demonstrate the potential to embed compassionate communities and related approaches in existing health care services while concurrently encouraging the development of compassionate communities outside of services. Common characteristics include:
 - using a person-, family- and community-centred approach
 - maintaining strong engagement with GPs, palliative care units and other health care services
 - building community capacity (e.g. through training for community members).

Compassionate communities and related approaches in Australia are generally effective but some face challenges in being sustainable.

Case studies provided strong anecdotal evidence on the effectiveness of their initiatives, some of which was supported by independent evaluations and peer-reviewed research studies. This includes improved outcomes for people at end of life, improved bereavement outcomes for their families, increased community cohesion and in some cases, reduce health care costs through reduced hospital admissions (see Section 4.1 for a summary of evidence on benefits of compassionate communities). Despite these benefits, some case studies experienced difficulties in maintaining consistent levels of activity during changes in funding. This was particularly the case where they relied on paid positions i.e. part-time coordinators, project workers or individuals to provide more individualised supports, rather than being fully run by community members/volunteers.

6 Implementation of compassionate communities in Australia

This section outlines the principles for implementing compassionate communities (as per the principles-based implementation guide), the enablers and barriers for implementation, how sustainability should be considered, and lessons learned from the case studies.

Caution with the term 'implementation'

Several stakeholders have highlighted that the term 'implementation' is problematic because it implies compassionate communities are a service that can be delivered to a community. All stakeholders strongly agree that compassionate communities are not a service. Rather, they are an environment in which people are activated and care for each other. Organisations such as universities, local governments, service providers and community organisations can support the creation and growth of compassionate communities using community development approaches, which aim to activate communities and develop their capacity to care for each other.

This section uses the term implementation to refer to the efforts by a range of people and organisations to work with community members to create and grow their own compassionate communities, recognising that these initiatives aim to empower citizens to maintain their own compassionate communities.

This section includes findings from examples of compassionate communities as well as other related public health approaches that may sit outside the formal definition of compassionate communities but adopt a strong public health approach and display many of the positive attributes of compassionate communities.

6.1 Principles for implementing compassionate communities

There are five underpinning principles that can guide and direct implementation of compassionate communities in Australia

These principles are adapted from the Ottawa Charter⁹⁸ to apply specifically to the development of compassionate communities and community and public health approaches to supporting people at end of life. These are outlined in Figure 11 overleaf.

These principles are a part of an Implementation guide developed by Nous. The implementation guide also includes roles for different stakeholders, key steps for implementation, success measures and useful resources. It has been provided alongside this report.

⁹⁸ World Health Organization, see n 10.

Figure 11 | Principles for the implementation of compassionate communities in Australia

Integrate community provision of palliative and end of life care into public health practice and policy

- Formalise and share organisational commitment to community development (e.g. publish on website)
- Adopt a Compassionate City Charter to drive civic change at a population level
- Develop policies and processes to promote and support people at the end of life, their families and carers, such as compassionate workplaces
- Respect differences and diversity in the community as individuals' experiences, needs and preferences across the spectrum of death and dying can vary significantly

Draw on community strengths to create supportive environments and generate advocacy

- Identify and build on existing community strengths, activities and organisations
- Aim to foster supportive communities that care for each other, reduce stigma and promote respect
- Engage community champions (individuals and organisations) to provide credibility, increase profile and awareness
- Be flexible and embrace a variety of solutions – compassionate communities and public health approaches can only operate on the available capacity within each specific community

Strengthen community development and action

- Support the community to define their own compassionate community, what it stands for and what it does
- Support community-led and -driven activities and initiatives to align as closely as possible to community needs
- Emphasise the development of networks to increase social connectedness
- Provide training and support to citizens to mobilise compassionate communities and ensure that actions are sustainable

Develop individual knowledge and skills about end of life

- Facilitate and normalise conversations about dying and end of life, including advance care planning
- Increase knowledge of palliative care, available services and other supports and how to access them
- Invest time in building the knowledge and skills of community members and volunteers, especially in finding, training and retaining volunteers with suitable skills

Re-orient health services to work in partnership with community

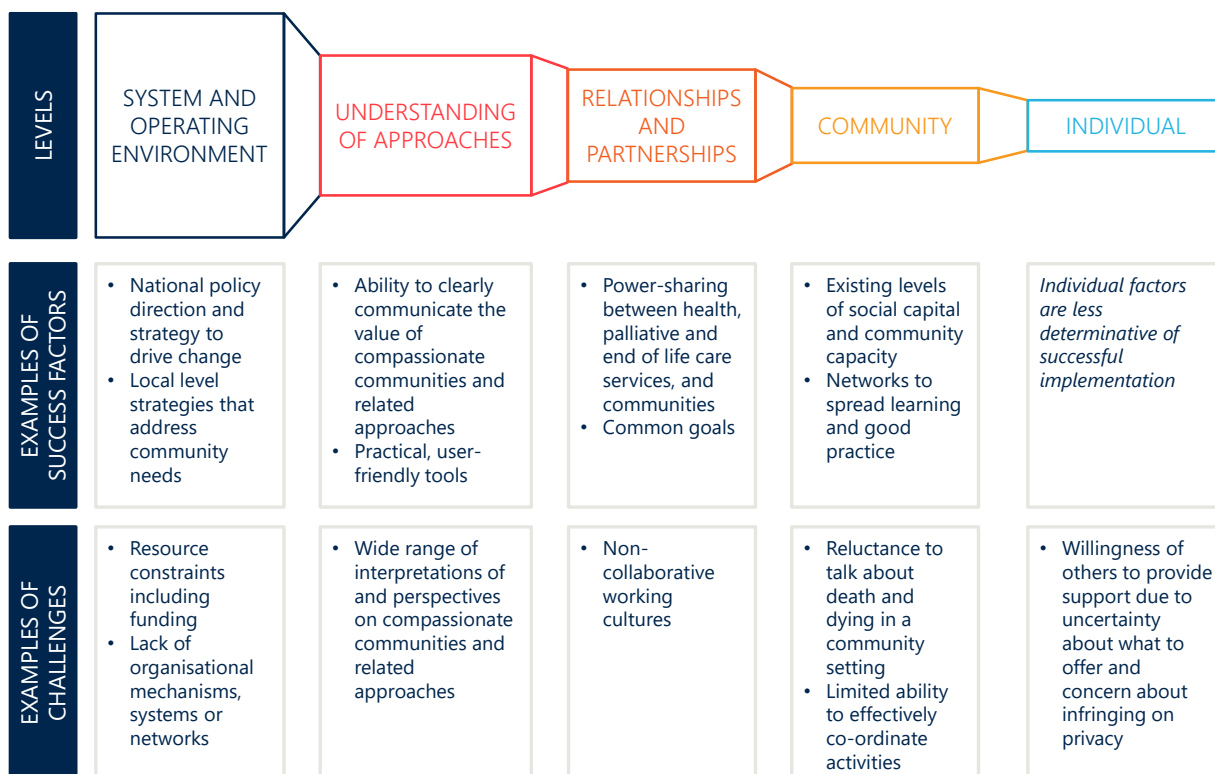
- Develop a system where individuals, families, carers, communities, social, health and aged care services can collaborate to deliver integrated support
- Focus on what matters to people at end of life and their families, including what is important to their quality of life and their preferred place of care
- Build a culture where the roles of all those involved in delivering palliative and end of life care – including health professionals and communities – are recognised, respected and supported
- Provide education and support for health services to broaden awareness of non-health services available to support end of life, and encourage power-sharing

6.2 Success factors and challenges to implementation

Case studies point to a number of success factors and challenges to implementation of compassionate communities

The success factors and challenges discussed below are based on the 12 case studies conducted for the study (see Appendix C for detailed case studies). The success factors and challenges to implementation of compassionate communities operate across a spectrum of levels – from an overall system and operating environment level, to understanding the approaches and interaction with service providers, through to the specific community and individuals in that community where implementation is taking place (Figure 12).

Figure 12 | Multiple levels across which success factors and challenges occur



A clear strategic and financial commitment to community development provides the enabling environment and licence for implementation.⁹⁹ Within this environment, it appears that a compassionate communities approach is more likely to be successful where there is presence of an organisational structure or network of some type to support activities (whether this is to drive activities or provide networks into the community).

A clear understanding of the model is also critical to set communities up for success.¹⁰⁰ One study cited the risk of the “high degree of conceptual ‘blurring’ to effective implementation and practice as a barrier to implementation.”¹⁰¹ Interestingly, a number of communities or clusters of communities either commenced activities after hearing a presentation on the approach, or launched their own efforts with a conference on the topic to set ambitions and share lessons learnt.

⁹⁹ Murray Hall Community Trust and National Council for Palliative Care Dying Matters Coalition, *An overview of Compassionate Communities in England* (2013); accessed at http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf.

¹⁰⁰ McLoughlin, K, "Compassionate Communities Project Evaluation Report" (2013).

¹⁰¹ Ibid.

The characteristics of the specific community in which implementation is taking place was identified as a critical factor, particularly the existence of a base level of social capital, empowerment and capacity¹⁰² (often aided by previous exposure to community engagement and development). The right relationships with and attitudes of service providers and other partners is also critical¹⁰³ and can require a mindset change, particularly in relation to concerns from formal health services regarding safety and quality of community-driven care.

At the individual level, stigma and lack of willingness to ask for help or lack of an easy way of asking for that help, can prevent individuals from getting the support they need.

With this framing in mind, the following sections summarise the success factors and challenges identified through the literature and the case studies.

Success factors include listening and aligning to community needs, building capacity of the communities and connecting with GPs, palliative care services and other health services

While success factors will vary depending on the nature of the approach (e.g. community-based health service versus community-initiated volunteer network), listening to the community and tailoring care and supports to their needs and preferences remains core. Common success factors identified in the case studies are outlined in Figure 13 below.

Figure 13 | Success factors for implementation from the case studies

1. **Listening to the community** to ensure that all activities and initiatives are aligned with community needs and priorities and are community-led and -driven where possible.
2. **Building the capacity of the local community** to deliver care where possible, under the following community development principles:¹⁰⁴
 - Promote death and grief as a natural part of life
 - Promote collaborative community culture
 - Support healthy end of life planning
 - Reduce fears and stigma
 - Build resilience in the face of grief and loss.
3. **Using a flexible and unbureaucratic model** to allow flexibility in the delivery of care, respect for the diversity of views on end of life and provide a supportive environment for volunteers.
4. **Using a person-, family- and community-centred approach** to ensure care is individualised but also caters for the needs of the broader cohort.
5. **Changing the culture within health care services** to embed compassionate communities, community engagement and public health approaches into business as usual.
6. **Using existing relationships and fostering new relationships** to ensure sustainability of compassionate communities, including through partnerships and building credibility with key communities (e.g. CALD communities).
7. **Engaging community champions** to provide credibility and increase profile and awareness.
8. **Generating buy-in and commitment from senior management and staff** in health and social service providers and civic institutions.
9. **Connecting with GPs, palliative care units in hospitals and other health services** to understand needs, share information, encourage referrals and identify where respective efforts are best directed.
10. **Collecting data, measuring outcomes and sharing learnings** to build an evidence base and make data-driven decisions.

¹⁰² Social capital is defined as those features of social organisation, such as trust norms and networks, can improve the efficiency of society by facilitating coordinated actions. In End of Life, this can adopt a micro position - i.e. focusing on specific networks and the benefits that accrue to the people within them. Horsfall, D, Noonan, K and Leonard, R, see n 34.

¹⁰³ Sallnow, L, Bunnin, A and Richardson, H, see n 8.

¹⁰⁴ Grindrod, A and Rumbold, B (2018), see n 12.

Challenges include low existing community cohesion, difficulty in shifting mindsets away from medicalised views of care, and funding constraints

Challenges to implementation in the literature and case studies often relate to community capital, existing cultures or practices in working and reliance on donations or other funding sources.

Common challenges and barriers identified in the case studies are presented in Figure 14.

Figure 14 | Challenges and barriers to implementation from the case studies

1. **Low existing community social capital:** Where there are a lack of existing networks, organisations and services to counter isolation and provide support at end of life, there will be a greater burden on projects to establish and embed these networks from scratch. This impacts timing of compassionate community development and potentially uptake and enthusiasm from the community, as the approach will be more foreign.
2. **Unfamiliarity with compassionate communities to palliative and end of life care:** Some community groups may be unable to immediately see the relevance of compassionate communities to their work. This may also be related to a reluctance to engage in conversations around death and dying.
3. **Difficulty in shifting mindsets away from medicalised views of care:** There may be tension between health system culture and requirements and family and community perceptions when attempting to shift from a medicalised view of end of life care to one where families and communities are a primary care giver.
4. **Health service concerns about safety and quality of care in the community:** Some case studies reported that local palliative care and health services were initially reluctant to accept or support their work. This could be for several reasons:
 - a. **Traditional orientation of health system:** Traditional health care systems focus on individualised and medicalised care, taking the focus away from community and relationship building activities.
 - b. **Limited time for staff to focus on health promotion:** Health services have a heavy clinical workload, leaving little time for health promotion and community engagement activities.
 - c. **Lack of understanding about model:** There can be a lack of understanding about how compassionate communities operate and misconceptions that community members will provide unsafe or inappropriate care or attempt to perform medical procedures.
5. **Funding and budget constraints:** Activities and initiatives which are resource-intensive can put a strain on funds. Community-led and -driven groups are often heavily reliant on donations and unpaid time of individual community members.
6. **Slow progress:** Preliminary phases of implementation (especially in capacity building, generating contacts and networks) can be slow. There may be some difficulties keeping people engaged and interested throughout lengthy processes.

It is important to note that a key strategic risk in implementing compassionate communities is the shift of responsibilities and costs from the formal care sector (for example, palliative care hospices) to the informal care sector (family caregivers). It is important to ensure that there are adequate resources and services in the community to respond to this shift.

Additionally, community development and capacity building work can be very resource intensive. Practical resources and tools should be made available to support the community.

6.3 Sustainability of compassionate communities

Compassionate communities aim to produce long-term positive outcomes

The sustainability considerations discussed below are based on the 12 case studies conducted for the study (see Appendix C for detailed case studies). Compassionate communities aim to complement the health care system through the provision of collaborative, community focused care, through partnerships between community members and health, aged and social care providers.¹⁰⁵ These approaches address the gap of

¹⁰⁵ Sallnow, L, Bunnin, A and Richardson, H, see n 8.

community empowerment and provide an alternative source of appropriate, sustainable social care, in turn releasing some of the strain on formal palliative and end of life care services.¹⁰⁶

Compassionate communities need to be, in themselves, designed with an objective of long-term sustainability and minimal reliance on external funding sources

In order to achieve long-term positive outcomes, compassionate communities to palliative and end of life care need to be, in themselves, designed with an objective of long-term sustainability and minimal reliance on external funding sources. Although many commentators consider compassionate communities a potentially 'sustainable model' working through existing structures, commentators recognise a need for financial, human and support resources to develop and coordinate communities, particularly in the early stages. The type of model adopted will also impact the ability for the compassionate community to be sustainable long-term.

This does not mean that the lowest cost model will always be the most appropriate – as emphasised throughout this report, the fundamental principle for development and implementation of compassionate communities is to be responsive to community needs. Communities will be starting from different bases, particularly in relation to social capital, and effective programs need to be cognisant of this.

The case studies highlighted several important considerations regarding sustainability (Figure 15).

Figure 15 | Considerations for ensuring sustainability from the case studies

1. **Effective approaches generate cultural change and embed a new mindset into business as usual.** All case studies highlighted the importance of producing cultural change and embedding compassionate communities **into the business as usual work of health services, civic organisations and local government**. Using a strategic relationship-building approach to develop long-term partnerships was cited as a key determinant of sustainability.
2. **Models which minimise administrative burdens and build on existing relationships and structures work well.** Administrative or bureaucratic barriers can reduce flexibility in the delivery of care (especially in consideration of the diversity of views on end of life) and place strain on community members. The most sustainable approaches in the case studies were those which leveraged community strengths, whether these were existing strengths or new strengths identified through the project. This reduced reliance on the project for ongoing operation.
3. **Educational resources can produce long-lasting benefits but must be tailored to different communities.** Some case studies highlighted the long-term benefits of developing educational resources which can increase awareness and knowledge of compassionate communities, but also increase death literacy which is then organically shared in the community. One example of this is in the Calvary Health Schools Project which produced a DVD and other learning materials. Another example is PCV's work with culturally and linguistically diverse (CALD) organisations to develop information resources for local communities. Case studies emphasise the importance of tailoring content to the local communities in consultation with them, and not relying on a 'one size fits all' approach.
4. **Community members sustain many organisations and should be valued, trained and retained.** The two established compassionate communities examined, Margaret River Angels and It Takes a Village, are reliant on large and stable community networks. Both case studies attributed their sustainability (in attracting and retaining communities) to remaining flexible and keeping formal structures to a minimum. The Calvary Health Schools Project also placed a large emphasis on seeking volunteers who were appropriately skilled and provided adequate support and mentoring throughout the project.
5. **Approaches which are resource-intensive or highly reliant on funding may struggle to remain sustainable.** Projects which rely on funding to recruit and retain project coordinators or managers can face issues where there are changes in funding or when funding is ceased. Two examples in the case studies are:
 - **Calvary Health Schools Project:** This project was highly resource-intensive and unable to be sustained after two years; continuation of the project past 2015 required ongoing provision of funding. During the project, the allocated funding was not sufficient to cover the costs of project management and resource production, so additional funds were sought.
 - **Strengthening Palliative Care in Victoria through Health Promotion:** While the educational benefits of the project were sustainable, one palliative consortium withdrew from the final year of the project due to a reduction in funding. There were major implications in the other two regions, and while some costs were absorbed by a consortium and partner

¹⁰⁶ Ibid; Abel, J, "Compassionate communities in end of life care", *Clinical Medicine* 18.1 (2018): 6-8.

organisations, the project concluded when funding ceased in 2011.

6. **Structures and systems need to be in place for projects to continue beyond the tenure of a strong inaugural leader.** Case studies which were community-initiated and -led tended to be established by and reliant on passionate individuals. Where institutional knowledge is contained by only a few, there is the risk that successful initiatives and activities are unable to continue when those individuals are no longer available. This risk was being minimised in a few ways: establishing local support groups who generate, hold and support ideas so that they are not reliant on an external organisation and become self-sustaining; developing management processes that perpetuate the core activities of the project; embedding EOL policies and practices into local government and civic organisations.
7. **Compassionate communities may be most feasible when seeking to respond to needs in defined clusters of the population.** Case studies from regional and rural communities displayed stronger informal relationships and volunteer networks, which are strong drivers of sustainability. This was particularly the case in the two established compassionate communities, Margaret River Angels and It Takes a Village. In case studies where the population size is larger, e.g. Compassionate Frome, specific supports and allocation of Health and Community Connector roles is geographically clustered around populations of approximately 20,000-30,000 residents.

6.4 Lessons learned from the case studies

Case studies point to a number of learnings for implementation and emphasise community leadership and responsiveness to community needs

The case studies provided several key lessons which should be considered in implementing compassionate communities and related approaches in palliative and end of life care (Figure 16). Almost all case studies emphasised the importance of listening and being responsive to community needs.

Figure 16 | Lessons learned from the case studies

1. **Understand that community development takes time**, especially when communicating the importance of compassionate communities and related approaches and ensuring buy-in from services and the community.
2. **Respect differences and diversity in the community** as individuals' experiences, needs and preferences across the spectrum of death and dying can vary significantly.
3. **Aim for community-led and -driven activities and initiatives where possible** to reduce reliance on funding, increase flexibility and align as closely to community needs as possible.
4. **Invest time and effort in measuring and sharing learnings** so that successes can be replicated, mistakes can be avoided, and evidence-based decisions can be made.
5. **Focus on relationship-building activities** as these are more sustainable and less reliant on funding than other passive activities. Use existing networks and leverage off the reach of formal institutions like local governments.
6. **Invest time in building the capacity of community members**, especially in finding, training and retaining community members with suitable skills, and ensuring they feel a part of the strategic direction.
7. **Be flexible and embrace a variety of solutions** as compassionate communities and palliative health approaches can only operate on the available capacity within each specific community and must reflect the vision and resources of the community.
8. **Not all compassionate communities require government funding**; small community groups require very little government funding to be effective and sustainable.
9. **Grant or seed funding over several years** can build processes and resources that continue to deliver benefits beyond the grant period.

7 Conclusion

This feasibility study has found that compassionate communities are feasible in Australia and can, when combined with broader public health approaches, deliver a range of benefits to people at end of life, their families and carers, communities and health systems. Compassionate communities are a core part of a public health approach to palliative care and are achieved through grassroots community activity and community development approaches.

This study found that there are multiple views across the sector as to the level of engagement required between communities and health services for optimal implementation of compassionate communities and public health approaches to palliative care. Some stakeholders hold the view that government or health services involvement is not essential to the success of compassionate communities, while others see partnership between governments, health services and community organisations as a key enabler for their success and sustainability. This study adopted a broad view of compassionate communities, seeing benefit in not limiting the usefulness of compassionate communities to one specific model. It is clear, however, that the approaches used may be supported by community organisations, governments, civic institutions, researchers or service providers but must ultimately be owned and driven by the community.

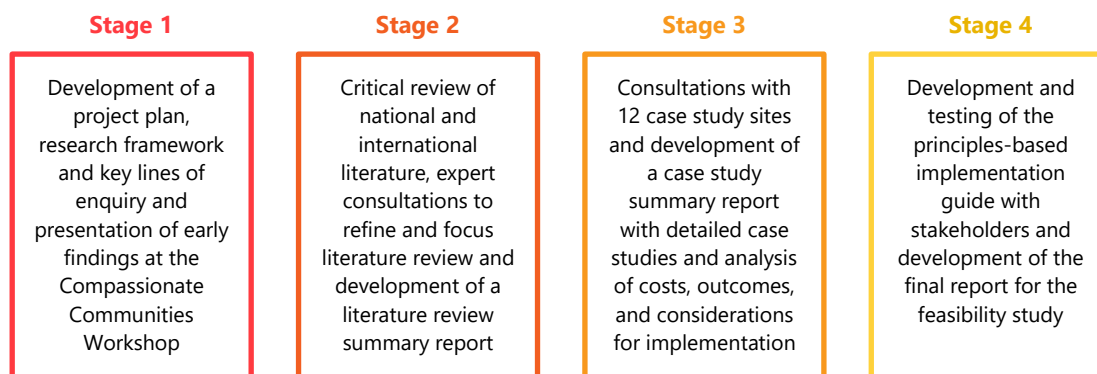
The achievement of ongoing, sustainable outcomes at the individual, community and health system levels remains a significant challenge. An increase in the number of people dying at home and consequent reductions in the use of institutional beds will require a broad set of reforms across community and governments, including health services and systems, to deeply embed public health approaches to palliative care, end of life care and bereavement in health care and civic institutions. A growth in the development of compassionate communities across Australia will be an important step in such a transformation.

This report and the accompanying Implementation Guide provide a useful resource tailored to the Australian context for individuals, communities, health services, other organisations and civic institutions, policy makers and system stakeholders.

Appendix A Methodology

This appendix describes the methodology used in this feasibility study. Nous conducted the project over four phases which are summarised Figure 17 below.

Figure 17 | Stages of the feasibility study



Stage 1: Plan and design

The objective of Stage 1 was to confirm the feasibility study scope and processes, and to set the study up for success. This stage involved a number of key steps:

- project launch meeting
- development of a project plan, including project charter, full details of personnel, detailed description of activities, delivery schedule and methodology, communication and consultation plan, and risk management plan
- confirmation of research framework
- development of key lines of enquiry
- development and dissemination of broad communication to interested parties.

Stage 2: Understand the evidence

The objective of Stage 2 was to examine the evidence about whether compassionate communities make a difference and add value to palliative and end of life care. This stage involved a number of key steps:

- critical review of national and international literature, including peer-reviewed literature, grey literature (including conference presentations on international models and the emerging benefits/outcomes realised)
- consultations with Australian and international experts to refine and focus the literature review, including representatives from academic and research institutions, and peak bodies
- development of a literature review summary report.

The stakeholders that Nous interviewed in Stage 2 are listed in Table 5 overleaf.

Table 5 | Stakeholders consulted in Stage 2 of the feasibility study*

Name	Title, organisation
Academia	
Professor Allan Kellehear	Academic Director, Digital Health Enterprise Zone (DHEZ-Academic), 50th Anniversary Professor (End-of-Life Care), University of Bradford
Dr Julian Abel	Vice President, Public Health Palliative Care International; Director, Compassionate Communities UK
Dr Bruce Rumbold	Director, Palliative Care Unit and Senior Lecturer, La Trobe University
Andrea Grindrod	Public Health Practitioner and Researcher, Palliative Care Unit and Senior Lecturer, La Trobe University
Peak bodies	
Dr Meera Agar	President, Australian and New Zealand Society of Palliative Medicine; Member, Australasian Chapter of Palliative Medicine Committee, Royal Australasian College of Physicians
Liz Callaghan	CEO, Palliative Care Australia
Dr Jane Fischer	President, Palliative Care Australia
Vicki Barry	Business Development Officer, Palliative Care Western Australia; Member, Compassionate Communities Network
Odette Wanders	CEO, Palliative Care Western Victoria
Colleen Johnstone	General Manager, Palliative Care Tasmania
State and territory governments	
Theresa Williamson	Acting Assistant Director, Person Directed Care and Worker Wellbeing, Department of Health and Human Services Victoria
Flora Dean	Policy, Planning and Projects Consultant, Community Planning and Strategy, Department of Health and Human Services Tasmania
Community organisations	
Kerrie Noonan	Director, The GroundSwell Project
Heather Engelhardt	Policy Development Officer, Aged & Community Services Australia
Kate Lawrence-Haynes	General Manager Policy and Advocacy, Leading Aged Services Australia

**Note that this list does not include people interviewed for the development of the case studies*

Stage 3: Assess feasibility

The objective of Stage 3 was to assess applications of compassionate communities in Australia and the UK to understand considerations for implementation, benefits and costs. This stage involved a number of key steps:

- consultations with 12 case study sites (including consultations on implementation) to gather evidence in relation to implementation lessons, costs and benefits
- presentation on the feasibility study progress and early insights at the PCA Compassionate Communities Workshop
- development of detailed case studies

- development of case study summary report, including analysis of costs, outcomes, considerations for implementation and lessons learned.

The list of case studies involved in the study is provided in Appendix C.

Stage 4: Finalise implementation guide and reports

Stage 4 drew together the emerging findings, developed the principle-based implementation guide and finalised all project reports. This stage involved a number of key steps:

- development and testing of feasibility study findings and principles-based implementation guide with the Department and key stakeholders
- development of the draft and final report.

A draft of the implementation guide was sent to the list of stakeholders below for feedback:

- Palliative Care Australia
- State and territory palliative care organisations
- State and territory governments
- La Trobe University
- Western Sydney University
- The GroundSwell Project
- Professor Allan Kellehear, Academic Director, Digital Health Enterprise Zone (DHEZ-Academic), 50th Anniversary Professor (End-of-Life Care), University of Bradford
- Dr Julian Abel, Vice President, Public Health Palliative Care International; Director, Compassionate Communities UK

Nous incorporated stakeholder feedback to develop the final implementation guide, provided alongside this report. Stakeholder feedback also informed the development of this final report.

Appendix B Summary of the Literature Review

Nous reviewed existing literature on compassionate communities as a key input into the project. The literature review was not intended to be a systematic review, but to identify information and evidence on the characteristics of compassionate communities. Nous' research approach drew on principles of Rapid Evidence Assessment (REA).¹⁰⁷

The literature review focused on the following key lines of enquiry:

1. What are the potential benefits of compassionate communities in Australia?
2. How effective and efficient are compassionate communities' activities at delivering outcomes?
3. How can compassionate communities be successfully implemented in an Australian context?

A brief summary of the key findings from the literature is provided below (Figure 18). These findings have informed the development of this report.

Figure 18 | Key findings from the literature review

- There are several emerging challenges for palliative and end of life care in Australia. These include population-related burdens, growing expenditures on health, unmet social care end of life needs, and the professionalisation and medicalisation of death and the dying process.
- The role of compassionate communities is in community empowerment and development, encouraging people outside of the formal health and social care system to be involved in holistic palliative and end of life care.
- Compassionate communities display a few fundamental elements. They typically: are based on community development, where health, aged and social care service have a complementary role; are initiated by communities in response to a community identified need; shift away from a professional, medicalised or clinical rhetoric; incorporate public health and health promotion principles; and use networks, carers and support to build on existing social connections.
- The literature indicates compassionate communities can deliver a broad range of benefits to people at the end of life, their families and carers and health and aged care systems; robust evidence is patchy. Cited benefits include: reduced burden on informal caregivers, improved quality of life, reduction of the care burden on health and social care professionals, increased sense of community inclusion and cohesion, and generation of financial savings through reduced hospital admissions and emergency presentations.
- Intended outcomes of compassionate communities typically relate to improving the experiences of people at end of life and their families and carers and facilitating community development and capacity building. Cited outcomes include: breakdown in the stigma of palliative and end of life care and hospice care, an open culture of talking about death and dying, growth of social capital in the community, reduced compassion fatigue and secondary trauma stress for staff.
- Compassionate communities are an internationally recognised concept, with examples of models existing across Australia, the UK, Canada and Asia. There are some established and many new examples of compassionate communities in Australia.
- Enablers for successful implementation exist at all levels, from individuals to the system – with a clear understanding of the compassionate community model and a base level of community capacity particularly important.
- Common barriers to implementation include confusion regarding the model and ineffectual relationships between service providers and community.
- It is difficult to determine costs associated with compassionate communities as they are often long-term, difficult to quantify and unique to each model; there are some common high-level cost categories.
- Initially, investment needs to be long term and more intense but there is some evidence that it can provide savings through decreased demand on specialist palliative care services.

¹⁰⁷ An REA provides a balanced assessment of what is known (and not known) in the literature about an intervention, problem or practical issues by using a systematic methodology to search for empirical studies; however, to be 'rapid', an REA makes concessions in relation to the breadth, depth and comprehensiveness of the search.

Appendix C Case studies

As part of the feasibility study, Nous conducted 12 case studies of compassionate communities and other related examples of public health approaches to palliative care from Australia and overseas. The purpose of these case studies was to understand best practice and key learnings for the implementation of compassionate communities in Australia. These case studies involved both a document review and consultations with key people involved in each initiative.

Case studies were identified through the literature review and/or stakeholder consultations. Nous presented an initial list of proposed case study sites to a PCA Compassionate Communities workshop, and added to the list based on participant's feedback.

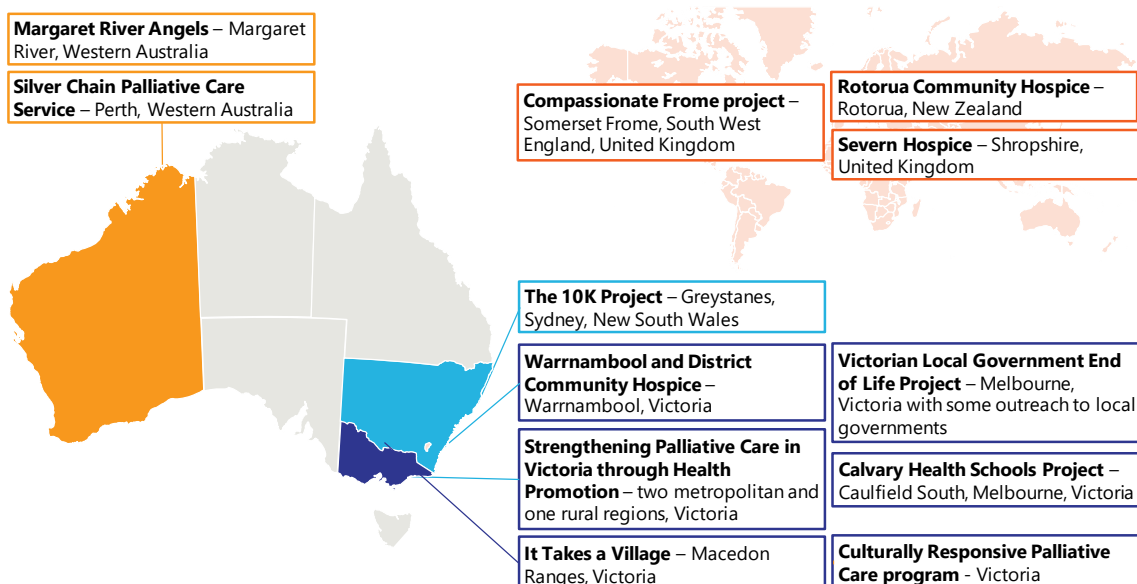
The 12 case studies conducted for the feasibility study are presented in Figure 19. They represent a range of locations and different types of initiatives, including (and not mutually exclusive):

- three initiatives led by a palliative care service, hospice and/or hospital
- five initiatives led by community organisations in partnership with health services
- four initiatives led by community organisations with little to no formal relationship with health services
- six initiatives delivered in regional towns and rural areas
- one initiative focused on culturally and linguistically diverse communities
- three international initiatives from the United Kingdom and New Zealand.

Some case studies involve community and at-home care delivered by palliative care services. While these may not strictly meet the definitions of compassionate communities outlined in Table 2 of this report, they were selected because they were frequently cited in literature and consultations and displayed many of the positive elements of compassionate communities.

The detailed case studies are provided in the pages that follow.

Figure 19 | Case studies selected for this feasibility study



Calvary Health Schools Project

Location Caulfield South, Victoria

Year commenced 2013 – 2015

Lead organisation La Trobe University (Palliative Care Unit), Palliative Care Victoria, Calvary Health Care Bethlehem, Sacred Heart Girls' College Oakleigh



Overview

The Schools Project was an experiential immersion program in palliative care for school students based at Calvary Health Care Bethlehem (CHCB). CHCB is an aged care facility specialising in palliative care. Under the Schools Project students conducted regular visits to the facility to interact with the residents and learn about death and dying. The Schools Project ran for two years from 2013 to 2015 through an agreement between PCV and CHCB. It was funded by the Victorian Department of Health and Human Services as a part of their strategy to ensure that Victorians are better able to support people with life-threatening illness.

The Schools Project had two objectives:

4. Encourage conversations about death and dying with students and community groups
5. Encourage students to develop a deeper understanding of death and palliative care.

Description of initiatives

The Schools Project provided a voluntary experiential immersion program in palliative care at CHCB for Year 10 students of Sacred Heart Girls College Oakleigh. CHCB worked with the students, school principal, deputy school principal, arts teacher and teachers. The students interviewed a range of staff at CHCB and spent time with patients. They used these visits to develop visual and narrative material from which a DVD resource was created. This DVD was used as a part of classroom death education sessions delivered by trained volunteers. A project coordinator was hired to liaise between CHCB and the school. Project activities are summarised below.

Key activity: Delivery of immersion and classroom sessions for Year 10 students on death and dying



“Bethlehem has a strong history of combining creative and spiritual care with public health approaches. We encourage sharing experiences of illness through creative mediums.”

Benefits and outcomes

Evaluation of the project was formally undertaken by La Trobe University. The project generated several outcomes including:

- **Deeper understanding of death and dying:** The majority of participants developed a new or deeper understanding of death and palliative care. Almost half of the participants described a decreased fear of death.
- **Increased confidence to talk about death:** Nearly half of participants reported increased feelings of confidence in talking about death, dying, palliative care, grief and loss. Some participants were able to speak for the first time about end-of-life issues with family and friends (sharing knowledge), while others could have these conversations more easily.
- **Deeper connections with others:** Participants described a greater empathy for others and an increased willingness to reach out to others and listen to their concerns. They reported that their own personal growth had led them to develop new relationships and strengthen existing relationships.
- **Increased support in grief:** Some students found their involvement in the project assisted them with their grief – four students were grieving recent losses and one student lost their grandmother during the project.
- **Personal growth and learning:** Students and volunteers reported feeling more confident in expressing themselves, feeling more open-minded, shifts in thinking and self-perception about life, purpose, empathy and compassion, self-acceptance, confidence, new perceptions and internal strength. Over a third of participants expressed a new appreciation for life, for example recognising the significance of “simple things” and gratitude.

Success factors

Factors that were critical to the successful design, implementation and delivery of this project included:

- **Using established relationships:** The Schools Project built on existing community assets and networks. The project was implemented in an identifiable and defined community, which made it easier to recruit and retain volunteers.
- **Listening to the community:** It was important to recognise the community as the expert, and therefore best positioned to determine what will or won't work in the community. In order to ensure sustainability, the project focused on keeping the community engaged.
- **Embedding community approaching into business-as-usual:** The project ensured there was staff willingness to engage in the activities in the long-term.

A parent of a student who was a part of an immersion session commented: “A work colleague of mine was terribly upset because her mother’s doctor had suggested palliative care which she understood to mean that her mother was close to death. I was able to explain to her that palliative care was not just about imminent death – one year on her mother is still alive and mostly pain free. She told me that it was great comfort to have my help – which really came from my daughter.”

Barriers

This project experienced several barriers:

- **Accommodating a highly structured school environment:** Schools are highly structured communities, making it difficult for them to partner with external organisations due to the time constraints on their curricula.
- **Limited time for staff to focus on health promotion:** Health services have a heavy clinical workload, leaving little time for health promotional activities. CHCB had limited ability to build community capacity themselves. While palliative care and community development is in CHCB's strategy, financial reporting mechanisms focus only on patient-related activities, creating a misalignment.
- **Funding constraints:** The budget did not cover the costs of implementing the project. Activities such as event management, resource development, transport for students, catering, publicity resources and venue hire all required external funding.
- **Unfamiliarity with death and dying:** Some parents expressed concerns about their children exploring issues of death and dying. Strong leadership and reassurance from Sacred Heart Girls College Oakleigh was required to overcome this.

Cost inputs and savings

The total resources expended (actual hours) by the project coordinator was 10 hours a week for two years (a total of 1060 hours). The actual funding provided was for seven hours a week.

Key costs included: training and supervising of volunteers, delivery of classroom sessions, and developing the DVD and facilitator's guide (which required additional funding outside the original project budget). The funding allocated to the project did not cover the costs of project management and resource production.

Sustainability

While the Schools Project achieved great outcomes, the project was highly resource-intensive and unable to be sustained after two years. Continuation of the project past 2015 required ongoing provision of funding, as program delivery was dependent upon the funded project coordination role. Additional funds were sought during the project to supplement the original budget and the project coordinator volunteered their time for part of 2015 to support uptake and implementation of the project in schools, however ultimately the project concluded that year.

The DVD continues to be used in schools to educate students on death and dying. While other schools showed interest in replicating the Schools Project, the significant time and resource commitment required from schools and health care facilities has meant it has not been taken up.

Lessons learned

There were several lessons learned, including:

- **In a formal partnership there must be a positive relationship at the senior management level:** A positive relationship between project managers and school management is vital to successful partnering with schools, including a firm appreciation of working to school schedules, responding promptly to opportunities and understanding their daily functions and demands.
- **Community development takes time:** It is important to factor time for communicating the importance of health promotion and community capacity building into the start of a project to ensure community and service buy-in. Community partnerships take time and required a dedicated role.
- **It is important to invest time in volunteers:** It is important to invest time in finding volunteers with suitable skills and recruit volunteers specifically to task. Retention of volunteers can be maintained through providing a sense of direction through planned objectives and strategies and inclusion in the design of the project.

Culturally Responsive Palliative Care

Location	Victoria, Australia
Year commenced	2013
Lead organisation	Palliative Care Victoria, Ethnic Communications Council of Victoria and the Multicultural Centre for Women's Health



Overview

In 2013, Palliative Care Victoria (PCV), Ethnic Communities' Council of Victoria (ECCV) and the Multicultural Centre for Women's Health (MCWH) launched the first Culturally Responsive Palliative Care Strategy 2013-2015, which continues today. This was in response to low awareness and uptake of palliative care services among many culturally and linguistically diverse (CALD) communities.

The Culturally Responsive Palliative Care project aims to raise awareness about palliative care and palliative care services among culturally and linguistically diverse (CALD) communities, and to improve their access to culturally inclusive and responsive palliative care services. This is achieved through community partnerships, a range of community education activities and training for palliative care services. The strategy is underpinned by health promotion and community development theories and all activities are developed with and tailored to the specific needs of different CALD communities.

Description of initiatives

The Culturally Responsive Palliative Care program was developed and is implemented through a partnership between Palliative Care Victoria (PCV) and the Ethnic Communities' Council of Victoria (ECCV), the Multicultural Centre for Women's Health (MCWH) (in the first year of the project) and other CALD community organisations. There are two core categories of initiatives:

Community education and capacity building	Service provider training
<p>Key initiatives</p> <ul style="list-style-type: none"> • Establishment of community reference groups • Training of bilingual peer educators • Community education sessions • Information resources in print, audio and video format • Other community engagement <p>Target audience: Range of CALD community members, organisations and peak bodies across Victoria, including Chinese, Vietnamese, Italian, Maltese, Turkish, Polish, Arabic speaking background, Greek Croatian and Macedonian communities</p>	<p>Key initiatives</p> <ul style="list-style-type: none"> • Training programs • Cultural responsiveness audits • Cultural responsiveness workshops • Information resources • Other training initiatives <p>Target audience: Palliative care services, including management, quality and clinical and other frontline staff</p>

All initiatives are tailored, recognising that there is huge diversity between and within CALD communities as well as among the service providers that support people at end of life. For example, when translating resources or delivering training, community reference groups and bilingual educators are an invaluable resource to ensure that the language and terminology used is appropriate for the audience, whether they are migrants who arrived recently or older migrants who came to Australia after the second World War.

“People said you need to understand there is as much diversity within our communities as there is between them.”

Benefits and outcomes

Between 2013 and 2015, the Culturally Responsive Palliative Care Strategy delivered:

- **150** education sessions for **4,846** CALD participants
- **27** cultural responsiveness training sessions for **420** staff from palliative care services
- **33** trained bilingual educators and **10** community reference groups.

A two-year independent evaluation¹⁰⁸ of the Strategy found the community education sessions increased participant’s awareness of palliative care and willingness to tell their friends and families about palliative care. Of those who responded to the evaluation survey, 29 per cent said they knew about palliative care before the session and 90 per cent said they had learned new things and would tell their friends and family about palliative care following the session.

The evaluation also found the Strategy had increased the cultural responsiveness of palliative care services. Ninety per cent of service providers that responded to the evaluation survey said they would be able to transfer what they had learned to their work.

Anecdotally, CALD communities have reported increased referrals to palliative care services, increased death literacy and improved communication and relationships between CALD communities and service providers.

Success factors

The Culturally Responsive Palliative Care program is based on health promotion and community development principles. Several factors have been critical to the program’s success:

- **Listening and understanding what’s important to each community** – PCV and its project partners meet each community face to face through a series of meetings, forums and conversations to understand their interests and preferences as well as common issues for people in the community. The project adopts a strengths-based approach, focusing on what is important to community members and community strengths that can be leveraged to raise awareness of palliative care services.
- **Tailoring initiatives to individual CALD communities** – CALD communities often report that translated health brochures are hard to read and therefore ignored by community members. PCV develops and tests all education sessions and information resources with each community it works with to ensure the information is clear, easy to understand and culturally appropriate.
- **Credibility with CALD communities** – without credibility, it is difficult to access community networks and gain the support required from communities to develop and deliver tailored education and supports. This requires trust, strong relationships and the ability to demonstrate that your services are focused on the specific needs of individual communities, not a tick box exercise.
- **Building and maintaining strong partnerships** – it is particularly important in early stages to put effort into understanding how the partnership can best work for the community, and then check in regularly to ask, “is the partnership working for you and can it be improved?”
- **Engaging community champions and high-profile individuals** – these people can play a major role in raising the profile of the program, building credibility and securing access to a greater number of people in the community. For example, PCV has engaged the Melbourne Turkish Consulate General to attend and support key events, which had a large impact on people’s views on palliative care.

¹⁰⁸ Palliative Care Victoria, Culturally Responsive Palliative Care Strategy 2013 – 2015: Final Evaluation Summary, Melbourne (2016).

Barriers and challenges

CALD people at end of life often report that they were not referred to or provided information on palliative care services when they were first diagnosed with a terminal illness. This remains a key barrier to increasing uptake of palliative care services among CALD populations.

Other barriers include low levels of awareness about death, dying and palliative care among many CALD communities and reluctance from families to seek help from the community to care for their loved ones at end of life. This stops people from asking for help and accessing the services that they require.

For palliative care services, a constant challenge is convincing their management teams that CALD engagement is core business and requires ongoing funding, not one-off project support.

Cost inputs and savings

The Culturally Responsive Palliative Care program is funded as part of PCV's core business. PCV supports a project manager who spends one to two days on average per week throughout the year, including busy periods of four to five days per week. This position is responsible for program management and establishing and maintaining partnerships with CALD community organisations and others. The project also provides funding for bilingual health workers to conduct community information sessions as well as funding for communities to run information sessions and other events.

PCV receives core funding from the Victorian Department of Health and Human Services. The Culturally Responsive Palliative Care program has also received funding from philanthropic organisations, including the Perpetual Trust Company, the Lord Mayor's Charitable Foundation, and Gandel Philanthropy.

CALD peak bodies and community organisations enable engagement and access to communities, help recruit volunteers from the community and provide a range of in kind supports.

Sustainability

Critical to sustainability has been the focus on long term partnerships with CALD community organisations. The Culturally Responsive Palliative Care Strategy was developed in partnership by PCV, ECCV and the Multicultural Centre for Women's Health through a long process of consultation with various communities. This partnership approach continues to define all activities under the program.

Also critical to sustainability is treating CALD engagement as core business. PCV provides funding for the Culturally Responsive Palliative Care program out of their core funding and recognises the importance of long-term funding support to sustain outcomes.

Lessons learned

The evaluation of the Culturally Responsive Palliative Care strategy identified a number of learnings. Most are applicable to supporting culturally appropriate care across other health and non-health services.

Learnings identified in the Culturally Responsive Palliative Care Strategy evaluation¹⁰⁹

- **Participatory and engagement strategies** are necessary to improve awareness of palliative care among CALD communities.
- **Fostering a conversation/discussion about palliative care** is crucial and print resources alone will not achieve this objective.
- The **participation of CALD communities in tailoring education and information** to meet specific cultural, spiritual and linguistic needs is essential to ensure the resources meet the communities' needs.
- The **participation of palliative care services** in project activities is valued and strengthens relationships, trust and understanding.
- **Long-term commitment and relationship development** are the necessary building blocks to ensure **community engagement and ownership**.
- Specific focus on the **ongoing evaluation of the strength and health of the partnership** by the partners is important when new partnerships are being developed and work is being done across sectors.

¹⁰⁹ Ibid.

It Takes a Village – Macedon Ranges

Location	Macedon Ranges, Victoria
Year commenced	2015
Lead organisation	It Takes a Village – Macedon Ranges



Overview

It Takes a Village began when three mothers in the rural Victorian community of the Macedon Ranges were diagnosed with terminal illnesses over a similar period. One of the mothers, Shevaun Noonan, had a large social network and received a huge amount of support from the community in the three years before she died. People cooked her family regular meals, drove her to doctor's appointments, minded her children, educated local school children about end of life issues and provided a range of other supports. Those without time to volunteer left money in the letterbox for her and her family.

After Shevaun's death, her closest friends reflected on the experiences of the other two mothers who had died without the same level of support. They established It Takes a Village in June 2015 so that other people at end of life could receive the same care and support as Shevaun did. It Takes a Village is entirely run by volunteers. It provides education and resources to people in the community so that they can help people at end of life to die well. Today, when people hear someone has a terminal illness the Macedon Ranges community swings into action to care for them and their family.

Description of initiatives

It Takes a Village is a community-run charity led by a group of volunteers in the rural Victorian shire of the Macedon Ranges. The charity adopts a community development approach to their work, aiming to build awareness and capabilities in the community to care for people at end of life. Friends and volunteers from the community speak to the person at end of life and their family to find out what support they want and need. They then set up online rosters for volunteers and provide a variety of support, ranging from cleaning the house and caring for pets to pastoral care, respite for families and help navigating the health system. ITAV is not a service provider but rather an educator and supporter of people who choose to offer help to each other at end of life.




It Takes a Village runs events, information sessions and training on end of life issues and care to a range of people and organisations in the community. They also provide training and resources to other volunteers from the community so they have the capabilities and knowledge to provide safe, appropriate and respectful care to people and their families. After three years, It Takes a Village has built a strong compassionate community in the Macedon Ranges, to the point where the community is able to act on their own to support people at end of life, with little or no assistance from the charity.

Today, It Takes a Village responds to requests and supports projects where they identify a need. For example, they are currently working with Shannon's Bridge, another compassionate community initiative in rural Victoria to help them develop a training manual for their volunteers. The charity is also working with a local suicide prevention group to help develop and train community volunteers that can respond at times of crisis. The team also regularly speak at conferences and other events to share their experiences and learnings.

"Now if other people are sick, our community swings into action."

Benefits and outcomes

The team at It Takes a Village say they have achieved multiple outcomes for people at end of life, their families and the community more broadly. These are summarised below:

 Benefits for the person at end of life	 Benefits for families and carers	 Benefits for the community
<ul style="list-style-type: none">• Improved quality of life• Able to be cared for and die in place of choice• Less stress and anxiety, which has been attributed to less pain• Fewer hospital admissions (their friend had two admissions in her last three years of life, which was very few for her type of cancer)	<ul style="list-style-type: none">• Lower burden of care• Less stress and anxiety• Better experiences for children of people at end of life (because they and their peers and teachers at school have been taught about death and dying)• Better long-term bereavement outcomes for families and carers	<ul style="list-style-type: none">• Increased community cohesiveness• Improved death literacy of individuals and organisations (e.g. schools, sports clubs, other local charities)• More willing and comfortable to talk about death and dying• Increased level of volunteering• Reduced burden on palliative care services and acute (hospital) services

The charity's co-founders emphasise that there is a strong link between individual and family outcomes. People at end of life often feel less anxious because they are receiving comprehensive support from the community and they know their families are receiving support too. There is evidence that heightened levels of anxiety can increase pain, and that calm patients can experience less pain. For families, knowing that their loved one was well supported and died well can improve bereavement outcomes over the long time. This improves their wellbeing and resilience and may mean they are less likely to seek psychological treatment or miss days of work or school.

"She (Sheuvan) lived well when she was dying. What kept her well was knowing that the people around her were well."

Success factors

The It Takes a Village team attribute their success to a **community development approach**. Rather than coordinate community responses when someone needs end of life care, the It Takes a Village team focuses on building the capacity of the local community to deliver this care themselves. This means the outcomes they achieved for Sheuvan have been able to be replicated for other people at end of life across the community.

Another key success factor has been the **close-knit rural community**. Macedon Ranges had a strong pre-existing social networks and many retirees with the time and capacity to volunteer. This means they have a large number of volunteers who are able and willing to support people at end of life, regardless of whether they know the person at end of life or not.

Barriers and challenges

In the early stages, It Takes a Village faced resistance from some palliative care and other health services. There was a misconception that the charity was attempting to provide medical services and a lack of understanding about how community initiatives can contribute to end of life care. After more than three years, the charity is still working towards a better understanding of how community-led care can complement and reduce the burden for formal health services.

Funding has also been a challenge. While It Takes a Village has very few operational costs, it relies on funding for training, education resources, community events, road trips and other activities. The charity has

struggled to find and secure funding beyond community donations because it is difficult to convince funders of the important role they play in supporting palliative care and improved end of life outcomes.

Cost inputs and savings

It Takes a Village operates on a small budget. A core group of five to ten volunteers run the charity and a much larger group of volunteers are trained in the community to provide care when there is a need. It Takes a Village receive most of their funding through donations from individuals and organisations in the community. This supports volunteer training, community development and other activities.

One of the charity's founders runs a funeral business and the charity receives administrative support, office space and other in-kind support from this business.

Sustainability

A community development approach has been critical to the ongoing sustainability of It Takes a Village. After three years of volunteer training, awareness raising and other community development activities, the Macedon Ranges is a largely self-sustaining compassionate community. Today, when someone is diagnosed with a terminal illness, there are many in the community who have the skills and knowledge to coordinate a community response, often with no assistance from the It Takes a Village team.

Wary of administrative and legal burdens involved in establishing a volunteer organisation, the team at It Takes a Village have deliberately kept the formal structures of their organisation to a minimum. This means the initiative runs with very little administrative work and costs.

Lessons learned

The co-founders of It Takes a Village identify several learnings from their work to establish and sustain a compassionate community in the Macedon ranges:

- **Respect difference and diversity in the community** – People's experiences, needs and preferences across the spectrum of death and dying are very different. It Takes a Village teaches community volunteers to never presume anything and always ask people at end of life what type of care they want and how they want to be cared for.
- **Ensure volunteers are trained to provide safe and appropriate care** – In line with a community development approach, the charity provides training to volunteers, families and community organisations on death, dying and how to provide care for people at end of life that is appropriate and safe, both for the person at end of life and for the volunteer. For example, the charity teaches people to understand their own self-care requirements, so they can maintain their social and emotional wellbeing while supporting others.
- **Build awareness of governments, community leaders, health services and others** – To secure support, it is important that key people and institutions in the community understand the value of compassionate communities' approaches and the tangible outcomes that are achieved for people at end of life, their families and the community more broadly.
- **Remain community-led and run** – While government support is important, It Takes a Village are determined to remain a purely community-run initiative. They are concerned that if government takes on responsibility for administering compassionate communities, they will become burdened in bureaucracy, dependent on government funding (and more vulnerable to changes in funding priorities) and unable to achieve the same outcomes as a purely community led and driven approach.
- **Understand the law** – While It Takes a Village does not provide any legal services, they recognise it is important for community organisations to understand what they can and cannot do, as well as relevant legislation for end of life care, such as Advance Care Directives.

Margaret River Angels Cancer Support Group

Location	Margaret River, Western Australia
Year commenced	2012 – present
Lead organisation	Volunteer-led by Lynda Donovan



Overview

Margaret River Angels is a volunteer-led local cancer group which is funded entirely through private and community donations, corporate sponsorship and fundraising. Margaret River Angels began in mid-2012 through Lynda Donovan and four other volunteers responding to a few local families who needed help. The group uses a grassroots approach to community development. The Margaret River community has a population of approximately 14,000.

Description of initiatives

Margaret River Angels volunteers provide families living with cancer at end of life with general support, including monthly food drops, dropping off and picking up children from school, gardening, cooking and cleaning. They also coordinate with local corporates to provide home renovations or other larger jobs as requested and have a loan service available for an electric bed and sofa.

Margaret River Angels currently has a register of 150 volunteers and primarily communicates with the community through a Facebook page. There are 285 individuals on a regular mailing list and nearly 300 businesses on a business mailing list.

Families can find out about Margaret River Angel's services through several channels, including word-of-mouth, referral by general practitioner, and brochures and pamphlets in hospitals, doctors' surgeries and shops.

Benefits and outcomes

Margaret River Angels, as a grassroots community group, has not conducted a formal evaluation of outcomes. However, the group has received informal feedback on their effectiveness in the community:

- **Families experience reduced pressure and workload:** Family members of people who are at end of life rely on the community to alleviate the additional workload that arises from illness.
- **Volunteers develop connections with others:** Volunteers reach out to others and listen to their concern, develop new relationships and strengthen existing relationships.
- **Families are encouraged to have a role at the end of life:** MRA provides logistical support around the person at end of life without being invasive.
- **Families are supported through grief:** Families can rely on the community to support them during a time of immense emotional upheaval.

"Families always mention Margaret River Angels at funerals. They really appreciate that we were there and that we gave them the help they needed."

Success factors

Factors that were critical to the successful design, implementation and delivery of this project included:

- **Listening to the community:** It is important to recognise the community as the expert who are best positioned to know what will or won't work in the community
- **Using established relationships:** Using established relationships, for example to recruit volunteers and seek out families who need support has allowed MRA to build on existing community assets and generosity. MRA also relied on corporate partnerships and sponsorships to drive fundraising and goodwill.
- **Using a flexible and unbureaucratic model:** This ensures volunteers do not feel overburdened. This also allows MRA to respect the diversity of views on end of life, including being aware of the wide spectrum of views on death.

Barriers and challenges

Margaret River Angels has experienced very few barriers. As a volunteer-run community group they rely heavily on volunteer time, donations, and community and business contributions. Given that they have no paid staff, they have limited time and capacity to apply for grants and other forms of funding. This means they mostly rely on small donations from individuals and businesses.

Cost inputs and savings

As a volunteer-run community group there are no major resourcing or administrative costs. Money raised from individuals and businesses generally goes directly to supporting people at end of life and their families.

Sustainability

Margaret River Angels have been operating for over five years, demonstrating that their network of volunteers and approach is relatively sustainable. The group is currently coordinated by one person, who is responsible for volunteer coordination, family communication and liaising with corporates and community fundraisers. While this means there is a lot of institutional knowledge held by one person, Margaret River Angels is currently in the process of formalising and documenting its operational and administrative processes so that this information can be shared more readily.

Lessons learned

There were several lessons learned, including:

- **Grassroots models work best in small communities:** Community members are more likely to participate and volunteer when there are fewer degrees of separation between individuals.
- **Volunteers should not feel overburdened:** It is important to ensure volunteers do not feel undervalued or and are able to change their commitments as required.
- **Not all compassionate communities require government funding:** Small community groups require very little government funding to be effective and sustainable. Margaret River Angels feels that grassroots community groups may risk losing flexibility if they must formalise their structures to meet funding requirements. There is however, a role for local government to support networking within the community.

Silver Chain's in-home palliative care services

Location Perth, Western Australia

Year commenced 1982

Lead organisation Silver Chain Group



Overview

Silver Chain Group's Hospice Care Service in Western Australia is a community-based, in-home palliative care service that has been operating for more than 35 years. It is the largest community palliative care service in Australia and supports around 600 patients in Perth. Through a nurse-led model, the service combines medical care with social and spiritual care for people at end of life, all of which is delivered in the home. The service is family-centred and families and communities are supported to be the primary care giver of people at end of life. Silver Chain adopts a public health approach to palliative care and reflects many elements of the compassionate communities approach. A recent study has attributed Silver Chain's Hospice Care Service to reduced hospital costs per patient, likely due to fewer admissions and shorter lengths of stay in hospital.¹¹⁰The service aims to:

- provide people at end of life, their caregivers and families with holistic and person-centred care
- improve comfort through effective symptom assessment and control
- enable people at end of life to spend time with the people closest to them
- minimise physical and emotional stress for people at end of life, their families and loved ones
- advocate on patients to ensure their rights are respected and appropriate care is accessible
- respect patient's right to make decisions to the greatest possible extent and assist them to make plans for the time when they may not be able to make decisions for themselves i.e. Advanced Care Planning; Enduring Powers of Attorney and Guardianship
- build community capacity to support people at end of life and their families.

Description of initiatives

Silver Chain is a not-for-profit organisation that delivers community health and aged care services throughout Australia. Silver Chain's Hospice Care Service in Western Australia provides specialist palliative care and in-home hospice care services across metropolitan Perth. It provides more than 90 per cent of referred community palliative care services in Perth. The service receives referrals from medical professionals and hospitals to support people with life limiting conditions to be cared for in the comfort of their own home. As a part of the broader palliative care network of services in Perth, Silver Chain works closely with hospital palliative care teams and in-patient palliative care units.

Silver Chain's Hospice Care Service is nurse led and delivered in people's homes. Patients range from older people to children and neonates. Services are tailored to patient's unique needs and include a mix of medical, nursing, psychosocial and spiritual care. Silver Chain also provides bereavement support to families and carers. Silver Chain Group's Hospice Care Service provides three core service offerings:¹¹¹

¹¹⁰ Spilsbury, K and Rosenwaxm L, "Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life," *BMC Palliative Care*, 16: 68 (2017).

¹¹¹ Silver Chain Group, *Submission on the consultation paper on the pricing framework for the Australian Public Hospital Services 2016-17*, 27 July 2015, accessed at www.ihpa.gov.au/sites/g/files/net636/f/Documents/silver_chain_group_-_consultation_paper_2016-17.pdf.

Metropolitan Community Palliative Care Service	Palliative Nurse Consultancy Service	Palliative Rural Telephone Advisory Service
In home specialist palliative care to clients with 24 hour nursing and medical care available in the home. Includes respite and bereavement support for families and carers	A palliative nurse consultancy service to public/private hospitals and residential facilities where client care is managed by a registered nurse 24 hours each day. The service provides advice, assessment, procedures, staff education and telephone follow-up to meet the care needs of a specific client.	Specialist advice and knowledge provided over the phone 24/7 to rural service providers regarding managing the palliative care needs of a specified client.

Benefits and outcomes

Silver Chain Group has a strong focus on measuring the outcomes of its service, mainly through activity and clinical data and involvement in research studies. A key outcome has been a reduction in palliative care related hospital admissions. A 2017 study found that patients enrolled in the community-based specialist palliative care service incurred 27 per cent less cohort-averaged hospital costs and a nine per cent reduction in inpatient-average hospital costs compared to periods of time not enrolled in this care in the last year of life. The study concluded that this was likely due to reduced hospital admissions and reduced lengths of hospital stays for people accessing Silver Chain's specialist palliative care services.¹¹²

A linked outcome is increased rates of dying at home. In 2014, approximately 2,000 Silver Chain clients receiving palliative care services died, with 65.9 percent dying at home. Of these approximately 2,000 clients, 865 clients had a recorded choice of place of death as being home with 81.2 per cent supported to achieve that choice.¹¹³

Silver Chain Group does not measure community outcomes however anecdotal feedback indicates the service is trusted with a strong reputation in the community.

"At community level, if you are at end of life, people understand that this means it is time for Silver Chain to come and care. We have a long experience of caring for people in Perth."

Success factors

A number of factors have been critical to the success of Silver Chain's palliative care service.

- **Family and community-centred approach.** Silver Chain's service delivery model adopts a community and family-centred, rather than a person-centred approach. This approach supports families (including close friends) and communities to be the primary care giver to people at end of life. The service aims to build the capacity of families and communities to provide the support needed by people at end of life.
- **Strong engagement with GPs, palliative care units in hospitals and other health services.** Silver Chain is well connected with the network of health services that support people at end of life in Perth. The group works closely with GPs, hospital palliative care teams, in-patient palliative care units and other health and aged care services. This means the service has high referral rates and care is seamlessly integrated with hospitals and other facilities when patients need medical care outside of the home.
- **Team of clinical, social and spiritual care practitioners.** Silver Chain is able to provide comprehensive care to patients and their families by employing a range of skilled and experienced practitioners,

¹¹² Spilsbury and Rosenwax, see n 110.

¹¹³ Smith, J. *Operational Research Series: Client choice of place of death* (2015). Perth, Australia: Silver Chain Group.

including doctors, nurses, social workers, volunteers, chaplains and care aids. These practitioners work as a team to care for the medical, social and spiritual needs of patients and their families.

- **Use of data to drive service design and delivery.** From the beginning Silver Chain has had a strong focus on collecting data to measure outcomes and continually improve its services. On a daily basis data is used to drive clinical decision making. Silver Chain provides data to the Western Australian Data Linkage System, supporting broader research on palliative care and community-based services.

Barriers and challenges

A key challenge has been shifting the mindset of health systems and communities from a medicalised view of end of life care to one where families and communities are the primary care giver. Silver Chain works closely with health professionals, families and communities to raise awareness about the role of families and communities in end of life care and build their capacity to provide this care.

“We are strongly supportive of a paradigm shift to community and families being the primary care giver of people at end of life. We believe this is essential to the sustainability of the health system.”

Another challenge is maintaining funding in a fiscally constrained environment. Silver Chain has successfully secured funding from the Western Australian Government for its community-based palliative care services for over three decades. As health costs rise it is important Silver Chain is able to demonstrate the value and cost-effectiveness of its model of community-based palliative care to maintain this funding.

Cost inputs and savings

Silver Chain Group’s Hospice Care Service is a non-for-profit service primarily funded through block funding from the Western Australian Government. The service receives referrals from GPs, specialists and other health professionals and is currently at capacity. Silver Chain is also supported by a network of volunteers.

Silver Chain’s specialist community palliative care services have been associated with a reduction in hospital costs through reduced hospital admissions and reduced lengths of stay in hospital (see page 48 above).¹¹⁴

Sustainability

While primarily dependent on government funding, Silver Chain has maintained a high quality and sustainable community-based palliative care service since 1982. It attributes its sustainability to its focus on understanding costs and benefits and ensuring it remains fiscally responsible.

Also important to sustainability is Silver Chain’s close linkages with primary and acute health services, which ensures regular referrals of patients and enables the integration of its community-based palliative care services with other parts of the health system.

Lessons learned

In addition to the success factors listed above, a learning from Silver Chain is that community-based providers can often achieve better outcomes than hospital outreach. While many palliative care units have practitioners that provide outreach services in the community, Silver Chain Group has observed that when a patient’s condition deteriorates, these practitioners are more likely to refer them back to hospital than to find ways to continue to support them at home.

¹¹⁴ Spilsbury and Rosenwax, see n 110.

Strengthening Palliative Care in Victoria through Health Promotion

Location	Hume, North and West, and Southern regions, Victoria
Year commenced	2007 – 2010
Lead organisation	La Trobe University (Palliative Care Unit), Palliative Care Victoria, three regional palliative care consortia



Overview

The Strengthening Palliative Care in Victoria through Health Promotion project ('Strengthening Palliative Care') established a Health Promoting Palliative Care (HPPC) program in three palliative care consortia. These consortia were located in two metropolitan areas and one rural area in Victoria. The project operated from July 2007 to July 2010 when funding by the Cancer and Palliative Care Unit of the Victorian Department of Human Services ceased.

Strengthening Palliative Care aimed to achieve three general objectives:

1. Strengthen the capacity of Victorian palliative care service planners, staff and volunteers to adopt a health promoting palliative care philosophy by providing education and training in health promotion approaches
2. Embed health promoting approaches to palliative care into Victorian palliative care services' strategic and operational planning, organisational policy and practice
3. Increase public awareness of, and participation in, palliative care provision by promoting partnerships between palliative care service and other primary care agencies, community service organisations and groups.

"There was a hugely positive reception in the community to the project. We didn't have to look far to see there were people in the community who wanted to talk about end of life care or participate in some way. A lot of the initiatives that were taken we never would have dreamed of ourselves, but they emerged from the community."

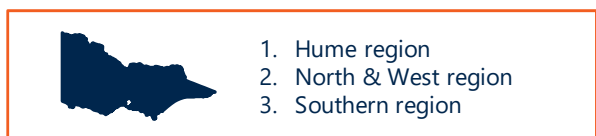
Description of initiatives

Strengthening Palliative Care combined a public health approach to palliative care with community development approaches. The project was based largely on a similar project in the Hume region, 'Building Rural Community Capacity Through Volunteering'.

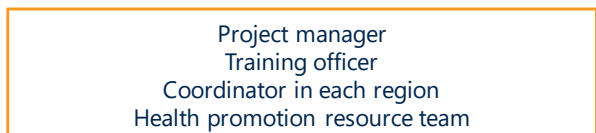
The project recruited a part-time project manager to coordinate the overall project, supported by a part-time training officer to provide all training. There were also part-time coordinators in each region with established credibility in both the palliative care service and the community, and with a developed health promoting palliative care perspective. A health promotion resource team promoted the project through regional community networks.

The key activities of Strengthening Palliative Care are described below.

THREE REGIONAL PALLIATIVE CARE CONSORTIA



DEDICATED PART-TIME STAFF



KEY ACTIVITIES

- Development of a local project assessment process for seed-funding
- Development of training and education program
- Development of easily comprehensible and shareable resources on community development approaches
- Building relationships within and across each region
- Sharing learnings

Benefits and outcomes

La Trobe University undertook a formal evaluation of Strengthening Palliative Care.¹¹⁵ The evaluation and interviews with key project stakeholders indicated the following benefits:

- **Increased understanding of palliative care services:** Community participants gained an understanding of palliative care services, how to use them properly, and how to participate. This generated an enhanced awareness of the needs and supports available.
- **Greater community capacity building:** The vast majority of participants developed a greater willingness and comfort in exploring issues of death and dying. Communities increased their active support of friends, family, neighbours, work colleagues and social acquaintances who are living with a terminal illness and their families.
- **Deepened understanding of HPPC:** The project developed an agreed working definition of HPPC in layman's terms for the purposes of organising activities and educating the communities. Staff in palliative care services felt their own understanding and use of HPPC was either reinforced or extended, and some services operationalised health promotion formally or incorporated HPPC into strategic planning.
- **Increased community-driven and -led activities:** Seed-funding allowed services, including palliative care services, to fund community-based activities, and community groups to initiate their own activities.
- **Greater partnership building:** There were a considerable number of formal and informal partnerships developed across palliative care services, health services, community-based agencies and community groups. This included local governments, integrated cancer services, Aboriginal Community Controlled Health Organisations, migrant support services, private aged care facilities, community health services, schools and community groups.

Success factors

Factors that were critical to the successful design, implementation and delivery of this project included:

- **Partnership and connections:** These should be actively built by a dedicated resource/s. Relationships should be built on trust.
- **Sharing learnings and collaboration:** This includes effective communication of concepts underpinning public health and community approaches. There is an important role for visible and knowledgeable champions.
- **Central and regional coordination of community members:** Coordination should be flexible, to allow community to organically lead activity and maintain sensitivity to the local context, including responding to changing attitudes.

¹¹⁵ Gardner, F, Rumbold, B and Salau, S, *Strengthening Palliative Care in Victoria through Health Promotion: Final Report*, La Trobe University Palliative Care Unit, Melbourne, Australia (2009).

- **Providing seed funding:** This encourages community and service activity, including smaller activities such as morning teas, youth groups and movie

Barriers and challenges

This project experienced several barriers:

- **Unfamiliarity with HPPC approaches:** Due to limited familiarity with HPPC approaches, some community groups were unable to immediately see the relevance of HPPC to their work. Community groups sometimes were not comfortable to share their learnings with others, partially due to fear of distressing staff or others.
- **Initial progress was slow:** The preliminary phase of implementation, including generating contacts and networks, was slow. There were some difficulties in keeping people engaged and interested through at-times lengthy processes, resulting in variation in activity depending on the time of year.
- **Variation in success across different regions:** There were significant differences in coordinating the metropolitan regions compared to the rural region. Activities and initiatives within a region tended to reflect the interests of the region coordinator, and there were no region-wide projects in the two metropolitan areas. This also meant there was some uncertainty about how to assess which contacts were most useful for developing partnerships.

Cost inputs and savings

The total cost for the final year of the project (July 2010-June 2011) was \$50,000. The key cost of the project was the recruitment of dedicated resources: 0.2 FTE project manager; 0.2 FTE training officer; 0.5 FTE coordinator in each region; and a health promotion resource team.

A total of \$7,868 was distributed to 20 projects across the three regions in Round 2 of the seed grants.

Sustainability

Sustainability was a key factor in the design of the project and in its conclusion. The educational benefits of the project are considered sustainable. For example, community members, volunteers and service staff continue to use newly-gained knowledge and resources. Some services operationalised health promotion formally or incorporated HPPC into strategic planning, creating ongoing benefits.

Across the duration of the project there was a change in emphasis from initiating activities to coordinating a balance between initiating new contacts and supporting previous contacts to extend their own activities.

The Victorian Department of Health funded the period of July 2010-June 2011 at a reduced level. This resulted in Southern Metropolitan Consortium's withdrawal from the final year of the project. The reduced funding also had major implications for the other two regions; coordinators hours in each region were reduced, and staffing, training and evaluation costs were partially absorbed by consortiums and La Trobe University Palliative Care Unit.

Strengthening Palliative Care concluded when funding ceased in 2011.

Lessons learned

There were several lessons learned, including:

- **Community work takes time;** the initial stages of implementation require frequent and explicit communication to maintain interest.
- **Stakeholders need to understand how HPPC approaches translate in practice:** Effective presentation of information is key to communicating complex ideas about health promotion, community capacity building and challenging perspectives about death and dying.
- **Seed-funding is an effective tool to encourage community activities:** It allows existing members of institutions, bodies and organisations to engage with the community.

The 10K project: Developing community well-being approaches for aged care facilities

Location	Greystanes, New South Wales
Year commenced	2018
Lead organisation	The GroundSwell Project, Southern Cross Care NSW & ACT, Western Sydney University



Overview

The 10K Project aims to reconceptualise aged care services and communities by forming networks of care and increasing social relationships and connections. The project is funded by Southern Cross Care NSW & ACT and is being delivered in partnership with the GroundSwell Project and Western Sydney University. It was established in early 2018 and will operate for three years, with the aim of building community networks and capacity so that benefits from the project can be sustained after the project finishes. The project supports residents in two aged care facilities run by Southern Cross Care and focuses on developing community resources and networks within a 10-kilometre diameter of these facilities. With support from a community development worker, the project supports a range of social and community engagement activities for residents.

The 10K Project has four key goals:

1. Use social network mapping to illustrate existing networks of community interaction for the SCC sites and any changes arising from their interventions
2. Identify the most useful strategies to embed a community development model which can be utilised by other facilities
3. Identify obstacles to the community development model and how they might be overcome
4. Identify and communicate examples of best practice in community engagement/ development in aged care.

Description of initiatives

The 10K Project model centres on establishing a presence in a residential aged care facility for approximately a year, to generate culture change and build capacity of staff and residents. The project employs a part-time community development worker based in the facility. The community development worker is responsible for developing community resources and networks, educating staff, residents, families and community members and coordinating community engagement initiatives.

The 10K Project started with a needs assessment in the facility and used a three-pronged approach:

1. **WHAT IS CURRENTLY WORKING?** *Continue this.*
2. **WHAT IS CURRENTLY NOT WORKING?** *Change this.*
3. **WHAT ARE THE NEEDS WE SHOULD RESPOND TO?** *Develop new responses.*

The project is designed to develop and maintain social networks for older people, including networks within the facility (i.e. with other residents), personal networks from before they entered care (e.g. local bridge club) and community networks within a 10km diameter of the facility. A key activity is building relationships between the facility and local community bodies, including pre-schools, primary and high schools, community centres, churches and faith-based organisations, neighbourhood centres, TAFE, universities, arts centres, business owners and businesses, garden centres, Land Care and voluntary organisations.

The 10K Project is part of a qualitative study which will take place over three years, across two Southern Cross aged care sites. Interviews focus groups and social network mapping will be used to measure and evaluate progress. It is anticipated that lessons from the first site will be shared with future sites and projects.

Benefits and outcomes

This project commenced at the start of 2018, therefore, no formal evaluation has taken place. Anecdotally the project personnel believe the project has generated several outcomes to date including:

- **Growth of social capital:** The project is developing an active, connected and engaged aged care environment. This includes improved relationships amongst residents and between residents and staff and increase in stories shared.
- **Increased wellbeing:** There has been an improvement in the wellbeing of residents, including greater appreciation of self and identity.
- **Development of a workable community development model:** The project is in preliminary stages of development of a community development model which may be replicated at other Southern Cross Care facilities. The project is already fostering good leadership in aged care, with informal sharing of learnings with other facilities.

The formal evaluation of the project will use social network mapping to measure outcomes (using the Duke Support Scale and interviews with residents).

Success factors

Factors that have been critical to the successful design, implementation and delivery of this project to date include:

- **Generating buy-in and commitment from senior management and staff:** There is a strong commitment, through governance and funding, from the aged care facility and partner organisations.
- **Focusing on changing the culture:** The focus of the project is on changing behaviours rather than introducing new activities. In embedding compassionate communities into business as usual, it is hoped staff and community will be able to continue producing positive outcomes following the formal conclusion of the 10K Project.
- **Focusing on fostering relationships rather than delivering passive activities:** Activities which encourage relationships between residents and the community can create longer-lasting changes. For example, the 10K Project invites school children to sing *with* residents together in a choir, rather than setting up performances of school children *to* residents.
- **Listening to the community:** The community development worker consults regularly with residents of the facility to test ideas and check in.

“We often talk about ageism in Australia but do little to address it. We think it is a part of the role of compassionate communities and the 10K Project to address ageism – not through doing a community campaign to reframe community perception of ageing but by actually working with older people.”

Barriers

This project has experienced a number of barriers to date:

- **Rigidity of the current service system:** Traditional health care systems focus on individualised and medicalised care, taking the focus away from community and relationship building activities.
- **Limited existing engagement with the aged care facility:** Anecdotally, very few members of the community are engaged with the Greystanes facility or aware of its existence. The project is focused on building key relationships so that opportunities for community participation can be communicated.

Cost inputs and savings

The only substantial cost of the project is the 0.5 FTE community development worker. There are associated research and evaluation costs related to Western Sydney University and The GroundSwell Project's involvement, the outputs of which will be used to develop training modules and resources.

Sustainability

Given the focus on changing the culture of the facility, most activities within the project concentrate on building relationships, which require limited funding injection. For example, bringing a school choir into the facility to sing with residents, inviting family members to Bingo night and setting up a 'residents representative' group.

Lessons learned

A number of lessons have been learned to date, including:

- **In a formal partnership there needs to be buy-in from senior management and staff:** This ensures that relationships and culture change are long-lasting. Community development approaches should focus on building the capacity of staff and embedding compassionate communities into business as usual.
- **It is important to measure and share learnings:** Successes and mistakes should be documented and shared between organisations and communities through both formal and informal mechanisms. A strong evaluation framework means outcomes from the project can be measured, better understood and more easily shared with others. This ensures compassionate community approaches can easily be adopted elsewhere.
- **Relationship-building activities are not heavily reliant on funding:** Relationship-building activities are relatively inexpensive as they are largely dependent on donation of community time.
- **Compassionate communities should focus on 'network – focussed care':** The focus should be on reframing services so that there is a focus on network – focussed care, not just person-centred care. This ensures that the needs of residents as a group are considered in addition to their individual needs.
- **Community development takes time:** It is important to factor time for communicating the importance of health promotion and community capacity building into the start of a project to ensure community and service buy-in.

Victorian Councils: Supporting Communities Around End of Life Project

Location	Victoria, Australia
Year commenced	2017 (for a three-year project)
Lead organisation	A partnership project between La Trobe university Palliative Care Unit (LTUPCU) and the Municipal Association Victoria (MAV)



Overview

The Victorian Councils: Supporting Communities Around End of Life Project aims to explore how local government can be involved in building the capacity of communities to view dying as a natural 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. La Trobe University Palliative Care Unit (LTUPCU) has partnered with the Municipal Association of Victoria (MAV) to design, implement and evaluate the project in Victoria.

LTUPCU identified local government as a sector to build community capacity on matters concerning dying, death and bereavement in community settings. The project is based on a Compassionate Communities approach that emphasises the importance of keeping people, who are ageing or living with life-limiting illness, connected with family, friends and neighbours. Using their expertise in community development, councils are being encouraged to work with their older residents through a range of initiatives, which will see end of life policy, planning and practice implemented within their local communities and an ongoing commitment to work around end of life beyond the funded project.

Description of initiatives

A community development approach will generate local responses to end of life matters 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. Three demonstration projects have been established in metropolitan to regional locations to explore different local approaches. La Trobe University and the MAV have designed a range of sector specific resources to assist councils in this work which are publicly available on the MAV website. One challenge for the project has been to develop resources with language appropriate to the local government and community settings where this work will take place. The implementation strategy for the project is summarised below

The project aims to:

- build the organisational capacity of councils around end-of-life
- build community capacity in end-of-life support through local government structures and networks,
- improve community understanding of healthier approaches to death, dying and bereavement, and
- evaluate the effectiveness of this approach.

Through the community development work of local government and involvement in preventive health activities, this initiative seeks to increase community knowledge, skills and involvement around the social dimensions of dying, death, loss and bereavement.

The project supports local government staff, particularly those working with older residents to understand and be capable of working with their communities around end of life issues. The project is encouraging councils to consider the inclusion of end of life in their health and wellbeing policies or ageing strategies. Building the capacity of council staff is being achieved through on-line training videos developed specifically for the project, along with a range of other targeted resources.

The project is utilising the leadership and capacity building skills of MAV and La Trobe University to build systemic change in end of life care at a community level. It is also leveraging council legislated responsibility for health and wellbeing which acknowledges the social determinants of health: where you live, work, and socialise determines your health and impacts on your death.

“This is a structured, place-based approach to end-of-life: a systemic change within a state-wide sector.”

Benefits and outcomes

La Trobe University is evaluating the project, and will identify enablers and barriers that enhance local government contributions to end of life care.

A significant and unique aspect of this project is the public health approach to end of life care. The project is building on the community development expertise of local government to keep people who are ageing or living with a life-limiting illness to remain connected and supported, not just by family and friends, but also by neighbours and the community.

The project is in its early stages with aims to achieve the following benefits:

- Increased organisational capacity in local government on end of life issues for the community
- Enhanced capacity within communities in relation to issues of death, dying, loss and bereavement
- Promotion of environments in the community that support healthy end of life approaches
- Promotion of dying, death and grief as a natural part of life
- Increased support for residents to receive care and die in their place of choice
- Improved supports for groups whose needs are often marginalised in service planning and provision.¹¹⁶

An recent evaluation of the project involved a survey of 79 councils involved in the project, with a 71 percent response rate. The evaluation found that:

- **Council commitment and intent to incorporate the end of life into council policies and practice is evident**, and data indicates a growing interest in end of life. In 2015, desktop research of council websites found no mention references to dying, death or bereavement in local government publicly available policies. In the data collection period of mid-2017, six months into the funded project, fourteen (n=14) councils (25 percent of respondents) reported a reference to end of life in council policies or strategies.
- **Just under half of the responding councils (n=25) reported at least one activity relating to the end of life.** Altogether 40 activities relating to dying, death or bereavement were reported. The majority (65 percent) of these related to council inviting speakers to deliver information sessions on legal and planning matters. A focus for the project is to engage community development approaches in councils to build community capacity and capability. It is expected that, as the project progresses we will see a shift in the types of community activities participating councils plan with their communities. These shifts will be measured in the later data collection phases of the project.
- **The capacity building and partnership approach for this project is proving effective.** The number of councils developing policy and initiating activities in ageing policies and programs demonstrates the benefits of the time spent in building collaboration between the partners. The results indicate that these strategies are effective both in strengthening the impact the project has on the sector and in producing early outcomes.

¹¹⁶ La Trobe University and MAV, *Victorian Local Government End of Life Project: Project Proposal 2016-2019* (2016).

Success factors

- **Careful planning.** Considerable effort has been directed toward ensuring communication and messaging is relevant and appropriate to the local government sector.
- **Time.** Allowing time for the project to develop its own momentum. Funding three demonstration projects to trial different approaches with different communities will provide valuable information to the project. Sharing the learnings with local government will be an important aspect of project development both while the project is underway and beyond.
- **Broad goodwill.** Governance of the project is shared between MAV, La Trobe University and the Department of Health and Human Services. Key stakeholders include councils, PCV, Health Issues Centre, Council on the Aging, Primary Health Networks (PHNs). All are supporting the project.
- **Identifying and fostering champions.** Starting the project in positive ageing has provided momentum to develop council leadership as well as project champions which will prevent the project being overseen by competing demands.

Barriers and challenges

Key barriers identified in the case study are summarised below:

- Adapting public health resources for councils. Most resources developed to address end of life issues are focused around palliative care, with the language and approach not directly relevant to the community development and public health approaches of local government. The project has needed to develop resources to end of life care that are relevant to the local government sector given this project has a public health approach.
- Time. Capacity building is a major strategy of this project: information moves from MAV and La Trobe University to councils and then into the community. People need time to absorb the information and explore how the ideas are relevant to their local area. It has taken time to identify what councils need to know to be able to work effectively on this issue.
- Funding. Extended multi-year funding would be ideal to further incorporate end of life into the policies and programs of local government. If funding does not extend beyond the current three years councils will need to drive the direction through their policies and public health plans, and the ageing and community development work supported by council funds.

Sustainability

Currently there are few council resources available to implement the end of life initiatives of the project, however embedding the project in positive ageing has anchored the direction well at this early stage of implementation. Some councils have already included end of life into policies and programs without funding, thereby validating this approach.

This project is generating interest nationally. A 'road map' is being developed to inform other states about how to work with councils using a public health approach to end of life care.

Lessons learned

The project team have identified several learnings from the project to date:

- **Councils are skilled at community development – “it’s what they do”.** A public health approach to end of life care can leverage the expertise of local councils to build community capacity around end of life. Councils are already connected with end of life through their involvement in ageing, cemeteries, monuments and suicide prevention: end of life care is part of the continuum of their work with community.
- **The public health approach shifts thinking away from service delivery,** encouraging people to talk about end of life, consider how and where they might die, and how communities can better support people as they approach death.
- **Grant funding across a number of years can build processes and resources** that continue to deliver benefits beyond the grant period.

Warrnambool & District Community Hospice

Location	Warrnambool, Victoria
Year commenced	2015
Lead organisation	Warrnambool & District Community Hospice



Overview

Warrnambool and District Community Hospice (WDCH) is a not-for-profit organisation supported by its local community. Specially trained volunteers assist families and friends to care for dying patients in their own home. WDCH evolved to fill a gap in the provision of palliative care, led by a retired palliative care physician and committed committee of management. Their model of delivery has evolved to now employ a general manager who trains the volunteers and co-ordinates their activities. There are currently 77 volunteers who support an average of four to five families at any one time.

Description of initiatives

WDCH's volunteer program displays many elements of compassionate communities and the public health approach to palliative care. A large network of specially trained volunteers assists families and friends to care for dying patients in their own home. Assistance is provided to families in whatever way possible outside of clinical care. This can include respite for the carer, supporting care of the patient (e.g. assisting with transfers into bed), or helping with domestic chores.

WDCH provides a service that existing palliative care services are unable to. For example, the local palliative care service volunteers are only allowed to work within normal business hours so do not provide, for example, overnight respite or assist with getting the client to bed. WDCH volunteers work when they are required – family-centred.

WDCH staff and volunteers also participate in various community events. The president speaks regularly to community groups, to raise awareness of end of life issues, the value of advance care plans, and the work of WDCH. This increases the death literacy of the local community as well as raising donations for the ongoing running of the hospice service. The End of Life Preparations: The Essentials workshops are conducted on a monthly basis at the local community centre and are free of charge. These two hour workshops cover Advance Care Plans, the death plan and funeral plan.

"Our vision is to provide people who are dying, with the option of compassionate care in their own home settings, meeting the living needs of those who are dying, as well as the needs of their family and friends."¹¹⁷

Benefits and outcomes

WDCH delivers a range of benefits to people at end of life, their families and the broader community. People who would prefer to die at home will have a better chance of doing so. Families and friends will be

¹¹⁷ Warrnambool & District Community Hospice, *Welcome to the Hospice* (2018), <https://www.wdchospice.org.au/home>.

supported through difficult times. There will be fewer inappropriate admissions to hospitals and nursing homes.¹¹⁸

The work of the volunteers reduced the burden of care on family through support in day to day tasks. Family members report reduced fatigue and feelings of isolation, allowing them to continue to provide end of life care at home.

The support of the volunteers also helps to reduce fear and uncertainty about the end of life both for the family and the person approaching the end of their life.

The speaking engagements are notable for normalising discussion of death and dying. They raise community awareness about services, advance care planning and improve people's ability to have difficult conversations about dying.

"We allow people to live at home until they die, with the care of their family."

Success factors

There are several factors that contribute to the effectiveness of WDCH's palliative care services and volunteers programs:

- Visionary leadership
- A management committee with a shared dream, and good relationships with other local organisations
- Good volunteer training (initial 10 weeks using Palliative Care Victoria modules, with ongoing training opportunities)
- Great volunteers with a "generosity of spirit"
- Taking the time to build a realistic business case. The original vision included a house with hospice beds until they realised that this was financially unsustainable.

Barriers and challenges

It took time to identify the model of engagement, understand the legal requirements and build a business case of what was possible. It was five years from the initial meeting of interested parties to the point of providing a service.

Funding is a constant concern. The management committee, and particularly the president, spend considerable time writing submissions to philanthropic trusts and seeking new ways to obtain financial support from the community. Ensuring they are well connected to local government helps their cause.

Finding a physical location for volunteers to meet also took time. Fortunately, WDCH was assisted by the local university and Vice Chancellor, who provided them with a three-year lease of an old farm house at nominal rent. This provides office and training space, and a 'home' for volunteers to meet.

"A road map would have been good."

Cost inputs and savings

WDCH is a lean business with one FTE managing 77 volunteers. This includes training, rostering, police checks, assessing clients and matching volunteers to clients. Funding comes from donations and philanthropy.

¹¹⁸ Warrnambool & District Community Hospice, *Hospice Q&A* (2018), accessed at <https://www.wdchospice.org.au/about/hospice-qa>.

Rent is subsidised by the university (WDCH pays around \$300 per year) and a significant amount of maintenance is undertaken by volunteers, keeping the capital costs to a minimum.

The End of Life Preparations: The Essentials workshops are conducted on a monthly basis at the local community centre and are free of charge. These two hour workshops cover Advance Care Plans, the death plan and funeral plan.

Sustainability

The hospice recently has been fortunate to obtain a one off grant from the State Government which will assist in the setup of a more stable fundraising process to ensure sustainability into the future. WDCH has several strategies to ensure the social and financial sustainability of the volunteer service:

Social sustainability	Financial sustainability
<ul style="list-style-type: none"> • Good volunteer training keeps the volunteers volunteering. • There is a waiting list of people who want become volunteers and receive training – demonstrating it is locally valued. • Having the house as a base is seen as important to the volunteers: somewhere they can meet. • The community sees the value of the services and is supportive. Speaking engagements and personal connections keep the work of WDCH known and, for the moment, the community wants it to succeed. • The role of the manager is significant in the support of the volunteers and the coordination of the care provided. 	<ul style="list-style-type: none"> • Currently implementing a corporate-giving program where local businesses commit to giving a small amount each week. • Costs are kept to a minimum. • Local community goodwill means ongoing volunteer support and some in kind and financial support from individuals and organisations in the community. • Management committee has a range of skills appropriate for running a business and is willing to volunteer their time.

WDCH relies on a charismatic leader who contributes a large amount of time, ensuring the funding of the organisation (writing submissions, engaging local businesses) and undertaking much of the clinical assessment that occurs prior to sending volunteers into a client's home. WDCH recognise that this is a risk to sustainability and have developed several strategies to mitigate this risk. They are clear on their offerings and what they will and will not do, to avoid over-extending the program. They maintain a strong connection and relationships between the management committee, managers and volunteers, and the goodwill of the community, which are not dependent on any one person to continue. They have also developed and documented policies and processes which can be shared with others. WDCH are sure they will endure beyond the inaugural president's tenure thanks to the established roles of the managers and volunteers and the drive towards the further development of a compassionate community by improving death literacy.

Lessons learned

Over the past two years, WDCH has identified several learnings:

- Good leadership matters.
- Good social networks make a difference.
- Good professional, clinical and organisational networks are important.
- Volunteer training is vital.
- Palliative Care Victoria provides an essential resource for training modules and access to networks.

The local community continues to see the value of hospice and is willing to provide financial support.

Compassionate Frome

Location Somerset Frome, South West England, United Kingdom

Year commenced 2014

Lead organisation Health Connections Mendip, Frome Medical Practice and Frome Town Council



Overview

The Compassionate Frome project began in 2014. The driving factor was a need to rethink the way the town’s medical practice considered the nature of illness. The rethink was prompted by concern for people who presented at surgeries with no clearly defined medical condition yet who evidently needed care and attention, and also by the number of patients who occupied hospital beds only for want of more appropriate means of tending to their welfare.

The project leads are GP Helen Kingston and Jenny Hartnoll, leader of the community development service at Health Connections Mendip. Frome Town Council has provided financial and strategic support. The essence of the project is enabling provision of more holistic healthcare and a population-based approach to wellbeing, through understanding and facilitating access to community-based programmes. One of the most significant aspects of the project has been its success in helping people make use of existing informal supportive networks. The scope is not limited to individuals at end of life.

Description of initiatives

The project identified four key areas for action, which are summarised below

Mapping and communication	Community connectors (CCs)	Support for community groups	Health connectors (HCs)
<ul style="list-style-type: none"> The first year was spent identifying all existing assets and strengths within the community Thousands were identified, and a shortlist of 400 local services and organisations was compiled A simple website was created to share information The website integrates with the GP patient record system to enable ease of information, signposting and referrals. Referrals are coded on the patient record. 	<ul style="list-style-type: none"> The role of CCs is to empower the community to support each other, through signposting conversations to available services. The premise is that the more people in the community who know what is available, the more community can support each-other Individuals undertake a free training session – available to anyone The project has trained 610 CCs to date CCs are not monitored, managed or supported in a ‘formal volunteer role’. 	<ul style="list-style-type: none"> The project has set up a range of local support groups – the project will hold and support groups through establishment however the goal is that they become self-sustaining There needs to be a community request for a specific group to be supported or a clear gap The project supports the voluntary sector, rather than just expecting all gaps to be filled. Activities include promoting groups, raising awareness, acting as catalyst, facilitating networking meetings and recruiting volunteers 	<ul style="list-style-type: none"> HCs are paid staff, located within the GP clinic. They work with people one-to-one across different environments Being situated within the GP clinic, and a paid member of the practice allows information sharing between GPs and HCs HC will work on what is important to that person and is affecting their health and wellbeing There are no specific qualifications required Over time, the aim is that HCs only support the more complex people

Benefits and outcomes

The project has delivered the following:

- **A community directory of health services:** For a population of 28,000 residents there is now a website directory of almost 400 varied groups and organisations offering support, advice, companionship and creative activity. This directory is linked to the GP patient information system, enabling GPs to sit with patients, identify potential services, and code referrals on the patient record.
- **Increased signposting and community empowerment:** The project has trained 610 community connectors to date. If each connector has 20 signposting conversations a year – this is 12,200 signposting conversations per year. These figures are not tracked or recorded. Community connectors are trusted to act on their training.
- **Improved quality of GP consultations:** Anecdotally, project feedback has been that GP consultations have been enhanced through the projects, with patients more actively engaged in their own care. Project surveys found an 83 per cent increase in their patient activation scale, and that 92 per cent of GPs thought patients benefited from the project.
- **Positive GP engagement and morale:** GPs have valued the ability to show compassion, the provision of tools to provide holistic care, and developing relationships outside of the practice. The project has generated a welcome ethos of collaboration, sense of agency, and teamwork.
- **Reduced emergency admissions:** While emergency admissions to hospitals across Somerset have increased by 29 per cent, Frome has seen admissions fall by 17 per cent, with a 21 per cent reduction in costs. This represents 5 per cent of the total health budget. No other interventions on record have reduced emergency admissions across a population. It is important to note that these results are not solely attributable to the community development activities undertaken through this project, there has also been concurrent initiatives to enhance the broader delivery of primary care.

Success factors

The project has been recognised both in the UK and internationally as a model of good practice. The Success factors identified by the project include:

- **One foot in community, one foot in primary care:** The model is one of community development embedded in primary care. Co-location of the Health Connections Mendip team and the Health Connectors as part of the GP practice has been critical in building the credibility and profile of the program, and in engaging GPs to support their patients to access community services. As the project team is employed through the GP practice, they are able to communicate directly with GPs and access patient data to understand and refer specific patients that might benefit through the project. The community directory of services is also directly linked through the GP patient information system.
- **Comfort with organic growth:** The project has evolved organically – reflecting how communities develop – and the team has accepted and embraced that. Actions have been responsive to community needs, and has leveraged and encouraged actions of passionate individuals along the way.
- **Trust in development and delivery:** The project was fortunate to have the trust of the clinical commissioning group in the development of the model – providing scope to be creative and innovative, make mistakes and learn. The project and broader team (health connectors and community connectors) are trusted to do what is best for the individual, and so feel the project belongs to them.
- **Multiple ways to be involved:** Critical is a recognition that everyone's experience is different. There are multiple ways to be referred or self-refer into the community groups, and a broad range of options. GPs, Health Connectors and Community Connectors signpost to options, but do not go as far as social prescribing.

"We will go where the energy is"

- Project lead

Barriers

While integrating with health services has not been a barrier as such, some practices have been slower adopters than others. Communicating benefits and training on the service for new GPs have been put in place to mitigate this. The other major barrier to the project has been the ability to invest time and resources in monitoring and evaluating progress. There has not been any measuring or quantifying of change in the GP setting. It also has not been possible to identify specifically what outcomes can be attributed to the community development component of the broader Frome initiatives to enhance primary care (which also include nurse practitioner care co-ordinators, discharge liaison nurses and nurse hub co-ordination).

Cost inputs and savings

The project commenced with seed funding of approximately £60,000 for two posts to build the network map and develop the website. This funding was through a clinical commissioning group innovation fund. The Frome Council also input £10,000 during the third year. The project now estimates an annual cost of £309,000 per annum for the area co-ordinator and health connector posts within GP practices. There are 2 FTE Area Leads and 6.5 FTE Health Connectors covering 11 GP practices and a population of approximately 115,000. While positions are employed within GP practices, funding has come externally not from the practice itself.

Savings have been summarised above (see benefits and outcomes) and estimated as a 21 per cent reduction in costs associated with emergency admissions over a three year period, equating to approximately £1,195,000.

Sustainability

The project has set up a range of local support groups. The project team has helped with establishment and promotion, and not in a way that incites reliance on financial or other support for ongoing operations. Where financial support has been provided to community groups this has often been small scale – e.g. £250 for resources/materials to cover running costs (i.e. tea and coffee, posters etc.) for a year.

The community services directory has been deliberately set up in a simple and user-friendly way and would be sustainable as long as a volunteer could be identified to manage updating. There are also some components of the model that operate under the groups Mendip Health Connections umbrella and would not necessarily be self-sustaining without the right volunteer to take over. For example there are 5 weekly Talking Cafes across Mendip currently run by paid Health Connectors.

Health Connectors are currently funded on a three year basis. Without this funding, the 1:1 support provided by these paid positions would not be possible.

Lessons learned

A number of lessons have been learned to date, including:

- **A whole of community approach is needed to support people at end of life:** Compassionate Frome operates across three levels: 1) awareness across the whole population; 2) support for chronic illness and those at risk of increasing isolation; and 3) support at end of life and bereavement. The premise is that by end of life it is too late to start building supportive networks. This needs to be done earlier and at a whole of population level.
- **Compassionate Frome has been a process of evolution, and not about being named and measured:** Allowing the project to grow organically has been important. Initially the project did not identify as being a 'compassionate community' but the objectives were aligned. It hasn't been possible to measure everything throughout the journey. The project team recommend focussing on measuring what you need to communicate the message, but also trust that those involved are doing the right thing, and look for other ways, such as patient stories, to demonstrate impact.
- **A flexible approach is key:** It is important to be flexible in the approach – "roll with what is bubbling up and fill the map in... if you get an enthusiastic person work with them, don't stick rigidly to the project plan" at the expense of missed opportunities. The project team needs to be comfortable with working within less defined structures and leverage the benefits that flexibility brings.

Compassionate communities in Shropshire

Location Shropshire, United Kingdom

Year commenced 2010

Lead organisation Severn Hospice



Overview

Shropshire’s compassionate communities (described as the Co-Cos) consists of volunteer networks that provide support to frail and vulnerable individuals at risk of loneliness and social isolation. The Co-Co network operates as a volunteer-led support and befriending service. The network was launched in January 2010 by Severn Hospice. There are currently 21 Co-Cos operating across the region, with an additional two in development at time of writing. The aim is to support the expansion of compassionate activities within the whole community. Clients receiving support include, but are not limited to, individuals receiving end of life care. Severn Hospice plays a key support role.

Description of initiatives

Severn Hospice works with local communities to develop their own free-standing volunteer networks – Co-Co Networks – to support the frail and vulnerable to remain active members of the community – thereby reducing social isolation and ‘crisis’ events. It is not a service provided by an organisation but rather a community development supported by Severn Hospice working in partnership with local General Practice.

Volunteer networks range in size from approximately six to fifty volunteers. The structure and activities of each Co-Co, being dependent upon available time and capacities of volunteers, varies considerably from community to community. Similarly, the type and frequency of support is agreed between each volunteer and client and will vary to meet the needs of each, but should not be more than 2 hours/week.

Despite this variation, there are three core roles to each Co-Co. There is also common process for recruitment, training and deployment of volunteers, aimed at assuring good practice and governance. Importantly, the request for Severn Hospice involvement must come from the community – only once “invited in” will the Hospice provide support. The core model has remained relatively constant since inception in 2010.

Severn Hospice	General practice	Volunteer Co-ordinator
<ul style="list-style-type: none"> • On invitation, provides information and support for the local community to develop and co-ordinate a network of volunteers • Delivers volunteer training (on request and regular delivery) • Conducts volunteer police checks and provides public liability insurance • Supports volunteer-co-ordinators with ad-hoc issues and concerns • Facilitates volunteer-co-ordinator events to share experiences and lessons learnt • Act as a broker between community and service providers where required 	<ul style="list-style-type: none"> • Identifies those with the greatest priority need in their practice population • Secures informed consent from the client for volunteer support • Acts as a point of reference for any concerns that the volunteer may have concerning the care for person’s health and wellbeing 	<ul style="list-style-type: none"> • Takes referrals from general practice, but also other service providers, family and community more broadly • Matches clients and volunteers • Undertakes review of ongoing support at regular intervals • Manages volunteer paperwork, expenses and provides ad-hoc support • Facilitates volunteer meetings to share experiences, issues and concerns • Feeds back issues relating to client health and wellbeing to general practice

Benefits and outcomes

An outcome audit (undertaken in 2011, but not repeated) found that for individuals involved with a Co-Co network, all measures of use of unscheduled i.e. urgent/emergency, care services decreased in the six-months post-matching. These measures included: visits to GP, phone calls to family doctor, emergency department attendances, emergency admissions, and calls to / admissions by out of hours services. The only metric that increased was planned hospital admissions – reflecting that volunteers and social connectedness cannot ‘cure’.

Qualitative feedback from clients and volunteers has been positive in terms of increasing community connection. Volunteers are typically older and retired. Involvement in the Co-Co has benefited them by learning new skills, social connections, and managing lifestyle changes in the transition to retirement.

Success factors

Co-Co networks have now been in place across the region for eight years. Over this time, the following Success factors have been identified:

- **Leadership and co-ordination within the Community** - The impetus for the development of a Co-Co volunteer network needs to be provided by a leader or leaders within the community itself. This leadership not only provides the initial impetus for change but also a potential point for the co-ordination of volunteers once the network is set up. If the initial contact changes, it needs to be replaced.
- **Action based on community priorities, not organisational ones** – There must be shared sovereignty in priority setting and planning, and commonality of language. In establishing the first Co-Co in 2010, the original framing was support for end of life care. Instead community prioritised the broader group of ‘frail and vulnerable’.
- **Support for the community from a trusted and stable organisation** – This does not need to be a hospice, but does need to be a well-known and local organisation to give an expectation of longevity to the model and be trusted to take on the brokerage role (for Shropshire this role could not be played by the local NHS)
- **Partnership with and close support of a General Medical Practice (or other service provider)** - Not only for the purposes of identifying those who would most benefit from support but also for securing their informed consent and acting as a point of reference for any concerns over the client’s health
- **Training, governance and indemnification** - In the absence of a formal organisational governance structure, virtual policy, procedural and governance arrangements need to be instilled to protect both the client and the volunteer. In the Shropshire model these include: reasonable preparation of citizen as volunteer, vetting and disclosure requirements, public liability insurance and regular review of the relationship undertaken separately with the client and volunteer.

“Co-Co is a bag of opportunities for citizens... Men in Sheds, Samaritan Listening are compassionate communities...we meet regularly to look at how we can overlay and refer across. We are trying to build the richness of compassionate community interventions in each place”

Barriers

Professional attitudes and risk aversion are a barrier to the overall model. The model is most effective when working with health practitioners who recognise the public health agenda that they are contributing to and know that they are not the “answer to health in their community”. Typically, it is less successful with short term visiting GPs who are less invested in their community. Risk-aversion is greatest when professionals view the model from a service provision lens – it is a community initiative, not a clinical service.

Locally, getting sufficient numbers of volunteers to match client demand can be a challenge for specific Co-Cos. Getting the right match is important in terms of the success and reputation of the model. Managing the boundaries of what volunteers can and can’t do can also be a challenge for local co-ordinators, typically because volunteers always want to do more.

Cost inputs and savings

There are cost inputs for each of the core organisations and positions involved. The main savings are in terms of reduced unplanned clinical admissions (though these have not been audited since 2011 and so are difficult to quantify). Typical costs and how they are managed are as follows:

COST INPUTS	
<p>SEVERN HOSPICE</p> <ul style="list-style-type: none"> Materials, training and support is delivered through a hospice nurse-educator role (estimated time of 2-3 days/month) Cost of police checks Cost of insurance Costs absorbed into Hospice operational costs 	Costs absorbed into Hospice operational costs
<p>GENERAL PRACTICE</p> <ul style="list-style-type: none"> GP community and care co-ordinator role (13 hours/week) extended to include Co-Co projects (estimated time of 3 hours/week, but varies on stage of development) 	There is an NHS community and care co-ordinator role funded for all GPs. No additional costs incurred
<p>COMMUNITY NETWORK</p> <ul style="list-style-type: none"> Travel allowance for volunteers (not always claimed) Fundraising events (i.e. coffee and cake mornings) 	Volunteer costs typically met by network through fundraising and/or community donations. In a small number of instances, the volunteer co-ordinator is also a volunteer.

In 2010, the initial establishment of the model and set-up of the first Co-Co was enabled through pilot grant funding. This enabled funding of a volunteer co-ordinator role for 16hrs/week. With the exception of this initial year, the volunteer co-ordinator has not been a separate paid role. There is no income for the Hospice through the model, but the Board is committed to involvement.

Sustainability

A key characteristic in the Shropshire approach to establishing a Co-Co network is to vest the responsibility for resourcing the network with the community. This means that the community takes responsibility for not only recruiting volunteers but also generating any funds required to support the network. This is generally done through fundraising events and donations from local businesses and individuals.

Grant or seed funding is the most effective way for government to support community development without impacting on sustainability. Funding should be targeted and time-limited, allowing the Co-Co to transform in some way. For one area, the local government has established a small fund for Co-Cos to apply for seed funding for specific activities (i.e. local town hall hire for three months to hold coffee and cake mornings to build some cash reserves to enable ongoing fundraising activities).

Lessons learned

- **Requests must be community-initiated:** The request for Severn Hospice to support development of a Co-Co must be generated first from the community. While no communities have 'failed', those that did not get off the ground did not have a strong enough community impetus or lead person/group from the community.
- **Start small and grow:** Encourage communities to start small and just get up and going. GPs can play a gate-keeper role on referrals to ensure this is manageable until the volunteer network grows, and it will.
- **Embrace a variety of solutions:** A Co-Co model can only operate on the available capacity within each specific community. The solution will reflect the vision and resources within the community in question. Every solution will look different and that is fine. Identify which parts of the model should be consistent (i.e. minimum volunteer requirements) for quality and safety reasons, but ensure flexibility on the rest.

Rotorua Community Hospice

Location	Rotorua, New Zealand
Year commenced	2005
Lead organisation	Rotorua Community Hospice Trust



Overview

Hospice in the Rotorua area is a concept of care rather than a place of care. This hospice has no beds¹¹⁹ and staff care for a high percentage of people dying at home. Until about a year ago the hospice had only a small office building as a base – it now has a day stay base where clients can have a hand massage or chat to a social worker. Rotorua Community Hospice provides comprehensive home-based care to all palliative care patients in the District.

“Many people think of hospice services as just a building, when in fact it is a philosophy of care.”

Description of Initiatives

In 2005 Rotorua Community Hospice became the single point of entry into palliative care for the District and gained recognition as the District’s specialist palliative care provider with establishment of a Palliative Care Coordinator role.

A key feature of the model is the way in which it has reversed the normal hierarchical management model to encapsulate the concept of patient centred care. The model of service specifically recognises that families, as well as receiving care from the hospice team, are themselves critical members of the team. Centred firstly on the patients, their family and whanau¹²⁰ (38 per cent of the Lakes District population is Maori), it is about focusing hospice services around the needs of these people rather than the problems of those who provide the service.

By implementing a rotating roster of three days on, three days off and working twelve hour days, the registered nurses (nearly all of whom have postgraduate qualifications in palliative care) are able to provide more continuity of care, be more flexible with visiting regimes and better able to support the main caregiver. When carers feel more supported they are able to care for their loved one at home for longer and prevent inappropriate admissions back to hospital or admissions into long term care facilities.

Another key feature of this model is that the hospice employs its own Home Care Assistants to provide the support care, rather than a caregiver from another organisation, to maintain continuity of care and not unravel the “tapestry of care” which is the essence of palliative care.

¹¹⁹ The hospice has a small budget to fund a patient into residential aged care if they are unable to be cared for at home at end of life.

¹²⁰ Extended family

The hospice has great rapport with local GPs and can call their mobile phones any time, including after hours. Relationships with the tertiary sector are strong, with access to the region's tertiary hospital (Waikato hospital) for specialist medical support via teleconference and a monthly clinic arrangement. Hospice staff also provide education to residential care facilities and hospital staff, as well as community health professionals. They use a 9 module course to educate all generalist nursing staff (in hospital and residential aged care) on the fundamentals of palliative care, on end of life pathways and advance care planning. Education is provided to GPs on EOL pathway and symptom management by Hospice RNs or medical specialists. In addition, they have been working with a church group running a 4-6 week course for people planning for end of life. They also provide grief and loss information.

Benefits and outcomes

The model of care supports families to enable their loved ones to die at home, which is a strong preference for the majority of the population. A very few clients are admitted to residential aged care where they are still supported by the same hospice team.

The recognition of the hospice as the single point of entry into palliative care simplified the palliative pathway for professionals and patients allowing collaborative planning for discharge from hospital of palliative patients.

"Our aim is to ensure the dying; their family and friends transition seamlessly through the health network."

Success factors

A critical factor in the development of this model of care was the extensive development of relationships – with the hospital and the community – that led to acceptance of its place in the community. Hospital staff were initially sceptical but came to fully accept the role of the hospice.

Other factors that underlie its success are the client-centred and team-based model of care, the single point of entry, recognition as the District's specialist palliative care provider and establishment of a Palliative Care Coordinator role.

The staff rosters ensure continuity of care and have a range of benefits for clients as well as staff.

Benefits of the roster arrangements:

- ✓ Uninterrupted days off
- ✓ Less time on call
- ✓ Even distribution of being on call
- ✓ There are Registered Nurses on duty 7 days per week
- ✓ More support
- ✓ More flexibility
- ✓ Financial benefits.

Barriers

The Rotorua Community Hospice service has overcome potential barriers through a strong leadership focus on developing relationships across the whole health system and the community.

Cost inputs and savings

Funding for the hospice is shared between government and fundraising from the community with government providing approximately 50 per cent.

The model of care with registered nurses also providing the support care was able to be accommodated without an increase in resources due to the long shifts worked by the RNs.

When the hospice implemented the '3 on 3 off' roster with twelve hour shifts the service increased by over 30 per cent at no extra cost to the organisation. The high percentage of the community who die at home suggests that there are few inappropriate hospital admissions for palliative care and therefore significant savings in terms of the avoidance of bed day costs.

Sustainability

The model of care has been in place since 2005. The Clinical Manager position has changed but the culture and philosophy remain well embedded and relationships with the other players remain strong.

Rotorua Community Hospice has low staff turnover. Ninety per cent of staff have been there for over five years and several have been there for over 10 years

Lessons learned

The development of the Rotorua Community Hospice has demonstrated that

- Strong relationships and engagement is critical to the creation of seamless networks of care
- The lack of beds in the hospice places full emphasis on home based care
- The role of registered nurse as single care-giver, providing supportive care as well as nursing, enhances continuity of care.

Appendix D Compassionate City Charter

The Compassionate City Charter developed by Alan Kellehear defines 13 social changes to the key institutions and activities of cities. These result in:

- changes across schools, workplaces, trade unions, churches and temples, hospices and nursing homes, museums and art galleries
- new initiatives such as memorial parades, incentive schemes and creative competitions
- increased publicity and awareness of government policies, services and funding opportunities
- increased consideration of diversity and how it shapes the experience of ageing, dying, death, loss and care.¹²¹

13 social changes from the Compassionate City Charter¹²²

1. Our **schools** will have annually reviewed policies or guidance documents for dying, death, loss and care.
2. Our **workplaces** will have annually reviewed policies or guidance documents for dying, death, loss and care.
3. Our **trade unions** will have annually reviewed policies or guidance documents for dying, death, loss and care.
4. Our **churches and temples** will have at least one dedicated group for end of life care support.
5. Our city's **hospices** and **nursing homes** will have a community development program involving local area citizens in end of life care activities and programs.
6. Our city's major **museums and art galleries** will hold annual exhibitions on the experiences of ageing, dying, death, loss or care.
7. Our city will host **an annual peacetime memorial parade** representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.
8. Our city will create **an incentives scheme** to celebrate and highlight the most creative compassionate organisation, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A 'Mayors Prize' will recognize individual/s for that year those who most exemplify the city's values of compassionate care.
9. Our city will publicly showcase, in print and in social media, our **local government policies**, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organisations.
10. Our city will work with local social or print media to encourage an **annual city-wide short story or art competition** that helps raise awareness of ageing, dying, death, loss, or caring.
11. All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how **diversity** shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.
12. We will seek to encourage and to invite evidence that institutions for the **homeless and the imprisoned** have support plans in place for end of life care and loss and bereavement.
13. Our city will establish and review these targets and goals in the first two years and thereafter will **add one more sector annually** to our action plans for a compassionate city – e.g. hospitals, further & higher education, charities, community & voluntary organisations, police & emergency services, and so on.

¹²¹ Kellehear, A, see n 2.

¹²² Ibid.